(UN)SETTLED BODIES:

A VISUAL PHENOMENOLOGY OF FOUR WOMEN LIVING WITH (IN)VISIBLE DISABILITIES

by

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(UN)SETTLED BODIES: A VISUAL PHENOMENOLOGY OF FOUR WOMEN LIVING WITH (IN)VISIBLE DISABILITIES

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ABSTRACT

Women living with (in)visible disabilities experience (un)settled bodies, bodies that visibly and invisibly shift into and out of periods of calm (settled-ness) and unrest (unsettled-ness) resulting in multiple, fractured subjectivities. Characterized by contradictions in physical appearance, behavior, and social expectations, this plural and paradoxical embodiment is misunderstood because it transgresses presumptive appearances of normalcy and the legitimate signs of a disabled body and identity.

Conceptually grounding a phenomenological understanding of (un)settled bodies in ways that are conversant with disability studies and queer theorizing, this study explores how four women, three living with multiple sclerosis, and one living with vulvodynia, experience their disabilities in (in)visible and (un)settled ways across everyday moments. In doing so, the study encourages a critical version of "sight" and "insight" beyond what "normally" meets the eye in relation to embodied identity. I create a language for experiences that have been unnamed, that are ineffable in their shifting subjectivities, that question or "crip" (McRuer, 2006) how we interpret bodies in society. Combining tenets of phenomenology, hermeneutics, and practices of (non)art photography, participants engage in a three-stage process of in-depth conversational interviews that are guided by the interpretive use of personally created photographs. Three "storied movements" informs the women's portrayals. The first story, (Un)Convincing Bodies, echoes the shifting personal, social, and institutional (dis)belief of an (un)settled embodiment and the (inter)personal tensions surrounding forgetting and remembering the presence of an (in)visible disability in women's lives. The second storied movement, the Fluidity of Identity, characterizes the "comforting-danger" of secreting (un)settled identities, blending-in, twisting subjectivities, and the unburdening of women's (un)settled selves. While participants prefer to secret and blend-in their conditions because of the cultural misunderstanding and skepticism surrounding (in)visible illness, there are moments that necessitate self-disclosure. Although disclosure incites bewildering silences, it is also cathartic and enables the politicization of (un)settling subjectivities. The third story, (In)Visible Wounds, illustrates the emotional shifts of living with a progressively unsettled body.

Implications for social work including crediting women's embodied ways of knowing, embracing fluid constructions that account for (un)settled bodies in service delivery, and debunking the rigidity of categorical imperatives for policy are considered.

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Opening Movement

Chapter 1

Introducing (Un)Settled Bodies

Women living with (in)visible disabilities commonly experience (un)settled bodies, bodies that invisibly and visibly shift into and out of periods of calm and unrest resulting in multiple, fractured subjectivities. Characterized by contradictions in physical appearance, behaviour, and social expectations, this plural and paradoxical embodiment is not well understood or accepted because it transgresses presumptive appearances of normalcy and what our culture deems the paradigmatic markers of a disabled body and identity (Kafer, 2003; Kleege, 1999; Montgomery, 2001; Sherry, 2004; Wendell, 2001). Bringing this reality to light Stone (1995) confirms:

> Most people have disabilities that are invisible [(in)visible] meaning that disability is not [always] readily apparent through casual observation and because. . . they are not readily apparent, their existence in the population tends to get forgotten and dismissed as inconsequential. . . nevertheless, [in]visible disabilities can limit individuals every bit as much as visible disabilities limit individuals (p. 417).

The spirited passion and intellectual curiosity guiding this research emanates from my history of chaos and calm in living with(in) a chronically ill, (un)settled body and is a testament to the fossilized stories archived within my flesh of the many women I have met in my professional practice as a social worker who endure this never-ending journey. Having said this, while my experience, memories, feelings, and thoughts pervade the interpretive fibre of this dissertation, I have deliberately chosen to focus my attention solely on the voices of the participants in this study. It is their voices and lives that have come out of the shadows to give life to this current work.

While an emphasis on invisible disabilities is increasingly evident in scholarship across disciplines (Charmaz, 1997; Moss and Dyck, 2002; Munson, 2000; Peters, 1993; Stone, 2005; Sveilich, 2005; Vickers, 2001b; Wendell, 1996), research exploring the experiences of women living with disabilities that shift from invisible to visible and back again remains largely absent (Gordon, Feldman & Crose, 1998; Joachim & Acorn, 2000). This absence echoes the un-familiarity surrounding (in)visible disabilities in our society. Since we are not attuned to the realities of bodies that (in)visibly slip between states of (un)wellness and (dis)ability, our society remains insensitive to this way of living. This dissertation is the first exploration within social work scholarship to combine the artistry of phenomenological interpretation with photographic representation to explore how four women, three living with multiple sclerosis and one living with vulvodynia,[1] experience what I define as an "(un)settled body" within the context of (in) visible disabilities.

Unsettling the Divide

The expressions "(in)visible disabilities" and "(un)settled bodies" are specific to this research[2] and denote connotations that demand explication. I begin first with the phrase (in)visible disabilities. Conceptually, there is no single scientific definition, framework, or language with which we can situate the experience of disability. Yet, language, ideas, and

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[1] I provide a detailed definition of multiple sclerosis and vulvodynia and my rationale for selecting participants with these (un)settling embodiments in Movement III: Crafting (Un)Settled Bodies within the section entitled Defining, Accessing, and Introducing the Participants.

[2] The reader should note that the terms invisible, non-visible, and hidden are commonly cited in the literature. Non-visible and hidden implies that the condition can be seen if only one would look and discover it. Invisible implies that the condition cannot be seen, at least in any obvious way (Matthews & Harrington, 2000, p. 406).

In this study, I place brackets around the word "(in)"visible to denote the fluctuations of the (un)settled body in both visible and invisible ways. This way of conceptualizing (in)visible disability as equated with an (un)settled body, differs from Zitzelsberger's (2005) bracketed use of the term that implies how women living with visible disabilities and physical differences experience their personhoods in visible and invisible ways.

discourse are fundamental to how we understand [all] disabilities (G. Williams, 1996, pp. 194-195). While Anderson (2000) emphasizes that the inclusion of persons with chronic illness within the category of the disabled remains controversial, I pay homage to the pioneering work of Susan Wendell (1996, 2001) who explicitly theorizes that chronic illness is a form of disability.[3] Akin to Wendell, I suggest, within the context of this research, that chronic illness that experientially fluctuates in visible and invisible ways is a kind of (in)visible disability.[3] Echoing the subjective and interpretive scope of this conceptualization, Sherry Peters (1993) articulates how fluctuating chronic conditions, including multiple sclerosis and lupus, implies living with a disability "sometimes." I accentuate Peter's theorizing to highlight an understanding that the embodiment of disability can slide between the visible (seen) and the invisible (unseen) depending on the material, situational, and contextual features that characterizes a woman's life in the moment.

> In terms of appearance, some disabilities fluctuate between . . . visible to invisible, from highly visible to less visible or the reverse. The fluctuation may involve a change in the *degree of disability* (e.g. an individual's disability may go into remission with the disability becoming invisible), *circumstances* (e.g. an individual's disability may become less visible if they are sitting rather than standing) or *environment* (e.g. an individual's disability may become more visible in certain locations such as a recreation facility) (1993, p. 26).

Equally relevant, living with an (in)visible disability in this research means living with an (un)settled embodiment.[4] I interchangeably employ the phrases (un)settled

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[3] I recognize, akin to Wendell (2001), that there are important differences between what she refers to as the "healthy disabled," persons whose physical conditions and functional limitations are stable and predictable over time and the "unhealthy disabled" who live with shifting periods of debility and "nearly normal" health. Having said this, I am cognizant that some individuals who identify as disabled may not consider themselves "unhealthy" despite their altering embodiment.

[4] While I extend an understanding of embodiment in relation to my discussion of the phenomenological lived body in Chapter 2, I briefly define it here as how we live and experience our selves and our world through our bodies (Wilde, 1992).

embodiment, (un)settled body, and (un)settled-ness throughout this work. In doing so, I propose that living with an (in)visible disability means living with(in) a body that (in)visibly fluctuates between periods of calm or "settled-ness" and volatility or "unsettled-ness." Mirroring Peter's (1993) perspective and following Margaret Vickers (2001) contention that chronic illness is disabling and not always hidden, I suggest that women living with (in)visible disabilities experience an embodiment that is neither always "settled," healthy, or able nor always "unsettled," unwell or disabled. Instead, women living with (in)visible disabilities reflect the complexity of dually inhabiting, moving between, and resting on the cusps of health, illness, ability, disability, visibility, and invisibility.

Although I equate an (un)settled embodiment with (in)visible disability in this thesis, I am not maintaining that all women living with chronic illness are disabled or that all women living with chronic illness would identify themselves as (in)visibly disabled in any way. What I am saying is that the women who responded to my study announcement felt a personal connection with the phrase "(in)visible disabilities" because they experience their bodies as (in)visibly shifting between periods of quiescence and chaos and regard this volatile embodiment as intermittently disabling or partially restricting their everyday functioning in a diversity of ways. In this sense, living with an (un)settled embodiment is not a discrete episode in the course of a woman's life (Bell, 2000) but a permanent intervallic way of being that exists on multiple continua and different dimensions (Fox & Kim, 2004; Vickers, 2001b).

More broadly, invisible or what I consider (in)visible disabilities are sometimes referred to as episodic, part-time, temporary, situational, recurrent, and inconsistent disabilities (Banks, 2003). These disabilities include but are not limited to conditions such as multiple sclerosis, chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, colitis, Crohn's disease, premenstrual syndrome, interstitial cystitis, vulvodynia, endometriosis, migraine headaches, environmental illness (multiple chemical sensitivities), lupus erythematosus, epilepsy, asthma, osteoarthritis, diabetes, cystic fibrosis, heart disease, chronic pain, cancer, and HIV/AIDS, (Vickers, 1997). While these conditions fit within the milieu of an (un)settled embodiment, my emphasis is on neurologically based conditions, specifically women's experience of multiple sclerosis and vulvodynia. These conditions can result in alterations in functional performance, mobility, and sensation as well as engender chronic pain. While some learning and psychiatric disabilities may reflect the nomenclature described, I argue they are embodied in qualitatively different ways beyond the scope of this project.[5]

(In)visible chronic conditions have no cure nor follow the typical illness trajectory of warning signs, illness, recuperation, and full recovery. Instead, the severity of symptoms, which are often painful and limit activity, may reflect acute exacerbations, chronicity, or both at the same time (Vickers, 2000, p. 134). Since signs do not always show up in obvious ways, individuals tend to look "perfectly fine" and consequently evoke suspicion from others (Charmaz, 2000; Donoghue & Siegel, 2000; Munson, 2003; Vickers, 1997; Wendell, 1999). Many (in)visible disabilities including epilepsy and inflammatory bowel disease have a social stigma attached to them and are considered culturally taboo to discuss (Donoghue & Siegel, 2000; Driedger, 2003).

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[5] While some individuals living with multiple sclerosis may experience difficulties with information processing, memory, comprehension, and other cognitive limitations like some individuals with learning difficulties, these aspects are larger considerations that have implications beyond the focus of this research. Similarly, fluctuations in relation to cognition, perception, and altered states of awareness for many individuals with psychiatric disabilities lie outside the boundaries of this work.

I am not the first person to "write against the grain" in forging a new territory for the (un)settled body within larger disability discourse. Tanya Titchkosky (2003) writes eloquently about straddling the material and discursive spaces of (dis)ability in visible and invisible ways in relation to her own dyslexia and her partner Rod Michalko's blindness. Margaret Vickers (2001a, 2001b) considers how the embodiment of chronic illness shifts between degrees of visibility, disability, and legitimacy within the context of the occupational environment. Pamela Moss and Isabel Dyck (2002) lay claim to the ways women living with chronic illness are "caught in-between" the material realities and discursive constructions of (dis)ability and the manner in which their shifting embodiment affects the negotiation of their everyday environments. Stressing the fluctuating nature of chronic illness, Moss and Dyck (2002) observe:

> Chronic illness [is] a state of waxing and waning. . . uncertainty. . . indeterminacy . . . fluctuation. This capricious movement inherent in chronic illness sets up individuals to experience both vigour and lethargy, remissions and flare-ups, 'good days' and 'bad days' sometimes months apart, sometimes within minutes of each other, sometimes in tandem (p. 16).

Although Moss and Dyck (2002) allude to the word "unsettled" in relation to the fluctuating body in chronic illness, the phrase itself is not fully developed in their analysis. What makes this study unique is that I work inside this emerging domain of shifting bodies by carving out the "(un)settled body" as the fundamental premise of this text. In doing so, I conceptually ground a phenomenological understanding of (un)settled bodies in ways that are conversant with disability studies and queer theorizing, thereby encouraging a more flexible, critical version of "sight" and "insight" beyond what "normally" meets the eye in relation to embodied identity. Equally significant, I take the notion of the (un)settled body to the next level by methodologically drawing on the complementary practices of (non)art photography to visually and interpretively convey how bodies and identities shift in (in)visible and (un)settled ways in their material and social locations. In this way, I break the silence of (in)visible disability by calling attention to and creating a language for experiences that remain unnamed, that are ineffable in their shifting subjectivities, that question or "crip" (McRuer, 2006) how we interpret bodies in society.

I engage the reader's curiosity by making a case that an (un)settled embodiment is both incredible and credible in its (in)visibly shifting materiality across different life moments and settings. I critically examine how this (in)credulity presents itself within the institutional, cultural, and social practices, relations, and ideologies that influence women's daily lives. I emphasize how this shifting (dis)belief enveloping women's (un)settled subjectivities encourages women to both resist and changeably enact the unsettledness of their identities in particular ways. I argue in favour of unlikely identifications and take the position that embodied identity within the context of an (in)visible disability is fragmentary, always in transition, and holds in tension homogenized albeit incomplete constructions of healthy, ill, and disabled bodies. Finally, I depict how the visibility of the unsettled body emotionally translates into the shifting (in)visibility of the social self in relation to attitudinal, ideological, and environmental barriers.

Since the discourse around what counts as disability is itself unsettled (Moss & Dyck, 2002, p. 108), I anticipate that some readers may feel uncomfortable and skeptical in considering chronic illness as a kind of disability or more precisely, to consider living with an (un)settled body as an (in)visible disability. Part of the apprehension and controversy surrounding the association between chronic illness and disability emanates from the longstanding debate hedged in the disability studies literature that ideologically polarizes "impairment" from "disability." The idea of impairment implies that disability is derived from the biological body, specifically abnormalities in system or organ functioning and/or appearance, whereas disability is considered a social construction through which society oppresses and excludes disabled people (Imrie, 2004, p. 287; Matthews & Harrington, 2002, p. 406). However, in relation to this research, I argue that this enduring divide is experientially porous rather than theoretically static.[6]

Wendell (1996) insists that disability whether congenital or acquired is an essential, pre-social biological difference overlaid with socially constructed ideas about the body. This argument is vital to understanding how the materiality of the body underscores my definition of (in)visible disability in this work. Aligning myself with leading interdisciplinary scholars (Barnes & Mercer, 2003; Bury, 1997, 2000; Lindgren, 2004; Matthews & Harrigton, 2000; Moss & Dyck, 2002; G. Williams, 1998, 1999; 2001; Shakespeare & Watson, 2001; Thomas, 1999, 2004; Vickers, 2001b), I contend that the shifting physical, social, emotional, and contextual dimensions of an (un)settled embodiment wreak havoc on the body and on one's sense of self. To undermine the significance of the lived body and the integrity of women's experiences is to deny how (in)visible disability pervades women's everyday lives. Bolstering this naturalistic standpoint, Liz Crow (1996) reminds us that "impairment *in itself* can be a negative, painful experience" (p. 219) and that no amount of social justice can eliminate the physical and psychological suffering associated with it (Wendell, 2001).

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[6] For an excellent discussion on this debate, the reader is encouraged to consult Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge: Polity Press.

At the same time, I am cognizant of the criticisms posed by some scholars (Abberley, 1987; Hahn, 1986; Oliver, 1990) who warn that any essentialist claims about biology situate a myopic conception of the disabled body as abnormal which in turn, become the basis for conferring social injustice and prejudice (Imrie, 2004). Having said this, as a woman living with an (in)visible disability[7] and an aspiring academic in the field, I stretch a perspectival arm out to Hughes (2002), Hughes and Paterson (1997), and Thomas (1999) in maintaining that a modernist uncoupling of impairment from disability binarizes rather than honours the experiential complexity of living with an (in)visible disability. Unquestioningly, I believe that women living with (in)visible disabilities in this project embody a biologically distinct materiality but one that is also socio-culturally pliant (S.J. Williams, 1998a). Thus, rather than ontologically and epistemically counterpoising the physicality of the body from its social construction, what I am positing is that experiencing an (un)settled body within the milieu of (in)visible disability is the entanglement of bio-psycho-social forces, circumstances, and contexts (Bury, 2000; Thomas, 1999). This position differs from Joan Scott's (1998) view that the danger of taking personal experience as an originary point of explanation precludes any critical examination of how difference is culturally systematized and ideologically constructed. Indeed, the perspective of disability I am emphasizing is, as Imrie (2004) outlines, one in which the intersection between the biological and the social come together, where the functional limitations of bodies become disabling as a consequence of broader social, attitudinal, and discursive relations (p. 5). I again consider the words of Wendell (1997) in advocating this stance:

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[7] Throughout this work, I employ the phrase "women living with (in)visible disabilities" in contrast to the phrase "women with (in)visible disabilities" which fractures the woman from the experiencing body (Marks, 1999; Michalko, 2002a; Morris, 2001).

> I believe that in thinking about. . . disability we need to strike a balance between, on the one hand, thinking of a body's abilities and limitations as given by nature and/or accident, as immutable and uncontrollable, and, on the other hand, thinking of them as constructed by society and culture as to be controllable by human thought, will, and action. We need to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognizing that there may be much suffering and limitation that they cannot fix (p. 45).

Further summarizing the futility of separating this seamless reality, Shakespeare and Watson (2001) purport:

> Impairment and disability are not dichotomous, but describe different places on a continuum, or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts. . . Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision (p. 24).

Study Focus

Situated within a visually-informed phenomenology, the primary purpose of this research explores how women experience living with an (un)settled body that (in)visibly shifts between periods of settled-ness or nearly normal health and episodes of volatility or (un)settled-ness. Since the materiality of bodies are inextricably embedded within personal, social, occupational, ideological, and institutional context(s), a second purpose of this inquiry demonstrates how rigid constructions of health/illness, dis/ability, and in/visibility are experienced in women's lives. By selectively focusing on ordinary life moments that break up, twist, and hold these tensions in place, this study provides a vital entry point where different versions of disability can unravel and be heard (Hamilton, 1997; Mintz, 2002; Titchkosky, 2001). Complementing these aims, a broader objective of this inquiry explores the significance of personal photography as an alternate point of contact for story-telling and story-showing (Bochner & Ellis, 2003) a more complicated understanding of (un)settled embodiment as a fluid, shifting continua of multiple identities and realities.

Research Objectives

Opening Dialogue

While I partially agree with Samuels (2003) that disability discourse is increasingly becoming cognizant of invisible disabilities, its theoretical and representational basis remains largely dedicated to visible unchanging impairments rather than bodies that live in the interstitial spaces of (in)visibility and (dis)ability in (un)settled ways. Drawing conceptually from my pilot study entitled *The Body Doesn't Go With the Head: Encountering and Transforming Images and Spaces of the Body-Out-Of-Whack* (Vick, 2003), this research inserts un-talked-of photographic images and experiential accounts of (un)settled bodies into our field of vision and thought through the unheard voices of women living with (in)visible disabilities. Innovatively opening dialogue that originates in lived experience and slides back and forth between its visual and textual representation will deepen conversation by evoking alternate ways of thinking more fluidly about disability and legitimating other possibilities for identity.

Creating Alternate Representations

While chronic illness is a major cause of disability (Wendell, 1996), the women in this study remain marginalized within the larger scope of persons living with disabilities and lack the opportunity to produce representations that speak to their lives. Consequently, this research relies on personal photography as a self-inscriptive medium to destabilize dominant assumptions, stereotypes, and representations of (dis)ability in favour of identities that contract and expand, speaking inside and outside the borders of health/illness, dis/ability, and in/visibility in everyday life scenes (Bochner & Ellis, 2004; Mintz, 2002). Conveying the power of photography in relation to this objective, feminist theorist Marianne Hirsch (1997) states:

> The structure of looking is reciprocal: photographer and viewer collaborate on the reproduction of ideology. Between the viewer and the recorded object, the viewer encounters, and/or projects, a screen made up of dominant mythologies and preconceptions that shapes the representation. Eye and screen are the very elements of ideology: our expectations circumscribe and determine what we show and what we see (p. 7).

Moss and Dyck (2002) stress that challenging the fixity of discursive categories opens spaces to engage in rewriting the body within and through competing renditions of what it is to be ill and healthy (p. 100). Supporting this focus, Clare (2001) and Titchkosky (2003) assert that recognizing (un)settled embodiment as both a standpoint and teacher in the midst of common doings and ordinary thought reflects a politicized space from which we can begin to think and act. Reiterating the importance of politicizing the experience of (in)visible disability, Moss (1999) contends "it is beneficial to emphasize routines and mundane acts of daily living, the stuff comprising our everyday life that makes us think as we think, believe what we believe, and act how we act" (p. 157). Hence, by coupling images and words, this research will enlighten and connect the "observer-turned-witness" (Radley, 2002, p. 8) in novel ways to bodies that live on the (un)settling borders of (in)visible disability.

Transforming the (Non)Disabled Gaze

Closely aligned with creating alternate portrayals and challenging representations, this research aims to transform the gaze of the reader-viewer by unsettling habitual ways of "seeing" disability and enriching current ways of thinking about bodies in our society (Mintz, 2002; Thomson, 1997; Wright, 2001). Building on Hughes (1999, 2002) and Shakespeare's (1994) assertion that the non-disabled gaze defines and shapes the experience of visibly impaired bodies, this research assumes an analogous twist. Similar to the non-disabled's reliance on visually based conceptions of the "normal body" for interpreting disability, persons living with disabilities visually assume a "disabled normality" (Hevey, 1997) in which impaired bodies and identities are discernible and static. This reified focus on the visibility of a disabled identity in relation to familiar bodily markers such as wheelchairs, white canes, and service dogs and the search for these indicators when disabilities are questioned, inversely parallels hegemonic ideologies and practices in which an understanding of disability becomes solely identical with such signs (Radley, 2002; Samuels, 2003).

Weaving Connections with Social Work

Transforming Visions, Transforming Lives

In translating the objectives of this work directly to social work practice, I invite the reader to reflect on the words of Cal Montgomery (2001):

> We speak as if some kinds of disability were visible and others weren't. Let me suggest a different approach: think about the ways different kinds of disability have become more familiar, and more visible, to you as you've gotten to know more disabled people (p. 1).

Bearing these words in mind, the heart of this research encourages practitioners to re-evaluate their own assumptions and perceptions by engaging with a more complex understanding of the experiential realties of (un)settled embodiment as another tier of the disability experience. In line with Ann Davis (2005) who endorses the inclusion of [in]visible disabilities within the category of disability, I maintain that our commonsense notions of (dis)ability as human service professionals and human beings is fundamentally flawed, demanding a radical conceptual reframing. Reflecting on dominant cultural representations of disability and their influence on the helping professions, Wendell (1996) stresses that there are important differences in the way disability is narrowly defined by service providers to fit bureaucratic mandates and the way it is experienced by individuals themselves. Offering a similar argument, Ferri and Gregg (1998) write that "disability" and "ability" are social constructs whose definition has a powerful impact on both the nature of service provision and access to services. Since women living with (un)settled bodies are characterized by an (un)marked identity that vacillates betweens periods of (in)stability yet often look well, a lack of professional sensitivity to this shifting embodiment sustains naturalized categories that denies access to crucial supports and services (Fox & Kim, 2004; Kafer, 2003; Moss, 2000; Moss & Dyck, 1999b). By awakening professional attention to the marginalized voices of (un)settled embodiment as teacher, (Michalko, 1998, 2002a), social workers can challenge problematic assumptions, attitudes, and discourses that in the end, sink beneath the skin of our clients as they impact on their everyday lives. In directing ourselves to these tasks, we can advocate new ways of seeing, understanding, and helping that calls forth the diversity of embodied experience.

Reflective Entry Points

This research illuminates a more complex portrayal of disability by exploring how bodies living on the borders of health/illness, dis/ability, and in/visibility are felt, enacted, and perceived in ordinary life moments, ultimately challenging the nature of disability representation itself (Corker, 1999; Garland-Thomson, 1997b; Titchkosky, 2003). This liminal existence, a paradoxical fusion that is never simply one way of being or another, entails living in-between shifting periods of (un)settled-ness that demands the negotiation of a (dis)abled identity contextually, situationally, and temporally (Brueggemann &

Moddelmog, 2002; Morris, 2001; Munson, 2003). By framing an understanding of (un)settled embodiment from this standpoint, several initial questions follow:

- What are the different ways women experience and ascribe meaning to the (in)visible
  (un)settled-ness of their bodies?
- In what ways does this episodic (un)settled-ness enact itself across ordinary life moments, settings, and temporal frames?
- In what ways does living in-between, shifting periods of (un)settled-ness enable women to negotiate passing into and out of a (dis)abled identity in ordinary moments, situations, and contexts?
- In what ways is (un)settled embodiment experienced as an (in)visible disability? A (dis)abled identity?

Secondary Research Focus

Eisner (1992), Norris, (1997) and Langer (1957) imply that the arts, or what I define as creative self-works in this research, invokes an alternate conversation or "encounter" between representation and interpretation in which we can discover the possibilities of human experience. Given that this study relies on photographic portrayals to illuminate the lifeworld of (un)settled embodiment, this study raises the question:

- In what ways can practices of inquiry using photography give voice to and transform our understanding of (un)settled embodiment?

Sketching the Path

Before shifting the discussion to the theoretical directions that inform the women's stories, I pause here and describe the organization of the thesis as a whole. Drawing on the symphonic origins of the term "movement" which denotes the distinctiveness and flow of various parts of a musical composition, I choreograph the dissertation into six principal movements that mirror the (in)visible "shifts" of an (un)settled embodiment. Within each movement, I organize the discussion into various thematic chapters. In the Opening Movement, I introduce the focus and objectives of the study, provide reflective entry questions that guide the research, and delineate the relevance of this current work within the context of social work practice. In the Second Movement, Theoretical Directions (Chapter 2), I situate the research in relation to the relevant extant theory. This discussion is not an all-encompassing exploration of every possible dimension of the experience of (in)visible disability but synoptically describes where the conceptual boundaries of the research lie. In the Third Movement, Crafting (Un)Settled Embodiment (Chapter 3), I provide an examination of the philosophical and methodological framings guiding the research. Select consideration is given to the various stages of data production and analysis that the participants and I engaged in. I also offer a detailed account of the interpretive steps I followed in representing the women's stories. Throughout this third movement, I outline the ethical considerations and the evaluative criteria underpinning this project.

In the Fourth Movement entitled (Un)Convincing Bodies, I braid the women's experiential accounts, photographic images, and my own interpretive analysis with an elaborated discussion of the literature presented in The Second Movement (Chapter 2, Theoretical Directions). Within this movement, there are five chapters. Commencing with Chapter 4, Fluid Sightings and Carnal Stirrings, I illuminate the material and sensory essence of (un)settled-ness as it (un)convincingly erupts within the body. In Chapter 5, The Odyssey of Diagnosis: (Dis)missed Bodies and Chapter 6, The Odyssey of Diagnosis:

Reprise: (Un)Imagined Bodies, I focus on the diagnostic journey, medical (de)legitimation, and epistemic invalidation of (un)settled bodies. In Chapter 7, (Un)Forgotten Bodies, and in Chapter 8 (Un)Forgotten Bodies Revisited: The Self in Flux, I explore the ways in which living with an (in)visible disability is interpersonally forgotten and remembered in women's everyday social worlds and explore the fluctuations in women's own forgetfulness in living with their (un)settled bodies.

The fifth movement describing the Fluidity of Identity is organized into three chapters. In Chapter 9, I portray the Secreting of Fluid Identities: (Im)Positions of Normalcy and follow-up in Chapter 10 with Blending-in Fluid Identities: (Im)Positions of Normalcy. Written as complementary chapters, chapters 9 and 10 differentially explore how women negotiate the fluidity of their (un)settled bodies and (dis)abled selves across everyday life moments and contexts. In Chapter 11, Unburdening Fluid Identities: Dialectical Tensions, I examine the complexity of strategically revealing a fluid embodiment.

I conclude the interpretive discussion with the sixth movement in Chapter 12 entitled (In)Visible Wounds. In this chapter that characterizes the third story, I distinctively highlight the visible and invisible emotional shifts in living with a progressive disability, touch on its significance for self-identity, and feature its socio-cultural foundation.

In the Closing Movement of Chapter 13 entitled (Re)Weaving Tensions: An Invitation for Reflection, I review the themes characterizing the study, highlight the conceptual and methodological contributions of this work, and comment on the value of employing photography as an interpretive tool and as a transformative personal process. I conclude with a discussion of implications for social work practice, outline areas for future scholarship, and provide final remarks in light of the suggested implications.

The Second Movement

Chapter 2

Theoretical Directions

Stitching together threads from corporeal phenomenology, the sociology of chronic illness, the disability studies literature, social constructionist versions of embodied identity, and lesbian, gay, transgender, and queer scholarship, this chapter spotlights a bird's eye view of select theoretical "tensions" of (un)settled embodiment. In stating the panoramic intentions of this chapter from the outset, it is important to stress that I develop a more comprehensive dialogue with the literature to accentuate the participant's voices and highlight the issues I raise throughout the study's interpretive analysis in Chapters 4 to 12.

In situating (un)settled embodiment within this blended theoretical milieu, I am simultaneously cognizant of their notional rivalry. Shakespeare and Watson (2001) and Hughes and Paterson (1997) argue that any post-modern theorizing of the body leaves no space for the palpable, natural body. Indeed, without a consideration of the materiality of the body, the body qua body is no more than a phantasm that disappears into language and discourse, replacing biologism with discursive essentialism (Turner, 2001). To redress this, I seek a confluence of material-discursive perspectives to provide a more flexibly inclusive analysis of (un)settled embodiment.

As a vital entry point, I situate an understanding of (un)settled embodiment by selectively focusing on the concept of the "lived body" drawing on Merleau-Ponty's (1962) *Phenomenology of Perception* and other writers who extend his work. Foremost, (un)settled embodiment is a way of being and having a body, the very stuff of our subjectivity (Grosz, 1994). Since the subjectivity of (un)settled embodiment cannot be theorized apart from its embodied experience, a corporeal phenomenological lens moves us away from a theorization *of* bodies to a theorization *with* bodies emanating from the voices of everyday lived experience (Thomas, 2002). By lived experience, I am referring to the physical, social, cultural, emotional, and political meanings that contexualize our embodied existence (Turner, 2001; Wilde, 1999). Extending a conception of lived experience that speaks to the core of this research, Eugene Gendlin (1962) avers:

> Meaning involves *felt* experiencing . . . . I use the word "experiencing" to denote *concrete* experience because the phenomenon I refer to is the *raw*, present, ongoing *functioning* (in us). . . . Experiencing is thus *implicitly* meaningful. It is something present, directly referred to, and *felt* (pp. 1, 11, 242-244).

Nested within the phenomenal body, I introduce the onset of (un)settled embodiment as a biographical disruption (Bury, 1982, 1997) or more pertinently, a continuous albeit shifting interruption (Charmaz, 1997; Honkasalo, 2001). Moving with biographical disruption as a stepping-stone, I address the emotional world of loss in living with an (un)settled body.

Culminating from these routes, I stress the dilemmas individuals experience in seeking institutional legitimacy and by extension, personal credibility through the process of medical diagnosis. Following this, I discuss the interpersonal and personal frictions individuals confront in living with an (in)visible disability. Next, I veer the course towards a post-modern, constructionist positioning of (un)settled embodiment as a fluid, ontological state of "in-between-ness" (Moss & Dyck, 2002; Titchkosky, 2003). I move on to extend a conceptualization of living in-between to the ways individuals negotiate their (un)settled selves through the identity work of passing which I later interpretively describe as secreting in Chapter 9 and blending-in in Chapter 10. I then discuss the tensions inherent to the issue of disclosure that I characterize as unburdening fluid identities in Chapter 11.

The Lived Body: A Corporeal Phenomenology

Corporeal phenomenology rejects a Cartesian paradigm of embodiment that divides the "objective" physiological body of medicine from the mind or the "subjective" body of personal experience (Turner, 2001). Arthur Frank (1995) and Drew Leder (1984) insist that one must look at human beings not just as a body but as a body *and* mind, an interplay of the physical, the psychological, and the emotional. Merleau-Ponty (1962) purports that the very basis of all human subjectivity is located not in consciousness or in the mind but in the lived, animated, experiencing body that is a site of meaning and source of knowledge about the world (Hughes & Paterson, 1997; Paterson & Hughes, 1999). Instead of saying, "I have my body" Merleau-Ponty affirms, "I am my body" (1962, p. 198). To be human is to live in the lifeworld of physical experiences, activities, and environments mediated through the body and its underlying biology (Iwakuma, 2002; Millward & Kelly, 2003, p. 159). In this sense, as Rosalyn Diprose (1994) indicates, "the body is not so much an appendage to the self as the very fabric of the self" (p. 108). Summarizing the nature of the lived body, Elizabeth Grosz (1994) observes:

> Insofar as I live the body, it is a phenomenon experienced by me and thus provides the very horizon and perspectival point which places me in the world . . . It is the body as I live it, as I experience it, and as it shapes my experience (p. 86).

Hughes and Paterson (1997) and Paterson and Hughes (1999) assert that the body is an experiencing agent that is as it is. In essence, we exist as our bodies and have access to their knowledge by connecting with and through them in our world (Crossely, 1994; Grosz, 1994; Sullivan, 2001).

As the very fabric of the self, the lived body not only forms the basis of our experience by virtue of us being and having a body but is also our way of being-in-the-world

(Crossley, 1994; Hughes & Paterson, 1997; Iwakuma, 2002). Our belonging or being-in-the-world is generated vis-à-vis our bodily senses as well as through our motility, language, and desires (Bannan, 1967; Diprose, 1994). The body does not just passively receive sense data but uniquely exhibits a bodily intelligence, affectivity, and openness that is fundamental to its sentience (Bigwood, 1991; Toombs, 1992). Operating within the phenomenal, sentient body is the corporeal schema, defined as a set of historicized or sedimented capacities, habits, gestures, and conducts that symbolize the texture of the self's social identity and one's existential difference in the world (Diprose, 1994; Merleau-Ponty, 1962).

While the lived body is innate to our sense of self, it is at the same time, intercorporeally constituted. Merleau-Ponty writes, "the lived body is neither exclusively a subject nor an object but both: it is intercorporeally constituted" (1962, p. 167). Arthur Frank (1995) speaks of the dyadic body stating, "the other's [body] has to do with me, as I with it" (p. 35). In this way, as Crossley (1994) implies, "subjects are not locked into their own private worlds but are in-the-world, a world shared by all" (p. 37). Hughes and Paterson (1997) underscore that above all else, the impaired body and by extension the (un)settled body, is not experienced in Cartesianized compartments but is a complex interpenetration of personal subjectivity and its cultural constitution. Ultimately, the personal experience of our bodies and identities is socio-culturally shaped and reciprocally, influences these relations and points of contact (Merleau-Ponty, 1962; Millward & Kelly, 2003; Shildrick, 2002; Sullivan, 2001). Having sketched the phenomenal body, I steer the discussion to the manner in which (un)settled embodiment materially debuts within the lived body.

The Lived Body as an (Un)Settled Body

In bridging an understanding of the lived body with (un)settled embodiment, Merleau-Ponty (1962) asserts that it is the lived body, the self's personal and social identity that are indivisibly lodged within it, and one's relationship to the lifeworld that breaks down with the onset of chronic disease and disability (Diprose, 1994). In the words of Merleau-Ponty, "it is the intentional arc [corporeal schema] which brings about the unity of the senses, of intelligence, of sensibility and motility . . . which 'goes limp' in illness" (1962, p. 136). Alternately stated, illness represents "dis-ability," the inability to engage the world in habitual ways (Toombs, 1992, p. 62). Any disruption to our bodily being alters our modus operandi, the physical and social freedom to "be" and act in the world in customary, stable ways and transforms the manner in which we perceive ourselves and are seen by others (Kvigne, Gjengedal, & Kirkevold, 2002). Thus, only when things go wrong with our bodies, when an existential otherness rises up against the experience of "being me" do they encumber our freedom to act in habitual ways (Gadow, 1980; S.J. Williams, 1996, 1998a). For Sally Gadow (1980), this bodily breakdown echoes a "disrupted immediacy" in which one's being-in-the-world, ruptured by incapacity, engenders a sense of "homelessness" within the body (Svenaeus, 2000).

(Un)Settled Embodiment as Biographical Interruption

The collapse of the able body into an (un)settled body is a uniquely private experience that others cannot readily feel with us and know (Hilbert, 1984; Hughes & Paterson, 1997; Millward & Kelly, 2003). Fluctuating early eruptions of an (un)settled embodiment that are initially ignored or belittled as part of the strains of daily life may include but are not limited to alterations in vision, mobility, sensation, as well as baffling episodes of severe pain (Charmaz, 1997; Cooper, 1997; Koopman & Schweitzer, 1999). Providing an arresting account of the frightening yet remitting signs of multiple sclerosis spreading wildly throughout her body, Miriamme Ara Krummel (2002) recalls:

> November 1996. I wake up Thanksgiving morning with numbness. . . a little more severe than usual. And with each morning until the middle of December, the numbness increases. This episode marks a change in the way my body unleashes the MS exacerbation, for now my episodes climb step by step to a peak and then retrace the steps back downward toward normalcy. After a few days of numbness that spreads up my limbs, I then notice the appearance of L'Hermitte's sign, an abnormal sensation of electricity or pins and needles going down the spine into the arms and legs. . . Next there is a tight band around my chest which causes me to fear that my breathing will shut down. . . As the episode peaks, I can hardly use my hands. I begin to walk so, so slowly. I feel disabled. For the first time, I feel diseased (p. 69).

These eruptions eventually culminate into what Bury (1982, 2000) defines as a biographical disruption. This carnal fracturing reflects the loss of the destination and map that guides an individual's life, thereby threatening an established sense of self and familiar ways of engaging with the world (Becker, 1997; Charmaz, 1983; Frank, 1995; Toombs, 1992). While Bury conjectures a sole insurgency in which the body fails to return to its normal state (Radley, 1997), I support Charmaz (1997) and Honkasalo's (2001) argument that biographical disruption is a process of successive albeit erratic interruptions given the fluid nature of an (un)settled embodiment. While the notion of biographical disruption has interpretive merit in thinking about (un)settled bodies, neither Bury, Charmaz, nor Honkasalo interrogates naturalized conceptions of (ab)normalcy, health, illness, (dis)ability, and a so-called normal life that come into play with an (un)settled embodiment. Following Moss and Dyck (2002), I suggest that biographical disruption while a significant reality of living with an (in)visible disability for many, ultimately impels individuals to redefine what normalcy, health, and illness means within the context of their everyday lives given the complexities that an (un)settled embodiment entails.

Since many individuals look healthy even during their worst exacerbations (Donoghue & Siegel, 2000), early life-interrupting flare-ups are paradoxically experienced as (un)real since they seldom leave lingering, visible traces. However, with escalating eruptions, a cyclic tension builds in which individuals spiral back and forth between believing that what they are physically experiencing has a definitive organic basis and questioning whether such carnal sensations reflect chimerical phenomena (Donoghue & Siegel, 2000; Charmaz, 1991, 2000; Cooper, 1997; Telles & Pollack, 1981). This friction of feeling (un)convinced by the ebb and flow of an (un)settled body inspires alternating feelings of (dis)belief that challenges and validates women's distinctive, intuitive ways of reading and knowing their bodies (Kvigne & Kirkevold, 2003; Moss & Dyck, 1999a, 2002; Richardson, 2005; Werner & Malterud, 2003).

Despite the (un)predictability and (dis)belief biographical interruption entails, the threat of shifting disintegration promises reintegration. As Frank (1995) avers, "what is unmade stands to be remade" (p. 172). Merleau-Ponty (1962) posits that persons living with chronic illness can recover their freedom through a re-inhabiting of the body. By (re)claiming lost or forgotten habits and acquiring novel bodily practices, the lived body as an (un)settled body remains full of possibilities and open to relearning how to negotiate its actions for being-in-the-world (Toombs, 1995, p. 16). Given this, the experience of (un)settling chronic illness must be (re)conceived within a broader context that transcends a view of the body as pathologically disrupted in favour of a body that continuously renegotiates a realignment or settlement between body and self in inventive ways (S.J. Williams, 1996).

The Emotive World of Biographical Interruption

While some persons living with (un)settled bodies experience the turbulence of illness cycles, for others, (un)settled embodiment spirals into a degenerative illness trajectory. It is the (un)spoken, emotional wounds accompanying the biographical interruption of (un)settling illness that I allude to here and take up further in Chapter 12.

Denzin (1984), Freund and McGuire (1999), and S.J. Williams (1998b) consider emotions as corporeal and socio-cultural existential modes that reflect the nexus of lived experience. Enriching the view in which inner and outer worlds merge, Denzin (1984) maintains:

> Emotional consciousness has a lived "realness" that is not doubted by the person. The emotional experience radiates through the person's stream of consciousness and is felt throughout the body. The reality of the emotion is held to be true by the person. . . . The world of emotion is distinct because inner meanings and feelings are revealed. . .while they are hidden and glossed over in the taken-for-granted world (pp. 93- 95).

By pervading all aspects of identity and life, the slow but steady biographical interruption characterizing a progressively fluid embodiment insidiously alters one's sense of control, independence, life-choices, relationships, and the promise of a secure future (Asbring, 2000; Charmaz, 1997; Sidell, 1997). There is often a sense of having two separate identities, the valued one relative to life before illness and the dramatically transformed or "lost" one thereafter (Asbring, 2000; Charmaz, 1983). Bury (2000) explains that any loss regardless of magnitude is experienced against a backdrop of normative cultural values that somatically reaffirms one is no longer a part of a healthy, able-bodied world and that things will never be right again. Noting this, the experience of loss within the context of an (un)settled embodiment is for some, the emotional experience of suffering that infuses the soul, or the core of our personhood, with feelings of grief, envy, shame, humiliation, guilt, inadequacy, isolation, loneliness, and despair (Frank, 1995; Kleinman, 1988; Pollack & Sands, 1997). Such feelings crushingly erode an individual's self-esteem and sense of human-being-ness and are experienced as an (in)visible silent form of suffering (Cassell, 1992; Charmaz, 2000; Dewar & Lee, 2000; Eeltink & Duffy, 2004; Frank, 1995; Gulick, 2001; Kralik, 2002; Lazare, 1992; Lubkin, 1986; Miller, 1997; Morse, 2000; Murray, 2001; Robinson, 1988; Royer, 1998; Starck & McGovern, 1992; Vickers, 2001b).

Despite corporeal phenomenology's efforts to enlighten our understanding of how bodies transformed by illness and disability are (re)experienced and (re)interpreted in the everyday world as *new* modes of being, several invectives are levelled at Merleau-Ponty's paradigm of embodiment. Feminist theorists in particular argue that Merleau-Ponty's myopic focus on the male, able body as *the* model of lived experience implies that there is a universal and thereby normal way for human beings to *be* that excludes other bodies and embodiments. Adding to this from a disability studies lens, Merleau-Ponty's analysis relies on a pathologized understanding of the impaired body that although amenable to adaptation through its metamorphic potential, remains "lacking" in its full capacity for humanness, thus reinforcing disablism (Paterson & Hughes, 1999).

While a phenomenological understanding of the (un)settled body enables us to capture and develop new and deeper meanings of the relationships between the body and self in relation to illness, impairment, loss, suffering as well as possibility (Charmaz, 1995), such lived realities are often disembodied from their larger social, cultural, political, and spatial milieus (G.H. Williams, 1996, 1998). This research seeks to quell this limitation by situating the lives of women with (in)visible disabilities within the socio-cultural and discursive framings enveloping women's everyday lives.

In sum, the physical breakdown of the body from a familiar, settled one into a chaotic (un)settled one is initially a frightening and seemingly biographically (sur)real experience. With mounting distress, women seek legitimation through medical diagnosis to prove to themselves and others that what is physiologically happening within their bodies is indeed real. I now turn to the search for diagnosis and the tensions emanating from this journey.

Diagnostic Crossroads: Experiencing (Ill)Legitimacy

An individual's pursuit of objective, medical "proof" to validate initial physical and sensorial eruptions that erratically eludes visibility is a search for convincing physical testimony of their (un)settled embodiment (Moss & Dyck, 1999a; Richardson, 2005; Wall, 2005). As official legitimators, physicians have the authority to bestow a medical inscription that credits (un)settled embodiment with the appropriate proof as having a biological rather than a psychogenic basis to self and others (Cooper, 1997; Hellstrom, Bullington, Karlsson, Lindqvist, & Mattsson, 1999; Sveilich, 2005; Sturge-Jacobs, 2002; Telles & Pollack, 1981). Introducing the tension of securing physical testimony in the "absent presence" of disease, Dorothy Wall (2000) who lives with the (in)visibility of chronic fatigue immune dysfunction syndrome relays:

> If someone is ill we want proof. A test, a diagnosis. Evidence. As a person with chronic fatigue immune dysfunction syndrome (CFIDS), I don't have much to offer. My body is intact. I have no crusty blood, no sour-smelling secretions, seeping wounds, swollen flesh. No unsightly scars, no bandages, tubes, bruises. No suspicious blood tests or X rays, no growths. My injuries are invisible, subtle in neurons, enzymes, cytokines, the intricate inner circuitry of the body that still eludes concise theories, that requires scientific minds to make a leap of faith, to become, as it were, believers (p. 23).

The quest towards diagnosis, which can be short-lived or extend over several months or years, is an emotionally onerous battle (Mendelson, 2006; Moss & Dyck, 2002; Vickers, 2001b). The body a person experiences and that which a doctor assesses are seldom the same (Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999; Wall, 2005). The breakdown of the body in chronic illness is not simply a medical issue; it has a subjective essence, a felt bodily sense that is an informative and powerful source of knowledge (Millward & Kelly, 2003; Sullivan, 2001; Toombs, 2004). Yet within biomedicine, a physician's evaluative attention resides largely in the confirmation of pathogenesis from the external body (Leder, 1984; Hughes, 2000; Moss & Dyck, 1999a). In order to receive diagnostic legitimacy, (un)settled embodiment must be axiomatic or "seen" within the body (Hughes, 2000; Honkasalo, 2001). Rhodes et al. (1999) corroborate the meaning invested in tangible, visual diagnostic testing as the pinnacle of patient credibility. These authors stress that women living with (in)visible episodes of chronic back pain confront a disjunction between the certainties of their embodied experience, especially as indicative carnal signs escalate, and medicine's clinical disconfirmation of their (un)settled realities. Commenting on the reification of lab tests and visible pathology to the exclusion of lived suffering, Wall (2005) indicates:

> [An] over-reliance on lab tests and visible pathology is itself the problem. When did we subdue the ambiguity and complexity of biology as to be able to determine disease legitimacy by tests and scans alone? What happened to the kind of seeing that goes on when the doctor looks at the patient, not only an MRI? What happened to . . . attention to individual suffering. . . Seeing the body piecemeal . . . we eclipse the patient, that complex person perched on the exam table (p. 27).

Herein lies the elemental tension of the mutable mystique of an (un)settled embodiment: early palpable signs of distress are not always uniformly visible or behaviourally static, thus challenging biomedicine's reliance on "hard facts" and measurable findings (Hilbert, 1984; Jackson, 1992; Lillrank, 2003; Moss & Dyck, 2002; Reid, Ewan, & Lowy, 1991; Vickers, 2001b). Conveying what existentially feels so real but that is medically unseen in its early stages is tolerated at best, and ignored at worst within the doctor-patient relationship (Nettleton, Watt, O'Malley, & Duffy, 2005; Wendell, 1996).

Adding to this tension, individuals rarely have the language, medical or otherwise, to communicate their experiences. Even when people *do* have a medically informed, linguistic arsenal at their disposal, such expressivity rarely reflects the phenomenal essence of their (un)settled bodies but merely opens the gateway for authorized physician-patient dialogue. Demarcating the combative nature of the medical encounter in which the impartial, rational objectivity of medicine rivals a person's subjective ways of knowing, Leder (1984) remarks:

> While few shun the services of the modern physician at times of serious illness, many patients experience aspects of their treatment as reductionist or dehumanizing . . . When the patient appears as physiological mechanism, the doctor may neglect personal communication (p. 36).

Overall, a formal diagnosis is dually controversial because while it can bestow relief and vindicate a person's bodily being to themselves and others, at the same time it can perpetuate suffering when it disconfirms one's "corpo-reality" (Asbring & Narvanen, 2002; Chircop & Keddy, 2002; Rhodes et al., 1999; Richardson, 2005; Ware, 1992; Vickers, 2001b). Conversely, an organically based diagnosis may also shocking or directly denied when it contradicts a person's appearance and variable periods of health (Kralik, Brown, & Koch, 2000; Sturge-Jacobs, 2002; Sveilich, 2005; Vickers, 2001b). Similarly, the incongruity of a psychosomatic diagnosis in the "presence" of an (un)settled embodiment, especially among women, contests the experiential reality of (dis)appearing cycles of impairment while at the same time, situates self-doubt and a shaky credibility among patients, a scenario I describe next.

Suspect Carnalities

As part of the diagnostic odyssey, scientific materialism equates the "real" with physically observable, somatic indicators of disease and discounts subjective experience as "unreal" or psychosomatic (Cooper, 1997; Jackson, 2005; Kugelmann, 1999; May, Rose, & Johnstone, 2000; Richardson, 2005; Schaefer, 1995; Sturge-Jacobs, 2002; Vickers, 2001b; Wall, 2005; Ware, 1992). This epistemic schism is evident in relation to the manner in which specific illnesses are socially constructed. For example, in relation to this inquiry, the biological basis and social profile of multiple sclerosis is well established in comparison with vulvodynia, a relatively unknown and originally psychologized disease despite its now known organic basis. However, as this study later exemplifies, neither condition initially appears as physically convincing to physicians, many of whom are predisposed to position women as "suspect cases."

Without an official declaration of illness, the (un)settled body remains materially dubious and an individual's integrity similarly specious (Asbring & Narvanen, 2002; Gibson, Cheavens, & Warren, 1996; Jackson, 2005; Register, 1999). Asbring and Narvanen (2002), Rhodes et al. (1999), and Ware (1992) stress that to feel delegitimized is to repeatedly experience disconfirmation of one's perceptions of reality and embodied experience. Ware (1992) cites two intertwined forms of delegitimation among women living with (in)visible illness: the trivialization of physical symptoms and a view of (un)settling subjectivities as psychosomatic (p. 350). Discussing the illegitimacy surrounding women living with chronic fatigue syndrome, Ware (1992) reports that women are disbelieved because they do not look sick or display any obvious signs of disability. More specifically, women's symptoms including fatigue, pain, and feelings of depression are belittled as a discomfiting consequence of the stresses of normal life rather than instances of fluctuating bodily (un)settled-ness (Moss & Dyck, 2002; Stone, 1995). With negative or inconclusive clinical findings, a relatively healthy appearance, and mounting scepticism among doctors, women experience a crisis of credibility. This crisis culminates into an emotionally painful interrogation of the very existence of women's symptoms and physician's ultimate disbelief (Asbring & Narvanen, 2002; Cooper, 1997; Gibson, 1993; Goudsmit, 1994; Lillrank, 2003; Moss and Dyck, 2002; Reid et al., 1991; Soderberg, Lundman, & Norberg, 1999; Sveilich, 2005; Thorne, Ternulf-Nyhlin, & Paterson, 2000; Vickers, 2001b; Ware, 1992).

Gibson (1997) links the so-believed frivolity of women's physical subjectivities to a heterosexist health system in which medical model paradigms construct women as discreditable. Since women living with fluctuating chronic conditions consult doctors for care more frequently than men and do not always present as visibly and consistently impaired as do more familiar kinds of disabled bodies (for example, spinal cord injured bodies), the unique needs and circumstances of their (un)settled bodies remain misunderstood and interrogated (Fox & Kim, 2004; Laurence & Weinhouse, 1994). Compellingly writing about the social and cognitive authority of medicine in (de)legitimizing her experience with myalgic encephalomyelitis, Susan Wendell (1996) avers that knowledge is only valid in western society when it is associated with institutional credentials where the definition of power and control over knowledge is patriarchally secured (Chircop & Keddy, 2003). Viewed in this light, it is a never-ending battle for a woman's embodied ways of knowing to be heard, respected, and expertly credentialed in their own right regardless of whether organic disease is manifest (Begum, 1996; Cooper, 1997; Laurence & Weinhouse, 1994). Wendell (1996) avers:

> Modern medical science. . . has a tendency to ignore, minimize the importance of, or deny outright any of my bodily experiences that it cannot explain. It can get away with this response, moreover, because the third-person, scientific view of my body has become the socially authoritative one, in comparison to which my descriptions of my bodily experience are highly personal and too subjective to have much social weight. My subjective descriptions of my bodily experience need the confirmation of medical descriptions to be accepted as accurate and truthful (p. 122).

By trivializing symptoms and delegitimizing women's carnalities as imaginary, doctors defame women's integrity, impugning them as the sole cause of their suffering (Lillrank, 2003; Mendelson, 2006). This medical hystericizing and moral invalidation of women's subjectivities is emotionally damaging and brazenly stigmatizing (Asbring & Narvanen, 2002; Ware, 1992). A dilemma unfolds as women confront the possibility of their own psychological disorder given the *almost* surreal subjectivity of their bodies and their unwavering faith in medicine, versus their unshakable trust in the integrity of their own bodies (Donoghue & Siegel, 2000; Jackson, 2005; Lillrank, 2003; Moss & Dyck, 1999a; Ratner, 1997; Stone, 1995; Vickers, 2000; Ware, 1992; Wessely, 2002).

Establishing personal credibility in living with an (un)settled embodiment is rarely an easy feat. The quest for legitimacy does not end with diagnosis but pervades an individual's social world in significant ways. In the following section, I delineate the interpersonal and personal frictions of living with an (in)visible disability.

(Inter)Personal Frictions

Living with an (in)visible chronic illness arouses confusion and disbelief. Given the importance western culture places on visual legitimacy to substantiate illness, the discrepancy between a person's outward bodily presentation and their inner experience of (un)settled-ness impels social others to ascribe a fictitious quality to their embodiment (Marris, 1996; Richardson, 2005; Stone, 2005). Even with a credible medical diagnosis, persons living with an (un)settled embodiment shift between being entirely disbelieved, momentarily forgotten, and acknowledged within the scenes of daily life (Donoghue & Siegel, 2000; Hilbert, 1984; Lipson, 2000; Marris, 1996; Matthews & Harrington, 2000; Olney & Brockelman, 2003). In her study of differently disabled people, Humphrey (2000) indicates that there is an invidious cultural scepticism and marginalization surrounding individuals with less tangible disabilities. Contrasting the purism of a visibly disabled identity with its less familiar, (in)visible counterparts she purports:

> There are people who are coming to see themselves as disabled in spite of not being recognized as disabled in the official or traditional discourses. . . people who have journeyed from a disabled to a non-disabled identity and sometimes back again, and whose disabilities are hidden . . . . The right to self-define as disabled has as its logical corollary the duty to accept others' self-definitions, but suspicions that people are not who they claim to be circulate . . . . the propensity to treat only tangible impairments as evidence of a *bona fide* disability identity clearly marginalizes those with [non]apparent impairments (Humphrey, 2000, pp. 65-67).

Peters (1993) contends that the responses of others, like the nature of (un)settled embodiment itself, shifts from rejection and indifference to one of acceptance and empathy temporally and contextually. The common thread attesting to this vacillating social (dis)crediting of (un)settled embodiment is the dissonance between physically appearing in good health and internally experiencing the chaos of bodily distress (Ware, 1992). Because bodily appearances, side effects of medications, behavioural indicators, and activity limitations shift in degree of visibility and severity and/or are not recognized as fluctuating indicators of (in)visible disability, this discord culminates in the discrediting of women's subjectivities (Grady, 2006; Soderberg et al., 1999; Stone, 2005; Sturge-Jacobs, 2002; Vickers, 2000). Comments such as "I don't think of you or see you as disabled" or "oh you look so well" (Krummel, 2001; Stone, 1993) denies individuals the opportunity to define their own shifting realities and negates the validity of embodied experience. Surprisingly, even when a disability *is* visible, individuals must remind others about the legitimacy of their (in)visibly fluctuating limitations because they are often ignored or misread (Taub, McLorg, & Fanflik, 2004).

Equally significant, when seeking accommodations and support services, persons living with (in)visible disabilities who often do not appear "disabled" confront widespread institutional bafflement and social delegitimation that is analogously plagued with cultural ignorance and reservations about the nature of an (un)settled (dis)abled embodiment (Davis, 2005; Driedger, 2003; Moss, 1999). Above all else, this lack of cultural awareness is in many circumstances, painfully degrading, affecting one's overall quality of life (Grady, 2006; Sveilich, 2005; Vickers, 2001a, 2001b). Attesting to the physical and occupational barriers surrounding women who struggle with the decision of (un)marking their (dis)abled bodies by using adaptive equipment along with the contestation of what legitimately counts as a verifiable disability, Diana Courvant (1999) who lives with chronic joint pain remarks:

> The cane was a difficult decision. I thought of the months I had already spent struggling to pull myself on buses, then not being offered a seat. I thought of the pain of those rides, clinging desperately to a pole. I thought of the every-day fear of not being offered a seat. And I thought of a cane. If I carried a cane, was I disabled? Would people offer me the seats in the front of the bus? And my co-workers: I had been taking my breaks without leaving my chair for several months, but was still asked to move or carry things. Would they stop? . . . Coming to work able one day, disabled the next? Did that require being hit by a car or run over by a train? Where was the line between ability and disability in my own life? (p. 102).

Reciprocally enlarging this canvas, the social (dis)crediting of (un)settled bodies invites similar shifts in an individual's own forgetting and remembering the corporeality of their (un)settled selves. Stone (2005) substantiates this claim emphasizing that women living with the effects of hemorrhagic stroke commonly forget they have disabilities because of their shifting (in)visibility coupled with the social dismissal of their realities. In addition to an individual's outward able-bodied appearance and the nature of relapsing-remitting disease, efforts to downplay or "invisibilize" limitations consistently challenge persons to sustain the conviction that their (un)settled bodies warrant legitimate consideration (Charmaz, 1991; Gordon, Feldman, & Crose, 1998; Stone, 2005; Sveilich, 2005; Vickers, 2001b). Conversely, incessant efforts to convince others about the volatile nature of their (un)settled bodies become constant self-reminders of the legitimacy of their situations (Vickers, 2001b). While many individuals want their (in)visible disabilities to be socially recognized, they do not want this acknowledgement at the expense of making their disabilities more explicitly visible and having their personas chronically stigmatized as "sick" or no longer "able-bodied."

I next introduce the notion of "fluidity" as an inherent feature of (un)settled embodiment that is especially conversant with the "intercourses" of queer identity. Theoretically positioning an (un)settled identity as mutable, contingent, and contradictory broadens the tensions described thus far and theoretically reflects how individuals negotiate the porosity of their (dis)abled selves.

Queering (Un)Settled Embodiment

While this research conveys that the (un)settled body has a biologically distinct, organic core, it is not the sole epistemic grounds for analyzing its essence. The cutting-edge work of queer studies scholars, including queer disabled writers and transgender academics, offers promise in expanding and complicating the ways we think about bodies that do not neatly fit into strained subjectivities (Brueggemann & Moddelmog, 2002). This literature is developed as a heuristic tool for guiding a nascent understanding of (un)settled embodiment within the context of (in)visible disability and substantively reappears in the upcoming discussion of living in-between and the negotiation of fluid identities.

The concept of fluid identity or what Atkins and Marston (1999) and Eli Clare (2001) refer to as the "messiness of bodily variety" is not unfamiliar to queer studies or queer disability theorizing. Paralleling the alliance between each discipline, McRuer (2003) and Sherry (2004) indicate that queer theory and disability studies stems from the lived experience of oppression, interrogates the construction and presumed naturalness of "the norm" (heterosexual and able-bodied), valorizes the voices of those with mixed gender/sexual identities and disabilities, and opens dialogue in which other possibilities for identity are revealed. Positioning the reader alongside her body to extol the virtuous (dis)harmony of her queer identity, Eli Clare (2001) expounds:

> I use the word *queer*. . . as odd, quirky, not belonging; and in its specific sense, as referring to lesbian, gay, bisexual, and transgender identity. . . . I know so clearly that my queerness, my disability, resides in my body- in the ways that I move, dress, cut my hair; in who I am attracted to and who's attracted to me; in my tremors, my slurred speech, my heavy-heeled gait; in the visceral sense of muscle sliding over muscle as I lie with my lover. . . Identity, of course, can live in many places all at once (p. 2).

In its most libratory sense, the terms "queer" and "transgender" or "trans" as Scott-Dixon (2006) heralds, are umbrella expressions that are not so much an embodied state or sexual orientation as they are fluid designations for identities that visibly and invisibly cross boundaries in terms of behaviour, self-presentation, and self-identity. Persons living with non-heteronormative mixed gender and sexual identities like persons living with (in)visible disabilities, exist in disarticulated ways outside of mainstream culture and their own distinct subcultures (Sandahl, 2003; Wilson, 2002). Such (in)visible bodies-at-odds excite discomfort because they possess the ability to live sometimes as male, sometimes female, sometimes healthy, sometimes ill, sometimes able, sometimes disabled (Colligan, 2004). Exemplifying the paradoxical material-discursive intersections of his female-to-male (FTM) trans identity, Bobby Noble (2006) explains:

> From the waist up, with or without clothes, I display a white male chest. Naked, from the waist down, my body reads as a conventionally female body even thought that is not how I understand it. Clothed from the waist down, my body displays sufficient signifiers of . . . masculinity and I'm just a guy . . . . I find myself at even greater loss when it comes to finding a language to describe myself. Just recently, I've settled upon the following paradox: "a guy who is half lesbian". . . . I'm still a guy who has chosen to keep the *F* on his driver's licence, thus inhabiting "normal abnormally" (pp. 98-101).

Similarly engaging in the complexities of her intersexed (a less preferred term is hermaphrodite) identity in a gender-dualist world, Gigi Raven Wilbur (2006) reveals:

> I live in the shadows. . . Why am I not allowed to have both a penis and a vulva? I was born with both- why do I have to choose? . . . . [I am] the third gender. I am neither female nor male, and I am both female and male. A living paradox. I walk on both sides of our society's gender line. . . . The hard part is living with the restrictions imposed on me by society. I am who I am, even if there is no name for me. I know who and what I am . . . But even people who do fit into one of the "normal" categories of gender don't always fit neatly. Wouldn't it be a lot better if we could just be who we are and not have to worry about labels? (pp. 67-69).

In her research exploring the transgender identities of individuals in Perth, Western Australia, Wilson (2002) similarly reports that it is a daily struggle for participants to live as they see themselves. Consequently, participants are forced to present themselves as an identifiable "normal" gender given the lean interpretive scope of cultural scripts that marginalize more variant bodies.

Fluid identities interrogate and disrupt dominant hierarchical understandings not only of gender and sexuality but disability as well (Colligan, 2004; McRuer, 1997; Sherry, 2004). "Queering" or complicating (in)visible disability and its corollary "cripping" queer identity, twists any imagined correspondence between bodily form, appearance, and functioning. Observing this representational reciprocity between queer theory and disability studies, Carrie Sandahl (2003) emphasizes:

> Queering describes the practices of putting a spin on mainstream representations to reveal latent queer subtexts; of appropriating a representation for one's own purposes. Similarly, cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects. Both queering and cripping expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity (p. 6).

Sandahl's juxtaposing of queer and crip identities is useful because it advocates the flexibility of identity in which mixed possibilities of "second skins" (Prosser, 1998) radically deconstructs "the normal,"[8] thereby enabling a representation of more pluralized embodiments. Conceptualizing (un)settled embodiment in and around queer and trans theory thus lays the foundation for opening critical spaces of (re)presentation where multiple subjectivities or different versions of the self are the norm (Budgeon, 2003; McRuer, 2003; Scott-Dixon, 2006; Sherry, 2004). By entertaining a "shifting-core" of multiple selves (Fawcett, 2000) and attenuating cherished cultural beliefs that the body is the unchanging anchor of identity (Garland-Thomson, 2002), we come closer to what Tobin Siebers (2001) refers to as "a new realism of the body."

Pioneering a critical voice advocating multiple subjectivities rather than absolute contrasts, albeit from the lens of visible disabilities, Garland-Thomson (2002) insists that like the queer body, the disabled body is contradiction, ambiguity, and partiality incarnate. As Mintz (2002) avers, it is only by accepting new, non-normalizing versions of disability

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[8] When I refer to the word "normal" (with or without quotation marks) throughout this thesis, I am implying following Lennard Davis (1997), what our society conceives of as a deviation from or non-conformance to ideals of bodies, physical appearance, and functioning. Thus, the "normal" body is what the (in)visibly disabled body partially "fails" to be. These norms, and more broadly the idea of norms, are as Davis (1997) writes, less a condition of human nature than features of a certain kind of society (p. 10).

that we can begin to entertain multiple enactments of disability based in lived experience. Concurring with Mintz, Colligan (2004), Lindgren (2004), Moss (2000), and Pinder (1996) remind us that since disability is not a universal experience, we must open ourselves to completely rethinking (in)visible disability in a way that resonates with its volatility, that interrogates the stability and continuity of an individual's identity. Arguing against the cultural trope of the universal disabled person, Crow (1996) demands an alternate understanding of disability based in lived experience rather than in cultural (mis)construction. Crow insists:

> We do not have to take on the non-disabled world's ways of interpreting our experience of our bodies. . . . If these interpretations are socially created then they are not fixed or inevitable and it is possible to replace them with alternative interpretations based on our own experience of impairment rather than what impairments mean to non-disabled people (1996, p. 60).

The heart of the interpretive kinship between disability studies and queer scholarship is that there are no cast-iron universals of sex, gender, man, woman, health, illness, ability, or disability that exists from the outset. Instead, there are only shifting, contingent, fluid bodies and identities that contract and expand from one side of the binary to the other and back again or resist a divisive embodiment altogether (Ekins & King, 1999; McRuer, 2003; Moss & Dyck, 2002; Price & Shildrick, 1998; Wilson, 2002). By transcending conventional ways of knowing and reading bodies, a fluid embodiment necessitates and creates new modes of language and representation that while culturally confusing, more accurately reflects its existential condition (Siebers, 2001).

Broadly, contextualizing (un)settled embodiment from the porthole of queer and transgender scholarship frees us from the grasp of pre-given, fixed identities, thereby undermining our fantasies of stable, enduring embodiments (Garland-Thomson, 2002;

Sedgwick, 1993). Both queer and (queer) disabled theorists strive to deconstruct hegemonic ideologies and the misunderstanding and inequities such toxic taxonomies preserve. I next expand this fluid theorizing of (un)settled embodiment to the dynamic relation of living in-between (dis)abled bodies, identities, and lifeworlds.

Living In-Between

Theorizing the space(s) between being acutely ill and being well is scant in the literature. Yet this orbiting, interstitial space of dual citizenship (Sontag, 1978) is where most persons living with (in)visible chronic illness dwell (Ironside, Scheckel, Wessels, Bailey, Powers, & Seeley, 2003, p. 173). In introducing the notion of in-between, I draw on the phenomenological-linguistic theorizing of Asenjo (1988) who conjectures:

> When we explore the contact of two words such as dis/ability and two realities such as health/illness, a middle, hidden one emerges. . . To describe in-between we must first grasp its existence . . . there is the in-between that links the words of a conversation; or the in-between of two lovers holding hands, that area of unspoken communication. The truth of in-between's peculiar existence is not in doubt while perceived, but the only way to achieve such perception is through a movement of the mind that begins with terms. Although a description of terms can never fully deal with this idiosyncratic realm that has its own laws and its own creativity . . . we see new regions through terms that become lenses, terms that are not ends in themselves but openings, crystals which reflect what lies beyond.
>
> In the landscape of in-between, nothing has fixed boundaries, nor is anything closed; terms are open doors, paths crisscrossed by countless other paths. . .an interworld [with] an all-embracing reality. . . . a blended inclusion. . . . [of] every possible standpoint (pp. 44-62).

For Didi Khayatt (2002), theorizing living in-between entertains corporeal contradictions and the hybridization of identities. According to Kyhatt, the boundaries of identity are elastic, sometimes accommodating fused alliances and sometimes embodying incongruities. This perspective does not reify flux or the complete dissolution of any one identity but highlights the constitutive permeability of moving back and forth between embodied states and identities (Sullivan, 2001). Referring to her fluid identity as a lesbian woman and scholar Khyatt exclaims:

> My identity had shifted, turned and twisted, contained contradictions, developed and acknowledged, only to be disembodied when I passed as straight, and then reclaimed proudly as I became progressively politicized by my reading and my work. . . . I did not neatly fit into any category. . . I fell between categories [and] was forced to rethink the categories themselves rather than attempt to disregard the peculiarities of my subject position that did not fit the identity (2002, pp. 491-493).

Women with (un)settled bodies excite discomfort because they wander from category to category, floating in classificatory social space as neither completely able nor disabled, sick nor well (Colligan, 2004; Jackson, 2005). Titchkosky (2003) urges us to understand living in-between as an [ill]legitimate fusion in which individuals highlight a precarious partiality and incompleteness by embodying contrasting assumptions, societal conceptions, and expectations while never being reducible to any of these. In this way, disability as a fluid, lived relation of in-between-ness is always something more because it brings to the fore the complexity which arises between cultural values, assumptions, and expectations (Titchkosky, 2003, p. 229). Illuminating this perspective, Titchkosky writes:

> Disability is grounded in the in-between of words used to articulate disability and the in-between of bodily experiences which make an appearance in everyday life. Disability powerfully represents the possibility of beginning something new from the position of being betwixt and between. . . . A multiplicity of interpretive positions is a key feature of all aspects of everyday life. Disability is always more because it powerfully represents, embodies, and brings to the fore the complexity of alterity which arises between cultural values and assumptions, societal conceptions and expectations. What is specific to disability is its ability to highlight the precarious partiality and incompleteness of . . . self and world, body and society . . . connecting the unexpected (2003, pp. 222-230).

In a ground-breaking study of women living with the (in)visibility of multiple sclerosis and rheumatoid arthritis, Pamela Moss and her colleague Isabel Dyck (2002) invite us to consider living in-between as neither a merging of opposites states of being nor an oscillation between polarities but an inhabiting of permeable borders that are fused, fleeting, and held in tension. Crossing into and out of these muddied waters reveals the [in]stability of identities and in effect, the porosity of (un) settled-ness. To quote Moss and Dyck (2002):

> Like bisexuals, women with chronic illness are "in-between" hegemonic discourses- not quite ill but not quite healthy, almost disabled, and almost abled, both very nearly normal yet nearly deviant. . . . [such] women are unassimilated others, existing at the interstices of *specific* identities. They destabilize notions of sameness and difference because within the amalgamation of *specific* bodies there exist no normative notions of health or of illness (pp. 33- 34).

Paterson (2001) characterizes this (un)settled ontology within a "shifting perspectives model" in which the (in)visibly chronically ill person experiences a shift between illness-in-the-foreground and wellness-in-the-foreground. Paterson remarks that as the reality of the illness experience and its personal and social context changes, the person's perspective shifts to the degree to which illness is in the foreground (is visible and a central focus) or in the background (is invisible and overlooked). Sanders, Donovan and Dieppe (2002) posit that such a shifting perspectives model is akin to a pendular swing whereby individuals co-exist as (dis)abled to the degree to which the (dis)ability is significant in their lives. Following Moss and Dyck (2002) and contra Paterson (2001), I contend that living in-between (dis)ability within the carnal milieu of this study is concurrently embodied as both background and foreground since permutations of (un)wellness and (dis)ability shift depending on the body's (un)settling materiality and situated-ness from day to day and sometimes moment to moment. In this regard, a woman is neither (un)healthy nor (dis)abled but resides somewhere along a continuum, sometimes inhabiting a mélange of unfixed subjectivities. Hence, what is socially (mis)perceived as an incongruous embodiment is in fact, a carnal template that speaks to the malleability of the (un)settled body. This mutability and the transgression of boundaries it implies suggest that no one identity is fixed or naturalized in relation to any other. As a result, each woman is multiply positioned as different versions of the self correspond with different versions of the body at any given time (Budgeon, 2003, p. 35; Moss & Dyck, 1999b). In this sense, Budgeon (2003) and Shilling (1993) suggest that the body and by implication one's identity, is an event or project, forever in the process of becoming. Underlining this position, Moss and Dyck (2002) imply that:

> Embracing the volatility of bodies in a politics of everyday life makes possible the emergence of self as a continual process, especially in relation to "bodies in context" with the ongoing negotiation of identity expressions (p. 166).

While able-bodied people usually experience a unity of body and self, women with (un)settled bodies experience a fluctuating (dis)ordered body and self-identity. In living with an (un)settled body, women meander in-between degrees of visibility, invisibility, health, illness, ability, and disability. These sometimes distinct and other times blended carnalities are at the heart of the notion of the fluidity of (un)settled-ness. Borrowing from the work of Ball (1972), Charmaz (1997), Millward and Kelly (2003), and Rosenberg (1979), I define self-concept as neither static nor given but as the private perception of one's attitudes, feelings, and self-evaluations held at any moment given the fluctuating nature of (un)settled embodiment. Elaborating further, Charmaz (1987) posits that such self-definitions:

> Include socially defined images of self, which influence and shape the person's evolving self. In this sense, the self-concept is an emergent structure. . . It may shift or change as the person reflexively interprets the identifications and images that self and others confer upon him or her (p. 284).

In *Modernity and Self Identity*, Anthony Giddens (1991) expounds a notion of identity more broadly as an unformed, unfixed, evolving concept that amplifies a more flexible understanding of fluid identities for this project. Rather than perceiving identity as predetermined and fixed, Giddens advocates the belief that we reflexively reconfigure ourselves in accord with multiple identities across time, space, and within our relationships. Giddens states:

> The self is a somewhat amorphous phenomenon. . . The 'identity' of the self, in contrast to the self as a generic phenomenon, presumes reflexive awareness. . . Self-identity in other words, is not something that is just given, as a result of the continuities of the individual's action-system, but something that has to be routinely created and sustained in the reflexive activities of the individual. . . . Self-identity is not a distinctive trait . . . it is *the self as reflexively understood by the person in terms of her or his biography* (1991, pp. 52-53).

In tandem with Gidden's sociology, there is no universal disabled person but only possible enactments of disability (Crow, 1996; Dyck, 1998). Supporting a vision of a more malleable, porous conception of the body and identity under the rubric of dismodernism, Lennard Davis (2002) evocatively advocates eroding the false consciousness of normalcy and by implication (dis)ability, by embracing new spaces where fractured, incomplete subjectivities and a plurality of bodies are the norm. Through the scope of dismodernism Davis reveals:

> The ideal is not a hypostatization of the normal (that is dominant) subject, but aims to create a new category based on the partial, the incomplete subject. . . . Impairment is the rule, and normalcy is the fantasy. . . . removing the veil of ideology from the concept of the normal . . . moves beyond the fixity of the body. . . dismodernism argues for a commonality of bodies within the notion of difference. . . . we are all nonstandard (2002, pp. 30-32).

Thus, in mediating their identities, individuals may portray a particularized identity that is temporarily fixed in time and context only to be eclipsed by another emergent identity that momentarily and differentially articulated creates yet another specific body (Moss & Dyck, 2002, p. 127). Summarizing the nature of fluid identities, Moss and Dyck (2002) exclaim:

> Identities of women with chronic illness fluctuate, vary in time across space, and are

> temporarily "fixed." They emerge in relation to "bodies in context" . . . any identity, contingent in its articulation, is unstable, ready to be de-linked and re-linked to a different set of relations or in a different space. The instability of any one identity is heightened for women with chronic illness because of the state of flux their bodies are in (p. 126).

The salient point within this conceptualization of fluidity is that individuals living with (un)settled bodies do not experience their bodies as impervious but rather as indeterminate, liquid borders that expand and contract within the material and discursive contexts in which they locate themselves (Moss & Dyck, 2002). To reiterate the words of Lennard Davis (2002), this (in)stability of the body is the rule and normalcy, the fantasy. Hence, fluidity becomes *the* universal template for the instability of all bodies and our shifting vulnerability across time as human beings (Shildrick, 2002).

Subverting an appreciation of fluidity is the reality that people typically conceive of identity in visual terms. People take each other's social identities at face value based on cultural norms of physical appearance and expected behaviours and (mis)assume membership in particular groups in the absence of visual or behavioural cues that would alert them otherwise (Clair, Beatty, & MacLean, 2005, pp. 80-81). Elucidating a reliance on visuality, Schlossberg (2001) concludes:

> Theories and practice of identity and subject formation in Western culture are largely structured around the logic of visibility. . . . We are subjects constituted by our vision of ourselves and others, and we trust that our ability to see and read carries with it a certain degree of epistemological certainty (p. 1).

Since health is narrowly defined as the absence of illness, this visually rooted conception occludes the experience of women who experientially and discursively fluctuate between being (un)well and (dis)abled (Kimpson, 2000). Articulating the reality of persons with visible physical disabilities, a perspective that extends to persons living with (in)visible disabilities, Shakespeare (1996) informs us "it is dangerous to overlook multiple identities and to assume that [dis]ability is the sole and significant identity" (p. 110). As an academic living with the (un)settled-ness of viral arthritis, Christine Overall (1998) identifies the challenges associated with negotiating the fluidity of identity between the spaces of (dis)ability.

> My attempts to present myself as disabled and to have other identities- writer, philosophy instructor, and so on- were sometimes met with disbelief and rejection. I was not permitted to have it both ways. . . Because disability is taken to be all-encompassing (either one is disabled or one is not, Davis, 1995) it is believed to allow no room for any other identity (p. 164).

Given that many women living with (un)settled bodies move between a sense of health and vibrancy and periods of distressing unwell-ness, such women "fall out of culture" (Hilbert, 1984) since they do not fit neatly into dominant constructions of ability, disability, health, illness, visibility, and invisibility. Adopting this line of reasoning, Titchkosky (2003) notes that in living in-between, individuals exist between many different and conflicting discourses and that [(in)visible] disability cannot be nailed down to any of them (p. 29). Hence, embodying these material and discursive interstices are ways of life rather than pre-ordained, divisive choices for women. Delineating this ontological (de)stabilization, Jackson (2005) conveys:

> [Individuals] not only straddle several boundaries but also wander from category to category in a "shifty" manner. They threaten the logic of [classificatory] system[s] by straddling . . . boundaries . . . . [they] are neither properly well nor properly sick [which] puts them betwixt and between the statuses of sick and well (p. 345).

Living in-between reflects a categorical dilemma that neither persuasively legitimizes ability nor validates disability since women experience a spectrum of jumbled materialities and a discursive fluidity that refuses ontological closure. Equating living in-between with a (dis)ordered journey towards a (de)stabilized identity, Moss and Dyck (1999b) stipulate:

> A journey based on a disease process that can force you to be inactive for weeks and be followed by days relatively symptom-free, can toss a woman into a state of disbelief and disorder- a destabilization of identity. These experiences lead women to hold simultaneously an ill and healthy, fixed and unfixed, stable and unstable identity (p. 171).

Connecting with Moss and Dyck's shifting (de)stabilization of identity, Mariana Ortega (2001), who draws on the work of Maria Lugones (1989), interrogates the ontology of embodying different worlds by arguing for a view of the self as a "world-traveller." For Ortega, an individual transcends monolithic notions of identity by crossing into and out of different ethno-cultural worlds in ways that justly entertains the merging of plural and contradictory selves. Primarily quoting Lugones (1989), Ortega exclaims:

> The self that I have called the "world"-traveler self is not just in one "world." One can 'travel' between these worlds and one can inhabit more than one of these "worlds" (2001, p. 282).
>
> In describing my sense of a "world," [an actual society, a construction of life] I mean to be offering a description of experience, something that is true to experience even if it is ontologically problematic (Lugones, 1989, p. 283, cited in Ortega, 2001, p. 11).
>
> Sometimes the "world"-traveler has a double image of herself and each self includes as important ingredients of itself one or more attributes that are *incompatible* with one or more of the attributes of the other self (Lugones, 1989, p. 289 as cited in Ortega, 2001, p. 13).

Despite the complexity and confusion inherent to this embodied praxis, Ortega postulates a sense of togetherness in this bordered homeland of in-between-ness.

> Even though we are multiplicitous, there is a togetherness to our multiplicity . . . Such "togetherness" allows us to have a sense of self and the perspective from which "I" can see that I have different attributes in one "world" as opposed to another "world" (2001, pp. 16-17).

A notable criticism implicated in any conception of (un)settled embodiment as existing in-between the worlds of health, illness, ability, and disability is that invoking these binaries perpetuates the very dualisms we seek to dismantle in the first place (Moss & Dyck, 1999b). While this is true on many levels, we cannot begin to unpack and take up alternate ways of seeing, experiencing, and understanding bodies that remain beneath our notice without critically interrogating the words we have spoken, written, ascribed, and inscribed.

To review, I have attempted to illuminate an essential foundation for understanding (un)settled embodiment that moves beyond dichotomous oppositions towards bodies that are fluid or multi-positional. Women with (un)settled bodies are neither completely able-bodied nor disabled, neither constantly ill or constantly well. Rather, women fluidly embody (un)stable identities that are always in transition and therefore always "in the making." In this way, theoretically positioning (un)settled-ness as the relation of in-between-ness frees us from the grasp of pre-given, stable, enduring identity categories by illuminating the fluidity of all identity (Garland-Thomson, 2002). With this recognition in mind, the normal and ordinary ways our culture has ready made for us to see and experience health, illness, ability, and disability are disturbed, thereby paving the way for an expanded understanding of (un)settled embodiment in the moment. Ultimately, it is the relation of living in-between (dis)ability in which there is no stable expression of the self but rather blended embodiments that enables individuals to claim and present different versions of the self. I next orient the reader to the manner in which individuals manage the fluidity of their (dis)abled selves in relation to the dynamics of identity management.

Negotiating Fluid Identities

Secretive Bodies

In his seminal work *Stigma*, Erving Goffman (1963) posits that even though some persons lack obtrusive, somatic indicators of disability, they are nevertheless stigmatized as failing to meet normate standards of an able-bodied society. Although Goffman distinguishes between the "discredited," individuals who display visible signs of disability and the "discreditable," individuals whose disability is invisible, persons embodying a corporeality that shifts between visibility, invisibility, health, illness, ability, and disability experience a more complicated relation to embodied identity. Coleman (1997) maintains that stigma is not the property of individuals but a humanly constructed perception bound to rigid cultural ideals that designate certain bodily differences (among other human differences) as inherently undesirable (p. 227). Directing our attention to the cultural construction of stigma, Goffman (1963) posits:

> Stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatized and the normal . . . . but rather perspectives . . . generated in social situations . . . by virtue of the unrealized norms that . . . play upon the encounter making it *natural* [italics added] to refer to the [person]. . . as stigmatized (p. 138).

Advancing Goffman's analysis, Coleman (1997), Morris (1991), and Shilling (1994) argue that one of the most pernicious consequences of visibly bearing a stigmatized body or bearing a body that (in)visibly shifts in relation to its stigma potential, is that individuals may develop and internalize similar (mis)perceptions as the non-disabled. Substantiating this perspective, Michalko (2002) and Shakespeare (1994) claim that the experience of illness and disability as a negative identity occurs within social relations where the body-of-functions with the ability to do things like everyone else is privileged over the [sometimes] broken down body, ultimately leading to feelings of inferiority. However, what is important to stress as Coleman (1997) argues, is that making the chronically (un)well feel responsible for carrying the stigma of illness allows the non-disabled to relinquish the onus for perpetuating the conditions that surround it (p. 227).

The friction of living with an (un)well body that slides between (dis)abled lifeworlds necessitates negotiating different identities across diverse moments, situations, and settings (Soderberg et al., 1999; Taub et al., 2004). Brueggemann and Moddelmog (2002), Gage (1999), and Samuels (2003) cogently attest that for persons living with (in)visible disabilities, the fundamental dilemma of passing and coming out, which must be renegotiated with each new situation (Atkins & Marston, 1999; Hillyer, 1993; Vickers, 2001b), is an ongoing struggle between secreting and revealing multiple, sometimes conflicting identities. Commenting on this predicament, Wendell (2001) contends that the ability to pass into and out of health, illness, ability, and disability deems an individual "not" the paradigmatic disabled person but a culturally unintelligible persona. Writing from the standpoint of almost always looking normal yet claiming and experiencing two identities, lesbian-femme and (in)visible disability, Samuels (2003) characterizes passing or secreting and coming out not as a misrepresentation of oneself but as the process of (re)negotiating (un)familiar assumptions about bodily appearance and functioning. Samuels remarks that the tension of passing into and coming out as heterosexual, gay, lesbian, bisexual, or queer, like passing into and out of health, illness, ability, and disability, muddles any assumption of a direct relationship between impairment and identification. This complicated identification of oneself as both (dis)abled does not mean freedom from normalcy but being in a position to question the relationship between static conceptions of normalcy and identity (Titchkosky, 2001). Attesting to this complex subjectivity, Ginsberg (1996) reveals:

> Passing is about identities: their creation or imposition, their adoption or rejection. . . the visible and the invisible, the seen and the unseen . . . . Not always associated with a simple binary, some instances of passing . . . demonstrate the multiplicity of . . . identity categories into which one might pass. Nor is the pass always permanent; it may be brief, situational, or intermittent . . . . The process and

> discourse of passing interrogates the ontology of identity categories and their construction (pp. 2-4, 16).

Resonating in part with this research is Ginsberg's stance that identity is a performative choice or something we (un)intentionally *do* in accord with certain circumstances. In this sense, we bring ourselves into being in the moment rather than existing in some predetermined state. Although far from culturally problematic, the reality of a (dis)abled identity is not an epistemological guarantee of a true or false persona but an ever-evolving array of potential selves.

Brueggemann and Moddelmog (2002), two academics who physically look normal despite their deaf and lesbian identities respectively, suggest that (un)settled embodiment is both real/claimed, stable/fragile, permanent/temporary, always in motion, and existing only in relation to other conditional identities, contexts, situations, and times. They insist and I agree, that we enact our bodies and present our identities in ways that coincides with cultural norms (for example, as healthy, able-bodied) or that transgresses and twists norms (for example, appearing able-bodied but experiencing difficulty climbing a flight of stairs). Raising the issue of how one manages an identity that is paradoxical, largely invisible, and provisional, Brueggemann and Moddelmog (2002) advise:

> We propose a pedagogy centered on the tension between passing . . . and coming out . . . in which identity disclosures initiate a process of consciously performing but also complicating a particular identity. . . We stand before our students as embodiments of the idea that identity is both credited and discredited, essential and fluid, a nexus of intersecting and contingent social positions (pp. 311-312).

Clearly then, the point of emphasis crucial for contextualizing this thesis is that not only are fluid identities ready to be constructed and deconstructed over time, but that discursive constructions for interpreting identity are equally unstable, contingent, and open to multiple interpretations (Titchkosky, 2001).

Offering an alternate interpretation, Joachim and Acorn (2000a) suggest that the conflict surrounding the body's enactment of any one identity at any given moment belies or invisibilizes other bodily experiences and identities. Addressing this discord, Peggy Munson (2000) who lives with chronic fatigue syndrome describes the secrecy of being in the closet with her disabling illness as both a freedom and more significantly, a form of oppression. Dorothy Wall (2005), who also lives with chronic fatigue, similarly raises the issue of passing as both a luxury and a burden. Conveying the harmful side of these dualities, Valerie Kimpson (2000) insists that passing as secreting erases and delegitimizes her subjectivity as a woman living with an (im)mutable body. She notes:

> In passing I abandon my history and my body and take on another appearance because my own is insufficient. . . I cheat myself of the chance to define [myself] . . . . passing is an act of erasure that requires others to see me in particular ways that make my disability invisible (pp. 322-323).

A predominant tension evident in the literature and echoing this study is that passing is adversatively a form of self-protection and a self-injurious undertaking (Hillyer, 1993; Royer, 1998; Wall, 2005). Given the patchy nature of (un)settled embodiment, conceptions of illness as a private matter, the social censure of "illness talk," and an absence of cultural understanding, individuals take great comfort in secreting their (un)settled selves (Beatty, 2004; Charmaz, 1997; Donoghue & Siegel, 2000; Matthews & Harrington, 2000; Richardson, 2005; Schneider & Conrad, 1980; Sveilich, 2005; Ware, 1992; Wendell, 1996; Vickers, 2000). In fact, maintaining this secrecy becomes part of portraying a credible self in daily life (Charmaz, 1991). Endorsing this perspective, Miller's (1997) study of women with relapsing multiple sclerosis demonstrates that because women appear healthy despite intermittent symptoms and can therefore pass, they prefer to conceal their condition. This concealment averts skewed social judgments about a woman's identity from a stigmatizing, misinformed public that fails to understand the (in)visible fluctuating nature of disease (Atkins & Marston, 1999; Charmaz, 1991, 1997; Lutz & Bowers, 2005; Royer, 1998; Tighe, 2001; Vickers, 1997).

While there is an ubiquitous sense of security and pride in circumventing the stigma ascribed to ill bodies in our society by passing as able-bodied (Beatty, 2004; Davis, 2005; Goffman, 1963; Jacoby, 1994; Joachim & Acorn, 2000a, 2000b; Matthews & Harrington, 2000; Scrambler & Hopkins, 1986; Vickers, 1997, 2000), many people experience frustration in living silenced, unsupported lives (Sturge-Jacobs, 2002; Vickers, 2001b). Describing the (in)visibility of chronic fatigue syndrome, Ware (1992) remarks that passing as secreting precludes the validation of the everyday realities of women's lives, thereby sustaining women's cultural alienation and the broader invisibility of (un)settling illness. Complementing Ware's findings within the context of epilepsy, Jacoby, Snape, and Baker (2005) contend that because individuals with (in)visible illness are culturally albeit unjustly evaluated as being of less social value than healthy individuals, maintaining the secrecy of an (un)settled embodiment becomes a self-fulfilling prophecy that reinforces feelings of self-stigma.

In a nuanced alignment with passing as a form of non-disclosure, women living with (in)visible disabilities also manage their identity(s) through what is conventionally defined in the literature as normalizing (Goffman, 1963; Hillyer, 1993; Royer, 1998; Vickers, 2001b) or what I refer to as "blending-in" their (un)settled selves. Differing from the secretive character of passing, blending-in, which I consider in the following section, is an (un)intentional active practice that permits women to capitalize on the mutability of their (un)settled bodies to negotiate an idealized social presentation of self.

Blended Bodies

Paralleling the refuge of passing as secreting are women's efforts to blend-in. I define blending-in as a "fluxing with" the (in)stability of an (un)settled embodiment in order to live as and be perceived as "normal" (Joachim & Acorn, 2000a, 2000b; Register, 1999; Royer, 1998; Vickers, 2001b, 2003). Deliberate attempts to blend-in or what Lisa Diedrich (2007) identifies as part of the "arts of doing illness" (p. 25), occur within the seeming incongruity of physically appearing well during blasting flares and without intentional effort when the body is relatively calm or settled.

Matthews and Harrington (2000) insist that women living with (in)visible disabilities are particularly vulnerable to shame because they experience their conditions as personal failures. Akin to secreting, individuals, especially women with (un)settled bodies, blend-in to elude the humiliation of having a "failed body" that defies cultural ideals of health, normalcy, beauty, and functional performance. However, this strategic practice poses risks to one's health (Atkins & Marston, 1999; Bury, 2000; Charmaz, 2000; Goffman, 1963; Hillyer, 1993; Royer, 1998; Vickers, 2001b; Wall, 2005). A predicament arises whereby on one level, individuals physically sacrifice themselves and exacerbate their conditions by ignoring bodily limitations to fit in with able-bodied society and on an alternate level, feel fraudulent in not being able to "live out" their genuine fluid selves (Ginsberg, 1996; Jackson, 2005; Vickers, 2003). Put differently, because the erratic nature of (un)settled embodiment permits normality with illness and enables women to meld with the mutability of their bodies, women want the social validation of being perceived as *both* healthy and able-bodied and periodically impaired.

Arguing a different tack, Ginsberg's (1996) analysis of passing and race offers a useful counterpoint. Here blending-in becomes a subversive strategy that transcends the limitations of an ableist society. Bodies are not exclusively able or disabled, sick or healthy but refuse suffocating closure by twisting cultural positionings. Ginsberg remarks, "passing has the potential to create a space for creative self-determination and agency: the opportunity to construct new identities, to experiment with multiple subject positions" (1996, p. 16). Echoing Moss and Dyck (2002), Samuels (2003), and Titchkosky (2001), the presence of (in)visible disability consequently mirrors spaces where women embody a plurality of possible selves that deconstructs conventional inscriptions in favour of more fluid, meaningful ones.

Inversely, blending-in cements inaccurate cultural assumptions that disability must always be a visible, static way of being (Kimpson, 2000; Stone, 1995). As long as disability remains invisible, it simply does not exist and remains delegitimized in our culture (Hilbert, 1984; Hillyer, 1993; Matthews & Harrington, 2000). Taking this reasoning further within the interpretive borders of this project, I suggest that because individuals physically appear able-bodied, they strive to secret and blend-in their chronic conditions as part of convincing themselves that they are not valid, "real" disabilities and ironically *because* of their disruptive, warranted impact (Charmaz, 1997; Sveilich, 2005). In doing so however, such individuals (in)advertently extol able-centric values by invisibilizing the multi-faceted realities of life with an (in)visible disability and the untapped knowledge this can offer us as a society about living with a more fluid embodiment (Anderson, 2000; Hillyer, 1993; Morris, 1991). Rod Michalko (2002) remarks that the brunt of such (in)direct ableism:

> Silence[s] the voice[s] of disability and keeps its standpoint invisible. . . ignoring the social fact that normalcy is socially structured and produced with an implicit set of

> assumptions. Silencing the voice[s] of disability allows normalcy to speak and to do so with one 'one voice' (p. 69).

Contrasting the proclivity to pass by secreting and blending-in is the conflict surrounding the disclosure of an (in)visible disability. In the ensuing section, I briefly review the tensions of revealing an (un)settled (un)convincing embodiment, a theme I address in-depth in Chapter 11.

Disclosive Bodies

Disclosure or the process of revealing personal information about oneself and granting access to secrets (Rosenfeld, 2000) is an integral part of managing an (in)visible disabled identity. While states of visibility and invisibility are cited in the literature, the decision to disclose a combinatory (in)visible embodiment remains poorly documented (Joachim & Acorn, 2000a, 2000b; Lowton, 2004). Contrary to disabilities that are steadily visible, persons living with (un)settling chronic illness remain well-below societal radar. This social (in)visibility poses both blessings and drawbacks.

On the whole, (in)visible chronic illness denotes a "stigma potential" that inhibits self-disclosure (Greene, 2000; Schneider & Conrad, 1983). Goffman (1963) indicates that the potential for stigma and its consequent public vilification, ostracism, and discrimination weighs heavily and shamefully on one's definition of self regardless of whether others are privy to the individual's condition. The decision to reveal an (in)visible disability across various life moments is a personally motivated, complex one. A person must evaluate the benefits of disclosure against the risks before (s)he is willing to expose themselves (Greene, 2000; Lowton, 2004). The decision to disclose is never final but consistently revisited in relation to the severity and visibility of symptoms as well as the nature of specific relationships, situations, and contexts (Charmaz, 1997; Derlega & Berg, 1987; Olney &

Brockelman, 2003; Petronio, 2002; Samuels, 2003; Sveilich, 2005; Vickers, 1997). Disclosure is thus a dynamic event concerning the control over personal information, self-presentation, and one's life, each of which are crucial for validating the self (Charmaz, 1997; Vickers, 1997).

Living with a chronically ill, (un)settled body is considered a private experience that is not willingly shared (Beatty, 2004; Charmaz, 1997; Moss & Dyck, 2002; Rosenfeld, 2000; Sveilich, 2005). Since persons have the option of expressing identities other than illness because they physically appear like everyone else, they can self-determine whether and to what extent they reveal their (dis)abled selves (Charmaz, 1997; Vickers, 2000). While intimate disclosures of (un)settled embodiment are shared with trusted others who are emotionally supportive (Derlega, Winstead, & Folk-Barren, 2000; Lowton, 2004), people living with (in)visible chronic illness want to be perceived in positive, socially valued ways. In fact, Afifi and Guerrero (2000) note that the desire to distance oneself from identity-threatening information is more desirable than being linked with positive impressions. Consequently, there is a conscious attempt to regulate the delicate balance between intimacy and distance, between the desire and/or need to express one's feelings and innermost thoughts, and the need to protect oneself from vulnerability (Charmaz, 1997; Lowton, 2004; Rosenfeld, 2000; Schneider & Conrad, 1983; Vickers, 1997, 2000, 2001b).

Shadowing this tension between intimacy and distance is the shame and humiliation one ascribes to being physically different in illness. Having something others don't understand, the fear of being (mis)judged as exploiting illness to one's advantage, and the emotional trauma of receiving pitying, probing, rejecting, and taciturn responses that affronts personal integrity is widely reported (Greene, 2000; Jackson, 1992; Lowton, 2004;

Myers, 2004; Petronio, 2002; Schneider & Conrad, 1983; Susman, 1994; Vickers, 1997, 2000, 2003).

Coupled with these fears, knowledge of (in)visible chronic illness is gravely misunderstood within our culture. Deeply sedimented stereotypes of chronically ill individuals as weak, sickly victims, malingerers, and trolling sympathy seekers and the social taboo surrounding the open dialogue of chronic illness and its minutiae competes with an individual's need to diffuse the silence of (in)visible disability to live more effectual, genuine lives (Rosenfeld, 2000; Sveilich, 2005; Vickers, 1997; Wall, 2000). Equally significant, the invisibility of (in)visible illness remains culturally sequestered because a "standard" nomenclature does not exist to bring it into societal view (Wall, 2000). With this in mind, individuals often choose to remain silent rather than use their energy to confront the ignorance and social aspersions of others (Goffman, 1963; Lowton, 2004; Sveilich, 2005; Wendell, 1996; Vickers, 2000, 2001b).

Most importantly, claiming an (un)settled embodiment around (in)visible disability means socially legitimating being variably (un)well. Clair et al. (2005), Joachim and Acorn (2003), Stone (1995), and Vickers (2001b) surmise that individuals with (in)visible disabilities carry an immense burden to legitimate their erratic embodiment. Coming out in the presence of what our culture envisions as a normal appearance is highly suspect for persons who are assumed normal to begin with yet partially disclaim this reality (Titchkosky, 2001). Because symptoms are primarily invisible or only subtly visible to an astute observer, individuals often keep the diagnosis of illness to themselves rather than expose themselves to the pain of being disbelieved (Moss & Dyck, 2002; Rosenfeld, 2000; Ware, 1992). Hence, the foremost struggle characterizing disclosure or what I interpretively convey in Chapter 11 as unburdening unsettled-ness, is convincing others about the shifting reality of an (un)well self in light of the discord between one's public presentation and private subjectivity. Endorsing this battle among women living with chronic fatigue syndrome, Hawaleshka (2002) acknowledges the difficulty women experience in coming out as disabled in spite of a seemingly able-bodied presence and getting others to accept the legitimacy of their interminable subjectivities. Likewise, Soderberg et al.'s (1999) study of women living with the (in)visible fluctuating realities of fibromyalgia highlights the negative attitudes, absence of cultural understanding, and the need to educate others about the legitimacy of (in)visible disabilities. Wendell (2001) supports these findings stressing that the (un)healthy disabled do not fit most people's picture of disability as permanently and predictably impaired and consequently experience difficulty having their disabilities socially validated. In fact, Wendell (2001) notes that even when individuals who appear normal decide to come out as [dis]abled, the end result may be that even after disclosure, they continue to be perceived as non-disabled and often revert back to passing as non-disabled.

While nondisclosure protects identity against harm (Afifi & Guerrero, 2000, p. 174), the other side of existentially living in-between states of invisibility, visibility, health, illness, ability, and disability encourages the disclosure of mixed bodies, subjectivities, and identities in a manner that bolsters identity (Samuels, 2003). Unburdening an (un)settled embodiment can be liberating and therapeutic by allowing people to develop and sustain trusting, authentic, emotionally supportive relationships in which they can fully be themselves in all their genuine diversity. Moreover, this disclosive freedom permits individuals to "vent" and mitigate feelings of shame and self-blame in carrying the burden of their fluctuating bodily limitations (Clair et al., 2005; Derlega et al., 2000; Rosenfeld, 2000; Schneider & Conrad, 1983; Wendell, 2001; Vickers, 1997, 2000). Equally momentous, self-revelation paves the way for crediting (in)visible disability in people's lives and cultivates a personal and political platform necessary for educating others and inculcating cultural understanding (Afifi & Guerrero, 2000; Clair et al., 2005; Derlega et al., 1993; Joachim & Acorn, 2003; Lowton, 2004; Moss, 1999; Rosenfeld, 2000; Schneider & Conrad, 1980; Vickers, 1997, 2001b).

Generally, since an individual's physical appearance is often indistinguishable from her or his healthy peers, decisions regarding identity management are typically clear-cut. The less physically visible the disability, the tighter the boundaries of nondisclosure in which the person silently trespasses between (dis)abled worlds. This does not imply that disclosure is a rare or unnecessary event. Rather, much deliberation is required when thinking about revealing an intimate aspect of oneself that is fleetingly visible and on par with this, barely deemed credible. Indeed, as Joachim and Acorn (2000a, 2000b) conclude, the tension of living in paradox between passing and disclosure for some individuals with (in)visible disabilities is an ongoing struggle since either way, individuals risk being misunderstood, stigmatized, or rejected.

I next guide the reader through the philosophical and methodological framings informing this study. As part of this discussion, I comment on ethical considerations as well as refer to the criteria for evaluating the merits of this doctoral project.

The Third Movement

Chapter 3

Crafting (Un)Settled Bodies

This third movement sets forth the philosophical and methodological framings situating this study from a visually informed, phenomenological lens. I divide this chapter into five main sections. First, I discuss several complementary framings inspiring this work including threads from feminist-informed orientations, descriptive phenomenology, hermeneutic techniques, and practices of photographic inquiry. Given this array of orientations, I want to clarify that the heart of this research reflects my own approach in which I integrate the self-expressiveness of personal photography within the hermeneutic-phenomenological approach as pioneered by Max van Manen (1997). I also stress the compatibility of several heuristic concepts as identified by Clark Moustakas (1990) that emphasize the embodied-ness of the practices of knowledge I am creating and that are tantamount to the dynamics of the research process.

In Section II, I describe the study's participants and offer a brief sketch of each woman. I refer to the participants by their real names since each woman chose to use her real name rather than a pseudonym as part of bringing her story forward. In Section III, I provide a comprehensive account of the procedures for data production and analysis. This section reflects a three-stage process that situates the sharing of personal photographs from the dialogic-interpretive scope of van Manen's (1997) hermeneutic-phenomenology with the interpretive techniques espoused by Moustakas (1990, 1994). Since the research activities intertwine, I connect the theorizing and methodological guidelines characterizing the work of van Manen and Moustakas because they substantively inform one another. However, I do allude to their distinct contributions in shaping the research where relevant. In Section IV, I focus specifically on interpretive techniques, particularly my own crafting of the women's narratives. I conclude this movement noting some of the challenges inherent in this project.

Interwoven in my discussion detailing the research procedures, I outline the evaluative criteria for reviewing the merits of this current work. These criteria do not represent discrete features but work in a complementary fashion throughout each stage of the research. Equally important, I elucidate ethical guidelines that are integral for safeguarding the interests and well-being of participants throughout each stage of the study. These considerations overlap and as a result, reappear in different stages of the research. I place particular emphasis on image ethics (Wang & Redwood-Jones, 2001) where relevant, given the implications of using photography as a tool for conversation, interpretation, and as a representational form.

Before proceeding, a caveat is in order. In describing each phase of the research process and the dynamics enveloping it, some of the vocabulary I employ reflects my own scholarly creativity in working within a phenomenological and hermeneutic tradition as well as my own experience of (un)settled embodiment that I share with study participants. Speaking to this craft of language, van Manen (1997) stresses that phenomenological research is a "poetizing activity" (p. 13), an evocative telling that allows us to discover what lies at the ontological core of our being and I would add, our being in relation to others within the research process. Where relevant, I take care in elucidating my intentions in evoking specific expressions that are epistemologically compatible with the phenomenological creation of a lifeworld-sensitive text (van Manen, 1997). In developing this reflexive language, I attempt to artistically bridge the ontological with the epistemological or in other words, convey how my subjectivity alongside the participants' (un)settled subjectivities experientially and procedurally infuses the research. In this way, I am suggesting new words and/or unfamiliar combinations of words and with this, edifying new understanding. Here van Manen (1997) states "the human science researcher is a scholar-author who must be able to maintain an almost unreasonable faith in the power of language to make intelligible and understandable what always seems to lie beyond language" (pp. xvii-xviii). Noting this, I am not implying that the uniqueness of the vocabulary I develop applies to all women living with (un)settled bodies but only to those women with whom I shared this research journey.

Section I

Philosophical and Methodological Framings

Feminist-Informed Framings

Taking partial root in a feminist-informed orientation, this research conceptually and procedurally begins from the conviction that all knowledge begins in human experience and legitimizes women's ways of embodied and emotive knowing as essential to creating knowledge (Bochner, 2000). This latter premise is especially vital since participants struggle with being perceived as convincing, valid constructors of knowledge in relation to their own bodies and lives. Reality or what is deemed "truth" is subjectively known, grounded in firsthand experience, and inwardly sensed. Hand in hand with these epistemic premises is the idea that reality is not immutable but characterized by ambiguity, fluidity, complexity, and contradiction. In this sense, there is no one social "reality" but rather a multiplicity of experiences, identities, and lives (Belenky, Clinchy, Goldberger, & Tarule 1997; Morris, 1992; Moss, 2002; Ramazanoglu & Holland, 2002).

Capturing women's lived experience in accord with these principles occurs within an inclusive, empathic relationship of connected knowing, an intersubjectivity that evolves between human beings over time (Belenky et al., 1997; Heshusius, 1994; Maykut & Morehouse, 1994; Michrina & Richards, 1996). Belenky et al. (1997) extend the notion of connected knowing as:

> An orientation toward understanding and truth that emphasizes not autonomy and independence of judgment but a joining of minds. Connected knowers develop procedures for gaining access to other people's knowledge. At the heart of these procedures is the capacity for empathy. Since knowledge comes from experience, the only way . . . to understand another person's ideas is . . . to share the experience. . . . . Connected knowing involves feeling, because it is rooted in relationship; but it also involves thought . . . . [it is] opening up to receive another's experience into [one's] own mind. . . . to understand other people's ideas in the other['s] terms rather than in [one's] own terms (pp. 55, 112-124).

It is this relation of connected knowing based in lived experience that recognizes the expertise and partnership of women living with (in)visible disabilities and opens new possibilities for subjugated voices to be heard (Feminist Pedagogy Working Groups, 2002; Kitchin, 2000; Ramazanoglu & Holland, 2002). Thus, this research seeks to uncover more embodied ways of creating and sharing knowledge, cultivates a vocabulary that reflects the intimacies of women's lives, and inspires an understanding of the uniqueness of women's positioned subjectivities. Although not specifically addressing the embodiment of women living with (un)settled bodies, Stanley and Wise (1993) aptly infer how women's experiences are traditionally defined from the patriarchal perspective of healthy, able-bodied men. They infer "women do experience reality differently by having different bodies [and] different physical experiences. . . We need a new language. . . this must come from an exploration of the personal, the everyday and what we experience" (p. 146). Reiterating this sentiment, Dorothy Smith (1987) claims:

> Women's standpoint returns us to the actualities of our lives as we live them in the local particularities of the everyday/every night worlds in which our bodily being anchors us. When women speak from their experiences . . . they produce knowledge that does not exist in dominant discourse (pp. 393-394).

From a feminist-informed standpoint then, this research honors and validates women's intelligence and values knowledge grounded in the nuances of their day-to-day lives as women. It is these often absent, ignored, and/or ordinary embodied moments that remain beneath our notice but that have the potential for beginning conversations and igniting a conscientization of critical issues affecting their lives as women living with (un)settled bodies.

Philosophical and Theoretical Foundations of Phenomenology

Complementing a feminist orientation, this research combines two schools of thought: the philosophy and methodology of phenomenology as a descriptive science, and hermeneutic research as the textual interpretation of lived experience. I combine each tradition within the hermeneutic-phenomenological approach as exemplified by Max van Manen (1997). Prior to providing some commentary on hermeneutic-phenomenology, some introductory remarks on the philosophical and theoretical foundations of phenomenology more generally are warranted. Within this research, I focus on descriptive or eidetic phenomenology that is defined as the pure description of lived experience (van Manen, 1997, p. 25).

Taking root with Edmund Husserl, the father of phenomenology, and expanded in the tradition of existential-psychological researchers at Duquesne University in Pittsburgh, descriptive phenomenological research as a human science is the study of lived experience or the direct lifeworld of the individual. Lived experience involves our immediate, pre-reflective consciousness of life, an awareness that is awareness unaware of itself (Dilthey, 1985, p. 223). Elaborating a definition of phenomenology as the humanist's science, van Manen (1997) stresses:

> Lived experience is the 'starting point' and 'end point' of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence- in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful (p. 36).

The task of existentially descriptive phenomenological research is thus to "borrow" other people's experiences and their reflections on their experiences to understand the deeper meaning of an aspect of human experience within the context of the whole of human experience (van Manen, 1997, pp. 9, 62).

In aiming to acquire an intimate understanding of the meaning of our everyday experiences as they are "given" to us or lived by us, phenomenology seeks to demystify the "essence" or nature of a particular lived experience. More specifically, phenomenology rests on the thesis that there are essential structures to any human experience and that each unique experience reflects distinctive essences that pattern the specific experience uniquely (Ray, 1994, p. 147). Within phenomenology, the word essence does not imply some kind of mysterious entity or discovery but a linguistic construction, a description of a phenomenon (van Manen, 1997, p. 39). van Manen (1997) conveys:

> A good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are able to grasp the nature and significance of this experience in a hitherto unseen way. When a phenomenologist asks for the essence of a phenomenon- a lived experience- then the phenomenological inquiry is not unlike an artistic endeavor, a creative attempt to some- how capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive (p. 39).

Hence, phenomenology seeks to mine the meaning of a particular way of being in the world by asking what internal structural properties or meanings make a specific experience *that* *kind* of experience (van Manen, 1997). Stated somewhat differently, phenomenology asks what it is that constitutes the nature of a specific lived experience. The essence or substance of an experience is adequately described if the description reawakens or shows us the lived quality and significance of the experience in a richer, deeper manner, if it brings into awareness that which tends to be obscure or evades the intelligibility of our natural attitude of everyday life (van Manen, 1997, p. 32). In relation to this text, I expand the meaning of essence more loosely to include the social and political contexts that embed the experiential.

Conversational interviews are the preferred vehicle for exploring and gathering experiential narratives (van Manen, 1997, p. 66). Addressing the necessity of this conversational relation, Moustakas (1990) writes, "if one is to know and understand another's experience, one must converse directly with the person. One must encourage the other to express, explore and explicate the meanings within his or her experience" (p. 26). Belenky et al. (1997) identify the necessity of "real talk" within such conversational relations, a way of dialoguing that reaches deep into the experience of each participant and draws on the analytic abilities of each (p. 14). The value inherent in this approach is learning about lived experience from the participants' perspective, legitimizing this perspective, and sharing it with others (Vickers, 2001, p. 33).

Hermeneutic-Phenomenological Framings

Informed by Martin Heidegger and the Dutch (Utrecht) School, hermeneutic research is the interpretive study of the expressions of lived experience from the frame of reference of the experiencing person in the form of talk, a text, and/or works of art to determine the meaning embodied in them (Lindsay, 1996; Moustakas, 1990, 1994; van Manen, 1997). Artistic works including the use of photographs in this study as well as paintings, collage, poetry, and other modes of creative expression are considered sources of lived experience that stretch our interpretive sensibilities by exuding a particular vision and language that gives alternate shape to lived experience and offers qualitatively different kinds of insight (van Manen, 1997).

In bridging phenomenology with hermeneutics, the task of hermeneutic-phenomenology is to construct a possible interpretation of the nature of a certain human experience through a combination of description, thematic interpretation, and insight as "given" to the researcher by the text (van Manen, 1997. p. 41). In this regard, hermeneutic-phenomenology employs modes of discourse and interpretation that merge the cognitive with the non-cognitive or "gnostic" and "pathic" ways of knowing. Respectively, these terms suggest that not only do we understand things intellectually or conceptually but also imply that our deepest currents of knowledge are experienced in corporeal, relational, enactive, and situational ways (Moustakas, 1994; van Manen, 1997).

While reflective interpretation is necessary to achieve a more meaningful understanding of lived experience (Moustakas, 1994, p. 10), experiential accounts and their descriptions are never identical to lived experience itself but are rather reconstructions of those experiences. The idea of transforming lived experience into a textual representation consequently values multiple stories, complexity, and conflicting interpretations (van Manen, 1997, p. 53), ultimately speaking to the essence of (un)settled bodies in this research.

Since an essential feature of phenomenological research is the encounter that occurs between the researcher and participant in creating the story (Moustakas, 1990), adopting a hermeneutic-phenomenological approach allowed me to connect with each woman in deeply personal ways, starting in the everyday moments where (un)settled bodies are lived-in, spoken about, and talk back (Titchkosky, 2003). In turn, reflecting on the compatibility of the feminist-informed, multi-voiced work of Lather and Smithies (1997) and Ellis (1997), I (in)directly "place myself in the picture" (Michrina & Richards, 1996) in relation to my own pre-understanding or storied biography of (un)settled-ness as part of nurturing this trusting, deep engagement with participants. Reiterating this position of autobiographical connections, Moustakas (1990) insists that the investigator must have a direct, personal encounter with the individual and the phenomenon being investigated (p. 14). For van Manen (1997), creating a lifeworld sensitive text not only reflects fostering the intimacy of lived experience but also considers the very act of writing about this experience as the nexus of hermeneutic-phenomenological scholarship. In other words, writing a phenomenological text is about creating meaningful research. In this way, the language, tone, and manner in which I chose to craft this thesis is essential to its interpretive significance.

Visual Framings: Photographic Interviewing

Complementing the hermeneutic-phenomenological approach, this study relies on the use of personal photography or "photographic hermeneutics," a phrase coined by Jenenne Nelson (1996) in her work with women living with breast cancer, as the essence for narrating, interpreting, writing about, and representing the lived experience (un)settled embodiment within the context of (in)visible disability. Since the aim of hermeneutic-phenomenology is to construct an animated and evocative description of human experience, photographs reflect a complementary medium for situating the person and seeing the possibilities of what it is like to have a certain kind of human experience. Two interrelated techniques influence this component of the research: photo-elicitation and photo-voice. I provide a brief overview of each approach to situate the reader's understanding of the conceptual and methodological canons guiding this study. I conceptually and procedurally expand on each of these techniques as they complement the hermeneutic-phenomenological approach throughout my discussion of the research stages.

The use of photographic interviewing in qualitative research and its integration with phenomenology is not new. As a tool for documenting personal experience, photo-elicitation first appeared in a paper published by John Collier (1957) who explored issues pertaining to mental health in Canadian Maritime Provinces (Harper, 2002, p. 14). Photo-elicitation also referred to as photographic interviewing, involves inserting photographs created by participants and or the researcher into interviews to stimulate conversation (Harper, 2002, p. 13). In looking at their photographs, participants tell stories in their own way, in their own language, and following their own rhythmic flow (Collier and Collier, 1986, p. 106). Proponents of photographic interviewing regard it as a post-modern dialogue based on the interpretive authority of the subject that evokes deeper elements of human consciousness than do words (Harper, 1998; 2002, pp. 14-15; Collier & Collier, 1986). In capturing the living of a life as phenomenology seeks to, photographs give us a sense of "being there" (Prosser & Schwartz, 1998, p. 116) beyond words, allowing us to enter into the participants' lifeworld in a more embodied manner. For Burgin (1982), photographs reflect discursive sites of complex inter-textuality or stories within stories that invoke an intensive seeing and reading from the same lens as the participant-photographer (Booth & Booth, 2003; Chalfen, 1998; Sontag, 1978). Newbury (1996) suggests that photography offers a vital point of contact for reexamining how we "see" disability in relation to the body. Accounting for Newbury's claim, this study thus relies on photography to twist society's visual posture in defining disability by breathing new life into alternate conceptions of healthy, ill, able, and disabled bodies (Finkelstein and Morrison, 1993).

Wang and Redwood-Jones (2001) and Weiser (1993) remind us that it is not the aesthetic and compositional value of photographs that is important but the interpretive meaning associated with them for participants. In line with this, it is essential to distinguish that the use of personal photography in this project is not art therapy. Art therapy relates to the therapeutic creation and viewing of art forms to help people who have experienced trauma (including illness) to get in touch with thoughts and feelings often hidden from the conscious mind. The emphasis is on the process of creation and is undertaken primarily for its healing benefits (American Art Therapy Association, Inc., 2005; WholeHealthMD.com, 2000). Within the boundaries of this research, participants engage with photography as an interpretive tool and an alternate entry point for phenomenologically capturing and reflecting on their lived experiences rather than as part of a psychoanalytic exploration of their inner selves. In this sense, participants' experiences, memories, and feelings are elicited through pictures as part of an embodied telling, adding a visual dimension to exploring the essence of (un)settled embodiment as opposed to promoting therapeutic self-awareness and well-being. Having said this however, I believe that any form of creative self-work as this study exemplifies, has the potential to inspire personal growth and thus is emotionally liberating.

Visual Framings: Photo-Voice

Originally referred to as photo novella or picture stories, the concept of photo-voice, the second visual method guiding this project, is credited to the work of Caroline Wang along with Mary Ann Burris and their colleagues (1994, 1996, 1997, 1998, 1999). Typically employed as a participatory action research strategy, photo-voice first appeared in a study of rural women in China and has evolved as an innovative visual method for exploring the lived experiences of many diverse populations including individuals with learning disabilities (Booth & Booth, 2003) and (in)visible chronic health conditions such as mental illness (Family Diversity Projects, 2004).

Grounded in Paulo Freire's (1970) education for critical consciousness, feminist theory, and documentary photography, photo-voice honors women's voices, values knowledge grounded in the subjective, everyday experience, highlights the social and political realities of people's lives, and echoes collaborative, dynamic working relationships with participants. As a technique, it shifts control over the means of documenting participants' lives from the expert to the layperson by providing people with cameras to document and reflect on aspects of their lives and identities from their own perspectives using their own images and words (McIntyre, 2003, p. 48). Put differently, photo-voice is about the point-of-view-ness of other people's worlds and making those worlds accessible to others (Supported Parenting for Mothers and Fathers with Learning Disabilities, 2004). By story-telling with pictures that intersect the biographical with the societal, photo-voice creates spaces for exploring the subjective, social, cultural, institutional, and political dimensions of participants' daily lives, bringing seldom heard voices out of the shadows and into larger society (Booth & Booth, 2003; Wang, 1999; Wang & Burris, 1994; Wang & Redwood-Jones, 2001; Wang, Yi, Tao, & Carovano, 1998).

Section II

Defining, Accessing, and Introducing the Participants

The participants in this study reflect a self-selected sample of four women between the ages of 25-44 who responded to a public announcement (see Appendix E) describing this study. Three women have multiple sclerosis and one woman has vulvodynia. While many chronic illnesses including various forms of cancer have relapsing-remitting periods, I chose to refine my focus (as cited in Chapter 1) to women living with a neurologically based disease as in the case of multiple sclerosis and as hypothesized in relation to vulvodynia. Taken together, both of these (in)visible disabilities (im)perceptibly fluctuate to alter physical appearance and functioning and elicit a specific subjectivity from an embodied gendered perspective (Anderson, 2000; Coyle, 2004; Hillyer,1993; Garland-Thomson, 1997; Thomas, 1999; Wendell, 2001).

Multiple sclerosis (MS) is an unpredictable disease of the central nervous system in which nerve cells lose their protective myelin covering that facilitates the transmission of messages within the central nervous system. Plaques form in place of the destroyed myelin and interfere with central nervous system communication. There are three clinical categories of MS: relapsing-remitting in which attacks of symptoms have complete or partial improvement; secondary progressive in which the disease progresses after an initial relapsing-remitting phase, and progressive in which disability slowly increases with or without relapses. The primary symptoms of MS, which can occur over a few seconds, minutes, days, weeks, or months include weakness of limbs, numbness and tingling, crawling feelings (parasthesia), electric shock-like sensations (Lhermitte's sign), difficulty with coordination, bladder urgency, speech difficulties, fatigue, and cognitive difficulties.

The majority of people with MS, typically women between the ages of 20-40, have relapsing-remitting episodes. Progressive MS is less common, occurring in approximately ten to twenty percent of the MS population (Multiple Sclerosis Society of Canada, 2003; O'Connor, 2002; Paulson, Danielson, & Soderberg, 2002; Rosner & Ross, 1992; Soderberg, Lundman, & Norberg, 1999).

Vulvodynia or Vulvo-Vaginal Dynia (VVD), originally referred to as "burning vulva," is a chronic inflammatory pain syndrome of the vulvar-vaginal area. Although not life threatening, this disorder has a significant impact on a woman's quality of life. The prevalence of VVD is uncertain due to its recent recognition. The disorder can occur at any age but commonly affects women during their reproductive years between the ages of 20-40. Onset can be acute or gradual and discomfort can be constant or intermittent. This condition can hurt anywhere from the pubic bone to the anus. Commonly, women experience an unimaginable and unbearable burning discomfort, increased bladder pressure, and urinary urgency some or all of the time. Typically, dysparunia or pain with intercourse is present. Standing or sitting for prolonged periods can incite severe bouts of knife-like pain. It is hypothesized that VVD emanates neurologically from abnormal pain circuits in the central nervous system. Other possible causes include injury to the pudendal nerve, trauma, genetic factors associated with the susceptibility to chronic vestibular inflammation, a localized hypersensitivity to candida (yeast), herpes-related viruses, and has been linked to women with multiple sclerosis. While there is no cure, treatment options include topical creams, tricyclic antidepressants, biofeedback, surgical intervention, and interferon injections (Friedrich, 1987; Lotery, McClure, & Galask, 2004; Masheb, Nash, Brondolo, & Kerns, 2000; National Vulvodynia Association, 2006; Stewart & Spencer, 2002, pp. 298-324).

Accessing Participants

I contacted the Toronto chapter of the Multiple Sclerosis Society and provided them with a copy of the study invitation/information letter (Appendix B) and flyers (Appendix E). This information was distributed to members through the Society's electronic newsletter. This process ensured that participation among women was completely voluntary. Angela and Lynda responded to the study's call for participation after receiving their newsletters. It is important to mention here that many of the women I spoke with through the MS Society did not meet the inclusion criteria for participation. For example, some women were not interested in working with photographs, many did not have the time to commit to the project, and a few lived outside of the city.

I also posted public announcements at University of Toronto campus bookstores including the Toronto Women's Bookstore as a way of diversifying the sample and reaching women living with other forms of chronic, fluctuating illness. As a result, Helen entered the study upon seeing a flyer at the Toronto Women's Bookstore. In addition, I sought the support of former colleagues at the Office for Persons with Disabilities at York University to publicize the study. Angie came to the study through the encouragement of a friend who saw a flyer posted at York University.

Participants initiated contact with me directly. It is important to reiterate that each woman self-identified as living with an (in)visible chronic condition for several years and expressed a connection with the phrase "(in)visible disabilities" despite the fact that none of the women had been previously exposed to this unfamiliar public articulation. What attracted each woman to the study was their experience of having a chronic condition that fluctuated from being invisible to visible, that (im)perceptibly shuttled their lives between periods of ability and disability. I felt an instinctive connection with each woman whose unparalleled enthusiasm for the project conveyed the kind of genuine commitment I was seeking over the course of the research. During our initial telephone conversation, I invited each woman to meet with me individually as part of a working dialogue session (Stage 1 of the research process outlined in a forthcoming section).

Common Denominators and Hesitations

Several features bind the four women together as study participants. Most significant, each woman self-identified as living with a chronic condition that fluctuated in visible and invisible ways between periods of calm and unrest and between varying degrees of ability and disability. Although not a random sample, the women were not familiar with each other in any way. I chose to work with women in early to middle adulthood since the likelihood of acquiring chronic conditions like multiple sclerosis and vulvodynia commonly occurs during this developmental frame.

Each participant expressed an intellectual curiosity and desire for working with photography to document her life as an (in)visibly disabled woman. In this respect, the women reflected an appropriate or "useful" sample. Yet, noting that the nature of this research appeals to women who are interested in working with photography and are perhaps more creatively inclined, some voices and representations are highlighted to the exclusion of others. While I did publicize the study through internet sites such as DAWN (DisAbled Women's Network) and the Toronto Fibromyalgia Network, many women who responded welcomed the opportunity to participate in interviews but felt vulnerable to expose some or all of their identity through photographs. This threat was especially salient in relation to women who feared jeopardizing their jobs where their (in)visible disabilities were not known about, ignored, or discredited as sometimes genuinely disabling.

Fitting with the logic of phenomenological inquiry, I chose to focus on a small number of women to facilitate the kind of prolonged engagement (Rodwell, 1998) necessary for creating a richly textured phenomenological analysis. Rather than the development of generalizable theory, the emphasis is on the in-depth exploration of the women's histories of (un)settled-ness (Gordon, Feldman & Crose, 1998; Kvigne & Kirkevold, 2003; Lisi, 1993; Locke, Wyrick Spirduso, & Silverman, 2000; Low, 1996; Olsson, Lexell, & Soderberg, 2005; Reynolds & Prior 2003; Schaefer, Ladd, Lammers, & Echenberg, 1999; Wilde, 2002). Conversationally, each woman was able to meticulously articulate the ways in which her body (in)visibly shifted back and forth from being healthy, settled, and able to sometimes being unsettled, unwell, and disabled. Equally relevant, each woman was capable of visually conceptualizing her "shifting materiality" photographically and created a visual portrayal that speaks to the lived experience of (un)settled bodies.

I did not anticipate that women with multiple sclerosis would comprise the majority of this small group nor did I envision that someone with vulvodynia would indicate interest given that I did not specifically refer to gynecological conditions in the study announcement. Having said this however, I did not deliberately exclude gynecological conditions but wanted to narrow my focus to a few (in)visible conditions. While I was medically familiar with vulvodynia and consider some gynecological conditions to fit my definition of (in)visible disabilities, I was initially hesitant that vulvodynia did not "materially match" the shifting embodiment of multiple sclerosis in relation to fluctuations in functional capacity, mobility, vision, fatigue, and chronic neuropathic pain. Within minutes of meeting Helen however, she persuaded me otherwise. While Helen does not share the fluctuating symptoms characteristic of Angela and Angie's relapsing-remitting MS, what mattered for this project was that she (in)visibly experienced exacerbating and remitting periods of chronic pain, fatigue, and altered physical functioning that had a neurological basis.

Beyond my initial reluctance to include Helen, the greater visibility of Lynda's MS in contrast to the shifting (in)visibility of Angela and Angie's MS and the fluctuating (in)visibility of Helen's vulvodynia, equally aroused early apprehension. Given that I was seeking women whose conditions moved between states of (in)visibility, how could I welcome the participation of someone whose disability was readily apparent? I wondered how Lynda's embodiment could possibly shift in the ways I was interested in capturing. Retrospectively, in embarking on this project, I myopically conceptualized (un)settled embodiment exclusively in relation to its shifting physicality. Lynda introduced me to another interpretive layer that I completely ignored. In describing how her MS (in)visibly shifted from being relapsing-remitting to increasingly visible and debilitating, Lynda accentuated how these (un)settling corporeal shifts mirrored an emotional (in)visibility in living with MS. Thus, not only was Lynda able to thoughtfully express, both verbally and photographically, the ways she experienced her MS in visible and invisible ways but extended the analysis to the (un)seen emotional undertones that impacts this experience. Hence, beyond the uniqueness of her story, I chose to include Lynda because although noticeably disabled, much of her unsettled embodiment is experientially invisible. Lynda's inclusion underscores how the significance of a disability can transcend the immediacy of its visibility to other modes of embodiment that are not readily apparent and often elude our attention.

Women living with stable, more physically restrictive chronic conditions whose bodies do not (in)visibly shift between periods of health/illness and ability/disability are not included in this study. Individuals with developmental (intellectual), learning, and psychiatric disabilities are not included since the experience of (in)visible disability within these populations, as stated in the opening chapter, is qualitatively different in relation to their material embodiment. Hence, given the small number of participants and the limited scope of (in)visible disabilities in this study, findings are specific to the group of women in this research although they may translate in some ways to the lives of other women living with (in)visible disabilities.

Additionally, the experience of men living with (in)visible chronic illness while a critical area of study, is not included since this inquiry focuses solely on the lived experiences of women. It is also important to note that while gender, ethnicity, class, sexual orientation, and disability intersect in many important ways, research accounting for such complexities leads to a more sophisticated analysis that is beyond the current scope of this project and is a more appropriate undertaking for future research.

Introductory Participant Sketches

I offer a small introductory sketch of each woman to familiarize the reader-viewer with participants and to contextualize the women's stories. It is important to reiterate here that each woman chose to use her real name as opposed to a pseudonym to bring (un)settled embodiment out of the shadows, thereby legitimating the experience of living with an (in)visible disability.

Angela is a 44 year old, white, divorced, queer, university educated, single mother of two boys. Angela was diagnosed with relapsing-remitting MS in 1998 after experiencing episodic changes in her vision and numbness in her hands and feet. Angela works full-time as a manager in a service organization that provides in-home personal support to persons living with physical disabilities including multiple sclerosis. She experiences MS-related difficulties with balance, walking long distances, blurry vision, and fatigue.

Angie is a 28-year-old white, single, "sexually open," university educated woman. She was diagnosed in 2002 with relapsing-remitting MS after experiencing episodic disturbances with her vision, mobility as well as altered physical sensations including numbness and pain on both sides of her body. Angie is a filmmaker, working full-time in the film industry.

Lynda is a 44-year-old white, heterosexual, married woman. She first began experiencing a range of bizarre, fleeting sensations in her arms, hands, and neck and thereafter, decreased mobility. Initially diagnosed with relapsing-remitting MS in 1988, Lynda's MS is now in a gradual progressive phase. At the time of the study, Lynda was no longer working in the paid labor force. She holds an MBA and is a former business manager of an elite luxury spa in Toronto.

Helen is a 25 yr old white, single, heterosexual woman. Helen first began experiencing intense, burning pain in her vulva at the age of 13. At the age of 22 in 2003, after many long years of seeking medical attention, she was diagnosed with vulvodynia, a relapsing-remitting chronic pain condition. Helen is a full time PhD student and works part-time at her university's writing-centre.

Section III

Capturing, Interpreting, and Representing (Un)Settled Embodiment

Data production and analysis reflects a three-stage process that seamlessly flows together through a collaborative effort in which participants are active, vocal partners in both content and process. This three-stage process features two intertwined sources of data: in-depth, conversational interviews and the use of participant-created photographs. Although each stage is not mutually exclusive, their activities differ and they are discussed separately. The three stages of data production, interpretation, and representation include:

- Working dialogue session
- Conversational-storyboarding interviews
- Crafting portrayals

Stage 1: Working Dialogue Session: Building Relationships and Mapping the Process

After initiating contact with me, I invited each woman to attend a working dialogue session. The working dialogue is a preparatory meeting guided by two complementary intentions: building rapport and a sense of partnership with participants and setting the foundation for working with photographs in stages two and three of the project. Essential to these objectives, a core focus of this first meeting addressed the women's comfort level in using personal photography as a tool for story-telling and story-showing their lived experiences and addresses issues of privacy, confidentiality, and informed consent.

Since power imbalances between the researcher and the participant are never fully equalized (Murphy & Dingwall, 2001; Weiss, 1994), this ground-work session minimized this differential by attending to an ethics of care in building trusting, respectful, inclusive relationships. Within the research relationship, women's expertise is validated and their participation reflects active collaboration rather than token participation throughout the inquiry (Davies & Dodd, 2002; J.M. Davis, 2000; Heyl, 2001; Kitchin, 1999, 2000; Lipson, 1994; Lloyd, Preston-Shoot, Temple, & Wu, 1996; Mercer, 2002). This session offered women the opportunity to voice questions and concerns and provided a mutual opportunity to "feel one another out" in terms of project interest, commitment, and interpersonal compatibility.

Working Dialogue Session: Issues of Privacy and Confidentiality

Rodwell (1998) indicates that protections that truly guard against participant privacy and identification are instituted only in a matter of degrees in interpretive research. As previously indicated, a primary objective of the working dialogue session from the outset is to ensure an ethical sensitivity that accounts for the women's comfort level in working with photographs in conversational interviews. Prior to this first meeting, each woman received a detailed study information letter (Appendix B) and consent form (Appendix C) outlining the nature of the study and the specific activities the women are asked to participate in. In addition, each woman received acknowledgement and release forms (Appendix D) that requested their permission for taking pictures, appearing in photographs, and obtaining the consent of others who may appear in their images. Cognizant of wanting to demonstrate the highest ethical standards in my work, I meticulously reviewed the information letter and consent forms with each woman during this first meeting, thereby encouraging the women to share their questions and concerns.

Demarre (2001) implies that the extent of privacy and confidentiality is a highly personal decision that rests with the judgment of each participant, a premise that underscores each stage of this project. Given that photographs are the foundation for narrating, interpreting, and representing (un)settled bodies, I was extremely vigilant to ensure that participants fully understood the ethical implications of privacy, confidentiality, and anonymity in using this medium. Throughout each stage of the research, the women self-selected all photographs collected, shared, and interpreted in conversational interviews, self-determined the extent to which their identity appeared in all photographs, in their visual portrayal, and in the final dissertation text (McIntyre, 2003; Thomson & Holland, 2005; Wang, 1999; Wang & Burris, 2001). This kind of self-censorship has proven successful in the photographic work of Brown, Aslin, and Carey (2003), Ferris (1998), McIntyre (2003), Wang & Burris, 1997; and Wang et al. (1998).

Taking direction from Brown et al. (2003), and Wang and Burris (1997), I provided guidance during this first meeting on camera usage, taking and selecting photographs from different perspectives in relation to the research focus, and options for preserving identity. To illustrate, photographs can be taken in multiple ways without revealing facial features or other identifying characteristics such as images that portray only a silhouette or profile image. At the same time however, I was cognizant of overwhelming the participants with too many guidelines that might dampen their creativity. I also offered the option of working with the women to take photographs under their direction. Within this scenario, McIntyre (2003) and Wang and Burris (1997) advise that the researcher must respect different styles of picture taking. With the exception of Helen, Angela, Lynda, and Angie independently took pictures and engaged the help of friends or family members when necessary to assist them. Prior to her first interview, Helen and I discussed how I would assist her in taking pictures, the nature of the pictures we would take together, and the degree of her identity in various photographs. I also reviewed with each woman the need to obtain written permission to take and use pictures of others (See Appendix D) without violating their privacy (Wang, 1994; Wang & Redwood-Jones, 2001).

Ensuring participants have the choice to review their photographs alone before their first interview is a fundamental ethical tenet of image-based research (LeClerc et al., 2002; Rich, Lamola, Gordon, & Chalfen, 2000). I offered each woman the option of taking in her own film(s) for developing so that she could review them privately first. For the sake of convenience, participants chose to have me pick up their film(s) and bring their pictures to the first interview. Thus, with the exception of Angie who chose to rely on pre-existing photos for her first interview, the women did not see their photos until our first conversation. This route proved fruitful in capturing the spontaneity of participants' reactions, thoughts, and feelings to their photographs in the moment during our first conversation.

In terms of written accounts both in their visual portrayals and in the dissertation text, each woman decided whether to use a pseudonym to protect her privacy (Brown et al., 2003; McIntyre, 2003; Wang & Burris, 1997; Wang et al., 1998; Wang & Redwood-Jones, 2001). Helen, Angela, and Lynda chose to reveal their full identity in photographs and to include their real name as part of bringing their stories forward. In contrast, Angie does not reveal her identity in her photographic portrayal but like the other women, insisted on using her real name in her descriptive account within the thesis.

All information collected from interviews including tapes, transcriptions, computer disks, field notes, and photographs were alpha-numerically coded and stored in a secure facility. Participants received copies of their interview transcripts to review if they choose to. In terms of data ownership, the negatives of all photographs and the visual portrayals remain the property of participants upon completion of the dissertation. However, I have access to the participants' work for subsequent publication and educative purposes.

Informed Consent

Prior to the first working dialogue session, each woman received an invitation/study information letter (Appendix B), consent form (Appendix C), and acknowledgement and release forms for working with photographs (Appendix D). Each document addressed different aspects of study participation including: the voluntary nature of participation and the right to withdraw from the study at any time; the nature and duration of all research activities; the benefits and risks of participation; the right to refuse audio-taping and answering any interview questions; the right to refuse to share photographs; the need to obtain informed consent from other people appearing in photographs; the opportunity to review interview transcripts; protections for data security, storage, and accessibility; terms of confidentiality; an offer to provide a summary of the study's findings, and a statement indicating the intent to publish and present the findings. Consent forms were signed during the women's first interviews and copies were given to each woman for her own records. As part of the collaborative nature of this project, all of these protections were reiterated with participants throughout each stage of the research. In fact, it is important to stress that the collaborative nature of this study and its sequential stages provided participants with sufficient time to contemplate the nature and extent of their identity throughout the project.

Each working dialogue was an hour and a half in length. At the conclusion of this session, I gave each woman a Kodak disposable camera (loaded with 24-exposure color film) and negotiated a flexible time-line for producing new pictures and selecting existing photographs from their own collections for our first interview. It is important to note that while specific time-lines were negotiated with the best of intentions, I was cognizant as a woman living with an (in)visible disability myself, how the women's bodily rhythms as well as my own would dictate and sometimes interfere with the scheduling of research tasks. Given this situation, the time between the working dialogue sessions, taking and collecting pictures, developing prints, and the first interview ranged between two to eight weeks. While this might seem like a drastic lapse in time, going with the flow of (un)settled-ness in the women's daily routines elicited insightful, emotionally piercing, and richly crafted stories.

Stage 2: Conversational-Storyboarding Interviews: Showing and Telling (Un)Settled-ness

The heart of stage two is inspired by studies drawing on photo elicitation (Aldridge, 2007; Frohmann, 2005; Radley & Taylor, 2003a, 2003b), photographic hermeneutics (Nelson, 1996), self-directed or auto-photography (Aitken & Wingate, 1993; Bach, 2001; Brown et al., 2003; Ferris, 1998; Frohmann, 2005), photo-voice (Baker & Wang, 2006; Booth & Booth, 2003; LeClerc et al., 2002; McIntyre, 2003; Wang & Pies, 2004), and photo-expressive work with memory books (Thomson & Holland, 2005). Within stage 2, I relied on personal photography as an alternate lens for entering more vividly into the lifeworld of (un)settled embodiment. Conversational interviews, guided by photographs taken and collected by each woman, acted as a catalyst for dialogue or as Harper (2002) suggests, "deep and interesting talk," reflection, and interpretation between the participants and myself. In turn, the participants' sharing and interpretation of photographs were responded to by my questions, reflections, and experiencing of the women's pictures and interpretive accounts. From an interpretive stance, van Manen (1997) implies that such conversational interviews increasingly turn into hermeneutic conversations since both partners reflect on the deeper meanings or themes embedded in experiences that bring the significance of the phenomenological question(s) to life. Joining van Manen, Weiser (1993) observes that whenever we view and converse about photographs with others, we find meaning being created in that very process (p. 67). With this logic in mind, participants and I dialogically moved back and forth between what Radley and Taylor (2003b) describe as making storied sense *with* photographs. Here, a sequencing of interpretation, clarification, and reinterpretation enabled various layers of meaning to emerge to reveal a more complex exploration of experiences from interview to interview (Bach, 2001; Harper, 1998; Hatch & Wisniewski, 1995; Heyl, 2001; Langer, 1957; LeClerc et al., 2002; Weiser, 1993).

It is important to stress that within the context of phenomenological inquiry, these interviews were not ruled by the clock but by inner experiential time. In other words, each woman completed her interviews when the opportunity to tell her story came to a natural point of closing (Moustakas, 1990). In conjunction with this, fluctuating levels of fatigue and pain in relation to the participants placed boundaries around the duration of each interview.

Ethically Sensitive Telling

Within stage 2, each participant began by "story-boarding" or thematically laying out photographs collected from personal albums as well as newly produced images that captured how (un)settled embodiment is lived-in in (un)settled ways across a range of ordinary life moments, activities, events, and settings such as at home, work, school, community and social settings, institutional contexts such as health care settings and other places and spaces of significance to the participant. These kinds of pictures as Eisner (1997) suggests, "put us there," moving the viewer inside the borders of the image as if we were physically there ourselves (Weiser, 1993, p. 4). Overall, this participant-directed photographic montaging (Spence, 1995) and ongoing co-interpretation uniquely captured the living of a life, structured the interview process in a manner that was dialogically meaningful for each woman, and enabled participants to assume control of their visual self-representation (Gowland, 2002; Harper, 1998; Jones, 1997; Newbury, 1996; Oliffe & Bottorff, 2007).

Kirsch (1999) notes that since participants cannot anticipate how they will respond to interview questions about their lives, some individuals may experience distressing reactions while divulging emotionally charged and sensitive information (Murphy & Dingwall, 2001). Recognizing the emotional risks associated with sharing personal stories and photographs and acknowledging the permeable boundaries between the roles of researcher, "friend," and therapist, I maintained respect for each woman's privacy by refraining from exploring sensitive topics participants did not wish to address. Furthermore, I remained attentive to stop any interview where necessary, provide immediate support, and with the participants' permission, refer them for ongoing professional counseling to address any emergent issues (Lipson, 1994). It is important to mention that these concerns did not present themselves with any of the participants during the study.

In agreement with Moustakas (1990) who states that genuine dialogue cannot be planned (p. 47), I began the interviews by facilitating conversational starting points that honored the social work dictum of "starting where the person is" and intermittently referred to interview guide questions (See Appendix A) that served as a tool to guide conversations and facilitate more introspective dialogue. Indeed, Davies and Dodd (2002), Kirsch (1999), Maykut and Moorehouse (1994), McIntyre (2003), and Rubin and Rubin (1995) all indicate that it is un-ethical, particularly within the context of phenomenological inquiry, to remain wedded to predetermined research questions since the manner in which participants may choose to tell their stories may not neatly fit with such structured questions. In this way, my use of a flexible guide provided participants with the freedom to narrate their experiences in a way that was meaningful for them throughout the interviews while providing some direction to the process (Kirsch, 1999; Michrina & Richards, 1996; Rodwell, 1998). Examples of some guiding interview questions included:

- How did you first know something was "not quite right," that what was happening was the "beginning of something?"
- What is it like to live with a body that keeps on changing?
- In what ways do you experience these shifts in invisible and visible ways?
- In what ways do your pictures evoke this visible and invisible shifting between periods of calm and unrest across different moments and contexts?
- In what ways do you think your pictures help tell the story of your experiences?

Often, participants instinctively anticipated my interview questions and steered our conversations toward these dialogic threads. I believe this anticipation derives from an unspoken bond and the tacit or implied bodily knowledge that participants and I share as women living with (in)visible disabilities. According to Michael Polyani (1969), all knowledge is rooted in acts of comprehension that are made possible through tacit knowing. This knowledge cannot be put into words but is derived from (in)visible clues experienced in the moment in our relationships with others. In *Knowing and Being*, Polyani exemplifies this implicit knowledge in relation to the reading of a physiognomy.

> In understanding the mood of a person- for example, worry- we note the furrowed brow the downcast eyes, the lowered body, the heaviness of movement . . . and other clues and tacit signs. . . Together they enable a reading of the person's state of being or mental outlook (1969 p. 182).

It is this similar embodied reading derived from the women's body language, facial expressions, and disposition in conjunction with an ineffable intuitive or "internal sensing" among us as women living with (un)settled bodies that became an inherent part of the research process and that dynamically guided the conversational flow. In describing intuitive sensing as essential to procedure, direction, and understanding Moustakas (1990) reasons:

> From the tacit dimension, a kind of bridge is formed between the implicit knowledge inherent in the tacit and the explicit knowledge which is observable and describable. The bridge between the explicit and the tacit is the realm of the between, or the intuitive . . . one utilizes an internal capacity to make inferences and arrive at a knowledge of underlying structures or dynamics. While the tacit is. . . ineffable and unspecifiable- in the intuitive process one draws on clues; one senses a pattern or underlying condition that enables one to imagine and then characterize the reality, state of mind, or condition (p. 23).

Moustakas (1990) further connects tacit ways of knowing to an experiential posture of indwelling, the fusion of an intimate empathic experiencing and deep connective knowing with another. He writes, "indwelling refers to the . . . process of turning inward to seek a deeper, more extended comprehension of the nature or meaning of a quality or theme of human experience . . . in order to understand it" (Moustakas, 1990, p. 24). Speaking to this indwelling posture, Shulamit Reinhartz (1984) writes, "I will never know the experience of others, but I can know my own, and I can approximate theirs by entering their world" (p. 365).

While I am not claiming that I can know the experience of all women living with (in)visible disabilities because I am a part of this world, I am suggesting, unlike Reinhartz, that there is an elusive, almost mystic rapport among women living with (un)settled bodies that individuals who do not live with chronic illness comprehend. Attesting to this viewpoint, Vickers (2001) declares "[there is] an unbridgeable chasm between those who understand the trauma of illness and disability, and those who don't" (p. 179). To clarify, I am using the word mystic not with the intent of conveying any supernatural or spiritual connotations but to emphasize in a similar vein to tacit knowing, an intimate relational dynamic between the participants and myself that indescribably happened through dialogue, the sharing of feelings, and the connection of our (un)spoken life experiences. Given that the phrase "tacit knowing" is conceptually and experientially relevant to the canons of phenomenology as described by van Manen (1997) and Moustakas (1990), I coin the phrase "mystic rapport" as a complementary layer to tacit knowing to reflect my inner experience in working with the women and reciprocally, to illuminate the women's connectivity to me. In this way, I ask the reader to consider my use of language as an attempt to develop new ways of framing understanding and talking about a phenomenology of (un)settled embodiment ontologically, epistemically, and procedurally within the context of this research.

Moving back into stage 2, each woman began by selecting individual photographs or groups of images that conveyed the early history of her (un)settled-ness across different settings such as in doctor's examination rooms, in hospital settings, at work, and across different temporal frames. As this process occurred, I encouraged the women to experiment with different arrangements of their photographs to elicit the complex experiential layers of (un)settled embodiment as well as to explore different ways of giving meaning to their experiences from multiple framings. Advocating the importance of working with photographs in this way, Bach (2001) and Leonard (1994) assert that since photographs hold multiple meanings, stories, and voices, there is never a fixed story or narrative closure in working with this medium. Examples of questions posed to respondents during our conversations as they engaged with their photos included:

- What kinds of things stand out for you as you look at the photographs you have taken and collected in light of living with an (in)visible disability?
- If someone else were looking at your photographs, what do you think they would see, feel, experience, miss, assume?
- What would you want someone to see, feel, and experience when looking at your photographs?
- What specific images, issues, questions, and concerns do you think your photographs convey that lead to a fuller understanding of your (in)visible disability?

It is important to mention here that storied groupings of photographs and the women's narratives rarely followed a logical sequencing but moved back and forth from theme to theme as they recalled the (un)settling rhythms of their bodies and lives.

This embodied immersion into the lifeworld of (in)visible disability evolved dialogically and pictorially as the women added new photographs from interview to interview. Harper (2002) writes, "when two or more people discuss the meaning of photographs they try to figure something out together. This is, I believe, an ideal model for research" (p. 23). Moustakas (1994) affirms that this dialogic revisiting or "art of testing" (Gadamer, 1975, p. 330) dynamically cements the validity of lived experience. Moustakas (1994) comments:

> In such a process in which I present myself to you and you present yourself to me there is an interchange of perceptions, feelings, ideas, and judgments regarding the nature of reality. A continuing alteration of validity occurs as people articulate and describe their experiences. Reciprocal correcting of reality takes place in social conversations and dialogues . . . In intersubjective communication the persons are testing out their understanding of each other and their knowledge of something . . . In

> the back and forth of social interaction the challenge is to discover what is really true of the phenomena of interpersonal knowledge and experience (p. 57).

Given this kind of interpretive exchange, a good phenomenological description is one that recollects lived experience through mutual dialogue and interpretation and is validated by transforming it into something we recognize, something we "nod to" as part of the spectrum of human experience (van Manen, 1997, p. 27).

Prior to each new interview in stage 2, I transcribed each woman's conversation and took notes to keep the conversations "alive" in my mind. I augmented my notes with emerging ideas, insights, questions, narrative tensions, and themes for further exploration with participants.

van Manen (1997) documents the importance of this interpretive follow-up with participants as stimulating the hermeneutic thrust of conversational relations:

> The researcher can go back and again to the interviewee in order to dialogue . . . about the ongoing record of the interview transcripts. . . . Once transcript themes have been identified by the researcher then these themes may become objects of reflection in follow-up hermeneutic conversations in which both the researcher and the interviewee collaborate. In other words, both the interviewer and the interviewee attempt to interpret the significance of the preliminary themes in light of the original phenomenological question (pp. 63, 99).

Participants engaged in two to four conversational-storyboarding interviews between two and a half to three hours in length. All conversational-storyboarding interviews were audiotaped with the participants' permission and took place in the women's homes. The time between interviews ranged between two to four weeks, depending on the women's availability. Each woman received copies of their interview transcripts. With the exception of Lynda who clarified an audio-related difficulty, none of the women offered alternate or additional interpretations. Prior to completing their portrayals in stage 3, I reiterated that participants could change their minds about whether to include certain photos but that once the photos were included in the dissertation, it would be too late to withdraw their decision to protect their identity.

Stage 3: Crafting Portrayals: Picturing (Un)Settled Embodiment

In stage three, participants engaged in reflexive writing with their photographs and the final assembly of their visual portrayals. The act of writing with photographs enhances meaning because it raises awareness of women's experience on a deeper level beyond conversation and is an empowering first step in transforming understanding for others. Moustakas (1990) and van Manen (1997) stress this thematic-reflective writing is not a rule-bound process, but a form of artistry in which the seeing and discovery of meaning slides back and forth from whole to part, feeling to word, experience to concept, and reflection to creative synthesis.

In a final round of interpretation, each participant talked through her photographic portrayal and accompanying textual pieces that exemplified her way of being-in-the world with (in)visible illness (Radley, 2002; Thomson & Holland 2005). In sum, this stage invites as Michrina and Richards (1996) suggests, an open process of comment, refinement, and correction in working through differing ideas and interpretations with participants while ensuring their photographic portrayals echo their voices with equal authority (Hatch & Wisniewski, 1995; Heyl, 2001). I later integrated these descriptive passages into the women's conversational dialogue that accompanies each photograph in the thesis as a way of highlighting their interpretive significance. I discuss this process in the penetrative reading stages in a forthcoming section. It is noteworthy to mention that Angie's three-dimensional portrait excludes any descriptive text. Instead, her sensory portrait, mirroring the embodied silence of her MS, conveys a silent, wordless language of its own. Thus, straying somewhat from the other women, Angie preferred to interpretively dialogue about her portrait in our conversations in a more open-ended way rather than attach fixed narrative descriptions to it.

This third stage occurred over one to two sessions between one and a half to three hours each. Over the entire course of the research, each woman engaged in five interviews with the exception of Lynda who participated in four interviews of longer duration.

Reflections on Vérité

In harmony, stages 2 and 3 evince what Piantanida and Garman (1999) refer to as vérité. Vérité rests upon the manner in which the research evidences verisimilitude, a feeling that the experience conveyed is lifelike, believable, and possible. It is also reflective of work that is emotionally impacting, evinces deeper levels of understanding, and demonstrates multiple voicing, a fairness that honors the equal representation of all viewpoints including their ambiguities, contradictions, and tensions (Blumenfeld-Jones, 1995; Eisner, 1997; Ellis, 1997; Ellis & Bochner, 2000; Gergen & Gergen, 2000; Richardson, 2000; Rodwell, 1998; Whittemore et al., 2001). In congruence with phenomenology, the aim of this study is not to portray facts but to convey meanings attached to experiences (Ellis & Bochner, 2000, p. 751). Resembling the memory books of young teens in the work of Thomson and Holland (2005), the women's portrayals in this project facilitates the introduction of a range of voices and meanings of (un)settled embodiment. In other words, this inquiry encourages women to be seen and heard (Demarre, 2001), to make the (in)visibility of their lives more visible or knowable (Weiser, 1993) by tangibly showing and telling the complexities of (un)settled embodiment through richly textured stories and unique portrayals that let contradiction shine through (Lather, 1993). Hence, since there is no "wrong" way to interpret photographic meaning within each woman's portrayal, and because objective "truth" of any image is an impossibility, every interpretation is "true" to experience based on how the women live and perceive their lives and how they "picture" their embodied selves photographically (Weiser, 2001).

Reflections on Opening Dialogue, Education, and Therapeutic Value

The women's experiential accounts and photographs are as Angie implies, "conversational pieces" that intellectually and emotionally compel us to question constructions of ab/normalcy, health/illness, dis/ability, and in/visibility and rethink the nature of disability as a multi-voiced reality (Sava & Nuutinen, 2003). Indeed, Eisner (1997), Ellis and Bochner (2000), and Piantanida and Garman (1999) insist that good research must embody therapeutic value, a way of enriching and enlivening conversation towards new understanding that inspires personal and professional introspection in everyday life. I believe that illuminating the lived experience of (un)settled embodiment visually and narratively invites points of contact that deepens conversation and alters the ways we interpret and identify what counts as disability experience (Crutchfield & Epstein, 2000; Eisner, 1991; Norris, 1997; Titchkosky, 2001, 2003).

Notes on Vitality, Creativity, and Aesthetics

Vitality and creativity are two allied features inherent to vérité. Vitality is the manner in which the project "comes alive" and appears to the mind's eye with a vividness embedded in moving rich descriptions, powerful images, and an imaginative craftsmanship (Norris, 1997; Piantanida & Garman, 1999; Whittemore et al., 2001). Taken together, the women's experiential accounts and visual self-works exude an aliveness that immediately confronts the reader-viewer with (un)surprising images in their (extra)ordinary-ness, plunging the reader-viewer with an "enlightened eye" (Eisner, 1991) into the complex depths of (un)settled embodiment in innovative, empathic ways (Bochner & Ellis, 2003; Ely, Vinz, Downing, & Anzul, 1997).

While it is not the aim of this research to examine the aesthetic appeal of each portrayal, some are more evocative although each retains a uniqueness. Lynda's memory book offers an emotionally stirring portrayal of her (un)settling disease progression whereas Angela's portrayal highlights the tension of legitimizing the reality of multiple sclerosis in the face of maintaining an able-bodied identity. Drawing on her creative talent, Helen crafts an arresting memory book emphasizing her sensory experience of vulvodynia through paintings, poetry, and several collages. Angie's three-dimensional self-portrait unlike the memory books created by the other women, captures the (un)settling sensory experience of her multiple sclerosis. The portrait excludes any text since as Angie states, "*it speaks for itself, where there are no words.*" Addressing Angie's position, Burgin (1982) states "even photographs without text are inscribed by what we may call 'photographic discourse' which like any other discourse, engages discourses beyond itself" (p.144). I return to a brief discussion of the women's portrayals in relation to the limitations encountered in this project at the conclusion of this chapter.

Section IV

Embodying the Craft/Crafting the Embodied: Layering Interpretations

Penetrative Reading(s): Part 1

With annotated interview transcripts and my research journals in hand, I immersed myself in a penetrative (re)reading of each transcript and began what I refer to as "big sweep thematizing." The basic purpose of thematizing within phenomenology is the descriptive categorization of textual accounts, moving from a more global analysis to the discovery of substantive patterns or themes embodied in the interview texts (Moustakas, 1990, 1994; van Manen, 1997). For van Manen (1997), a theme is an interpretive tool for getting at meaningful aspects of lived experience within interview texts (pp. 87-88). He reasons that in discovering themes "we try to unearth something 'telling,' something 'meaningful,' something 'thematic' in various experiential accounts" (van Manen, 1997, p. 86). Since reflective writing is the very activity of doing phenomenological research (van Manen, 1997, p. 132), I was extremely sensitive to creating an embodied language that emanated from the women's own bodies as well as from my own imaginative constructions and experiencing of (un)settled-ness. However, I remained mindful that such thematic phrases do not do justice to the fullness of "lives lived" but only point to aspects of the phenomenon (van Manen, 1997, p. 92).

This big sweep analysis and the (re)cycling of interpretations that follow are guided by a combination of modified interpretive approaches including interpretive phenomenological analysis (Smith, Jarman, & Osborn, 1999) and the detailed line-by-line approach described by van Manen (1997). With line-by-line reading, I lifted out clusters of sentences or single statements that elucidated the main thrust of the meaning of each theme (van Manen, 1997, p. 93).

Penetrative Reading(s): Part 2

Blending these methods of phenomenological interpretation, I moved into a more nuanced, interpretive cycle using a color-coded organizational system outlined by Fitzpatrick, Secrist, and Wright (1998) to re-thematize the data. Each color represents an embodied movement or theme including its related sub-themes. In the end, all transcripts reflected a vivid rainbow of colors illuminating what I eventually identify as the text's primary interpretive "tensions." The essence of this stage provides a more focused text and is where I really began to apprehend the themes within the data.

Cutting, Pasting, and (Re)Constructing: (Re)Shaping the Text(s): Part 3

Despite these penetrative readings, I instinctively felt the magic of a well-crafted analysis was missing. I wanted a greater physical connection with the data that would flesh out a more refined analysis, energize and enliven the process, and unlock the study's conceptual mystique. Here I looked to the words of van Manen (1997) who confirms that phenomenological research requires that we not simply raise questions but that we "live" the questions, that we "become" the questions (p. 43). Moustakas (1990) points to this immersion as essential in awakening oneself to the various layers of embodied experience (pp. 28, 31). Acknowledging that I already lived my research questions in the sense of belonging to the lifeworld of (in)visible disability and that my experiences and sensitivity would significantly influence the meaning I would ascribe to the women's stories, I sought to integrate this lived-in-ness in a way that would enable a more embodied, tangible (re)shaping of the data.

While many qualitative research texts advocate the use of computer software programs for helping researchers to manage their data, this study necessitates a deeper experiential engagement between data and researcher. Here I agree with Coffey (1999) who believes that computer programs alienate the researcher from "being with" the data physically, taking it out of our hands and into the deep recesses of soul-less machination. This kind of depersonalization forces interpretations into homogenic frameworks that stifle the intimacy, creativity, enthusiasm, and emotionality (Coffey, 1999, pp. 153-154) that I believe are hallmarks of sound interpretive work.

In entering this hands-on stage, I began making numerous copies of each color-coded interview text. Referring to each text in turn, I began cutting up different segments of dialogue that I then glued onto 8 x 5 index cards. I labeled each card with the initials of the participant, interview number, date, and the page number the passage appears in the original transcript. I then reviewed each "dialogic card" and recoded the data in relation to the color-coded system previously cited. Over the course of several weeks, this process yielded well over eight hundred cards!

Moustakas (1990) and van Manen (1997) put forth the view that creating depth of meaning is like creating an art object that has to be approached again and again (p. 132). In this sense, the researcher repeatedly returns to the data to determine whether the qualities derived from the data embrace a valid depiction of the experience being investigated. Given the overwhelming number of data cards, I began re-sorting all the cards into thematic piles. Drawing on the concept of imaginative variation (Moustakas, 1994; van Manen, 1997), I aimed for as much interpretive insight as possible as I experimented with different configurations of dialogic cards. Complementing this process by turning to image-based interpretive approaches espoused by Sandra Weber (2003), I began to lay out and connect the women's photographs with groupings of thematic cards as a way of more fully seeing, interpreting, and writing about the women's experiential accounts. I reflected on how my interpretations resonated with and differed from the participants' meanings. Weber recommends a dialectical approach that moves back and forth from whole to part, looking for details and messages that speak to each other, tensions within and between photographs, and "images within images" (Weber, 2003). In working interpretively with the photographs and equally important, writing about/with them as sources of lived experience to expand phenomenological themes, I drew on several guiding questions Weber outlines. Examples of such questions included:

- How do the images speak or relate to each other? How are they the same? How do they differ? What stories do they convey?
- What are the counter-texts or the hidden messages?
- What groupings make sense?
- What is your emotional reaction to the photographs?
- What might these reactions signify in terms of interpreting the images?

I continued this thematic sorting and visual layout by contemplating what thematic properties were (in)essential in determining the nature or essence of an (un)settled embodiment. It is here that I also drew on the women's narrative descriptions of their photographs in their visual portrayals and/or articulated during our conversations. Moustakas (1994) associates this step with seeking possible meanings by varying frames of reference and relationships between themes. In his view "the researcher understands that there is no single inroad to truth, but that countless possibilities emerge" (Moustakas, 1994, p. 99). Clarifying this further for the reader, I turn to van Manen (1997) who advises:

> In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is. To this end the phenomenologist uses the method of free imaginative variation in order to verify whether a theme belongs to a phenomenon essentially (rather than incidentally) (p. 107).

As part of developing themes and using the images to create and amplify the written text, I coined the photographic captions for each image. In doing so, I considered the women's descriptions and the context(s) in which their photographs appear in their visual portrayals and/or relied on the how the photographs were interpreted during our interviews. Figures 2 and 16 depicting watercolor paintings of the vagina and Figure 8 entitled "Relapsing-remitting signs: Tree branches covered in snow in a three-dimensional portrait," are artistic images created by Helen Anderson and Angie Driscoll respectively for this project. Each of these women asked that their full names accompany these images and appear in their respective captions as a way of honoring their work.

Within the context of doing hermeneutic phenomenology, imaginative variation also calls upon one's ability to self-dialogue, to bring one's self-awareness of the phenomena to the fore. Essentially, the data is within me and it is through my own intuition, feeling, and reflexive thought that I can explore interpretive possibilities (Moustakas, 1994, pp. 11-13). Bringing my own experience of (un)settled-ness more consciously into the analysis positioned me inside the data in a way that I believe would not have been possible otherwise. At the same time, I was conscious of Conrad's (1990) position that "the very process of categorizing and coding that lays the basis for analysis, also 'shatters' the data and disembodies it from the person who produces it" (p. 1258). In keeping with the tenets of phenomenology, I stayed close to the women's stories by assiduously "writing in" and preserving the tensions and contradictions that stretch the reader-viewer's interpretive sensibilities and equally important, that guard against textual closure.

Rigor within the Research Process

Regardless of form, there is an obligation for all qualitative research to demonstrate rigor, clarity, consistency, and integrity in relation to the application of research practices and analytic techniques (Davies & Dodd, 2002; Kvale, 1996). Remaining sensitive to variations in process, the sequencing of collaborative dialogues guided by the recursive co-interpretation of photographs in stage 2 and the crafting of visual portrayals in stage 3, attests to the rigor and integrity of the data because each is procedurally reflected in the research process itself (Whittemore, Chase, & Mandle, 2001).

Authorial Presence, Reflexivity, Representation, and Reciprocity

Bochner and Ellis (2000), Richardson (2000), and Thorne (1997) define authorial presence and reflexivity as the ways I visibly bring myself into the research process. Personally, living in the world of (un)settled-ness invites an articulation of the unsaid in developing my interpretive insights, shapes the language I employ in the analysis, and reflects the "movement" of the dissertation text as a whole.

As a researcher, I am responsible for how participants' lives are ultimately conveyed in the final research (con)text (Ramazañoglu & Holland, 2002; van Manen, 1997). I have carefully detailed the steps I follow in layering-in my own interpretations towards a storied synthesis. Kirsch (1999) reasons that "interpretive conflict is inevitable in qualitative research since we can never fully enter someone else's consciousness nor see reality through other's eyes" (p. 49). In this way, as Murphy and Dingwall (2001) contend, the researcher must think about how to respond to and present conflicting representations in the research process and its ultimate product(s). Throughout the dissertation, I have taken great care to "write in" and preserve the richness and complexity of the women's portrayals. In this way, words and images work in unison to ensure the inclusion and authenticity of participants' voices whether speaking individually, in tandem, or juxtaposing perspectives.

Reciprocity denotes a give-and-take relationship in which the aims of mutual respect, collaboration, negotiation, and learning form the core of the relationship between researcher and participants (Kitchin, 2000; Morris, 1992; Weiss, 1994). As a researcher, I honor the women's voices in good faith as conversational partners in the hermeneutic recycling of meaning making and as craftswomen of their visual portrayals. Since participants function as full collaborators during each stage of the research, the final research text(s) highlights co-ownership of the data (Kirsch, 1999; Lloyd et al.1996). As co-authors, participants will determine whether and how to make their portrayals available to persons living with disabilities, community professionals, institutions, and the general public. Ultimately, participants may wish to develop a local community photo-text exhibit.

Reflections on the Place of the Personal as Political

A fundamental critique of phenomenology is the difficulty in shifting from private lives to the larger socio-political structure (Paterson & Hughes, 1999; Paterson & Hughes, 2000; G.H. Williams, 1996, 1998). In one sense, this research is a photographically inspired politics of (self) representation (Parmar, 1990). By blending the personal complexities of an (un)settled embodiment with its socio-cultural framings, this research offers women a forum to visually and descriptively open pathways for alternate dialogue and pierce the cultural stigma, harmful attitudes, (mis)representations, and injustices that permeate the lives of many persons living with (in)visible disabilities. Such critical consciousness raising helps us explore our own feelings and beliefs about ourselves and others, directly encourages more empathic and sensitive interactions with persons living with (in)visible disabilities, and develops our understanding of fluid embodiments that are often unconvincing in their materiality (Mullin, 2000). Ultimately, my future aim is to extend the dialogue and accessibility of this project beyond the academy to a community photo-text exhibit at service agencies, libraries, and hospitals.

Research Challenges

One criticism leveled in the disability studies literature is that narratives often perpetuate negative cultural stereotypes that direct attention to the ordinariness of normalcy and the deviance of illness and disability, thereby failing to consider a wider socio-political analysis (Barnes & Mercer, 2003; Titchkosky, 2003). To counter this, this research offers alternate ways of seeing and interpreting (un)settled subjectivities in a number of ways. First, this study aims to undo stable, discursive constructions of ab/normalcy, health/illness, and dis/ability by interrogating the very stability of such categories. This kind of discursive deconstruction has implications for the way we construct and interpret all bodies within private, public, and institutional contexts. Second, the co-constructed nature of this research attests to a commitment in bringing issues of (in)visible disability to center-stage not only within the academy but in the commonness of our daily lives. Finally, touching on the latter, this research offers and suggests accessible forums for sharing stories of (un)settled embodiment and advocating for the rights of women and persons living with (in)visible disabilities.

From both a practical and interpretive vantage point, a notable difficulty characterizing this project relates to the "breaking up" and incorporation of the women's visual portrayals into the dissertation text. While I attempt to present a faithful rendition of the women's photographs as they appear in their visual portrayals, removing each image from the descriptive context in which it originally appears and thematically repositioning them within the text in relation to my own interpretations alters their meaning in some respects.

While the images and accompanying textual pieces within the memory books crafted by Angela, Helen, and Lynda presented less difficulty in their modification for scanning and direct transfer into the dissertation, Angie chose to develop a very large, three-dimensional self-portrait that went beyond the practical guidelines of this study. While the essence of Angie's portrait blends individual photographs into a "sculptured-painting," her larger-than-life portrayal posed some early, frustrating challenges. For example, I grappled with how I would interpretively (re)present her portrait in relation to the substantive coherence of other women's memory books given its distinct composition. Related to this, I struggled with how I would integrate the portrait visually into the thesis text given its imposing proportions. I allayed my first concern by asking Angie to provide me with copies of the photographs she created which I directly scanned into the dissertation. However, since some of the negatives were missing after she completed her portrait, I had to think of alternate ways of including Angie's images in the thesis. Since Angie's portrait reflects four separate panels (head, right arm/hand, left arm/hand, and torso/legs), I was able to place the smaller extremity segments of the painting directly onto my scanner and experiment with their arrangement in the text. While this presented some difficulty in working with the scale of the pieces, it proved a viable option.

Equally relevant, while the reader-viewer certainly encounters a strikingly embodied interpretation of Angie's experience with MS through her photographs in the text, it is really by personally interacting with her portrait in its entirety, with its cutout "windows" inside which each photograph is strategically positioned, that one can fully engage with its sensational artistry. Thus, while Angie's portrait offers a uniquely evocative portrayal of her (un)settled body, its physical composition is entirely different from that which appears in this text. Hence, unlike the other women's portrayals that were compositionally easier to integrate in ways that preserve the faithfulness of their representations, Angie's photographs while sensorially fascinating, remain artistically de-contextualized in the physical absence of her sculptured painting.

In addition with the obstacles surrounding the integration of the visual portrayals, the project took longer than anticipated, a difficulty similarly identified by Booth and Booth (2003) in their study of mothers with learning disabilities. The entire process of taking pictures, engaging in interviews, and creating visual portrayals occurred from November 2004 to June 2005.

Having provided a thorough discussion of the study's philosophical, methodological, and interpretive framings, an extensive account of each stage of the analysis along with the ethical considerations and pertinent evaluative criteria for reviewing this work, I now veer the discussion to the interpretive heart of this dissertation. I present the next several chapters reflecting the three main interpretive movements, (Un)Convincing Bodies, the Fluidity of Identity, and (In)Visible Wounds with some introductory comments to guide the reader-viewer through the impending analysis of the women's embodied narratives.

The Interpretive Movements: Introductory Notes

In each interpretive chapter that follows, I aim to illuminate a phenomenology of (un)settled embodiment in an alternate way than is conventionally delineated in the chronic illness and disability studies literature. Akin to Vickers (2005), I recognize the need to seek and share complexity and instability through a polyphonic text. In doing so, I deliberately structure the forthcoming analysis in a way that preserves the fluid cadence and multiphrenia (Gergen, 1991) of (un)settled embodiment through a (dis)continuity of voices weaving in and out of health, illness, ability, disability, visibility, and invisibility. Overall, each interpretive movement does not stand-alone but ripples through one another in a multi-directional fashion.

As a point of analytic departure, the core of the interpretive analysis reflects a dynamic reading of two symbiotic narratives. The first story, (Un)Convincing Bodies, characterizes the fourth movement and is the vital anchor threading throughout the entire text. The sequencing of the (Un)Convincing Bodies Movement reflects five interrelated chapters that emphasize the primary tension between the shifting biological materiality of an (un)settled body and a woman's seemingly contradictory physical appearance. In Chapter 4, Part I: Fluid Sightings and Canal Stirrings, I explore the (un)believable onset and shifting subjectivity of (un)settled embodiment within the context of the lived body. I venture forward in Chapter 5, Part II: The Odyssey of Diagnosis: (Dis)Missed Bodies to describe the struggles women experience in seeking medical validation of their (un)settled bodies. As an extension of chapter 5, I resume the journey towards diagnosis in relation to the psychologizing of the (un)settled body through Helen's story in Chapter 6, Part III: The Odyssey of Diagnosis Reprise: (Un)Imagined Bodies. In Chapter 7, Part IV: (Un)Forgotten

Bodies, I illustrate the frictions between interpersonally substantiating the reality of an (un)settled embodiment as a way of encouraging others to remember its presence and the ways in which it is socially forgotten across everyday life moments. In Chapter 8, Part V: (Un)Forgotten Bodies Revisited: The Self in Flux, I address how the women themselves experience conflicting efforts to forget and remember the veracity of their (un)settling conditions. I deliberately structure each chapter in the (Un)Convincing Bodies movement to preserve the textured push and pull of the women's stories as they move back and forth in describing the (un)convincing-ness of their experiences. In being cognizant of this intent, the reader-viewer will experience continuity and contradiction within the women's stories. Such an intent encourages a multi-voiced way of telling stories that asks the reader-viewer to leave the narrative where it lies (Vickers, 2005).

In the fifth movement, I illuminate the second story referred to as The Fluidity of Identity. This three-part movement expands the (un)convincing bodies tension by focusing attention on how women living with (un)settled bodies negotiate their identities as they reside between (un)well (dis)abled worlds. I divide this fifth movement into three chapters. In Chapter 9: Secreting Fluid Identities: (Im)Positions of Normalcy, I analyze how women (un)consciously secret the reality of their (un)settled selves. In Chapter 10: Blending-In Fluid Identities: (Im)Positions of Normalcy, I illustrate how women work with the mutability of their bodies to blend-in their (un)settled selves within able-bodied society. In Chapter 11: Unburdening Fluid Identities: Dialectical Tensions, I highlight the dilemmas surrounding the issue of disclosure. Moving beyond the two cores narratives, I emphasize a sixth movement in Chapter 12 entitled (In)Visible Wounds. Within this chapter, I explore the (in)visible emotional fluctuations of an (un)settled embodiment and its impact on self-identity. This chapter emphasizes the uniqueness of Lynda's story as she lives with the (un)settling progression of multiple sclerosis. At the conclusion of each interpretive chapter, I provide a summation of the themes characterizing the women's narratives. The intent of these sections is to highlight the common tensions and the uniqueness characterizing the women's experiences rather than to reiterate the depths of their nuanced phenomenological accounts.

Throughout the interpretive chapters, I thematically weave the participants' voices with liberal passages from various disability-related narratives. This contrapuntal text does not always reflect the verbatim sequencing of interview dialogue nor is this my intention. In attempting to create a texturized story that moves between words and images, between the voices of lived experience and the voices of the academy, between the seen and the unseen, I have chosen to italicize participants' narratives from the standard typeface of this work. Equally important, the reader will recognize that I draw on some voices more extensively not to privilege one perspective over another or to imply that some experiences are more valid, but to encourage a closer reading of the women's lives while emphasizing the diversity of (un)settled embodiment across different interpretive layers.

Within each chapter, I remain faithful to the participants' language in describing the lived essence of (un)settled embodiment and emphasize certain words or phrases within the women's accounts with capital letters to stress the meaning conveyed and their emotive import. In many instances, given the phenomenological and hermeneutic framings grounding this research, I also draw on my intuitive understanding, an unspoken, nuanced sensitivity in living with an (in)visible disability, to craft words and expressions that texturize and enliven the interpretive dialogue. I feature autobiographical narratives from the disability studies literature as “data” and draw extensively on interdisciplinary scholarship pertaining to (in)visible disabilities including chronic fatigue immune dysfunction syndrome (myalgic encephalomyelitis), fibromyalgia, environmental illness/multiple chemical sensitivities, chronic pain, and various musculoskeletal syndromes that (in)visibly share some of the hallmarks of an (un)settled embodiment with multiple sclerosis and vulvodynia.

The Fourth Movement

(Un)Convincing Bodies Part I

Chapter 4

Fluid Sightings and Carnal Stirrings

I situate this fourth movement from a phenomenological interpretive lens to illuminate how (un)settled embodiment begins within the lived body as a volatile, disruptive, (un)imaginable state of being and its unpredictable cycling back into quiescence. Commencing with the (un)convincing character that the volatility of (un)settled embodiment bestows, I explore the manner in which women paradoxically experience the intimate realness yet (un) believable inception of erratic, alarming, and often perplexing signs of (un)settled-ness. While I first touch on the experience of biographical disruption (Bury, 1982), my emphasis in this chapter examines the beginning of (un)settled-ness from the vantage point of its bodily essence, its shifting materiality rather than as a global life disruption. I reexamine the concept of biographical disruption in Chapter 12 where I explore the (in)visible emotional experience of loss associated with an (un)settled embodiment.

Fluid Sightings and Carnal Stirrings: (Un)Settling Interruptions

Whether suddenly or more gradually, the experiential reality of an (un)settling onslaught of "fluid sightings" and "carnal stirrings" among the women in this study is characterized by a threatening, capricious process that dislocates a past, familiar embodiment from a present, unfamiliar embodiment (Charmaz, 1997; Hellstrom et al., 1999; Sveilich, 2005). I define fluid sightings as unexplainable "sensory happenings" that shift in and out of a woman's sight and or bodily observation, whereas carnal stirrings are more broadly nuanced, "physical inklings" that signal that something is beginning to happen within the body. Becker (1997) affirms this shifting reality commenting that since embodiment encompasses a person's historical experience of their body, the known, familiarly experienced body is profoundly altered when the flow of bodily experience is disrupted in daily life (pp. 81, 137). Susan Wendell (1997) emphasizes her own estrangement from her formerly healthy body this way:

> I experienced a . . . profound alienation from my body. After a year spent mostly in bed, I could barely identify my body as my own. I felt that "it" was torturing "me," trapping me in exhaustion, pain, and inability to do many of the simplest things I did when I was healthy. The shock of this experience and the effort to identify with a new, disabled body, made me realize I had been living a luxury of the able-bodied (pp. 267-268).

Equating the ontological assault (Pellegrino, 1979, p. 44) of the early whispers of (un)settled embodiment with the notion of dys-appearance, Drew Leder (1990) reasons that the body (in)visibly disrupted by illness or disability becomes a central aspect of experience. He writes, "whilst in one sense the body is the most abiding and inescapable presence in our lives, it is rarely the thematic object of experience" (Leder, 1990, p. 1). However, with the disruption wrought by illness and disability, the body paradoxically dys-appears, becoming exceedingly present in experience albeit in an alienating and dysfunctional manner (Leder, 1990, p. 84). For Gadow (1980), this disruption results in an objectified self as "other," a foreign body no longer recognized and entrusted as one's own.

While Bury (2000) implies that early, insidious signs of chronic illness make it difficult for a person to distinguish them from "normal" experience, Charmaz (1991) infers that the onset of (un)settled embodiment vis-à-vis what I refer to as fluid sightings and carnal stirrings, is unquestioningly a jarring and distinctive process as opposed to a single event (p. 27). Affirming this reality Charmaz (1995) insists that "the unity of prior embodied experience is shaken . . . people with illnesses compare their present body with their past body. . . Experiencing multiple bodily losses . . . intensifies feelings of estrangement . . . from one's past familiar body, [and] a loss of self" (p. 662). Thus, only when the body loses its silence (Ohman, Soderberg, & Lundman, 2003, p. 538) does it become a problematic focal point, disrupting our freedom to engage with the world and present ourselves in customary ways (S.J. Williams, 1996, 1998a).

Building on Leder's analysis, Bury (1982, 1996), Charmaz (1983, 1997), Pinder (1995) and S.J. Williams (2000) argue that a disordered embodiment, which I equate with bodies characterized by a fluctuating (un)settled-ness, culminates in what I earlier allude to in Chapter 2 as biographical disruption. The nature of this disruption involves an estranged feeling of the body's "leaving normal" that consistently calls into question one's personhood, sense of normalcy, and routinization of daily life (Thomas-MacLean, 2002). In the *Wounded Storyteller*, Arthur Frank (1995) writes, "in the beginning is an interruption. Disease interrupts a life and illness then means living with perpetual interruption" (p. 56). Recollecting and interpreting the meaning of her own initial biographical disruption, Angie reflects:

> *The constancy of inhabiting your body in a totally altered way doesn't go away. Once it happens, you're constantly thinking about your body in a different way . . . The Angie that had NO limitations doesn't exist anymore or has been irrevocably changed, irreversibly changed, or killed maybe . . . . Before this happened I had a really positive relationship with myself and my body . . . . It's almost like I KNEW a better life kind of or it's just that you become nostalgic about what you remember was like better. . . Cause like I knew my body for twenty-five years in a certain way.*

Simon Williams (1996) metaphorically refers to what I define as the (dis)continuity of biographical disruption as the dance of dys-embodiment, a mobile (dis)harmony between one's bodily presence when it is settled or physically calm and a hyper-vigilant immersion in negotiating (un)convincing, seemingly (un)real sensorial happenings when it is unsettled. Explicating this pendular unfolding, Williams implies:

> Dys-embodiment and re-embodiment are different existential modes of being within the context of an unfolding, uncertain, unpredictable illness trajectory. . . the individual's experience of chronic illness is typically characterized in terms of a movement from an initial state of embodiment, to an oscillation- or dance of identification if you will- between feelings of dys-embodiment and attempts at re-embodiment (1996, p. 39).

Writing from a parallel position about the unpredictable (un)settling periods of crisis and quiescence that make the body (un)stable and (un)reliable within the context of myalgic encephalomyelitis (also known as chronic fatigue immune dysfunction syndrome) and rheumatoid arthritis, Moss and Dyck (2002) comment:

> At onset, health appears to deteriorate while illness gains ground. Symptoms intensify, bodily sensations fade into one another . . . symptoms fluctuate from month to month, day-to-day, hour-to-hour and can even roam form body part to body part over short intervals. . . . Maneuvering through this process of destabilization, women exist in a state of ceaseless instability (p. 84).

Hence, from a corporeal vantage point, the onset of (un)settled-ness transforms the lived body in which self and body are unified to an object body that becomes a source of puzzling constraint in its opposition to the self (Gadow, 1980).

The start of something new, in which there is no going back to normal (Radley, 1997), is not an identical process among women. Women experience variations in relation to early auras or carnal stirrings, pace of onset, and parts of the body affected. This beginning of the body's transitioning to and from volatile stretches frequently engenders surreptitious, disturbing, perplexing, and frightening changes to the material body (Hellstrom et al., 1999). Equally important, while experiencing fluctuating, sometimes intensifying symptoms, women are forced to confront the destabilization of the *notion* of a healthy body (Moss & Dyck, 2002, p. 84). Wendell (1989) points out that our society's paradigm of humanity as young and healthy is simply that- an unexamined set of idealized albeit rarely realized conceptions and images of the ideal (p. 89). Yet the myth of bodily perfection remains de facto, a taken-for-granted reality especially among women (Stone, 1995). Chronic illness as expressed vis-à-vis weakness, pain, loss, and suffering is reserved for those whose bodies are deteriorating with older age. Speaking to society's human paradigm and the primacy of able-bodied standards, Ann Davis (2005) exclaims:

> A society's 'human paradigm' both embodies and expresses its beliefs about what human beings are and what (in a particular society) people think they ought to try to be. . . It gives substance to people's understanding of fulcral concepts like wellness and illness, health and disease, and ability and disability. . . our society's human paradigm treats being able-bodied as both normal and normative and accords a special primacy to being (and being seen to be) able-bodied (p.6).

The beginning of (un)settled embodiment shatters this ableist illusion with its volatile presence. The body is no longer consistently healthy and competent but rather hovers back and forth between (un)wellness, between what once was and what is at any given moment.

As the participants' stories reveal, the inception of (un)settled embodiment begins with carnal stirrings and fluid sightings, experientially ephemeral almost phantasmagoric moments. Merriam-Webster's (2003) Collegiate Dictionary defines phantasmagoria as a constantly shifting, complex succession of things seen or imagined (p. 928). This conceptualization blends what somatically feels like the impossible with the possible, the real with the surreal, and the seen with the unseen. Such tensions pits a woman's conviction that what is organically happening to her body is almost imaginary against her intuitive inkling that something is desperately wrong (Donoghue & Siegel, 2000; Charmaz, 1991, 2000; Jackson, 1992; Telles & Pollack, 1981). Supporting this (un)real phenomenal conceptualization of (un)settled-ness, Moss and Dyck (2002) claim that "a series of assaults on the body sets up a perplexing web of [de]stabilizations, which when read collectively. . .

produces in some women a response of incredulity or impossibility" (p. 86). I now turn to these fluid sightings and carnal stirrings, beginning with Angela and later rely on Angie's narrative for an in-depth immersion into the (in)visible world of (un)settled bodies.

At thirty-two, Angela was a married energetic woman working full-time when she suddenly began experiencing fleeting sensations of numbness in her feet and upper and lower body. In spite of feeling "psychotic" at times, as if she was imagining this bodily strangeness, Angela initially normalizes this on and off "cold deadness" as odd but not serious enough to merit greater concern. Charmaz (1997, 2000), Cooper (1997), Koopman and Schweitzer (1999), Milliken and Northcott (1996), and Sveilich (2005) stress that because the early symptoms of (in)visible illness are so mysterious and fleeting, they are ignored, explained away within common everyday events, or not given into immediately. However, given Angela's maternal genetic predisposition to multiple sclerosis, she anxiously vacillates between feeling (un)convinced that something more serious is happening. After returning from a trip up north to her grandmother's home, Angela is convinced that the feeling or lack of feeling more precisely, of numbness in her feet is a "different kind" of sensation unlike anything else she has ever experienced. Increasingly concerned that her body was not going back to normal, Angela consulted her family doctor armed with a self-diagnosis of MS that her doctor was quick to dismiss (Cooper, 1997). Since she was in the first trimester of her first pregnancy, diagnostic testing was delayed. During this time, Angela's phantasmic fluid sightings intensify to altered sensation in her hands and changes in the clarity of her vision that she describes as "*a finger full of Vaseline smudged over your eye*." Recalling the nature of these (un)believable, (in)visible signs of (un) settled-ness that variably (dis)appear Angela relays:

> *It all started . . . we're talking about eight years ago, I got this numbness in my feet, and I got it sort of within my girth area and um at that point, my aunt had just been diagnosed with multiple sclerosis. I went on the internet and researched everything and did the I'm pretty sure I have MS. So I went to my family doctor and said you know, my feet are numb and I really think I'm exhibiting symptoms of MS . . . . It was March because we spent March break up north at my grandmother's house. He was checking my feet and he's like "I think what happened is that you got a little bit of frostbite on your feet" and I'm like, "no I didn't get frostbite on my feet! It's different. I know it's different". . . . [It was also] in my hands . . . at one point, it was all in my torso. It was odd. It felt like you were wearing a girdle. There was sensation but it was numb. [Then] my eyesight really started getting worse and worse and I went to my optometrist and she said, "You know there's something wrong with the nerves in the back of your eye."*

The shifting (dis)appearance of the numbness in her feet, hands, and upper body however completely abate during her first pregnancy and throughout the three years in which Angela breast-fed.

> *You actually go into a remission when you're breast-feeding and when you're pregnant. My pregnancy was great. I had no symptoms at all . . . I hadn't been diagnosed at that time so I ended up breast-feeding for three years just because it was so healthy for me.*

Although the quiescence of symptoms during pregnancy is corroborated by O'Connor (2002) and Rosner and Ross (1992), the likelihood of a relapse increases afterwards. Indeed, this settling down period proved short-lived as Angela's body once again began cycling back and forth between (dis)appearing sensations of numbness. Given the unwelcome return of her (un) settled-ness physically and emotionally, Angela reconvened her quest for diagnostic confirmation.

> *This took quite a few years . . . I went [back] to the neurologist I'd seen before . . . he said, "Your evoked potentials [a neurological exam] showed that you could possibly have MS" and I'm like . . . "I've been spending four years feeling like I'm PSYCHOTIC basically!" So they waited just until after Z was born to do the MRI . . . and it was confirmed that I did have MS.*

While Angela's story does not end here, I return to her odyssey towards diagnosis in Chapter 5. I continue here with the phantasmic path of (un)settled-ness by introducing Lynda's narrative.

Lynda's unanticipated entry into the (un)settling world of relapsing-remitting multiple sclerosis which ultimately culminates into a secondary progressive stage of the disease, interrupts her life at the age of twenty-eight with a roller coaster ride of bizarre physical signs that seemed (in)conceivable at the time. Married and ambitiously climbing the managerial career ladder at a luxury spa, Lynda first experienced a patch of numbness in her leg. Always in good health, this seemingly innocuous incident evolves into to a "foggy spot" in her field of vision. These strange events continue mushrooming into what Lynda describes as "creepy-crawling, spidery sensations" running up and down her head and neck and into her arm. Such sensationally scary episodes functionally seize up Lynda's arm, hindering her from writing at work. These (un)real feelings quickly receded and then Lynda began limping, finding it impossible to walk without the assistance of a cane. Lynda details her fear-provoking fluid sightings and carnal stirrings that seem physically impossible yet eerily real in their "aliveness" within her body.

> *My original symptom was a patch of numbness in my leg . . . . I had a blind spot in my field of vision . . . a very foggy area . . . I mean all these symptoms are so bizarre and diverse and . . . they've all gone away except when I moved to progressive MS. Another symptom I had . . . the most bizarre thing and I'm very glad I don't have it anymore because it was just creepy, it felt like underneath my skin there were spiders crawling from my forehead down to my neck and through my ear and into my arm and it was just bizarre. And when it was happening, I'd get these little episodes that would last for ten seconds, and when it was happening, my. . . right arm . . . I'd be sitting at my desk at work . . . and I would not be able to write and it was really, really scary . . . . And then in my leg . . . this was when I was relapsing-remitting. . . I had an episode where I was limping and couldn't walk without a cane. It was a very brief episode that lasted about a week. Its inconceivable until it happens to you right?*

Contrasting Angela and Lynda's (un)settling signs of distress but paralleling their (in)visible fluctuating nature, Helen first began experiencing an (un)relenting burning sensation with sexual intercourse at the age of sixteen. Vacillating between periods of intense pain in her urgency and frequency to urinate along with intolerable pain during sex, Helen initially believes this burning sensation, mirroring the rawness and discomfort of a bad sunburn, is normal for a young woman beginning sexual activity. Helen describes the ebb and flow of this painful burning "down there."

Figure 1. Flaming and fire: Embodying the onset of (un)settled-ness.

> *I was about sixteen and it was starting to feel like after sex it sort of felt like a yeast infection but that never actually turned into a yeast infection . . . that would last for about a week . . . [with] itching, burning, some discharge. I end up in so much pain. It's different at different times . . . The best way I could describe it is like someone stuck a serrated knife in my urethra. . . At other times, it's kind of like having a*

> *REALLY BAD SUNBURN DOWN THERE. It's cyclical. When it's a larger problem, it's a constant burning pain. It feels like FIRE . . . [Like] embers embedded in my flesh, like hot coals applied to my genitals. A general FLAMING AND FIRE down there.*

Living with the fluidity of burning, fiery, knife-like pain for several years, Helen moves on to narrate how this (un)real fluctuating pain affects her life as an early graduate student. In spite of appearing well and seemingly coping with the rigors of a graduate career, the fluctuating intensity and paralyzing nature of her pain prevents Helen from focusing on her academic work. Helen's cycle of pain is so intense that at one point she contemplates withdrawing from her program.

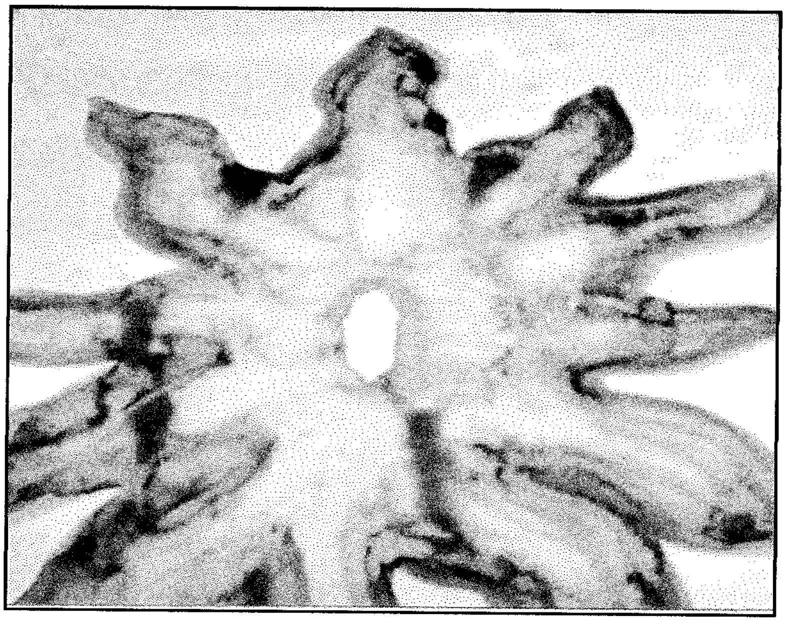

Figure 2. Watercolor painting of the vagina. Courtesy of Helen Anderson.

> *Things started getting really bad when I was doing my M.A. I think the hardest was trying to function NORMALLY and pretend everything was okay and getting a degree while feeling like crap all the time . . . Our lectures were three hours and we had a break in the middle but basically during those whole three hours, I felt like I had to go to the bathroom and I was just in a lot of pain. I was on heavy painkillers and totally spaced out all the time. I couldn't focus on my work. . . There were times I considered dropping out . . . I had this UTI [urinary tract infection] and I was just in so much pain . . . There were nights when I was doing my M.A. and one time, I ended up in the emergency room because I was just beside myself in pain. . . . There are certain times when I'm . . . just paralyzed in a sense by the pain . . . it can knock me out of commission for a while. It doesn't all the time.*

Helen further brings the (in)credulity of her (un)settled embodiment to life in a striking watercolor painting of her vagina in the opening page of her visual portrayal. This image, radiating the stark rawness of Helen's vaginal pain, accompanies a lyric Helen quotes from singer Ani DeFranco that states, "my cunt is built like a wound that won't heal." Helen's intention in introducing her portrayal with this image and message is to plunge the reader-viewer confrontationally into the phenomenal essence of what her body feels like- a gaping wound that oozes, weeps, and burns, a body that will never be whole and reclaim its intactness. Helen reasons, "*It's quite a jarring image or at least to me it seems the image and the quotation are quite jarring. [I want] to arrest the viewer and be like there's something wrong here.*"

As each of the preceding narrative passages reveals, Angela, Lynda, and Helen glide back and forth between experiencing nagging sets of carnal stirrings and fluid sightings, having confidence in their subjectivities, and questioning whether such phantasmic embodied-ness is valid and worthy of genuine concern. This scenario is buttressed by Kvigne and Kirkevold's (2003) study of female stroke survivors whose bodies cycle between periods of (in)visible (in) stability. These authors report that the disturbing and unintelligible alterations of an (un)settled embodiment provokes disconcerting feelings of (dis)belief and ambiguity that envelop women in an (un)settling world as they witness their bodies change from a familiar stable one to a volatile unfamiliar one (Richardson, 2005; Werner & Malterud, 2003).

At twenty-five, Angie was a dedicated university student whose stressful life of late nights, poor eating habits, and sitting for extended hours at a computer completing assignments seemed ordinary. Identifying herself as someone always in good health despite occasional sinus colds and bouts with the flu, and physically active in sports, Angie rarely thought about her body's functioning since it always performed in desired ways. An active social life and an ideal job waiting in the wings were all part of Angie's life prior to her dreamlike induction into the (in)conceivable world of (un)settled-ness. Trapped in what feels inescapably real but physically impossible to make sense of, Angie recalls her initial "something else is going on here" moment.

> *It was 2002 . . . I was really, really working hard at school doing a lot of editing for a bunch of documentary films I was working on and I wasn't eating properly and I wasn't sleeping and I was staring at a computer screen all day. And then I had this WEIRD visual disturbance. I couldn't see in front of me. I couldn't see properly. It was kind of blurred and I thought oh, I have eye strain or something . . . Like I was going to Ryerson and just like crossing the street at Yonge and Dundas was TREACHEROUS because I didn't know if I was about to walk into someone or get run over by a car. It was really terrifying. I couldn't see. Everything in front of me was like distorted [and] doubled and would quiver . . . Every morning I would wake up in the dark and I wouldn't want to open my eyes. And then when I did if it was the same or worse I would get upset. I felt like a FREAK. Like it might not have been visible but I think my actual eyes were giggling. People told me that they BARELY noticed anything. You know, if you're in really good health . . . it's scary you know. You know something is wrong immediately.*

Radley (1997) infers that as a medium of communication, the body has a way of appearing well and of appearing ill and the movement between states of health and illness and illness and health are not always readable or existing in a ready-made state (pp. 50-57). Given this position, Hilbert (1984) avers that the onset of painful and impairing bodily sensations is a uniquely private experience that no one else can feel, know, or experience (p. 373). Paralleling Angie's experience, Donoghue and Siegel (2000) stress that signs of [in]visible chronic illness often elude the observation of others because not only are they are subjectively experienced but even in its worst exacerbation, can preserve an individual's "ordinary" or so-called "normal" appearance. In view of this reasoning, Moss and Dyck (1999a) imply that women living with unsettled bodies like Angie consequently "fail" at being normatively ill and disabled because such elusive and ineffable signs of (un)settled-ness challenge how we are socialized to perceive what counts as a disabled embodiment.

Attempts to make sense of illness in terms of biographical events give meaning and structure to an otherwise chaotic world (Williams & Popay, 1994, p. 123). Recalling the exact date of April 2, 2002 at 12:00 p.m., Angie invites us deeper into another identifying moment (Charmaz, 1991) in relation to her changing eyesight.

> *I was living with my parent's way out in the west end . . . and I used the subway. For the duration of the subway ride between Dundas and Royal York it [the visual disturbance] just like disappeared. It was incredibly WEIRD. Basically, when I got on the subway, I could not read a poster, like an advertisement, and by the end, I could. Like everything just sort of dissolved . . . So by the time I was off the subway, I could read a poster and I was like okay this is getting better. And after that, it probably took like two days and it was perfectly fine and I just didn't think about it really.*

Adding to these early, fluid, (un) believable moments of (un)settled-ness, Angie narrates an episode where she experiences escalating, terrorizing sensations of bodily numbness that seem too unreal to be happening. Young (1990) accounts for this embodied transmogrification as a split subjectivity, a doubling of one's customary body and one's body in the moment that reveals "myself in the mode of not being myself" (p. 276). Uncertain what she will confront or how she will feel on any given day, many women like Angie experience a deeper embodied immersion with each new cycle of alienating symptoms in which they learn to read and respond to their bodies in unfamiliar ways (Canadian Working Group on HIV and Rehabilitation, November 2003; Joachim & Acorn, 2003). Associating the unnerving sensation of numbness with the once pleasurable recreational use of cocaine, Angie comments how this (un)settling deadness (un)believably spreads and intensifies throughout various parts of her body to the point where it engulfs her very being. Yet, it is this same unbridled colonization of Angie's body that eventually evinces the physical testimony others can witness.

Figure 3. A line of cocaine: Feeling numbness

> *I felt light headed and I had this INCREDIBLE, INCREDIBLE, headache and it was very different . . . it was crazy because I always have bad sinus head colds . . . and the bottoms of my feet were numb which is the first time I ever felt that and it was really cold, and weird and numb almost like my feet were asleep . . . and then my left eyebrow slash nostril was numb . . . and I had twitching eyes. Like, if I looked towards my peripheral vision . . . I couldn't hold on, I almost had less flexibility . . . The only comparison I have is like COCAINE. When you do cocaine, you use the residual cocaine and put it on your gums to make your gums numb and it's a high and its fun. At least I associated it with fun before this stuff.*

Vividly elaborating what feels like an imaginary albeit very real downward spiral of an out-of-sync body (Plach, Stevens, & Moss, 2004), Angie states:

> *From then it was the BIG ONE where the numbness in my eyebrow and nostril on the left side spread like wildfire . . . it was facial numbness on the entire left side . . . and numbness is really difficult to determine unless you're poking it . . . I had to EXPLORE my body in like a different way. Like I don't usually poke myself and it was almost like in the shower, it was another FORCE on my body that indicated hey your face is numb Angie! It wasn't like a sensation, its numbness right. It's lack of sensation. So it's really weird like the shower helped me to determine how far it had spread and stuff because I couldn't feel the water on my head. It was almost like the showerhead was squirting out on one side only . . . . I could move but the right side, which I still had sensation on, I couldn't move it. Like when I went, [raises her eyebrow here] "surprise," I couldn't move it. It wouldn't crinkle on the right*

> *side. . . it would only crinkle on the left side, the numb side. Like I felt like a freak because half of my face was moving with normal animation but the other one seemed paralyzed but it was reversed to the numbness if that makes sense.*
>
> *So I went to the hospital . . . and I woke up . . . early in the morning . . . and my entire left leg and arm were numb slash asleep. And that's like NEW. . . It was like shocking, terrifying, horrible . . . I had a headache on my left side, I had nausea, I had numbness like totally extended down to my lower lip and up to my mid head and my cheek and my eyelid . . . And I started having that visual disturbance thing again . . . A friend of mine was telling me like when I would look that way [looks to the left], my actual eyeball would like DROP DOWN . . . . it was numb [and] painful. . . it's especially bad if you've ever had your feet fall asleep because when you actually stand on them its excruciating pain, like pins and needles horrible . . . so painful. It was sort of numbness and jiggling eyes . . . . At its apex, it was up to my belly button, completely numb. And the freakiest thing probably was just my crotch was numb . . . I was constantly reminded every time I went to the bathroom. I could not feel, like when I wiped it was painful and I couldn't feel where . . . my vagina was, my ass was. That was really, really terrifying . . . and it seemed not to be stopping. . . . I didn't want it to go in my hands and my arms. . . It was colonizing more and more of my body . . . . When I talk about numbness, it's not something you can see [so] I was excited when half of my face was numb and the other half wasn't. One numb side wasn't crinkling or responding to me frowning and stuff and I was like thank God! There's proof. PHYSICAL, OUTSIDE PROOF! A doctor will hear me. My friends can see this. I was so excited!*

At the same time however, the visibility of this extenuating carnal evidence and Angie's credibility come to a crashing halt when further carnal stirrings prove visibly indiscernible. In the next section, I continue with Angie's story focusing on her attempts to photograph this cavalcade of carnal signs.

Trace(less) Realities: Photographing the Phantasmic

Extending an understanding of (un)settled embodiment to its (in)credulous fluid sightings, Angie conveys how fleeting carnal happenings engender a sense of "dis-ease" (Shildrick & Price, 1996), a capricious (un)easiness that (in)visibly creeps across her body like a shadow or the eerie calm before an impending turbulent storm. Toying with Angie's sense of reality, the phantom-like (dis)appearance of (un)settled-ness sometimes leaves physical traces such as deeply grooved indentations on her wrist and at other times, vanishes without a trace. Such (un)marked signs like the (in)visibility of her numbness, are momentary, evaporating as quickly as they came. Thus, witnessing and holding onto any identifiable signs of (un)settled embodiment however small, becomes disappointingly impossible as they fade before Angie's eyes.

Figure 4. The calm before the (un)settling storm.

> *MS [is] a FUCKING DISEASE that ravages you . . . It's almost like the way it OVERTAKES- creeps, like it creeps slowly and takes over more and more of my actual physical anatomy . . . It's almost like a curtain, a shadow creeping across you and then the shadow receding again kind of. . . . Sometimes it [the MS] will leave TRACES that may or may not disappear.*
>
> *At this point, they disappear . . . . When I wake up, I have these deep, like if you look at your wrists you have these deep whatever wrinkles or grooves in your wrist when you bend it. But after a night of sleeping, I'll just have them and they'll be extremely deep. There's like a TINY MARK and it'll disappear from what has happened the night before. But sometimes it's gone by the time I wake up you know?*

An intriguing connection Angie illuminates is how she attempts to visually document or "make real" the existence of her fluid, episodic signs of (un)settled-ness such as the deep, grooved indentations in her wrist upon waking. Commenting on the power of photography as a touchstone for reality, Susan Bell (2002) asserts that photographs lend an air of authenticity to a person's claims about their experiences. Viewers believe that there is something authentic or accurate about a photographic likeness (Adams, 1994, p. 466, cited in Bell, 2002, p. 24). Yet, in trying to convince us, Angie fails to photographically capture the carnal evidence of these trace(less) realities because they too are forever in transition and impossible to seize in the moment. Since the essence of (un) settled embodiment in this scenario is its fluidity from moment to moment, Angie must convince herself to believe in the integrity of her own body, to believe what seems both (sur)real given the transient nature of (un)settled-ness. Angie stresses:

> *It's almost like you have to force yourself to believe in, I don't know, the truth of it. It's so easy to deny . . . you're the only one seeing it. And you can't even capture it in a photograph. . . . I jumped out of bed to photograph my fucked up wrist . . . . [but] it's like I can MISS IT.*

Sontag (1978) remarks, "a photograph. . . is a trace of something directly stenciled off the real, like a footprint" (p. 154). However, given the erratic "reality" of (un)settled embodiment, such vestiges of embodied truth, unlike Sontag's footprints, resists indelible impression. Expressing the necessity of fabricating photographic proof of a bruise from having blood repeatedly drawn in the hospital because her camera fails to capture the existence of the "real" one Angie relays:

> *I had this HUGE, massive bruise from the bitchy nurses . . . This is not my arm. That is fake . . . I fabricated it after. . . [with] the imaginariness of it all, you have to recreate it in order to make it like vivid to people . . . It's just so weird how the recreation, it almost has to be recreated rather than captured in the moment. It's just like it was there and no one was around and even my camera wasn't cooperating . . . This is the most false reality ever and yet it will speak to more people . . . It's kind of so fucked up and kind of crazy that you can't capture this stuff on film.*

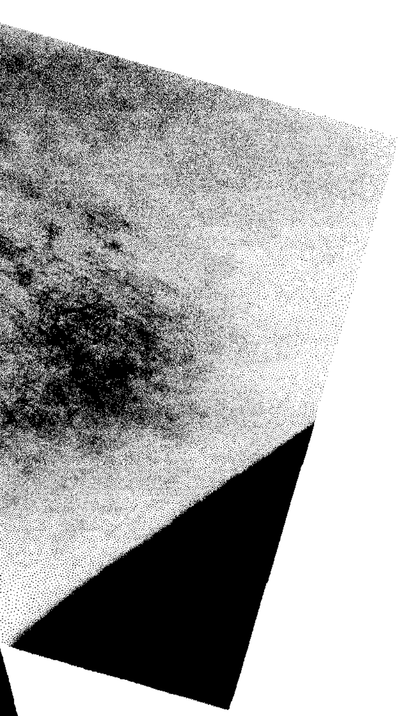

Figure 5

Figure 6. Fabricated bruises: Creating proof.

Here, the myth of photographic truth gives the illusion of being a simple transcription of the real, traces touched directly by the events they record (Hirsch, 1997, p. 7). In this respect, Angie's attempt to convince us of her own corporeality culminates in an illusion of the illusiveness of (un)settled-ness. Broadening this way of thinking, Vickers (2005) reminds us that in relation to individuals with [in]visible illness, much of our supposed understanding of "reality" or what we believe is, in actuality, simply an image of reality (p. 83). The everyday reality of (un)settled-ness is thus both (in)credible as symptomatic of its (in)stability. In (re)constructing the reality of (un)settled-ness pictorially, Angie illuminates that for people living with (un)seen disabilities, their embodiments are often seen and felt as fleeting reflections and images that are not enduringly "real" (Vickers, 2005).

Visually concretizing this tension of (un) settled-ness and its (sur)real aura in her three-dimensional self-portrait proves more fruitful for Angie. Describing a photograph of icicles positioned inside a hidden, moveable flap near the bottom of the portrayal to symbolize her feet, Angie observes:

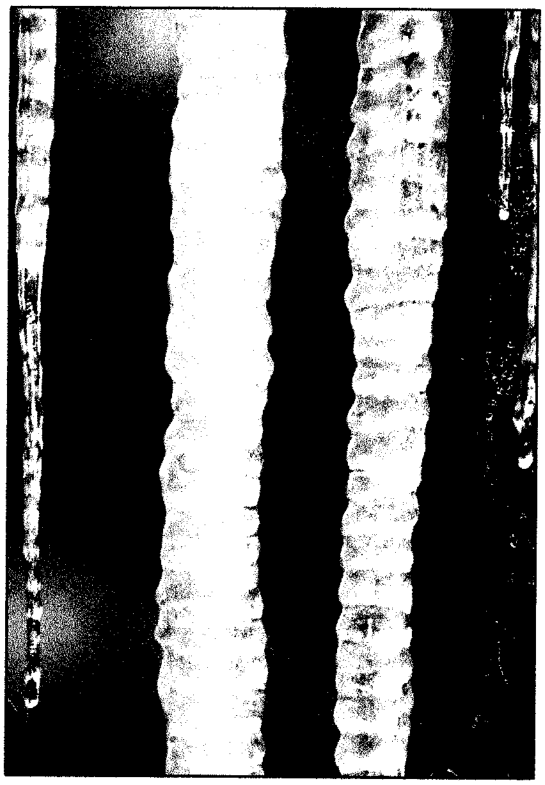

Figure 7. Icicles: (Dis)appearing numbness

> *It kind of reminds me of numbness . . . But it's more. Maybe it's the fact that at the end of the day, they're like icicles [her feet] and they'll melt. Like a relapse-remitting sort of thing. These things happen but they always recede.*

Reflecting on the uncertainty and temporariness of her (un)settled-ness in relation to her portrait Angie says:

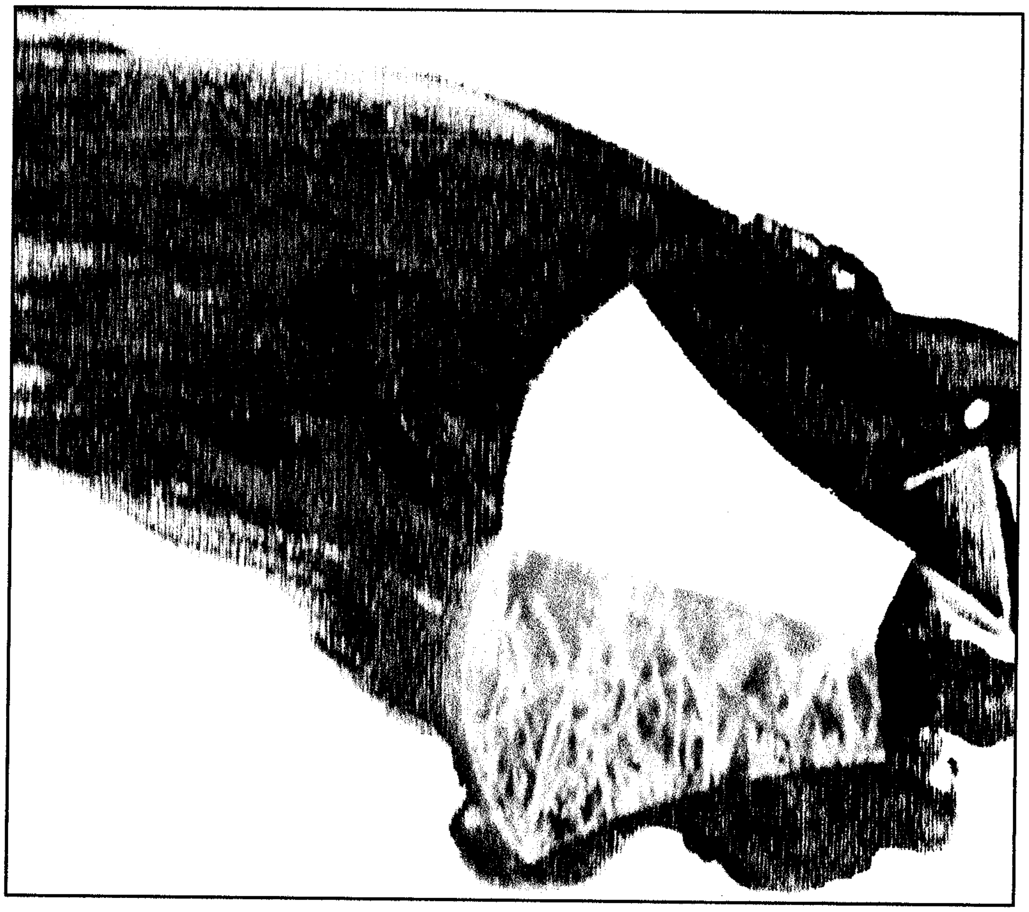

Figure 8. Relapsing-remitting signs: Tree branches covered in snow in a three-dimensional portrait. Courtesy of Angie Driscoll.

> *If we were to look at this in fifty years, there would be flaps that would be ripped-off because they would be visible all the time . . . Like this portrait wouldn't work. [Now] I can hide all my flaps. All my flaps close but some day my flaps may not . . . It's just like waiting for whatever plaques to . . . become inflamed.*

The shifting (in)visibility of bodily changes catapults Angie into what feels like a (sur)real or phantasmic world where it becomes easy to doubt such transient carnalities despite their undeniable physicality. This attitude deeply echoes the essence of (un)settled embodiment among the women in this study. It is problematical to (dis)believe that flare-ups that erupt out of nowhere, shifting from moment to moment, hour to hour, and roaming from one body part to another could have any kind of existential basis. This view is supported by Charmaz (1991) who affirms that "the events ill people experience seem surreal [or] unreal. . . throw[ing] them into another reality without warning" (p. 31). Utilizing the metaphor of journeying back and forth between a (de)stabilized body, Moss and Dyck (1999a) underscore the complexity of unsettled embodiment as a continuous, ever-changing reality where movement between [a]symptomatic periods inspires feelings of disbelief and disorder.

Angie further articulates this endemic (sur)realism as the co-existence of two inter-twined, (un)conscious worlds paralleling states of sleep and wakefulness. Within this scenario, no one realm predominates; the reality and the fantasy of (un)settled-ness exists simultaneously. Angie believes what is happening within her body, specifically her feelings of numbness, are in fact only imaginary and far-fetched nocturnal episodes. Since Angie cannot visually see her vital organs and the neural pathways deep inside the inner recesses of her body, her numbness and other evanescent sensations seem dream-like and thus, unconvincing in their corporeality. It is from this dubious materiality that Angie shifts between (in)validating that what her body is showing and telling her is indeed existentially real.

> *[There is] a constant coexistence of two planes of reality. The PHYSICAL REALITY which is sort of WAKEFUL and then there's this unconscious dream reality. . . [a] coexistence of two things . . . that don't exist in any sort of CONSCIOUS way . . . . That's how I engage with my MS in that wakeful/not wakeful, conscious/unconscious, sleep/awake, dream way.*
>
> *Basically a lot of my MS stuff . . . is doing its handy work or whatever, progressing totally behind my back. Like I'm not conscious of it at all. It's like totally invisible what it's doing to my brain, my spine . . . A lot of my symptoms like my numbness happen when I'm SLEEPING . . . It's almost as if I'M SLEEPING and it's happening while I'm asleep.*

> *The fact there are plaques on my brain, to some people that would be like probably really freaky. But to me, like my brain, my insides, like my heart, my organs are kind of like a FANTASY . . . I don't see them. I believe they exist . . . But you know what I mean? The MS is almost like IMAGINARY . . . it's kind of UNBELIEVABLE. Sometimes I'll wake up in the middle of the night just to roll over and so it's like almost a DREAM that I remember that my entire arm wouldn't move because it was asleep or whatever in the midst of my dreaming. So a lot of the MS to me, it's almost like a dream, it's not happening.*

Angie is caught between giving credence to what is happening sensationally inside her body and feeling skeptical about the extent to which her body's volatility is "believable enough" since her numbness is fleetingly felt and unseen, happening while she is asleep rather than in a heightened state of awareness. Put another way, Angie lives with the tension of experiencing the ontological realness of losing bodily feeling yet feels like what is happening within her body is surreal and unbelievable, as if she is "dreaming up" these sensory disturbances. Charmaz (1991, 2000) corroborates this perspective stating that individuals who experience a plethora of bewildering symptoms with the onset of chronic illness find it problematic to trust their own bodily sensations when they remain invisible or as with Angie, provisional as they fluctuate in (un)settled, (in)visible ways.

Conversely, it is exactly this wavering, (in)visible (un)settled-ness that Angie is amenable to and takes comfort in. Angie takes refuge in the fact that as long as her flare-ups happen while she is asleep, as long as her body maintains its silent promise, she can ignore the nerve-racking (dis)orderliness that (un)settled-ness brings in its "wake." In fact, the estrangement, distress, and fear (un)settled embodiment entails becomes increasingly more manageable and less threatening for Angie because of its relapsing-remitting nature. Justifying this viewpoint, Angie claims:

> *When it [signs of multiple sclerosis] are apparent in my waking life, its like crossed this boundary. We have an unspoken rule like do what you want at night while I'm*

> *asleep but once it crosses the boundary to wakefulness, that's when I have to confront it.*
>
> *I like the idea of it's almost like if you don't see it, its okay. It's easier to ignore or not acknowledge if it's not present. Once it starts to leave marks that don't go away, traces that don't just fade, then it's not cool. There is something about the temporariness of it that makes it more manageable . . . And the fact that it's also quite invisible in many respects but like totally transient. Like I still have moments where I feel like there's nothing wrong. I feel pretty good . . . . These symptoms resolve themselves and then I can be like symptom-less for a while versus symptomatic all the time.*
>
> *When I have an attack it pretty much resolves itself. At the end, there's nothing left over. I don't have any facial numbness today . . . I can't feel sorry for myself when I'm having those kinds of positive outcomes. Lot's of people don't and I'm very fucking lucky.*

Since Angie's numbness occurs at night and leaves no waking traces of its damaging albeit dream-like essence, Angie feels fortunate that she can cling to the hope of a return to normal as if the illusive essence of her MS is in fact, implausible.

Summary

The intention of this chapter sets the tone for entering into the fluctuating materiality of an (un)settled embodiment and unearthing an alternate language emanating from this experience. Whispered, fleeting bodily sensations that whimsically come and go and erratic episodes that dramatically alter a woman's functioning and/or mobility biographically characterize the onset of an (un)settled embodiment. The (un)predictable cycling of these carnally bizarre, early warning signs disrupts women's customary ways of living and relating to their bodies. It is here that a carnal expressivity derived from the women's bodies themselves comes to the fore. These bodily "happenings" vary between being existentially "(un)convincing" as they surreptitiously (dis)appear in and out of women's sight. Such "telling moments" of carnal transmogrification are ignored and justified as part of the "normal" bodily stresses and strains in daily life at the outset of one's journey into (un)settled-ness. However, with an intensification of symptoms, women quickly learn to (re)interpret their bodies in alternate ways as they leave the familiarity of their unchanging able bodies behind.

Since the material reality of an (un)settled embodiment is a private experience that no one else can witness or feel, it commonly eludes the attention of others. Unable to persuade others about their mounting (in)visible physical distress, women remain at the mercy of their bodies and alienated in their experience.

Equally tenuous, because participants typically appear healthy during these seemingly surreal flare-ups, they spiral between trusting their own bodily knowledge and remaining distrustful of their own carnal readings. On most occasions, these phantasmic eruptions vanish, leaving no convincing, residual traces. The struggle to hold onto even the most trivial albeit legible sign of bodily distress is nearly impossible given the (in)stability of the body's cycling back and forth between periods of crisis and quiescence. For example, speaking to a diffuse sense of numbness within her body that no one else can see, Angie comments that such bodily eruptions are almost illusory- they seem unreal in the moment but are unquestioningly alive within her body. In fact, Angie's attempts to convey such fantastical changes photographically attest to the very ambiguity of an (un)settled embodiment. Even the smallest visible indicator of unsettledness remains beyond static capture, thereby placing shifting doubt in the minds of many women like Angie that what is carnally happening is indeed worthy of genuine concern. This waxing and waning exacerbates the burden of proof women carry in trying to materially substantiate their (un)settled selves. Participants struggle to convince themselves of the integrity of their bodies, to validate what seems both real and surreal simultaneously. Yet, it is this carnal ambiguity that becomes axiomatic for comprehending the (im)plausibility of women's (un)settled subjectivities.

Having provided an exploration of how the onset of (un)settled embodiment conflictingly presents itself from calamity to calm and back again in an (un)convincing manner, I now move to the (un)convincing nature of an (un)settled embodiment within the odyssey of medical diagnosis. Within this milieu, women struggle between seeking concrete evidence of their (un)settled bodies through medical evaluation and inscription, and sometimes consciously deny a positive diagnosis in light of visible, corporeal proof.

(Un)Convincing Bodies Part II

Chapter 5

The Odyssey of Diagnosis: (Dis)Missed Bodies

In the previous chapter, I focus on the (un)convincing beginning of (un)settled embodiment from the perspective of the lived body. In this chapter, I connect the "missed" and dismissed" materiality of women's (un)settling illness trajectories with the odyssey of medical diagnosis. To disentangle the seamless tensions within this embodied movement, I intentionally divide the discussion into two chapters: the odyssey of medical diagnosis and at times, its "conscious denial" (chapter 5) and the psychogenic dismissal (Munch, 2004; Vickery, 1980) of (un)settled embodiment as imaginary (chapter 6). To amplify the depths of (un)settled embodiment in this chapter, I weave in and out of a mixture of (un)settling accounts, calling forth each woman's voice separately, sometimes more expansively, as well as in tandem where embodied tensions flow through several stories.

Diagnosis is the cornerstone for legitimizing women's problems (Cooper, 1997; Donoghue & Siegel, 2000; Hellstrom et al., 1999; Milliken & Northcott, 1996; Moss & Dyck, 2002; Sveilich, 2005). The search for diagnosis relates to three concerns: the desire for treatment and cure; the need to convince oneself and others that pain and suffering is real; and perhaps most importantly, the confirmation that one is sane in interpreting their embodied experience (Hilbert, 1984; Lennon, Link, Marbach, & Dohrenwend, 1989; Register, 1999). The adage "if it is not diagnosed, it does not exist" (Vickers, 2001b) aptly resonates with the carnal discord women in this study experience. (In)visible (un)settling conditions, by their transient nature, are silently embodied, looming in and out of women's lives. Initially, (in)visible illness is often challenging to diagnose. Women commonly endure a traumatic battle to convince themselves and their doctors that their (un)settled embodiment while not always visible because it shifts in and out sight and physical intensity, corporeally exists. Influencing this tension, Sveilich (2005) and Vickers (2001b) confirm that diagnosis is often a prolonged process that can occur over several months or years as evidenced in the stories of Helen and Angela, or almost immediately over a period of days or a few weeks as Lynda and Angie's narratives demonstrate. Armed with the subjective convictions of their (in)visibly patchy bodily experiences yet spiraling in and out of the fringes of self-doubt, Angie and Helen embark on an (un)settling road, sometimes encountering several crossroads, in their quest to make sense out of a confusing constellation of (un)settling bodily signs. Conversely, Angela seeks diagnosis to (dis)confirm her own self-inscribed suspicions of MS whereas Lynda's diagnostic foray proves just as (un)believable as the physical onset of her (un)settled-ness.

Writing from the position of living with the (in)visibility of myalgic encephalomyelitis, Wendell (1996) points to the social and cognitive authority of western medicine as having the incontrovertible power and expertise to describe our bodies to ourselves and legitimate them to others. Reflecting this assertion, Lennon et al. (1989) indicate that for many individuals with chronic illness, the search for a medical explanation for their suffering is reinforced by the need to convince others that their pain is genuinely real (p. 120). Without this authoritative verification, there remains a palpable sense of mistrust of the body and in oneself. Writing extensively on the diagnostic journey as a rite of passage (Moss & Dyck, 1999b, p. 158) in which there is an inscriptive promise of identification as a *specific* body and the personal credibility connected with this, Moss and Dyck (2002) emphasize:

> A diagnosis . . . is crucial for women to negotiate the journey through chronic illness; it acts as the ticket for the journey. Obtaining that ticket is itself a rite of passage, a crossing of a threshold (1999b, p. 164). Through diagnosis [the etching onto the body of a particular inscription], women's ill bodies are made culturally intelligible. Diagnosis, central to biomedicine, legitimates an ill body by naming a specific disease process. . . This naming through diagnosis also contributes to individual and social understandings of ill bodies by attaching an accepted explanation of a chronically ill body that makes sense biomedically to a *specific* body. The diagnostic process as part of biomedical discourse is a primary method of legitimating ill bodies. . . Because of this privileged stature of diagnosis in society. . . if no disease process is 'discovered' operating in a body or no illness is declared as an 'official' diagnosis, then that body becomes invalid discursively (pp. 84-85, 93).

Physicians invested with the power to designate bodies as healthy or diseased rely heavily on the anatomical and biological materiality of the body (Moss & Dyck, 1999a, p. 384). For Angie and Helen, the (un)stable materiality of their (un)settled embodiment counteracts their self-confidence in their lived, biological body. This state of affairs translates into a struggle to be listened to, to have one's unique embodied ways of knowing valued and believed by the medical community (Begum, 1996; Cooper, 1997; Lisi, 1993; Wall, 2005). The epistemological axiom "to be 'real' is to 'show up' visually" (Rhodes et al., 1999, p. 1196) underscores how medicine authorizes disease and how Angie and Helen seek to convincingly concretize their unsettled bodies through technological imaging. Addressing the interpretive power of diagnostic imaging to read the cavernous, inner world of the body, Rhodes et al. (1999) stress:

> Sophisticated tools for visual diagnosis all create an 'inside' body, another world that can be seen, accurately represented through drawings, photographs and computer images. . . . The inside of the body corresponds to visual images of it. The body is 'filled' with organs that can be made visible... [like a] landscape through a window. . . This 'view' is objective, showing the body as it 'really' is. . . [and that] variations in people's bodies can be measured against norms [or] objective standards that show what is typical and what is deviant (p. 1193).

Even during their worst exacerbations, Angie, Helen, Angela, and Lynda "look fine" even healthy while variably functioning (with)out difficulty in relation to their (de)stabilized bodies. Consulting a personal journal in which she documents her early flare-up periods, Angie communicates how the tension between her privately known bodily experience and its diagnostic (mis)perception manifests when her first MRI (magnetic resonance imaging) test disconfirms the numbing chaos spreading throughout her body, ultimately challenging her faith in the inner workings of her body.

> *The neurologist performed a neurological exam that came up normal. That was on the seventh . . . It was almost if by that weekend when I went in for that MRI, I remember it [the numbness] was like ten times less. I almost felt kind of bad about getting the MRI. I felt like I wasn't really sick . . . . like the first time it was gone within a subway ride. The second time it was gone within a day. It always resolves really quickly. By the time I went in for the neurological exam, it resolved to such an extent that I was normal. This guy didn't listen to me, kind of totally dismissed me. I mean, who knows your body better than you do right?*

Continuing with her (un)settling saga as she refers to a photograph symbolizing the interiority of her (mis)firing neurons, Angie recollects her exceeding frustration at her mounting but inscrutable body of evidence.

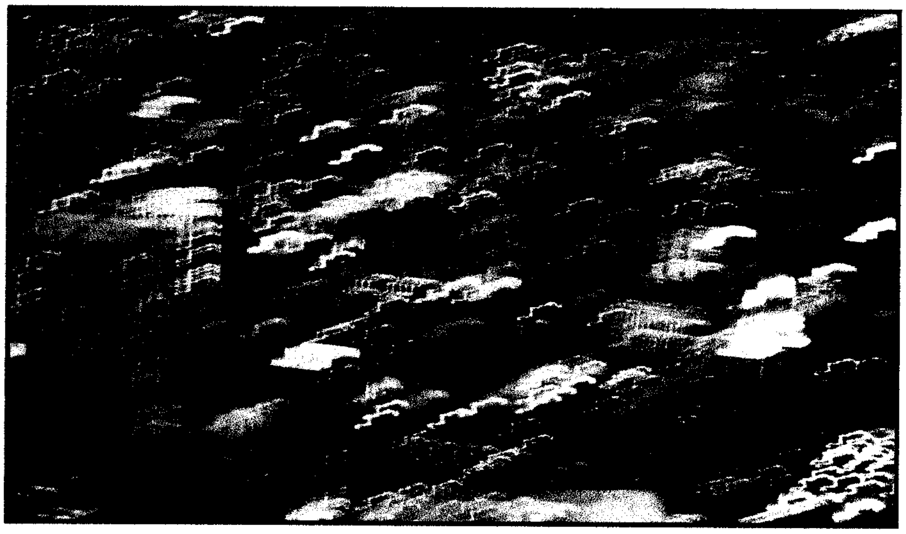

Figure 9. Electrical flashes of lightening: (Mis)firing neurons.

> *I had a [second] neurological exam done by Dr. S. . . . and again that was normal. It was almost like I went to the hospital too late. . . like I didn't catch it right on the worst day . . . but I think if you have an MS plaque it's there, but at the same time, I thought I'd missed my window almost.*

> *On the twelfth of June . . . . all shit broke loose. I had a backache in the morning and by the afternoon my right foot and ankle are subtly numb and my hand is fleetingly numb on the right side. By the thirteenth, [in] my back, I have this shooting, aching pain . . . and the left and right bottoms of my feet are numb. I remember the right side went first . . . and the left side was kind of lagging behind . . . then they sort of started to match up. . . but it was that fast. Like twelve in the afternoon it started and by, it was ridiculous, like I saw a neurologist that morning and he was telling me "YOU'RE FINE." And by the afternoon, it's like "uh hi, I can't feel my lower body." And that just kind of made me crazy. It just seemed you know IS THIS REALLY HAPPENING TO ME? Because these doctors are telling me oh you're fine that morning and it's like they can't see this but I feel this and I can't prove it.*

The fluctuating, volatile nature of (un)settled embodiment as Angie suggests, makes diagnosis and her credibility as a patient almost impossible. Lending credence to this scenario, studies of women with (in)visible chronic back pain (Rhodes et al., 1999) and women with repetitive strain injury (Reid, Ewan, & Lowy, 1991) demonstrate that the apparent transparency of diagnostic testing to reveal "everything happening on the inside" paradoxically belies both the objective and subjective proof of women with (un)settled bodies. Echoing the nature of false alarms inherent in the cycle of (un)settled embodiment, Asbring and Narvanen (2002) and Ware (1992) acknowledge that the veracity of illness accounts among women living with the (in)visibility of chronic fatigue and fibromyaliga are challenged because like Angie, their outward "able-bodied" appearance contradicts their private, inner turmoil. Given this invisible, deceptive barrier surrounding (un)settled embodiment, Kugelmann (1999) implies that patients with (in)visible conditions need their pain ((un)settled-ness) to prove they are in pain (p. 1668). Yet conveying this agonizing proof becomes a heavier burden than the symptoms themselves. Powerless to catch (un)settled-ness in its wake, nor substantiate any visible lingering traces through neuro-imaging or clinical examinations, Angie misses her window of opportunity to convince her doctor of her memorable albeit ghosted corporeal history. This reflection is supported by

Koopman and Schweitzer (1999) who affirm that in the pre-diagnostic phase, appointments with specialists often occur when signs and symptoms of multiple sclerosis are no longer obvious, giving the appearance of an illusory illness. Yet, as soon as Angie's body returns to normal, another insidious cycle of numbness takes hold, whispering its presence while stealthily smoldering like wildfire. This numbing silence remains undetected by doctors who assuredly determine that Angie is "just fine." Yet looming behind this conviction, (un)settled-ness is ready to creep up and take hold of Angie's body again. This frustrating seesaw of volatility that deeply colonizes Angie's body one moment and seemingly masquerades as functional calm the next inspires Angie to move between feelings of (dis)belief, to question her conflicted subjectivity, and more importantly, to sustain her struggle to convince herself and her doctor that she is not crazy, a sham or a fraud (Moss & Dyck, 2002).

Upholding Angie's unpredictable ethereal scenario, Moss and Dyck (1999b) imply that since (un)settled-ness tosses a woman to and fro between health and illness and (re)commencing the whole cycle once again, the typicality of bodily functioning and daily living loses its meaning. Instead, volatility becomes an expected way of life (Moss & Dyck, 2002). Living with the (un)settling effects of scleroderma, Anderson (2000) illuminates the ever-changing meaning this kind of volatility implies.

> From day to day it is totally unpredictable. Unlike a disease which is the same each day or one in which there is a slow but steady decline, in my case I never know when I wake up how things are going to be. . . . Will it be one of those rare days on which I have unaccustomed energy and can do whatever I want, even though I will pay for it the next? Or will it more likely be a day of fatigue and pain. . . . There is a feeling of "here we go again," which is difficult to dismiss. This unpredictability is hard to live with. . . . it is in fact a major disturbance of life (pp. 38-39).

Building on this (un)settling transitioning, Charmaz (1991, 1997), Richardson (2005), and Sveilich (2005) stress that the unpredictable (in)visible flow of chronic conditions hinges on whether a woman is having a good or bad day. Specifically credited with the conception of good days and bad days, Charmaz (1997) indicates:

> Criteria for good and bad days shifts as someone's condition improves or worsens. Good days become much better as health improves. . . . as illness progresses, this process works in reverse. A bad day gets worse- sometimes dramatically so. . . Cycles of quiescence and flare-ups foster. . . how meanings of a bad day change. . . . Lesser bad days allow for more elastic definitions. . . [but] bad days become certain, expected, and predictable. Yet exactly when they will occur and where they will lead remain unpredictable (p. 53-55).

Since the progression of (un)settled embodiment is itself in flux, women cannot predict from day-to-day whether they will have a good or bad day. Unpredictability becomes predictable and anticipated. When symptoms are quiescent women feel relatively normal and function like their old familiar selves. Such periods of calm reflect minimal intrusiveness of symptoms and greater control over one's body, mind, and actions. On a bad day however, symptoms flare and a woman's body is out-of-whack, chaotic, and unruly rather settled down. Women feel out of self since they exercise less control over their embodied selves (Charmaz, 1991, pp. 50-52). Supporting this construal, Paulson, Danielson, and Soderberg (2002) indicate that men living with fibromyalgia experience disability as a paradoxical reality of (in)visible fluctuations of pain, weakness, and fatigue while at other times experiencing periods of wellness and calm enabling the presentation of a so-called normal body and identity. Drawing parallels among women living with the variable (in)visibility of chronic back pain, Richardson (2005) insists that such corporeal tempestuousness makes it easy for a lot of women like Angie to miss symptoms because they cannot anticipate when their bodies will flare up and how long each episode will last.

Accordingly, as the women in this study illustrate, the body has its own (un)settling agenda, an internal rhythm that eludes objective description and detection and thus, does not always comply with the fixed expectations of biomedicine. Given this reality, a woman's identity as a credible person with a (de)stabilized body suffers.

Alternately, the shifting (un)predictability of (un)settled embodiment moves beyond having sets of good and bad days. While this is certainly one perspective espoused in the chronic illness literature, living with the ambiguity of an (un)settled embodiment implies as Moss and Dyck (2002) connote, reflexively stepping back and destabilizing experiential scripts of health, illness, ability, disability, a "good" day, and a "bad" day that are tightly woven into the ableist fabric of our society. Transcending a view in which women are *either* revitalized and able to live up to able-bodied expectations of appearance and performance on a good day or are worn-out, and incapable of meeting hetero-normative expectations of able bodies on a bad day merely resuscitates monolithic notions of embodied identity. In other words, one is either able and close to normal on a good day, or disabled and consequently deficient on a bad day rather than jointly straddling seemingly opposing material and discursive spaces (Rose, 1993). Valerie Kimpson (2000) who lives with an episodically (in)visible disability remarks that since health is myopically and dichotomously defined as the complete absence of illness (and illness, the complete absence of health), the reality of being healthy and chronically ill denies any experience of bodies that are habitually in flux or what she deems as "transgressive." Kimpson declares, "I feel pressure to portray myself as either "sick" . . . or "not sick". . . I want to shift other's . . . understanding of what it is like to be living . . . beyond dichotomous oppositions" (2000, pp. 321-323). Since, identity is always in transition as Garland-Thomson (2002, p. 20) insists, we must open ourselves beyond comforting habits of seeing, reasoning, and binary thinking about bodies to imagining other malleable possibilities. I revisit and expand the threads of this discussion in the fifth movement describing the fluidity of identity. I now reorient the reader back to the medically (un)convincing fluid sightings and carnal stirrings that are part of phenomenal essence of (un)settled embodiment.

Whispered Murmurings

The body a woman experiences and that which a physician treats are seldom the same (Rhodes et al., 1999). Working out of a phenomenological tradition, Eugene Gendlin (1962, 1992) explains that the sentient body always transcends discursive meaning. Epitomizing the body's self-sentience symbolically as "..." to indicate its inchoate essence, Gendlin purports:

> Our bodies sense themselves in living in our situations... It senses itself living-in its whole context- the situation. . . . Your bodily "..." *is* your situation . . .The body-sense *is* the situation. . . .The bodily. . . can contain information that is not (or not yet) capable of being phrased. . . . All thinking involves the bodily . . . to some degree. . . There is no language in which to discuss what is more than language. . . . Language elaborates how the body implies its situation. . . We sense our bodies not as elaborated perceptions but as the body sense of our situations. . . . a bodily implying of speech and thought (1992, pp. 344-353).

Gadow (1980) indicates that the subject body in illness speaks an unfamiliar language that one must learn to perceive and interpret (p. 181). Substantiating this contention, Rosenblum (1997) infers "we trust that the body knows things before the mind does. Our job is to mind the body, to mine the body, to interpret its language" (p. 101). Beyond attempts to concretize her numbness and altered sensory experience diagnostically, Angie conveys the equally dispiriting challenge of giving voice to and convincing others about her (un)settledness by relying on a "carnal semantica," a private, implicit stream of feelings that her body evokes but that medicine cannot fathom. While Gadow and Gendlin concur that the sensate body elides discursive intelligibility, its carnally embedded whisperings are what guide us in translating bodily experience with any dialogic lucidity. Arthur Frank (1995) reiterates:

> The body eludes language. . . The ill body is certainly not mute- it speaks eloquently in pains and symptoms- but it is inarticulate. We must speak for the body, and such speech is quickly frustrated: speech presents itself as being about the body rather than of it (p. 2).

While I partially support the contention that bodily experience often exceeds everyday vernacular and that women with profoundly debilitating symptoms do not always have the language to describe their subjectivities, an observation similarly cited by Nettleton, Watt, O'Malley, and Duffey (2005) in their study of medically unexplained illness, the body is not unintelligible and voiceless. On the contrary, I believe that the body itself *is* language, an organic expressivity whose private stirrings "speak" within us and to us in unique ways. In this sense, carnal stirrings and bodily signs are anything but wordless (Gadow, 1980). Instead, they demand a corporeal sensitivity to embedded callings that only the individual can "hear." To illustrate, Angie illuminates an intimate fibrous attunement that enables her to speak from and with her body rather than about its (un)settled-ness. As Corbin (2003) substantiates, "people learn to trust their body's language- the sensations that it sends" (p. 258). Heeding her body while being pricked with pins during a neurological exam, Angie's bodily sensations whisper to her, conjuring up the sentient murmurings of what feels like a rippling pebble on a pond. Angie conveys this emotive, sensorial metaphor to connect her doctor more vividly to the interior essence of her numbness from the inside out. Angie recounts:

> *I remember being in the hospital and trying to explain the sensation of the numbness. They would prick you with pins . . . it was one of their clinical examinations and I remember the pain of the pinprick, like I could feel it, but I described it like it was in the distance. It was like a distant pinprick, and it was like a pebble on a pond, it had like a ripple effect. I felt it but it would almost ripple, like the numbness kept the*

> *pinprick at a distance . . . like it rippled through the numbness. . . and that's how I described it to the doctors and they totally didn't like it . . . it took too long and it was way too artsy or something. I remember my doctor listening to that and I was going into extreme detail almost to make it as precise as I could . . . [and] this doctor wrote one word and I was like "what the fuck did you write?" He didn't write rippling and distant . . . it was some medicaleese term for I don't know, numbness. After that, I just stopped describing it the way it actually felt because it was so effortful, exhausting. . . I just started to describe it in really perfunctory, medical terminology. It almost like distanced me from what I was feeling . . . I was making it very cold and medical . . . it wasn't messy, it wasn't emotional. You feel like a piece of shit because everything's been shorthanded and it's like your personal experience holds very little weight . . . they don't listen to you. They think they have it all figured out.*

Speaking to the inner voice(s) guiding women's ways of knowing, Belenky et al. (1997) suggest how such subjective, intuitive knowing demands an inward listening and focused observation within the self. As these authors suggest, subjective knowing, as Angie exemplifies, is an intuitive sensitivity, something experienced and felt rather than prematurely thought (p. 69). Since people do not speak in a predetermined language of symptoms (Corbin, 2003, p. 258), such biomedical semiotics impedes an expression of sensate experience anchored in personal meaning. As DiGiacomo (1992) acknowledges, the word "symptom" is a medically disembodied interpretation of what individuals experience rather than what they knowingly discern. Ultimately, Angie's innate poetics only serves to intensify the communication gap, exhaustively estranging her from her doctors and reinforcing her lack of credibility as someone too corporeally avant-garde to warrant serious consideration.

In *The Dialogic Imagination*, Mikhail Bakhtin (1981) speaks to the conflicted relationship between authoritative (scientific) and internally persuasive (subjectively engaged from within us) discourse and the manner in which this discursive conflict compels some women like Angie to capitulate their own ways of meaning making to be heard. To quote Bakhtin:

> The authoritative word demands that we acknowledge it, that we make it our own; it binds us. . . It is, so to speak, the word of the fathers. . . . It is therefore not a question of choosing it from among other possible discourses that are its equal . . . It's language is a special . . . language . . . It is akin to taboo, i.e., a name that must not be taken in vain (1981, p. 342).

Cooper (1997) asserts that while women with chronic fatigue experientially "knew" that something was "wrong" and expected their doctors to transfer this knowledge into their own understanding, rarely did doctors and patients share the same understanding of this embodied knowledge (p. 197). Scarry (1985) notes that pain, which I extend to the sensory experience of (un)settled-ness, defies language. Kleinman, Brodwin, Good, and DelVecchio Good (1992) state, "pain occurs on that fundamental level of bodily experience which language encounters, attempts to express, and then fails to encompass. . . . The experience of chronic pain includes much more than the raw physical sensation: pain creates problems of control and meaning-making" (pp. 7-8). Dorothy Wall (2000), a woman living with the (in)visible debilitating effects of chronic fatigue syndrome addresses the disjuncture between medical language and the sinuously encoded language enveloping the flesh.

> Ironically, medical language works to narrow and flatten the complex, personal encounter with illness, reducing lived experience to notations on physiological and biochemical states. . . . It's hard to develop a personal language . . . to share our experience . . . Those of us with CFIDS find ourselves developing our own language (I feel 'episody') that operates as a private code . . . rather than a source of connection with the well [and the gatekeepers of medicine] (pp. 28-29).

In trying to exhume a corporeal language of possibility (Ironside et al., 2003) to convince doctors of their pain, Peggy Munson (2000) argues that the patient and the doctor antithetically stand in the borderlands of their separate physical knowledge offering halting translations (p. 107). It is this interpretive chasm sustaining the (in)visibility of her embodied experience that Angie desperately tries to metaphorically bridge with her doctor but to no avail. Paralleling Angie's experience, Barbara Rosenblum (1991) speaks to the inexpressibility of words to describe her own (un)settled body in living with cancer.

> When you have cancer . . . you must learn a new language, a new vocabulary, and over time, as symptoms converge and conflate, you learn the deeper structure of its grammar. When you have cancer, you are bombarded by sensations from within that are not anchored in meaning . . . . Sometimes I can hardly use the human language to tell how I feel. I am often frustrated by the way the limits of language circumscribe my ability to communicate events in my body. . . [I am] challenged to find words to apply to sensations I've never had before, challenged to find meaning and stability despite a changing body (p. 138).

Even beyond the confines of biomedicine, Lynda illuminates how the English language specifically, and North American culture more generally, fails to capture the embodied-ness of her MS claiming:

> *MS shows me just how bereft the English language is of adjectives. If these feelings were commonly experienced, there would be adjectives to describe them but there's only a handful of people who are experiencing them so it's not going to make it in the lexicon. I used to joke that maybe in Swahili they have a word to describe these spiders that are underneath your skin crawling.*

Clearly, physicians operating within the orthodoxy of biomedicine expect any articulation of illness be it settled or unsettled, to fit within its discursive framings. (Moss & Dyck, 1999a). Wendell (1996) accentuates the dismissal of the lived body declaring "our phenomenal descriptions are at best treated as weak evidence for the truth of medical and scientific descriptions and are almost never treated as even weak evidence *against* a medical or scientific description of our bodies" (p. 119). Documenting the experience of women living with breast cancer, Mathieson (1994) draws an interesting parallel indicating that despite the centrality of "body talk" to the experience of chronic disease, medicine marginalizes the experiential meaning of illness and has yet to create a receptive space for this voice. Consequently, women like Angie strive to articulate their embodiment in such painstaking detail only to have physicians de-subjectivize their bodies by documenting a short-hand medical inventory that they believe more accurately mirrors the "hard facts" of clinical discourse as opposed to the phenomenal language of (un)settled bodies (Wendell 1996). In the end, as Angie implies, this medically alienating discourse literally "writes over" the (un)settled body, ignoring and discrediting its material subjectivity.

Discounting the language of the body is as Kleinman (1988) and Wall (2005) suggest, also connected to the lack of training physicians receive in eliciting, listening empathically to, and exuding an interest and respect for personal experience. This Cartesian rupture between objective and subjective knowing interferes with rather than supports women's confidence in the intimate knowledge of their bodies, and ultimately loops back to their shifting sense of (un)convincing-ness about their experiences altogether (Wendell (1996). Here, I highlight Susan Griffin's (2000) compelling paper *From What Her Body Thought: A Journey into the Shadows* where she writes extensively about the devaluing of embodied knowledge.

> Regarding your own body, it will seem like almost any other opinion carries more weight than your own. As you are told what in the range of your complaints has meaning and what has none, or even at times what you ought to be feeling, your own knowledge weakens. . . . your faith in yourself will be shaken. . . . all along you suspect that while you labor to paint a portrait of a territory your doctor has never experienced in his own body, he will weigh laboratory results far more heavily than your testimony. . . . Somewhere in the breach between your own knowledge and medicine's ability to apprehend it, you cease to trust the knowledge of the body. . . . bodily knowledge belongs to a lower order. Not only is the patient's testimony by definition subjective and therefore scientifically inferior to the seemingly more objective opinions of professionals, but sensual evidence itself is deemed by science to be untrustworthy (pp. 33-38).

As Angie's narrative illustrates, medicine rebuffs embodied ways of knowing, supplanting a vacant, authoritatively "legitimate" jumble of alienating metaphysical facts in place of the silent wisdom that flows through a woman's body. Wendell (1996) summarizes these two discordant positions affirming: "medicine can undermine our belief in ourselves as knowers since it can cast authoritative doubt on some of our most powerful, immediate experiences" (p. 122). Ultimately stripped of the only meaning and understanding that makes sense to women like Angie, medicine contravenes embodied ways of knowing, disbelieving and illegitimating the nature of (un)settled embodiment.

(Un)Convincing Selves: Diagnosis and Conscious Denial

After a series of neurological exams, two MRIs, and three consultations with different doctors, Angie's concerted efforts in pursuing a diagnosis and convincing doctors of her tumultuous physicality proves successful. Lillrank (2003), Lutz and Bowers (2005), Mendelson (2006), and Miller (1997) all hold that diagnosis often brings great relief among those suffering with chronic conditions. However, even with a legitimate diagnosis, Angie remains skeptical, feeling caught up in a dream-like state as she vacillates between feeling (un)convinced that her MRI images are just as (un)real as the (un)settled-ness she experiences. Lillrank (2003) supports this impression noting that women with (in)visible back pain vacillate between believing their embodied experience and believing the explanations of medical experts. Extending this line of reasoning, Moss and Dyck (2002) suggest that diagnosis, as a process of inscription, can be as devastating as the physical sensations of an illness (p. 103). Angie pictorially captures her diagnostic shock and her incredulity of a biomedical inscription of MS with an image echoing the vast gaping holes in her brain as simulated in her MRI testing. Angie explains:

> *I saw the second guy Dr. S. and he went over the [first] MRI with me and he pointed out some little dots but he seemed very, very reticent in diagnosing anything . . . like it was sort of like "YOU MAY HAVE MS" and that was good enough for me to be like "no I don't" you know what I mean? . . . And it was like three strikes you're out kind of thing. You need to have three exacerbations or whatever before they diagnose it. So I just had this weird thing happen to me and maybe it will*

> *never happen again. You know that's what you're always thinking. . . . Based on the [second] MRI, the doctors told me "we found several plaques on your spine. You have MS pretty much. You most likely have MS" which was the second strike. I think it's like possible, probable, definite. It was passed the possible and into the realm of the probable. . . But it was like the proof. . . I was like its only probable right. I still had hope . . . . I saw [the third] neurologist. . . It was sometime in the summer of 2002 . . . and he was "you DEFINITELY have MS. You have multiple plaques on your spine and on your brain. I've seen this a million times or in the very first stages."*
>
> *The proof of MS to doctors occurs in a way that you can't readily see. You have to use MRI technology . . . . The only proof of MS was my MRI . . . . The only reason you believe, the only like actual physical traces it leaves are these lesions on your brain and on your spine that you can only see on weird photographs that they take in this coffin-like MRI machine . . . Like how it's proven to you. . . how you're supposed to just believe it and then carry on with that knowledge. It's so easy to like dismiss it as a dream.*

Figure 10. Concrete evidence: Brain lesions.

Expressing a different perspective, Tori Ellison, an artist living with multiple sclerosis who integrates X-rays into her abstract paintings, speaks to the convincing ontological powers of diagnostic imaging as surrendering her body's mysterious opacity. She comments:

> I find these records peculiarly fascinating. It is almost as though the X-rays, and other forms of imaging the body, are proof of my own existence . . . beyond my outward appearance and experience (Ellison, 1997, p. 275, as cited in Kevles, 1997).

Unlike Ellison, Angie remarks on the seemingly illusive experience of her diagnosis as inscribed through the concrete, scientific proof of MRI technology. Photographically connecting a movement from presence to absence and absence to presence with mesmeric flashes of lighting to the (in)conceivability of diagnostic imaging, Angie comments that this photograph, akin to her MRI images, seems too fantastical a rendering of what MS feels like and ought to look like physiologically to be believed.

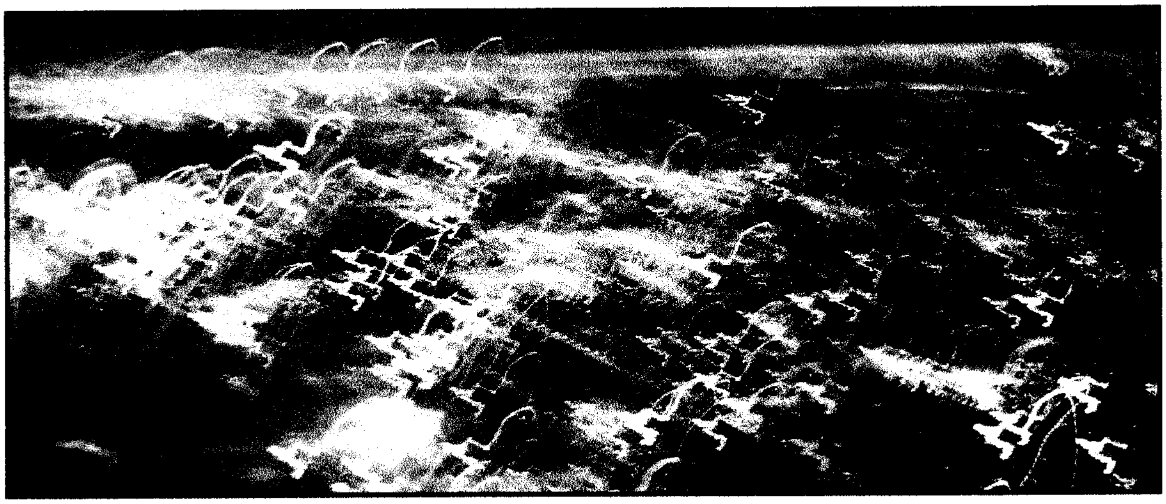

Figure 11. (Un)believable neuronal firing.

> *It reminds me of . . . what your insides must look like or what color neurons look like when they're firing. . . like an MRI, it's like foreign. If I were to say to you this [picture] is your brain, this is you, it's kind of, like you don't believe it.*

Resonating with Angie's incredulity of the technological construction of her (un)settled body, I am reminded of Ian Hacking's (1999) text *The Social Construction of What?* Hacking philosophically distinguishes between kinds or classifications of embodied persons, specifically the *idea* of particular bodies as socially constructed phenomena. My reaction in reading Hacking's work inspired my reflection that the diagnostic signification of Angie's body as an "MS body" pictorially characterized by mismatched neuronal firings is inconceivably constructed as a *particular kind* of body for Angie- one that seems existentially fantastical. Stretching this incredulity further, this same visual representation reflects the unthinkable idea to Angie of being medically constructed as *that kind* of person- someone with a neurological disease, namely MS. Extending the experiential surrealism of her diagnosis to her skepticism and rejection of it, Angie maintains:

> *I was pretty much in denial, like hard-core denial . . . I was shut down to it . . . I had lead a really, healthy, active fucking life! All of a sudden, this is happening to me. . . I was in such denial that I was just well okay, fine. Maybe I have MS but I don't have the MS those other people have . . . I have special MS. My MS is totally specific to me and it's like resistant to any traditional medicine or whatever. I just wasn't ready to engage with it daily or in any way really . . . I don't think I've accepted it yet. I'm still in denial and I don't know if that ever goes away because I knew my body for twenty-five years in a certain way.*

Given her previous healthy lifestyle, Angie cannot fathom how the (un)settled-ness of MS has silently infiltrated her body and her life. To help her digest this unsettling (in)conceivability, Angie distances herself from MS as a disease by ascribing a magical, inimitable quality to its embodied-ness that she believes distinguishes her from others, that transcends conventional intervention, and that is less ominous to her sense of self.

Underscoring the tension of receiving a diagnosis that accounts for the bizarre happenings of (un)settled embodiment but that seems carnally impossible, Charmaz (2000) remarks "illness does not seem real and the person may claim the diagnosis is wrong because they don't look or feel sick" (p. 282). Kugelmann's (1999) study of people experiencing chronic neck and back pain reflects the two-sided tension inherent in this study that not only are individuals like Angie medically disbelieved because of what cannot be physically seen but also distrust what doctors tell them about their condition when their own experience (sometimes) contradicts medical authority (p. 1669). Articulating the manner in which she instantly dismisses her diagnosis as an implausible reality given her good health, Lynda says:

> *I saw O'C last week. He looked at my file and said I was diagnosed in 1988 but when people over the years have asked me when I was diagnosed I've said . . . 1990 or 1992. So I was surprised to hear 1988. So that was denial. That was way back when I was perfectly fine, I was perfectly fine. I really, really, deep down believe he made a mistake. I remember the doctor saying it [the MS diagnosis] and having absolutely no emotion about it.*

Lynda further recollects:

Figure 12. An (in)conceivable diagnosis.

> *I was just too stupid or . . . I'm fine; it's not MS. That was such an overwhelming piece of information that my defense mechanism kicked in and said, assume the best because anything else is intolerable . . . Other people with that same diagnosis would have maybe had the sense to take it seriously. . . I didn't take the diagnosis seriously enough in retrospect. It had absolutely no effect on my life. I didn't make any concessions for it. It was just impossible to think that well I feel fine right now, there's nothing wrong with me. I can walk fine. It was just inconceivable to me that I was going to get worse. I just couldn't conceive of it.*

Exploring this conscious denial from a different position, Angela talks about how her calm acceptance of her MS diagnosis is inversely perceived by her doctor as apathy if not an outright rejection of her ability to assimilate and accommodate this reality. Accentuating her doctor's reasoning, Robinson (1993) contends that women with chronic illness often experience negative judgments from health care professionals who see normalizing reactions and practices as evidence of denial (p. 20).

> *I don't ever recall crying after I found out about my diagnosis. Like sitting down and having that OH MY GOD CRY . . . The whole denial thing you know initially with my doctor that was his big thing. [He] was like . . . "You've just been diagnosed. Do you need counseling at this point?" And I was like "no." And he [said,] "well maybe you're in denial". . . . I was like "no. I'm not in denial about it. I'm just not going to get bent out of shape about it. I'm not going to sit in your office and cry when you diagnose me. I'm just going to have to figure out how I'm going to do this and that's it . . . ." I've spent my whole life working with people with disabilities and I realize that it doesn't kill you, it's just going to make you different . . . that knowledge really made a difference in the way I was accepting [it] . . . [but] I wonder am I not dealing with this because I'm not feeling this way and that's how I'm supposed to be feeling. . . I question myself that it just hasn't affected me the way it's supposed to . . . I have this book for people who are newly diagnosed with MS and they list all these different ways you should be feeling . . . the anger, the questioning, it's almost like the stages of mourning or grieving. Wow is there something wrong with me? You wonder . . . am I not coping with this? I do have a habit of if you just ignore it, it will go away . . . . Who knows down the line. Maybe someday MS will smack me across the face.*

The conflict Angela portrays here is one of wavering (dis)belief. Given her professional knowledge and experience in working with persons with physical disabilities and given that her MS is not consistently disruptive in her everyday life, it is easier for Angela on some level to validate her diagnosis by extricating it as something she has and can live with rather than something she is. Believing the inscriptive truth of diagnosis in this sense acknowledges MS as a disease rather than an acceptance of its experiential significance as part of Angela's identity. Inversely, Angela questions whether she is deceiving herself because she is not experiencing the normal, culturally sanctioned process of loss and grief associated with traumatic illness (Kubler-Ross, 1969; Rosner & Ross, 1992). As Angela suggests, the normalizing institutional discourses associated with disability-related organizations like the MS Society describe the shock, denial, anger, and depression commonly expected following diagnosis and pathologizes individuals as being in denial or not willing to confront the reality of their diagnosis when they fail to express this emotional sequencing. Donoghue and Siegel (2000), Rosner and Ross (1992), and Telford et al. (2006) challenge this stage model of adjustment insisting that acceptance or admitting the truth of being (un)well is a process that occurs in unique ways over one's lifetime rather than something attained once and for all. Register (1999) and Sveilich (2005) add that people with chronic illness grieve on their own schedules and come to terms with their bodies and altered lives when the time is "right" or personally appropriate. While there is certainly no proper way of responding to a diagnosis of chronic disease, I believe Angela's self-professed oblivion to this over-whelming reality given its periodic prevalence in her life is in effect, her way of coping with the pendulous nature of living with an (un)settling disability that shifts in and out of visibility.

Summary

This chapter directs the reader-viewer's attention to the journey women endure in seeking a medical diagnosis and personal credibility for their (un)settling symptoms. Since indicators of (in)visible chronic illness cycle back and forth between periods of calm and unrest, it is often challenging to medically corroborate in its early stages. Angela, Angie, and Helen invert legible cultural scripts of what it means to be healthy, ill, able, or disabled by presenting combinatory embodiments that fluctuate between and/or simultaneously occupy health with illness and ability with disability. In this regard, the body is constantly (un)settled and thereby (un)convincing in its indeterminate subjectivity.

Seeking a medical diagnosis is an emotionally draining rite of passage that spans between several days to several years among the participants. The quintessential struggle threading through each woman's early entrée into the world of diagnostic legitimacy is having their volatile bodies medically inscribed with a particular diagnosis and thereby validated as a body of genuine concern to themselves and others. As Angela, Angie, and Helen's stories attest, it is a struggle for some women living with (un)settled bodies to be heard without negative judgment, to have their embodied ways of knowing deemed credible, and to present convincing testimony of their shifting bodies when their outward appearance and functioning belies their suffering.

While the orthodoxy of scientific materialism demands visible detection through diagnostic imaging and quantifiable measurement to bestow a medical inscription of disease, participants often miss capturing erratic flares in their wake because they cannot anticipate from moment to moment and/or day to day when their bodies will spiral out of control. In turn, many doctors dismiss many women like Angela, Angie, and Helen in the early phases of diagnosis because their bodies resist any stable biomedical reading of disease. Consequently, a scenario ensues in which there is a revolving (mis)trust between the credibility of doctors and the incredulity of their patients, between the discursive intelligibility of biomedicine, and the perspicuity of the body.

A conflict surrounding who the authoritative constructors of knowledge are and what constitutes compelling knowledge comes to the fore of this interpersonal mistrust. From the women's accounts, the reader-viewer witnesses how intuition, feelings, and subjective experience are insubstantial testimony as set against the persuasive positivism of biomedicine. Participants scrupulously describe how they struggle to be seen and heard as believable patients while and the same time, experience tremendous misgivings as they desperately try to assure doctors that their suffering exists. As Angie recounts, poetic, embodied descriptors of her mounting internal chaos rivals the sterile, alienating vernacular of biomedicine, ultimately rupturing the communication between patients and their doctors. However, as the cycle of (un)settled-ness evolves, participants grow exceedingly confident in the integrity of their bodies and themselves that something is genuinely "wrong."

In remaining steadfast on the diagnostic trail, eventual diagnosis inspires relief and self-validation in legitimizing illness. At the same time, despite a woman's desperate attempts to convince doctors of her (un)settled body, a formal diagnosis may be (un)convincing because it contradicts a woman's primarily healthy physical appearance and fluctuating episodes of wellness. While diagnostic images make the ontology of the body "visible" and ascribe credibility to disease, at the same time, these images as Angie implies, also appear substantively unreal, distanced from the body in their mysterious opacity. In a similar vein, Lynda's diagnosis of MS sustains this tension of (dis)belief because on the one hand, she is convinced that drastic physical changes to her vision and functional mobility are real indicators of disease while on the other hand, she remains suspicious because such flares quickly recede, restoring her body "back to normal." These scenarios differ from Angela who although relieved to have her suspicions of MS confirmed after many months, questions her willingness to accept her diagnosis at the outset. Given that institutional and organizational discourses pertaining to acceptance and coping in chronic illness stress that denial is commonly the first anticipated reaction, Angela questions the sincerity of her reaction, as does her doctor who remains unconvinced by her pleas to the contrary.

Given the tremendous controversy surrounding a woman's credibility in seeking a diagnosis, I continue to explore the tension between the somatic and the psychosomatic, between the physicality of an (un)settled embodiment and the medical dismissal of (un)settled bodies in the ensuing chapter focusing specifically on Helen's narrative.

(Un)Convincing Bodies Part III

Chapter 6

The Odyssey of Diagnosis Reprise: (Un)Imagined Bodies

Traversing the path to diagnosis with an erratic body that creeps in and out of (un)settled-ness embodies a slippery slope. While diagnosis typically brings relief, it can also become an albatross when it fails to confirm an organic cause for (un)settled-ness (Asbring & Narvanen, 2002; Jackson, 2005; Register, 1999; Wall, 2005). I resume the story of the odyssey towards diagnosis in this chapter focusing specifically on the psychosomatization (Jackson, 1992) of the (un)convincing (un)settled body. In doing so, I lay emphasis on Helen's diagnostic pilgrimage (Reid et al., 1991). Helen's diagnostic journey is a protracted, emotionally traumatizing, and infinitely complicated one. Unlike the initial, (un)believable warning signs of multiple sclerosis exhibited by Angela, Lynda, and Angie for which there are definitive diagnostic tests, vulvodynia is a comparatively unknown, fluctuating chronic pain condition that presents a greater challenge to diagnose. Elaine Scarry (1987) reminds us that since pain is an invisible inner experience, a feeling we cannot observe or measure directly (Jackson, 1992, p. 140), many women like Helen struggle harder to establish its institutional credibility.

Sharing the initially protracted medical dismissal Angie describes, Helen consults with thirteen doctors and endures nine years of inexplicable pain before receiving any definitive answers about her (un)settled body. Alluding to photographs of her gynecologist's office and photographs of specimen bottles, Helen's encounters with medical doctors are disturbingly alienating, disembodied experiences. Delineating scientific medicine's contribution to this alienation, Wendell (1996) contends:

> The authority of scientific medicine. . . contributes to our alienation from our bodies and our bodily experiences. . . the cognitive authority of medicine in the doctor-patient encounter gives far more weight to the doctor's metaphysical stance, undermining the epistemic confidence of patients in the importance of their bodily experiences. . . This can leave [patients] not only isolated with their experience but feeling . . . alienated. . . further from their own bodies (pp. 119-120).

Narrating a photograph of the sterile anonymity of her gynecologist's office that symbolically reflects the separation between the lived experience of her body and its disembodied abstraction as a disease state Helen writes:

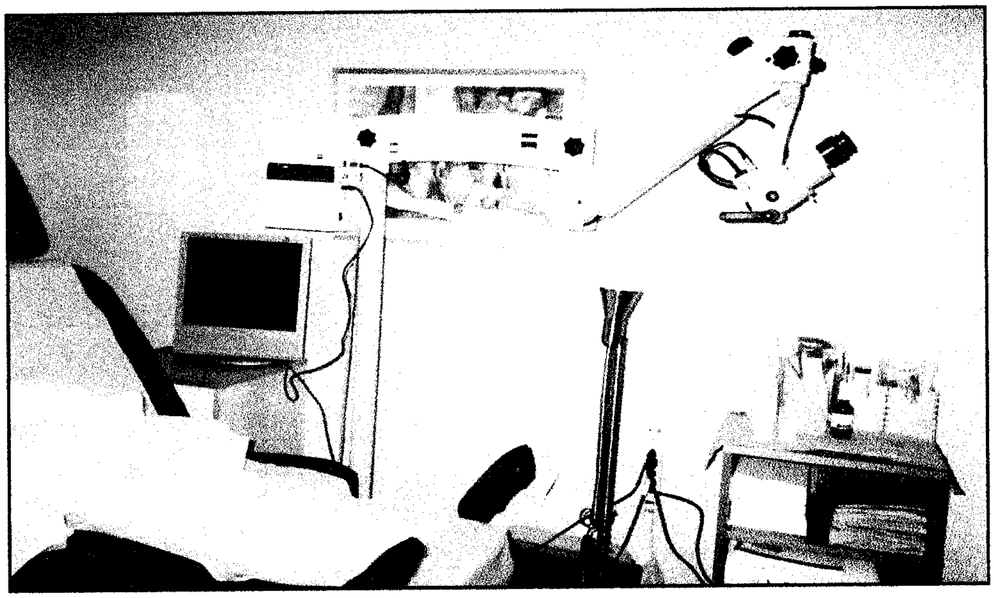

Figure 13. The gynecologist's office: The disembodied body.

> *Wrapped in scratchy paper sheet, body contorted to be poked and prodded and scrapped and swabbed and tested and analyzed and diagnosed . . . You become this sort of specimen as opposed to a full human being. . . You as a person with experiences, with emotions, with sensations . . . are just totally cut off . . . It's a denial of your physical sensations, which is strange when you're in a place because of your profound physical sensations.*

Rarely offering any compassion from a more holistic perspective to the woman within the body, Helen's is nothing more than a diseased body, a medically fragmented, depersonalized jumble of flesh, fluid, and organs whose voice is silenced as doctors scrutinize her body with their cold steel arms of instrumentation. Helen's (un)settling painful sensations that initially encourage her to seek medical attention are thus as she implies, objectively scrutinized and cauterized from her subjective embodiment as a woman (Kralik, Brown, & Koch, 2001).

Since Helen's vulvar pain is episodic in nature and not readily visible, laboratory tests and physical examinations cannot identify it in the same way as other more visible, familiar gynecological conditions. Describing the (un)settled body from a state of health to illness, illness to health, and back again, Moss and Dyck (2002) reiterate Helen's frustration proposing that such transitioning itself defies the biomedical model and eclipses definitive testing. Helen articulates:

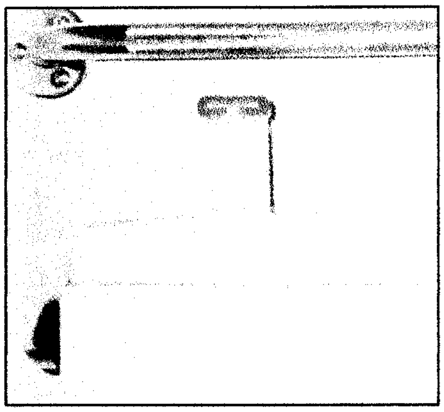

Figure 14. Problematic testing.

> *I've had to pee in so many freaking bottles . . . and the tests results always come back fine so the doctor says you're fine . . . . I went from one doctor to the next . . . One doctor would get exasperated and say go see this person and go see that person. . . . And that's sort of an experience I'd like to communicate here with displaying the testing and stuff because time and time again they're like "everything's normal."*

Rhodes et al. (1999) observe that diagnostic testing embodies the obvious, concrete, solid proof that vindicates women's claims of (in)visible chronic pain. Since tests pinpoint where it hurts, women accord significant credence to diagnostic imaging's promise of revealing the inside of their problematic bodies. With each visit to the doctor and with each test, Helen becomes hopeful that at last she will have an answer (Donoghue & Siegel, 2000, p. 10). As the next passage reveals, Helen desperately hopes her cystoscopy (internal examination of the bladder) will grant an affirmative diagnosis that something is physically "wrong" with her. When her test results indicate that she "is fine," Helen is emotionally devastated, having placed all her faith in scientific materialism's promise that her body's truth will reveal itself.

> *I was sent to a urologist [for] interstitial cystitis and the cystoscopy . . . they put a camera through your urethra, which is incredibly painful, and they told me "okay, you know, everything's fine." And I was really putting a lot into this test because I finally thought okay that's it, this is what I have. The test will come back positive and then they'll know what I have and great! And the test came back negative and I was absolutely destroyed. After the cystoscopy I was in a sort of change-room . . . a cubicle with no door . . . I was just enclosed all by myself. So it kind of felt like I was in my own little world or totally shut off or isolated . . . and I was crying behind there and kind of whimpering and I guess an orderly or a nurse said from behind the curtain "are you okay in there?" And I'm like "yeah, yeah I'm fine". . . . But I was so upset because I WAS quote unquote "fine" and it was the doctor telling me that there was nothing wrong with me that made me so upset. But there IS something wrong with me . . . . I felt so shut out and dismissed. You know, "okay, stop bothering us, there's nothing wrong with you already. We've done all these tests. There's nothing wrong. Leave us alone . . ." That sort of dismissal is really, really, frustrating . . . everyone was just like "nothing's wrong."*

Asbring and Narvanen (2002) claim while doctors may initially be predisposed to women's (un)settling symptoms prior to testing, their attitudes may turn accusatory when tests disclaim any evident pathology. Articulating medicine's oversimplified schema of the division between real and unreal pain, Jackson (1992) comments:

> Real pain originates and is maintained by well-understood organic factors whose causes are completely beyond the control of the patient. Any pain with. . . psychological factors is to some degree unreal because of the nonphysical nature of these causes and the problematic nature of responsibility for them (pp. 143-144).

Hilbert (1984) posits that pain presents a unique case due to its perceived location inside the individual that is often not verifiable from the outside (p. 366). Yet given this experiential situation, women still carry the burden of producing scientific evidence despite the fact that their fluctuating and often covert symptoms refute diagnostic detection (Chircop & Keddy, 2003). Epitomizing Helen's disillusionment in medicine and her own body's failure to testify to its (un)settled reality, Hilbert (1984) claims:

> One of the great ironies of chronic pain is that sufferers are disappointed by what to most people is good news- that nothing is wrong with them- for such news seems to document their inability to experience their bodies correctly, adding to their suspicions that there really must be something wrong with them (p. 370).

Since medical knowledge and technology are never completely accurate nor reliable (Davis, 2005), Hilbert's words typify the omnipresent dilemma that Helen, and previously Angie, experience in seeking a diagnosis with an (un)settled body. Since the empirical lens of biomedicine as an insider's view cannot detect deeply embedded, variably (in)distinct sensory sensations, such mystification culminates in persuading doctors that (un)settled embodiment is not somatic but psychosomatic in nature. As Ware (1992) writes, "part of the popular cultural meaning of psychosomatic illness is that its symptoms are defined as 'imagined'. . . and [one's] experiences are discounted as 'not real'" (p. 352). Goudsmit (1994) refers to this institutional cynicism as the psychologizing of women's "questionable" embodiments and that such an ascription often has little or no evidence as its basis (p. 7).

When looking at the intersections of gender and (in)visible disability, there is a tendency among medical and allied health professionals to discount women's symptoms by euphemizing them as self-induced complaints. Reviewing sexist practices in women's health care, Munch (2004) addresses how gender-biased diagnosing among physicians mislabels women's somatic complaints as non-serious and/or psychosomatic in the presence of both organic etiologic factors and when underlying pathophysiological conditions are unknown. Munch observes, "the default toward psychogenic causal explanations particularly in the instances of obscure etiology certainly affects both women and men; however, this seems to occur more frequently with female patients" (2004, p. 102). In their book *Outrageous Practices: The Alarming Truth About How Medicine Mistreats Women*, Leslie Laurence and Beth Weinhouse (1994) observe:

> Women's complaints are dismissed by doctors far too often- and much more readily than men's. . . . If there is no obvious cause for a woman's medical complaint, her condition must be all in her head. . . there's a long legacy of writing women's organic diseases off as emotional disorders. . . . Women's pain is more misunderstood and overlooked. The tendency to dismiss women's health concerns stems not only from the belief that women are more emotional but that they are more emotionally unstable than men (pp. 259-261).

Considering the phenomenological essence of (un)settled embodiment described in the opening chapter of this movement (Fluid Sightings and Carnal Stirrings), I believe the experience of being (un)well momentarily or synchronously challenges the definition of illness itself. Embracing Hughes' (1999) interleaving of perception and discourse onto the ontological conundrum of (un)settled embodiment, this scenario translates into a struggle between scientific materialism's equation of the "real" with objective knowledge and the anatomical body, and the "unreal" with a devaluing of the experiential body and embodied knowledge among women. In *The Patient Patients,* Helen Roberts (1985) attests to this epistemic divide between objective and subjective knowing.

> Women and doctors (even if those doctors are women) don't just have subtly different viewpoints about health, they inhabit different worlds. Doctors have the power to define what is, and what is not, illness, what is and what is not appropriate behavior in a patient; and what is to go on in the consulting room (p. 2).

By subscribing to an understanding of health and illness and ability and disability as an either/or materiality (one is ill *or* well, able *or* disabled) rather than confining one day and liberating the next, medicine as an authoritative body and the arbiters of objective knowledge denies more mutable forms of embodiment (Jackson, 1992; Moss & Dyck, 2002, p. 59).

Telles and Pollack (1981) suggest that although an individual's feelings are the common basis for determining whether anything is wrong, they are considered insubstantial phenomena and are not easily believed. Even when, as Ann Davis (2005) cautions, physicians attribute credibility to their patients, they often have clear views about what is appropriate for people of a certain age or gender to do or try and thus may see their patients' symptoms as self-caused (p. 69). In the subsequent exert, Helen reveals how she alternates between being convinced that her pain is (un)imagined. At first, Helen's doctor trivializes her pain implying that it is common among women Helen's age to experience "discomfort" when they first become sexually active. When a suggested treatment plan advising additional lubrication and abstaining from pain-inducing sexual activities fails, Helen's doctor blatantly ascribes a psychogenic explanation for her pain.

> *From the time I was sixteen I was asking doctors about it and it was just use more lub[rication]. That was their answer . . . At the beginning I think I was convinced that maybe this is normal you know, the way doctors treat it and sort of dismissed it . . . Maybe this is how it is. I'd never known different. My first sexual encounter was like maybe this is what sex is and I was well, this sucks!*
>
> *I went to the doctor about it again . . . years later and she suggested it was a psychological thing. [She] suggested different ways of cutting off all physical contact with my partner and slowly reintroducing physical contact. That didn't work. She seemed to suggest I was having these problems because it may have been painful [that] I was becoming so afraid and tensing my muscles and everything. So, she suggested if it [sex] was slowly reintroduced and we would stop certain activities that made me uncomfortable, I would become more comfortable and more relaxed and therefore feel less pain.*

Historically, numerous medical conditions have been and continue to be targets of gender-biased stereotypes about women's nature and women's bodies (Munch, 2004, p. 102). In fact, vulvar burning in the absence of abnormal physical findings and pain with sexual intercourse was traditionally classified as a psychosomatic problem (McKay, 1989). Clearly, dismissing Helen's pain as a discomfiting consequence of sexual activity neglects its experiential import and explicitly and wrongfully blames Helen for being too sexually anxious as a woman. While it is illogical to suggest that psychological factors are insignificant to the experience of (un)settled embodiment (Munch, 2004), the salient point here is that psychologizing (un)settled-ness bespeaks a horrific insensitivity that catapults Helen into even greater distress (Asbring & Narvanen, 2002; Munch, 2004; Robinson, 2000).

The intensity of sexist diagnosing coupled with its corrosive demoralizing invites a kind of "crazy making" that catalyzes Helen's spiraling back and forth between (dis)believing she is imagining her pain. Donoghue and Siegel (2000) and Lutz and Bowers (2005) maintain that when a woman attempts to describe pain to her physician and is met with bafflement or suspicion, she can easily begin to question is it really that bad? Am I imagining it? If I take my mind off it, will it go away? This kind of self-questioning encourages Helen to feel personally and morally responsible for her suffering (Sveilich, 2005; Vickers, 2000; Wessely, 2002), for making herself sick, for bringing it on herself (Jackson, 2005; Stone, 1995; Vickers, 2000, p. 138). Writing from the perspective of women living with (in)visible chronic facial pain, Link, Marbach and Dohrenwend (1989) imply that a woman is not only thought to be the cause of her pain because of some deep-seated personal flaw, but should be able to control it (p. 119).

As Helen narrates, it is not her bodily fluids (urine and vaginal cultures) being evaluated but the integrity of her personhood that is threatened under medicine's omniscient microscope (Jackson, 1992; Robinson, 2000). With a medically dubious embodiment and blemished character in tow, Helen feels like she is on trial, wrongfully accused for self-creating pain that is beyond her control. Indeed, Werner and Malterud (2003) caution that it is hard work being a credible patient since doctors and their patients inhabit different embodied worlds. Attributing symbolic reference to a photograph of a toilet, Helen describes how she repeatedly tries to provide physical testimony of her (un)settled-ness through multiple urinalyses. Helen attempts to persuade a jury of medical experts who have the power to pronounce a verdict of health or illness to trust in her bodily confidence and honor her voice as a woman. Striving to achieve this credibility in which her embodied testimony is less an issue of seeing than of believing and being (Frank, 1995), Helen passionately conveys:

Figure 15. The body on trial.

> *You're trying to constantly PROVE to other people and yourself. It's like you're always on trial. It's not your urine being tested; you're being tested. Like is this for real? Is there something really wrong? Is she telling the truth? Is it all in her head or is it in her body?*
>
> *I felt like I was creating this . . . and that I was a bad woman because I was making all this up . . . I felt like I was doing something wrong. Why can't you just relax about it Helen? Why can't you just forget about it Helen? Why can't you just make the pain go away? Why do you have to keep imagining this pain?*

Trapped in a private reality that obviates the production of objective evidence, Richard Zaner (1983) addresses the epistemic tension between empiricist notions of truth and Helen's self-doubt as a living, knowing body positing:

> We are led . . . to the conviction that our everyday, life-wordly understanding and experience of our own alive bodies are fundamentally wrong, specious, and thus to think that our own most fundamental experiences are yet fundamental deceptions. Not trusting ourselves thus, we perforce are led to place our trust in others- in experts

> in the body- to tell us about ourselves. . . [We] view ourselves in the ways medicine views us and our bodies, we come to be alienated from ourselves and our most intimate experiences (p. 154).

Helen continues exclaiming:

> *I think physical failure is often equated with moral failure . . . especially when you're speaking in terms of conditions that involve not talked about parts of the body . . . [Like] the vagina . . . we seem to equate this stuff with being dirty or unsanitary.*

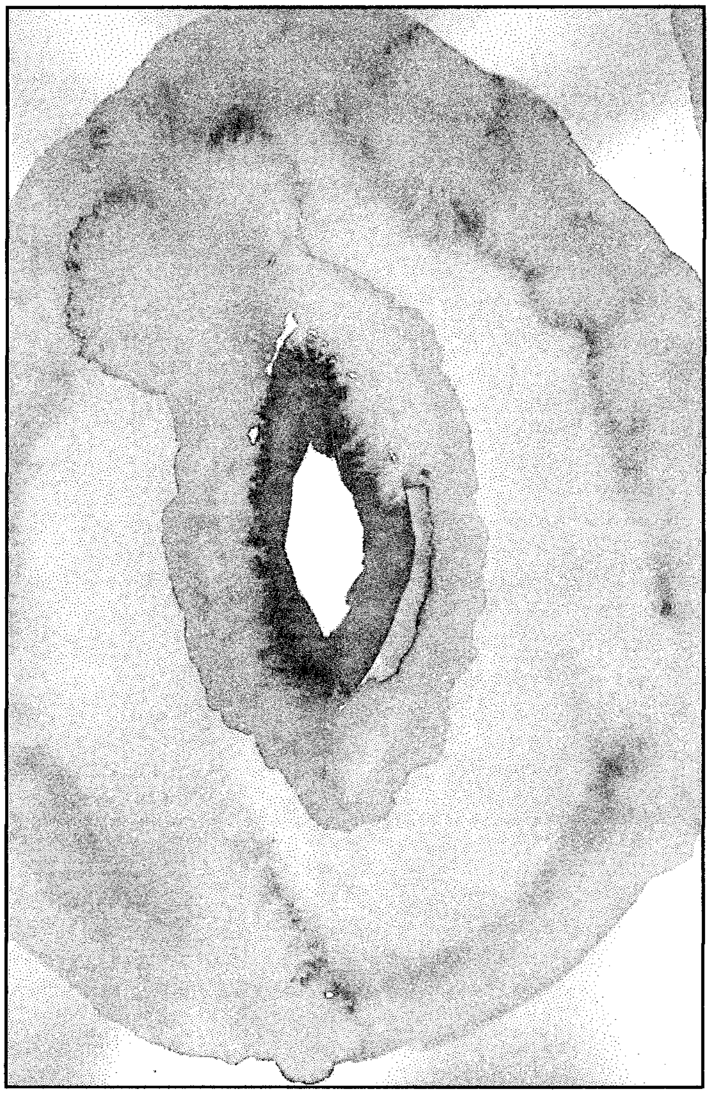

Figure 16. Watercolor of the vagina: Un-talked-of bodies and (un)real pain. Courtesy of Helen Andersen.

> *I was convinced it was something in my head until I started getting infection after infection. Even when the symptoms didn't go away but my tests came back clear, I was like okay, what's wrong in my head? Am I sort of imagining symptoms? When*

> *the pain got really bad and I was having to go to the bathroom constantly, that's when I knew that it wasn't something I was imagining; it was real.*

Werner and Malterud (2003) substantiate Helen's concerns reporting that rather than taking the (un)settled body of women living with chronic pain seriously, it is their moral characters and psyches that are consistently tested, checked and assessed (p. 1414). Lillrank (2003) takes this assertion a step further arguing that in denying women's pain, doctors strip many women like Helen of their right to define their bodily condition as an essential part of the self (p. 1051). Unquestioningly, Helen is mired in a no-win situation. Providing urine sample after urine sample and undergoing test after test, she is wrongfully accused for her suffering. Her (dis)appearing cycle of incapacitating pain while existentially undeniable, remains unseen and unheard, a theme similarly reported by Soderberg, Lundman, and Norberg's (1999) study of women living with fibromyalgia and Gibson's (1993) study of women living with multiple chemical sensitivities. Addressing this observation from the scope of women living with myalgic encephalomyelitis, Moss and Dyck (1999a) verify that without an appropriate diagnosis that fits their symptoms, some women like Helen consequently feel obliged to view illness as their own fault and doubt their bodily sensations (pp. 383-384). Wendell (1996) attests to Helen's culpability indicating that success at being healthy in our society is perceived as if it were a moral virtue. As a part of this morality, Wendell further stresses that "in a culture which loves the idea that the body can be controlled, those who cannot control their bodies are seen (and may see themselves) as failures" (1996, p. 269). In the end, Begum (1996) implies that de-subjectivizing pain as unreal supports an underlying moral, stigmatizing discourse that implies women living with (un)settled bodies like Helen are "crazy" and must pull themselves together (Cahn, 2003; Jackson, 1992). Taken together, this legacy of blaming women and medically hystericizing their subjectivities (Dumit, 2006; Laurence & Weinhouse, 1994; Sveilich, 2005) is I imply, a way of deepening women's invisibility and is a far more traumatic situation to bear than the complexity of (un)settled embodiment itself.

Within this psychologizing context, we slide back to the discord between looking healthy and claiming a (dis)ordered body. Helping professionals unfamiliar with (un)settled embodiment or who perceive (in)visible disabilities as among the new psychiatric disorders (Werner, Isaksen, & Malterud, 2004), situate their views in accord with the myth that anyone who looks well and has the energy and persistence over several years to remain on the diagnostic trail like Helen are not genuinely suffering. Ware's (1992) study of women living with the (in)visibility of chronic fatigue syndrome emphasizes the paradox Helen experiences of being in pain on the inside while outwardly exhibiting seemingly good health. Ware reasons "[women] complained of being disbelieved or not taken seriously because they 'don't look sick.' They are. . . not obviously disabled. . . they may function relatively normally, at least for a time. . . and react with intense frustration being told they 'look great!'" (1992, pp. 350-351). While it is unreasonable to claim that doctors do not experience chronic illness themselves, doctors cannot ethically afford the kind of arrogance implied in patronizingly (mis)assuming they know what it is like to live inside an (un)settled body. Ann Davis (2005) extends this viewpoint insisting:

> Even when doctors have robust knowledge about the physical causes of a particular disease or dysfunction, this does not enable them to know what it is like for an individual . . . . we need to be wary about asserting that medical professionals' observations about the "objective" soundness of an individual's body should be accorded primacy over the testimony of the person who is (or claims to be) suffering. Because such an assertion systematically discounts the reports and the experiences of the ill person, it both bespeaks callousness and institutionalizes a posture of disrespect (pp. 36-37).

Stressing the psychological harm doctors do in dismissing women's (un)settled bodies, Wendell (1996) offers:

> If a patient goes to doctors with symptoms . . . that the doctors cannot observe directly or verify independently of what the patient tells them . . . and if they cannot find an objectively observable cause of those symptoms . . . the patient is liable to be told, 'There is nothing wrong with you,' regardless of how acute or debilitating her/his condition feels to the patient. I do not believe that most doctors realize how frightening and confusing such a pronouncement is, how it can shake a patient's self-confidence and undermines her/his relationship to reality (p. 123).

Aligning these positions with Helen's border crossings between (un)wellness that instills shame and self-doubt in her mind, I concur with Ware (1992) who maintains that in essence, the struggle for credibility is a struggle over what constitutes reality for women with (in)visible disabilities. Analogous to Helen's feelings of shame and rejection, Ware verifies that "the shame of . . . sufferers stems not from the fact of having an illness but from being told they do not. Their shame is the shame of being wrong about the nature of reality" (p. 354). Acknowledging this disquieting implication, Ware ardently insists that there are not real and unreal disabling illnesses but only a fluidity of embodied realities that transcends the fixity typically attributed to chronic conditions. Noting this position, Asbring and Narvanen (2002) declare that caregivers must believe in and confirm (un)settling ontologies even if, and I would add especially if, this suffering is variably (im)perceptible. In the end, recognizing women's lived subjectivities for what they are cultivates more elastic conceptions of health, illness, ability, and disability rather than shallow, rigid characterizations that further impair women.

After years of seeking a diagnosis, intermittently questioning the veracity of her own body, and being (mis)perceived as a malingerer or the worried well, Helen experiences an anti-climactic sense of relief upon diagnosis (Charmaz, 2000; Vickers, 2001b). Bringing this situation to life, Helen recalls:

> *Finally, I went to a gynecologist in Toronto . . . he identified that I did have vulvodynia and urethral-dynia and started me on medication for that . . . I just wanted an answer. I knew something was wrong. Everyone kept telling me I was fine so I just wanted some tests to come back positive and start treatment from there. [So] there was something physically wrong with me. Because doctors who did the tests they'd say "everything looks fine, everything's clear."*
>
> *And that's really what I felt it was like in that the medical community was as I said, very dismissive and kind of like "you're fine, you're normal." And I knew that wasn't the case. And considering the first symptoms started to appear when I was young . . . it was like eight, nine years of being dismissed . . . it wasn't until I saw the thirteenth doctor that he could finally tell me what was going on. . . but before . . . it was "you're fine, nothing's wrong."*

After thirteen years of suffering in and out of bouts of exasperating pain, Helen receives medical exculpation through the sanctioning of a confirmed diagnosis. Unlike Lynda's immediate incredulity and similar to Angie's changing (dis)belief, Helen's diagnosis vindicates her longstanding suffering. As an inscriptive practice, diagnosis offers Helen a sense of unity for her volatile symptoms and a way to make sense of her lived experience (Moss & Dyck, 2002). Raising the issue of diagnostic closure, Lillrank (2003) avows, "to be finally diagnosed was a great relief; to be taken seriously as a person was the greatest relief of all" (p. 1052). Reifying this diagnostic triumph in her visual portrayal, Helen directs the reader-viewer's attention to the legitimacy of medical discourse in defending the reality of vulvodynia and claiming this re-inscription of her body as one that is legitimately ill. Referring to the credible voice of medicine in her visual portrayal, Helen writes:

> *This is a doctor's words . . . There's currently no cure for vulvodynia. Treatments are directed toward alleviation of symptoms. . . the cause of vulvodynia is unknown and each woman's symptoms are unique. No simple treatment works all the time . . .*

it takes time to find a treatment or combination of treatments that will decrease or alleviate pain.

In the initial absence of inconclusive findings, a number of women like Angie and Helen confront a disjuncture between their body that has become an ongoing negative and constraining influence in their lives and the normality of their test results (Rhodes et al., 1999). Angie and Helen's early experience of having their subjectivities repeatedly denied despite constant protestations to the contrary that they *feel* things and are "not fine" parallels Lillrank's (2003) exploration of women living with the elusive nature of chronic back pain. Unwavering in their experiential knowledge of their bodies despite its resistance to visual diagnosis, women feel deeply affronted when their pain is dismissed. Ultimately, Asbring and Narvanen (2002) stress that helping professionals cannot automatically interpret normal examination results as evidence that there are no physical causes of distress. Clearly, without a reciprocal respect for women's ways of knowing their bodies, women plummet into a never-ending quagmire of self-doubt and silence.

Summary

Building on the journey towards medical diagnosis, I bring the reader-viewer more profoundly into the phenomenal world of (un)settled embodiment as a suspect carnality as reflected in Helen's narrative. Within this chapter, the struggle for institutional credibility moves in tandem with the wavering (mis)trust between authoritative bodies, between the expertise of the objective body of medicine and the lived, subjective body as a way of seeing and knowing. In returning to the tension of appearing healthy but episodically experiencing debilitating chronic pain, many women like Helen call attention to the (in)fallibility of medicine as they undo established blueprints of what it means to be healthy and what it means to be ill. While diagnostic evaluation provides hope that the body's (un)settling truth will eventually reveal itself, it also disillusions women, leaving them trapped without convincing testimony of their suffering. Without empirically visible, clinical findings and without the legitimacy of an authoritative diagnosis, (un)settled bodies baffle the medical establishment and are ultimately in many cases, trivialized and "de-scribed" as psychosomatic figments of a woman's imagination. This is not to imply that chronic illness does not have psychosocial undertones but that oversimplified schemas of health and illness and "real" and "unreal" pain cultivate an unqualified, gender-biased diagnosis that dismisses what constitutes "reality" in the lives of many women like Helen living with (in)visible illness. This kind of psychosomatic dismissal (Jackson, 1992) carries the implicit message that a number of women like Helen are morally responsible for their pain and deepens some women's vulnerability and isolation in their experiences. Such institutional indignity catapults numerous women like Helen into greater anguish as they cycle back and forth between defending and doubting their subjectivities.

Rivaling the psychologizing of (un)settled embodiment, this chapter also spotlights the unrelenting resilience and conviction that many women like Helen hold as "embodied knowers" of their corporeality. Countering repetitive, negative clinical findings, Helen rejects discrediting, demoralizing institutional discourses of her own "crazy making" in place of honoring her body as an oracle of truth. While not all women living with (un)settled bodies ultimately receive a medical diagnosis, it is their tenacity in defending an embodied ethos that this study attests to.

Having guided the reader through an exploration of the onset of (un)settled embodiment followed by the journey towards medical diagnosis, I next focus attention in the forthcoming parallel chapters to the manner in which living with an (un)convincing (un)settled body is interchangeably forgotten and remembered by others and by the women themselves across everyday life scenes.

(Un)Convincing Bodies Part IV

Chapter 7

(Un)Forgotten Bodies

I organize this chapter into two ostensibly polar but entwined tensions: the ways (un)settled embodiment is interpersonally forgotten in relation to contradictions in physical appearance and the suspicion it evokes and the ways it is remembered across everyday life moments. Rather than static episodes, forgetting and remembering like (un)settled embodiment itself, is fluid, varying from situation to situation (Peters, 1993). Given the shifting visibility of their disabilities, the social responses women receive are sometimes rejecting and other times embracing but rarely a destination reached once and for all (Charmaz, 1997; Donoghue & Siegel, 2000; Olney & Brockelman, 2003).

Throughout this chapter, I sometimes blend women's storied accounts and at other times, highlight the uniqueness of particular narratives to demonstrate the multiple threads of (un)settled embodiment as an (un)forgettable reality. I first introduce the tension of forgetting and remembering within the context of (not) looking (dis)abled and the manner this presents itself in women's everyday lives.

Looking (Dis)Abled

Radley (2002) implies that the question of the acceptability of illness and disability, which I extend to fluctuations in forgetting and remembering (un)settled-ness, is very much one of appearance. Even with a medically verifiable diagnosis, the (un)settled body and its biomedical inscription of multiple sclerosis and vulvodynia remains invisible (Cunningham & Jillings, 2006; Moss and Dyck, 1999a), thereby sustaining its (un)convincing nature. One of the most psychically draining struggles women identify after receiving a medical imprimatur is persuading others to acknowledge the (un)settling reality of their chronic conditions. The tension of forgetting and remembering a woman's (un)settled-ness is enveloped as Titchkosky (2003) ascertains, within idealized cultural maps of health, illness, ability, and disability. These settled topographies of (dis)ability as Hughes (2002) and Siebers (2004) assert are un-questioningly [mis]read off an individual's physical appearance. Sustaining this view in her research with female university students living with chronic illness, Jung (2002) asserts that a visibly damaged or disordered body is visually seen as incontrovertible proof of disability than is the body of an (in)visibly chronically ill person (p. 192). Given the reified equation between disability and visibility, Jung writes:

> Disability is not a category of a natural kind; it is a means by which an idiosyncratic and personal experience of illness or impairment can be made visible. . . The failure of chronic illness to properly fit the ideological framing of disability means that suspicion and skepticism. . . are routinely activated (2002, p. 196).

Personally attesting to the challenge of proving her (in)visible disability in the absence of disability's typical physical presence, Titchkosky (2001) concedes:

> If I am to prove my experience is the experience of disability, I have to rely on normal conceptions of disability to do so. . . I have to show that despite my appearance of normalcy, I embody a difference that I want others to experience as disability (p. 4).

Since social affirmation depends on one's ability to see illness in obvious and consistent ways (Vickers, 2001b, p. 68), participants report that a physical appearance of wellness often, but not always, interpersonally invalidates the existence of their (un)settled bodies and inspires misunderstanding about having a disability "sometimes" (Kugelmann, 1999; Peters, 1993; Rosner & Ross, 1992; Stone, 2005, 2007).

Posing the question of whether disability must always be visible, Stone (1995) insists that people have difficulty imagining that someone who appears able-bodied may nevertheless have disabilities, and consequently, commonly believe such (in)visible disabilities are not "real" disabilities (p. 418). Moss (1999) speaks to this (un)settled-ness in absentia stating, "when a woman talks about people not being able to 'see' her pain unless there are splints, canes or wheelchairs I know what she means" (p. 158). Such misguided thinking denies women the ability to define their own reality (Stone, 1993, p. 1) and given this predilection, many women like Angela avoid risking the social rejection that reminding others of their disability often entails. To illustrate, Angela recalls a story characterized by the unspoken (mis)assumption that MS is supposed to look noticeably incapacitating for others to remember and socially validate.

E. used to have a friend who came over every day after school and his mother would come and pick him up . . . every time she'd come to the door she'd stand and talk to me for a while and I'd always sit on the stairs and talk to her. Finally one time last year she came in and said "M told me you have MS . . . . How come I never noticed?" I [said] "do you notice when I talk to you I'm always sitting on the stairs and I'm never standing up talking to you?" She's like "yeah." "That's because I have MS. I sit on the stairs and talk to people. I don't stand up and do it."

Figure 17. The guise of normalcy.

Under the guise of normalcy, Angela's "more or less" ordinary physical appearance as she sits on the stairs to talk, while offering much needed relief from the draining limitations of MS, is socially perceived as an ordinary act reflecting an "ordinary body" rather than an effective strategy to accommodate her fluctuating (dis)ability. Rarely is any thought given to the fact that someone who appears "just like us" or in other words, seems able-bodied, may nevertheless embody alternate aspects of identity.

Without the use and visibility of her canes, Lynda does not outwardly appear "disabled," thereby making the reality of her MS less visible and plausible for others to acknowledge and recall at times. Strengthening this reflection, Fitzgerald (2000) notes that people assume people are "disability free" if they cannot see some evidence of a disability (p. 255). Recounting an incident at the grocery store, Lynda speaks to this (dis)harmony in looking normal without the visibility of her canes while leaning on her shopping cart, and invisibly being in agony while waiting for assistance.

Figure 18. Looking (dis)abled, being (in)visible.

> *I went up to the butcher counter to order something and nobody was there. So I was standing there and standing there and standing there and my legs . . . I'm always so scared when I go shopping . . . that I'm not going to make it. Whoever was there on duty probably could see me from wherever . . . saying she can wait or let her go ask somebody. People ASSUME that you are able-bodied, that it's not a big deal for you to stand. When I finish grocery shopping, I'm in agony.*

Stone (2005) and Sturge-Jacobs (2002) allude to this apparent mirage of (un)wellness implying that the invisible calibrators of disability mean that women are not commonly recognized as disabled. Articulating her experience of "lookism" (Atkins & Marston, 1999), of living with the (in)visible (un)settled-ness of a traumatic brain injury, Sharon Dale Stone (1999) communicates:

> Others may not always be able to see my disabilities, but they are always with me. And it is the very invisibility of my disabilities that can cause me the most difficulty. Because I don't fit normative conceptions of what someone who is disabled is supposed to look like, I find that others make all sorts of assumptions about what I can do. But because of my disabilities, I either cannot fulfill expectations, or else I must do so with a great deal of effort. It would be a lot easier if everyone would just accept that disability carries no particular "look" (pp. 310-311).

Cheri Register (1999) reminds us that while the able-bodied want recognition that they are normal, persons living with (in)visible disabilities want recognition that they are sometimes *not*. Lending support to this pivotal argument, Peters (1993) and Vickers (2000) confirm that since contradictory, shifting appearances occlude the embodied reality among women living with (in)visible disabilities, they are frequently forgotten or dismissed.

Attesting to the spaces of contradiction that permeate (un)settled embodiment, I highlight Lisa Walker's (2001) text *Looking Like What You Are* in which she explores the relationship between physical appearance and sexual identity. Delving into Walker's book she declares, "If there has to be a lesbian in [my] family, at least she looks like a regular girl. . . when other lesbians assume that I am less than they are because of the way I look, they devalue me" (pp. xv-xvi). Launching into a broader discussion on identity politics, Walker purports "invisibility is nonexistence. To be invisible is to be seen but not heard, or to be erased entirely- to be absent from cultural consciousness" (p. 1). Paralleling the (in)visibility of Walker's lesbian identity which I connect with the embodiment of (in)visible disabilities, she notes "privileging the visible takes part in the discourses that naturalize socially constructed categories [able/disabled] . . . [such] privileging elides other identities that are not constructed as visible" (p. 193). Hence, since (un)settled embodiment transgresses conventional images and understandings of what disability ought to look like and *be* like, (un)settled bodies, like the unmarked lesbian bodies Walker contemplates, remain elusive and beyond familiar representation.

Mirroring Kimpson (2000) who observes "I live in a world which has difficulty with a person who is. . . ill but appears 'well'" (p. 321), Angie's MS is often forgotten because she appears able-bodied and on most days, physically functions as well as her peers even with her MS-related pain and fatigue. While genuine features of her (un)settled embodiment, the pain and fatigue Angie experiences tends to be forgotten as visible or knowable indicators of her MS. Angie refers to the tension between looking fine and feeling "MS'Y," giving credence to her body's visceral codes and other's mistrust of the authenticity of such deeply rooted knowledge. Exploring the (in)visibility of chronic pain, Richardson (2005) alludes to this juxtaposing tension commenting that "pain is doubly paradoxical. . . it depends on social action to make it real to others, yet that very same action can also arouse suspicions about its reality" (p. 342). Exemplifying this reality, Angie grants:

> *Fatigue is one of those symptoms that is highly unpredictable . . . I know it's MS when there's no good excuse for it. Like if I've played hockey for an hour, yeah, my legs should feel weird, wobbly, shaky, a little bit weak, or over-exerted. But when I'm just standing and I just got up from a nap or something and it's like weakness, that's MS. Anytime your body is doing something that is unexplainable, irritating, or painful, or just like sensationally out-of-the-ordinary, is like MS'Y.*

For Angie, feeling "MS'Y" means validating her sensorial muse and invoking its presence to remind others about the existence of her MS. Richardson (2005) stresses that appealing to MS in this strategic way visibly dramatizes the validity of Angie's pain under the guise of an otherwise normal appearance and legitimates its future remembrance. This contrasts with flaunting illness whereby an individual separates their present self, experience, and feelings from their portrayal of it (Charmaz, 1997, p. 127). Charmaz (1991) implies that validating MS in this way offers Angie protection from the demands, expectations, and assumptions of others since this haptic knowing as Angie states, is rarely interrogated by others. Enlightening and reminding others about her condition Angie emphasizes:

> *When I'm feeling MS'Y its like I have no agency, my body is not mine . . . . I'll say something's MS'Y and I know it will get a certain reaction . . . . [It also] elevates the pain of something . . . it's [a] serious conveyance of the seriousness of what you're feeling. It's like INVOKING an incantation. You're invoking the MS. It's a tool to silence other people cause they're not going to attack you or even question this MS thing, they're not. It's like putting you're foot down . . . It's like an extreme assertion to other people. Like they will leave you the fuck alone if you make it about your MS.*

Angie further contextualizes her MS'Y ways of knowing and the skepticism it evokes. Moss and Dyck (2002) and Donoghue and Siegel (2000) stress that when a disclosure produces no visible support for claiming illness, many women like Angie experience suspicion from others. What I am suggesting here however transcends disclosure and the (in)visibility of a disability, a subject I explore at greater length in Chapter 11. What I am conjecturing is that feeling MS'Y is an *intuited feeling* that Angie experiences as part of her (un)settled-ness and that this physical summons, evoked through her body and verbally relayed, is often forgotten by others as an experiential testament to the legitimacy of Angie's MS. In urging her friend to acknowledge her MS-related fatigue after a hockey game, Angie induces a specious mistrust and dismissal of her embodiment rather than the respectful remembrance she demands.

> *When I was at hockey . . . I took this really bad hit. This woman hit me . . . she bounced off my facemask . . . I was really exhausted after that game. I don't know if it was that hit and my legs were shaky. . . I was just wiped out, really wiped out. I barely carried my bag . . . I didn't want to go to the end of the [subway] platform because we take the subway. I was like "I can't, I can't, like I don't want to anymore, I want to stop here!" And my friend. . . likes to do things in certain ways. . . and I usually go along with it. I would have gone to the end of the platform but I just*

> *couldn't. . . . I said "I kind of feel a little MS'Y. . ." and it was weird because . . . my friend was kind of, like she didn't believe me. . . Her initial reaction was kind of like "aw c'mon, let's go." She's used to me being capable, very physical and capable . . . This time it was different in that my body was telling me NO. STOP! . . . And I had to obey that.*
>
> *It's bizarre. The ways in which the outside world experiences your MS, which is kind of an internal experience. [It's] difficult for them to experience it outside of your interpretation of it . . . My friends and my family and my coworkers. . . they have to believe what I'm telling them is like what I'm experiencing . . . they experience my MS through my descriptions because often there is no physical correlation.*

Mirroring Angie's felt but unseen MS'Y-ness, Soderberg, Lundman, and Norberg (1999) and Sturge-Jacobs (2002) indicate that the more invisible the disability's pain and fatigue, the more one's integrity is called into question. Contrary to the misleading adage "if you don't look sick, you can't be sick" (Soderberg et al., 1999), it is the ontological converse for Angie who looks well while feeling physically ravaged that embodies an intellectual distortion for others.

The confounding (dis)connection of looking good and feeling unwell conspires against Angie in the form of disbelief and peer pressure. Looking like one is able-bodied does not make one more able-bodied or make one healthier (Davis, 2005, p. 7). As a result, because women are often not visibly ill, they are not treated as if they are ill, which has repercussions for the way they see themselves (Moss & Dyck, 2002, p. 142). Sitting on the sidelines during a hockey game, Angie looks perfectly fine but endures widespread skepticism among her teammates that her un-seeable suffering exists. In turn, forgetting Angie has MS and being coerced to join the game inspires feelings of self-doubt, shame, as well as the dismissal of Angie's MS'Y feelings as something perhaps she is carnally misinterpreting and can manageably tolerate.

> *Last week I went to hockey but I didn't play and just being there, it's just weird. When people are sick, other people relate to sick people in like weird ways. It's almost like there's a disengagement . . . like they don't quite believe you. Obviously I look fine. It's that appearance of looking fine and being in pain. And then you start to think well maybe I'm not really in that much pain. Or maybe this has nothing to do with MS . . . . like there's peer pressure involved. Like YOU LOOK OKAY, DO WHAT EVERYBODY ELSE IS DOING!*

In being sick but ostensibly fit (Pinder, 1996), Angie does not look like she is suffering in pain. Instead, Angie (in)visibly remains on the sidelines, teetering between being disbelieved and forgotten by others and deeming her pain unworthy of the interpersonal recognition she seeks.

In keeping with the paradox of not looking disabled, I shift back to Angela's narrative to demystify an understanding of the tension between forgetting and remembering. Unequivocally, our culture's insistence on visible, concrete signs of impairment to legitimate its presence is deeply problematic for Angela in relation to her colleagues at work (Samuels, 2003; Vickers, 2001b). Moss and Dyck (2002) hold that there are prescriptive norms of what it is to be "normally ill" in society and these serve as blueprints for understanding chronic illness in general (p. 96). Given this, what happens when chronic illness does not present normally? When the blueprints oscillate between being (un)readable? Bringing this argument into sharper focus, Stone (2005) posits:

> With regard to the body, we learn to take it for granted that. . . everyone may be placed into the category either of those who are disabled, or the category of those who are abled. Moreover, we are taught to believe that, by attending to visual and or/auditory cues, it is easy to tell who belongs in which category. . . for those who do not appear to be disabled, we tend to judge them according to conventional standards about what constitutes acceptable behavior. The hegemony of dualistic thinking means that there is the assumption of an unproblematic divide between disabled/abled. . . there is no room for recognizing that those who appear to be abled may nevertheless have unseen [or (un)seen] difficulties (p. 294).

Considering this perspective, Peters (1993) writes, "unlike individuals whose disability is unchanging in its visibility to others, individuals who have a disability sometimes lack consistency in the appearance of their disability, although their disability remains with them (p. 1). Noting this, Hilbert (1984) observes that the likelihood that anyone will remember an individual has an (in)visible disability, even when they know about it, can fade over time. Angela's MS, while known about, is not immediately obvious in a way her supervisor recognizes as "the look of MS." In *The Body's Memory*, Jean Stewart (1989) aptly reflects Angela's confounding appearance remarking, "people apparently think they know what disabled folks should look like. I startle them; clearly I'm not helpless, not pathetic or sickly" (p. 132). Given her normal appearance, Angela's supervisor questions her inability to work late and (mis)perceives her written work as careless and sloppy rather than recognizing Angela's difficulties with stamina, visual acuity, and fine motor skills as discernible signs of the (un)settled-ness of her multiple sclerosis (Rosner & Ross, 1992). Reinforcing this point, Vickers (2001b) states that even those familiar with one's disability may not recognize certain signs when they are visible. In forgetting and dismissing these telling signs, Angela is expected to maintain the same pace of work and rigorous demands of an able-bodied employee since she looks just like everyone else (Montgomery, 2001; Stone, 1999, 2005). Angela observes:

> *My boss doesn't buy it . . . we have to do a lot of overtime work . . . [I tell her] I know it needs to be done but if I do this, I'm not going to be able to cook my kid's supper tonight. I have to remind her I'm tired or I can't do it, or I have an appointment at the MS clinic at 10 o'clock and won't be able to come into work until eleven. Like you really have to spell it out for her. Where I think if it was more visible, I wouldn't have to spell it out quite so much.*

Elaborating Angela notes:

> *I make an incredible amount of typos and my handwriting is terrible and she'll comment and I'll be like "J, I have MS. It affects my hand-eye coordination and I can't see very well." I do constantly have to remind her that this is part of it.*

Moss and Dyck (2002) verify that a common complaint among women living with (in)visible disabilities like Angela is that no one sees their disability because they look okay and function fairly well most of the time, thereby challenging the monolithic notion of what it is to be disabled. Ann Davis (2005) advises that physically, functional difficulties can substantially limit an individual's activities even if other people cannot easily identify the source of such limitations (p. 2). Stone (2005) reports that the ostensible able-bodied appearance of women living with the effects of hemorrhagic stroke prompt others to deny their difficulties and akin to Angela, must incessantly explain themselves since their visibly healthy bodies mislead others to have expectations they cannot meet. As Angela points out, "*in always having to prove who you are and what you need, women with (in)visible disabilities are the forgotten disabled.*" Angela indicates that without the concrete, physical testimony to prove her disability, it is almost impossible for other people to comprehend the amorphous nature of (un)settled embodiment. Consequently, Angela experiences ongoing frustration at the ignorance of others and must constantly justify that her embodied reality despite her appearance, is indeed real.

While there is nothing glaringly evident in Angela's physical appearance to suggest that she is (dis)abled, many (in)visible disabilities as Charmaz (2000) asserts, do not elude the notice of a discerning observer (p. 286). Accordingly, to a (dis)abled woman "in the know" who *intuitively senses* disability with a practiced eye (Charmaz, 1991, p.122), Angela's difficulties are plainly indicative of an (un)settled embodiment. Despite Angela's supervisor's lack of awareness, I believe such un-sensitized others (Goffman, 1963) can learn to see differently by honing in on these telltale signs of (un)settled-ness. Advocating this view, Ann Davis (2005) advises:

> What is unseeable by us is not imperceptible. Although humans tend to accord primacy to vision as a means of acquiring knowledge of the external world, we know that we cannot infer nonexistence from invisibility: what is unseen by humans, and even what is unseeable by them, is not therefore nonexistent or even necessarily imperceptible (pp. 42-43).

Sustaining this position, Vickers (2001b) argues:

> The knowing observer will often be able to 'see' illness that is [in]visible, through being tuned into the behavior (or other indicators of illness) of that person in certain situations. For example, the knowing observer might note the deaf person lip-reading, or the person with multiple sclerosis taking special care holding the railing when scaling or descending stairs. Thus, it is possible, in my opinion, to 'see' illness that is [in]visible (p. 153).

Exemplifying another instance of the incredulousness of (un)settled-ness at work, Angela conveys how the (in)visibility of her MS-related fatigue physically taxes her energy after visiting three clients but remains crudely forgotten and misjudged by colleagues. Donoghue and Siegel (2000) claim that "despite looking 'fine,' [and functioning like everyone else], a person may be suffering greatly" (p. 91). Missing the visual, familiar signifiers synonymous with constructions of who is and who is not disabled (Hughes, 1999) rather than unfamiliar (in)visible signs like crushing fatigue, Angela defies the traditional scripts of disability that others rely on in committing disability to memory. Although Vickers (2000, 2003) implies that when others are unaware of (in)visible disability no allowances are made for it, this research suggests that even when (in)visible disability is intellectually recognized, it is often forgotten in the present and its challenges are rarely attenuated. It is clear that Angela expects her colleagues to empathize with her declaration of fatigue that is part of her MS even though it is not readily apparent. Angela discloses:

> *I was out in the community the other day and I did like three clients. I had to go back to the office before I came home. I was in the office and it was just like "whoa, I'm exhausted!" And they're like "why?" right. "I just saw three clients. I was out in the community all morning. I am really tired." I had to explain "and this is part of my MS."*

Peters (1993) implies that the incongruity between a so-called healthy appearance on the outside and the experience of (un)settled-ness on the inside constrains women in their relations with others. If a woman is not physically twisted up or "crippled" in a way someone can see, people have a hard time believing a disability is real (p. 4). While multiple sclerosis manifests itself in the inexorable fatigue Angela feels and communicates, this evidentiary sign is ignored or simply not intellectually and experientially understood by fellow colleagues for what it is- an (in)visible, disabling feature of an (in)visible condition (Flesner, Ek, & Soderham, 2003; Vickers, 2003). Sharing Angela's plight, Julienne Lipson (2000) who lives with environmental illness declares, "I do not look ill. . . . Some colleagues "forget" about my problem, others do not understand how serious it can become, and a few people do not take it seriously" (p. 284). This reflection parallels findings revealed by Mendelson (2006), Sturge-Jacobs (2002), and Kralik, Telford, Price, and Koch (2005) who report that fatigue among chronically ill women is not only periodically all-consuming but is an invisible feature of women's subjectivities that fosters a lack of understanding and misunderstanding among others. Dr. Paul O'Connor, a Toronto neurologist specializing in multiple sclerosis affirms that fatigue can be quite disabling and contributes significantly to the disability of MS. Since fatigue is vague, subjective, and hard to measure, its debilitating effects do not receive the recognition it deserves (O'Connor, 2002, p. 20). Adding further support, Donoghue and Siegel (2000) emphasize that "fatigue for those with chronic illnesses. . . appears regardless of activity or inactivity. . . it simply exists in and of itself and no medication, positive thought, or rest can relieve it" (p. 7).

Corroborating Angela's experience among her co-workers, Wendell (1996) explains that we live in an able-bodied world that is structured as if everyone can work and play at a pace without any kind of illness or pain, as though no one were ever dizzy, incontinent or simply needed to sit or lie down (p. 39). Enriching this perspective, Stone (1993) and Vickers (2001b) suggest that women with (in)visible disabilities like Angela who look normal and self-impose able-bodied performance standards are perceived as being able to surmount whatever seemingly normal aches and pains they suffer and are encouraged to ignore the limitations imposed by their bodies. However, it is this stiff upper lip and grin-and-bear-it philosophy as Jackson (2005) suggests that inspires doubt by others. The other side of this conundrum as Stone (1993, 1995) intimates, is that in attempting to substantiate their fatigue, some women like Angela are disparaged for claiming a disabled body and failing to withstand the daily grind of life. To quote Stone (1993):

> Everyone is allowed, on occasion, to have headache, an upset stomach, or the common cold. But no one is allowed to let such ailments interfere with daily tasks. . . Those who dare to call attention to their bodily 'imperfections' are shunned [or disbelieved]. Their demonstrated inability or refusal to 'rise above' the body is taken as evidence of their inferiority, and they are not taken seriously (p. 3).

While overwhelming fatigue experientially enacts itself as part of Angela's MS, it is simply insufficient evidence of a genuine disability status among her peers. After all, implicitly underlying this questioning by her colleagues is the fallacious assumption that if someone has MS they should "look disabled." Because of this wrongful reliance on familiar visual appearances, rarely is disability socially conceived as a mélange of (un)familiar appearances and realities (Siebers, 1994, p. 20). Hence, Angela's body is a forgotten one and her verbal remonstrations only exacerbates her unsettling experience with her peers since reminding them inspires their forgetfulness rather than their empathic understanding.

Conveying the meaning of fatigue among women living with secondary progressive MS like Lynda, Flesner et al., (2003) and Olsson, Lexell and Soderberg (2005) cite that MS-related exhaustion consumes the quality of women's lives and thus differs from fatigue experienced in ordinary health. Holding numerous degrees including a Masters of Business Administration, Lynda similarly illuminates the backlash of how others forget her (un)settled-ness. Even with a more obvious disabled appearance, Lynda stresses that there is still rampant skepticism of her (un)settled embodiment. This is especially prominent in relation to the (in)visible, fluctuating, debilitating fatigue and the cognitive impairment that consumes Lynda's life and precludes her employment (Flesner et al., 2003; Kralik et al., 2005; Vickers, 2001b).

Figure 19. Pretty wallpaper and wrongful assumption

> *It's a very subtle thing . . . I took this photo of my degrees because it's quite a contrast. You'd think this is an accomplished person . . . I know some people say, "why don't you work at home? You've got a computer. You've got your MBA . . . ." They make thoughtless comments like "well you could work . . ." I mean that sounds fine in theory but I have fatigue and that fatigue is a terribly invisible thing. . . .*

> *Fatigue is invisible but insidious enough to turn my university degrees into pretty wallpaper . . . There's lots of people that work in wheelchairs. And that's true but they don't have a stamina issue.*
>
> *When people make these statements "whoa, you should be able to work because look at that MP that's paralyzed from the neck down or Barb Turnbull." They still don't have the stamina issue. They certainly have a lot of challenges but there are a lot of challenges they don't have. For me to get out the door in the morning, I can't even have a shower because the heat knocks me out . . . . And then there's the cognitive stuff with MS too. I'm increasingly aphasic. I have a great deal of difficulty processing information . . . and my memory is going . . . . none of that stuff is visible. You know, well "why can't you work?"*

More than Meets the Eye

The incongruity of not looking disabled and experiencing (dis)ability culminates in hurtful (mis)assumptions. Vickers (2000, 2001b) argues these common myths stem from knowledge stigma, a lack of or incorrect knowledge and fatuous beliefs among the (non)disabled. Vickers insists, "when conditions are very serious, and have been diagnosed as such, the appearance of wellness in the bearer contributes to problems of misunderstanding" (2001b, p. 69). This state of affairs is especially complex for women living with (un)settled bodies who often look like they can meet able-bodied standards but have serious medical problems that are not always obvious (Davis, 2005). Recollecting an incident at a friend's wedding, Angela confronts psychically damaging assumptions about her behavior by refusing to "visibilize" her disability with the presence of her cane. Vickers (2001b) notes that behavioral characteristics associated with multiple sclerosis such as ataxia (loss of balance) are often misconstrued as a drunken stagger rather than the (un)settled gait of MS. Angela opens this discussion, highlighting the misunderstanding surrounding her (un)stable body.

> *There are times when I wish I had my cane with me so people would know that I have MS. Things like my friend's wedding in August. By the end of the wedding, I was zonked. It was an outdoor wedding and it was really gravelly and one of [the*

> *bride's] brothers did the "oh, you're really shit-faced" and I'm like "no, I had a glass of wine at supper . . . I have MS and I'm stumbling on the gravel." And in situations like that I wish I had my cane just so I could validate why I'm stumbling. Fatigue the way it shows, the way it comes out. . . I stumble, I fall into the wall, I'll trip. . . . I bang into people. It's socially unacceptable behavior . . . . [So] when you see somebody staggering up the stairs . . . think there may be a REASON why this person is stumbling or not moving. DON'T JUDGE. That's what pisses me off the most. People passing judgment. Never assume anything.*

As Angela's story suggests, this lack of cultural understanding perpetuates feelings of shame and frustration among women living with (in)visible illness who are socially (mis)perceived in negative ways because their disabilities do not behaviorally manifest as more forgiving or "conventionally disabling" as do more familiar visible, physical disabilities.

Portraying herself pictorially and descriptively as a woman who is desperate to keep physically fit to prevent further functional loss, Lynda comments how her husband forgets and misunderstands the nature of her MS because it is not always *there*, visually present and habitually embodied in the same manner all the time. Specifically, Lynda articulates how her husband (mis) perceives her exercising as a testament to her physical vitality and endurance rather than as a qualitatively different burst of energy that comes and goes with the (un)settled-ness of her MS.

Figure 20. Working out in the basement.

> *It's a huge part of my life that I exercise daily . . . . When I tell people that I do a daily workout, they are impressed because with my canes and walker I don't look capable of a workout . . . . I'm just doing what I can to stretch and try to build up any little bit of extra strength I can. . . . It requires a different type of stamina than to get down on your knees and have to get up from cleaning the floor or getting dust-bunnies from under the bed.*

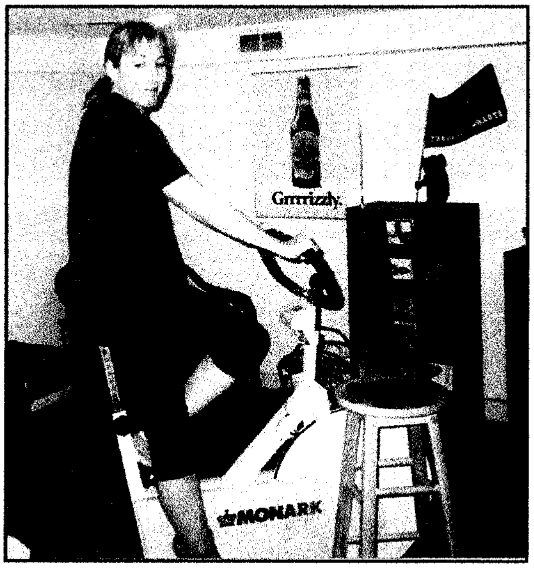

Figure 21. Working out in the basement.

> *It's a totally different kind of thing . . . when I do it, there's nothing else I can do. That's my limited steps . . . My stamina is so low that I don't break out in a sweat and I don't even elevate my heart rate . . . . I can barely do it. . . . And I don't know if my husband really understands that I can do this exercising but it requires different muscles and different stamina than to do house cleaning.*

Lynda's reality mirrors the observations of Werner, Steihaug, and Malterud (2003) who allude to a husband or partner's misunderstanding of their spouse's (in)visible musculoskeletal pain and changing bodily limitations. Similarly, in her research focusing on the lives of women living with invisible disabilities, Veronica Marris (1996) insists that it is difficult for others to remember the various things a woman can and cannot do because of conflicts in physical appearance and differing energy levels. Calling attention to the (dis)order innate to (un)settled bodies and contradictions in appearance Richardson (2005) emphasizes:

> Unpredictability may manifest itself in the body, whereby sufferers do not know from day-to-day where the pain will appear. . . there may be. . . variations in pain levels within one day, although outwardly there is very little difference in a sufferer's appearance (p. 36).

Ultimately, Ann Davis (2005) implies that it is emotionally damaging for persons living with [in]visible disabilities to shoulder the extra burden of continually informing and reminding others about their condition and having to rebut the social presumption that "what you see is what you get" (p. 72). Providing another case in point[9] of contradictions in physical appearance and expectations, of appearing well and being (mis)perceived as indolent Lynda remarks:

Figure 22. More than meets the eye on garbage day.

> *Garbage day. Also known as angst day. When you pass my house on garbage day, and you see me sitting at the window after the collectors have come and gone, do you think "look at that lazy woman. Won't even come out to the driveway and bring in her bins that are blocking the sidewalk". . . . People always park on the street . . . and when they see [my] garbage cans . . . blocking their vehicle and they see me at my desk in the office they must think, "She's right there sitting in the office. How lazy can you be? . . . . now I've got to move her cans". . . . [But] there's always more to everything than meets the eye . . . You can't make assumptions about what's in*

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[9] The "blurry" quality of this photograph is intentional and reflects the visual disturbances Lynda experiences from her MS.

> *front of your eyes. . . There's so much to this disease and it's so complicated. I used to assume that someone like me sitting in the window was just lazy leaving the garbage cans out like that. . . . Few people educate themselves on it [MS] . . . so they make all kinds of erroneous assumptions . . . . If you see someone sitting at the window on garbage day with bins blocking the driveway, don't assume that their lazy . . . You've got to question all of your assumptions, all of them. Don't jump to conclusions. And that's hard because it's human nature to categorize everything, to label everything immediately.*

Both of Lynda's examples illustrate the intertwined deceiving and frustrating tension between looking physically capable to others of engaging in every day activities like house cleaning and the removal of garbage cans from the street and being functionally incapable of performing such tasks. Physically appearing *as if* you are healthy and able-bodied and convincing people otherwise, especially when they cannot see that you feel unsteady on your feet, fatigued, and afraid of falling for example, counteracts the experiential essence of (un) settled-ness. The paradox of looking (almost) able-bodied and being able to for example, engage in physical exercise *as if* a woman were completely well, underscores the myths surrounding (dis)ability. Kelley and Tedder (1993) highlight similarly flawed assumptions made about people with visual impairments such as all blind people cannot see, see alike, read Braille, and are especially sensitive or talented in relation to other senses such as hearing (pp. 104-106). Hence, bodies that seemingly look normal like Lynda's, and outwardly perform in accord with able-bodied expectations with their impairments, disrupts our cultural logic about what legitimately counts as health, illness, ability, and disability. Twisting such cultural orthodoxies sets a precedent for eradicating arrant misunderstanding of what it means to live with a body that is functionally cooperative in certain circumstances, yet unstable and unreliable in others.

Offering a further incident, Lynda relays a disconcerting story about how a fellow student from her graduate business program erroneously equates her sometimes-disabled appearance with being perpetually sick. This misguided association not only offends Lynda but calls attention to our cultural insensitivity towards (in)visible disability.

> *A person who was in my MBA class, we were talking about something in my learning team and S made the comment "don't you feel that way because you're sick?" . . . I was barely affected but used a cane from time to time so they knew about it [the MS]. And the choice of words he used stayed with me forever because "I'm SICK." But I don't think of myself as sick . . . . But there are those who hear something like MS and think why doesn't that person even go on living? Why don't they just kill themselves and put themselves out of their misery? But it's not misery . . . It's just "other-abled" . . . Nobody even noticed it . . . Nobody spoke up and said, "Don't call her sick". . . . But that's the perception. If you have MS, you're sick . . . . When S called me sick I didn't look sick and I wasn't using my cane that day . . . so it wasn't anything visible . . . . and yet he still called me sick . . . It's a cop-out to make assumptions that any kind of chronic condition makes a person sick because there's just infinite variations on how a person can be disabled.*

While not always physically appearing disabled with the use of her cane, the biomedical inscription of MS, like its experiential (un)settled essence, is misperceived by Lynda's classmate as an abnormal state of being permanently unwell. A hurtful, unwarranted comment like this albeit not socially perceived as damaging and inaccurate, once again signals how the lack of societal awareness and the (mis)assumptions it fosters is an inescapable reality for women living with (in)visible disabilities. In this scenario, living with multiple sclerosis is (mis)construed as a life of perpetual sickness and suffering. Partially rooted in the logic of the Parsonian sick role (Parsons, 1951) that defines illness as a deviant state, Lynda's colleague offensively characterizes her as stably sick and thereby (an) "invalid" among her healthy peers. Royer (1998) affirms this socially tainted academic excommunication stating "being a "valid" person is a continual struggle for chronically ill people, and being "invalid" means. . .being discounted and devalued" (p. 58). Viewed in this light, Lynda's role and contribution to her graduate learning group is carnally stained since she is perceived as a permanent outsider within a society geared towards those of sound mind and body.

Paradoxically, forgetting and the faulty assumptions associated with it, is also endemic among women living with (in)visible disabilities themselves. Vickers (2001b) mentions that persons living with (in)visible disabilities do not always recognize, empathize, and consider all of the nuances of all (in)visible disabilities and cannot be expected to do so. Recalling a surprising meeting at work with a client living with fibromyalgia, Angela reveals:

> *This week I did an assessment on a woman . . . with fibromyalgia . . . she needed home-making services not personal support care . . . she got really angry . . . she did the "I hope you never end up with a disability and know what it's like to fall through the cracks!" . . . I just want to throw it back and to say "actually I'm right where you are baby!" . . .You can't make comments like that to people and this is someone IN THAT population who can't even acknowledge that this person may be there too but I don't know it.*

Extending this incredulity and lack of understanding, Angela surmises how persons with more visible, stable disabilities would also completely disregard the (in)visible limitations imposed by her MS.

> *You know, someone who has a severe physical disability, I've had clients who can't walk, can't feed themselves, can't toilet themselves. I can just picture a response "What's your problem? Oh, you trip and stumble sometimes. I can't feed myself."*

An equally staggering event is that Angela admits that she too has difficulty remembering the (in)visible reality of other's (un)settled bodies, especially in relation to her boyfriend's arthritis. Angela catches herself in the irony of her own forgetfulness as she misreads her boyfriend's refusal to get together one evening.

> *This one guy I've been dating right now . . . the guy with the really bad arthritis. It's funny that I have problems accepting his . . . things as valid and that's really something I've been thinking about for the past couple of weeks. I called him last week and [said] "do you want to come over?" and he was like "actually I can't. I*

> *really just pushed myself today and I just need to spend the night at home and not do anything because my knees are really hurting and I just want to sit down." For me, it was like, Oh, like it would be TOO MUCH to come over and OH MY GOD I FELT TERRIBLE! I have to stop myself a lot . . . You don't see it with him . . . I'm not very empathetic or understanding.*

Analogous to the woman living with fibromyalgia Angela describes in the previous example, Angela (mis)judges her boyfriend in accord with visual cues of (dis)ability. Consequently, some women like Angela fail to remember as they interact with others in their ordinary life moments that others may be similarly afflicted with (in)visible illness despite the fact that they too look well and function more or less in an able-bodied manner.

Institutional Bafflement: The (Un)Convincing Gray Netherland

Returning to Angela's occupational environment, interpersonal forgetting shades into and exposes the institutional bafflement surrounding personal accommodation. Angela's request for a larger computer monitor is suspect, demanding medical documentation by her supervisor to prove this adaptation is genuinely disability-related. Angela comments:

> *I squawked for a bigger monitor and she was like "why?" And I'm like "because I can't see very well" and she was like "can you get a note from your doctor?"*

Considering Angela's comment, Cal Montgomery (2001) remarks that "because the [in]visibly disabled. . . are suspect, people ask why we need accommodation rather than what accommodation we need" (p. 2). Elucidating this reasoning, Ann Davis (2005) comments:

> The revelation of an [in]visible disability can often be greeted with a skepticism that can be both difficult and painful to dispel. Since it is impossible for most laypersons to verify the truth or falsity of many claims of [in]visible disability, an interlocutor's willingness to believe that the individual has an [in]visible disability may be contingent on his or her willingness to assume that the person is both credible and informed. . . . The provision of medical certification. . . categorizes and reifies the disability (pp. 64-65).

Historically, people who require wheelchairs have been the most visible members of the workforce to seek accommodation. Given the shifting (in)visibility of (un)settling health conditions, rarely are the practical needs of those affected recognized. Driedger's (2003) study of women working with (in)visible chronic illness echoes the disbelief of (un)settled embodiment that Angela experiences and demonstrates how necessary accommodations are not always obvious and justifiable to employers. Since her disability is not readily noticeable and counters the presumed "look of disability," Angela must constantly defend her accommodational needs as a way of both validating her MS and ensuring her supervisor acknowledges its presence in her professional life.

Kuglemann (1999) implies that pain, which I extend to (un)settling conditions, is something that must be objectively produced if it is to be knowable and credible. However, in interrogating what convincingly counts as being disabled, Stone (1993) infers "as anyone with knowledge about disabilities knows, there are all kinds of disabilities and many of them are not [always] obvious" (p. 11). Contrasting her supervisor's cross-examination of the (in)visibility of her MS with a fellow co-worker's clearly observable, impairing arthritis and her right to have her work schedule modified, Angela contends:

> AL: *There's three of us supervisors and one of them has arthritis in her ankle. They reduced the number of community visits that she has to do because of the arthritis in her ankle. And I do the "but" and I could ask but nobody's said "oh well how about you?"*
>
> AV: *Is her arthritis in her ankle more visible?*
>
> AL: *Yeah and she limps really badly and she's had surgery on it so it's very valid. Most of the staff just caught on that she uses a cane sometimes . . . she'll get a fold-up stool if she's going out in the community. She'll bring her little stool so she can sit. Hers is much more visible than mine.*

While the effects of Angela's MS are manifest vis-à-vis reduced stamina and low vision, such "sightings" albeit a very real part of MS, remain largely invisible and institutionally contested in comparison with the evident physical limitations of Angela's colleague. Confirming this scenario among university students with (in)visible disabilities, Olney and Brockelman (2003) assert that students whose disabilities are not readily apparent experience greater difficulty securing accommodations than their peers with more visible disabilities because faculty believe they are "making it up."

Elaborating this scenario, Angela states, "*I always joke around with my director and do the I can start bringing in my cane everyday and be your token disabled person in the office" and she . . . laughs [and] really dismisses me.* Underlying Angela's remark however, is the crux of an (un)settled embodiment. By visibly exhibiting her body as disabled, her supervisor will immediately remember and believe Angela has multiple sclerosis. I again call upon the words of Cal Montgomery (2001) who sums it up best: "when non-disabled people look at 'the disabled,' they see wheelchairs, picture-boards, helmets, hearing aids and white canes. . . the tools we use. And these tools. . . equal disability" (p. 1). Hence, unlike using a cane or a wheelchair that culturally symbolizes and sanctions a legitimate disabled identity, signs that are less obvious and unfamiliar, that shift between (in)visibility in performative and more nuanced ways, are not perceived as disabling and are thus discounted from the outset. In not seeing Angela's MS, in equating physical disability with the immediacy of the body's physiognomy, her director's eyes remain myopically closed to its reality.

In keeping with the issue of equitable accommodation, I move beyond Angela's workplace into broader public space. The (in)visibility of Angela's MS, specifically the fatigue and compromised balance issues she lives with, while unnoticed by fellow commuters on the bus, subway, and stairways arouses annoying looks from patrons using an accessible elevator. While it is beyond the borders of this dissertation to engage in an in-depth sociopolitical examination of policy and access issues in relation to persons living with (in)visible disabilities, I want to pause at length here to emphasize just how insidiously Angela's social (in)visibility as a (dis)abled woman permeates her life.

Angela refers to how persons with (in)visible disabilities are forgotten in public access planning. Ironically addressing a page in her scrapbook devoted to "accessible" transit as orchestrated by the Toronto Transit Commission (TTC), Angela stresses:

> *The criteria for Wheel-Trans is so ridiculous. If you can walk up four stairs you're not eligible . . . some days when I walk to the subway, on a hot day in the summer . . . I'm like I don't want to even do this . . . their elevators are designed for people in wheelchairs, scooters, walkers, or other mobility devices and baby strollers. That whole (in)visible disability is not even there. . . what about pain, fatigue, vertigo, and minimal balance? Because I get the dirty looks if I use the elevators . . . . People with (in)visible disabilities, we fall through the cracks. We're not even eligible to get the support even though there are many times it's certainly needed.*

Lacking the adaptive accoutrements of more visible physical disabilities or what Moss and Dyck (2002) refer to as surface inscriptions that straightforwardly mark the body as deviant or abnormal (p. 93), Angela, as Megan Jones (1997) implies, "is not 'handicapped enough,' [and] only legitimately 'special' if [she] looks that way" (p. 3). Clearly, since Angela exists outside of archaic bureaucratic parameters developed by the public transit system that equates able-bodied-ness with the capacity to ascend four steps, her subjective experience of having a pain-infused, fatigued body is materially and institutionally forgotten, ultimately denying her right to accessible services. In this sense, as Angela implies, persons with (in)visible disabilities "fall through the cracks" and are forgotten because they are not visibly and permanently disabled in the same way from day to day. Reiterating Angela's plight, Moss (2000) characterizes herself as "falling between the cracks" within the academy in relation to the (in)visible (un)settled nature of her body. Although there is a politics to claiming living in-between (dis)ability and attempting to speak, act, and think from this position (Titchkosky, 2003), Moss maintains that such self-politicization, especially for female academics, is institutionally and socially unthinkable.

> Faculty members with chronic illness could be said to fall between the cracks. We have to work completely or not at all . . . be fully abled or fully disabled . . . there is no category for a person with chronic illness to fit in . . . most often we are cast as not quite abled and not quite disabled, somewhere between the *distinguishable* spaces of ability and disability . . . . There was no acknowledgement that I exist in between spaces (pp. 288-291).

Moss and Dyck (1999b) argue that defining what constitutes disability politically is deeply problematic, especially when considering conditions that resist permanent constructions. Policies rooted in hegemonic conceptions of (dis)ability focus on the scrutiny of the body as predictably self-revealing and capable of consistently performing certain tasks (Moss & Dyck, 2002, p. 119). More to the point, Moss and Dyck (2002) contend "as with women not fitting normative images of being ill, disability also exists within the hegemonic notion of a 'disabled body'. . . women with chronic illness tend to be marginalized within dominant notions of disability" (p. 108). Although we often believe one must be either totally able or totally disabled with no in-between (Stone, 1995, p. 418), women living with (in)visible disabilities live with a foot in two different worlds: the world of the healthy and the world of the illness (Rhoads, 1994). This embodiment is considered experientially impossible within the realm of social and public policy. Speaking to this in-between-ness, Angie comments, "*it's like having one leg in one world and one in the* *other . . . like two different lives, and they can co-exist.*" In being neither properly well or properly sick, Helen adds, "*It's not as though I'm totally outside of society. I do fit in but I don't.*"

Characterizing the volatility of an (un)settled body and (dis)abled identity as inhabiting a "gray area," a liminal communitas (Turner, 1967) seesawing between the spectrums of ability and disability and the borders of cultural and institutional constructions, Angela contemplates:

Figure 23. Seesawing between (dis)ability.

> *There's this group of able-bodied people and this group of disabled-bodied people and there's all these people in-between. But our society as a whole views these two as very separate and they don't see that continuum. I don't belong in either world. You don't belong to either group. You're not an able-bodied person but I don't put myself in the disabled-bodied group either. You're in this like little gray netherland that you know able-bodied people don't thoroughly get . . . . You're in a real, gray, gray area and it's sort of like the straight-gay-bisexual area. You have that ooh little gray area that nobody will accept you in either one . . . . For me, it's more of a continuum . . . . This gray area is a spectrum but in that spectrum, there's like a hundred different categories.*

Questioning whether this in-between gray area of (dis)ability is even a legitimate experiential construction, Angela reasons:

> *The public has distinct definitions . . . Can you call this a category? Is this gray area really there? . . . . It's that lack of external understanding, even internal understanding also. There's not a lot of people you can speak to who will understand, who will get that lack of belongingness to either group.*

For Moss (2000), such crude classifications and the ideologies perpetuating them speaks to a lack of awareness that anything exists between one category and another, between an absence and a presence, between nothing and something (p. 288). Augmenting Moss, Ann Davis (2005) admits:

> What is problematical is that we have not addressed the presuppositions that underlie our adoption of our standard modus operandi. We have failed to recognize that there are many more subtle and pervasive mechanisms of inaccessibility and exclusion that may both exacerbate disability and limit the participation of disabled persons in the life of the society. This applies both to those whose disabilities are visible and to those with [in]visible disabilities: to those who clearly do not meet able-bodied standards and to those who meet them but. . . have [in]visible disabilities (p. 55).

However, as Angela implies and Titchkosky (2003) avows, while claiming one's place betwixt and between raises the possibility of inserting alternative ways of being into the world, such possibilities for insertion typically remain unarticulated since people living with (in)visible disabilities themselves do not consciously conceptualize how they embody in-between-ness as a legitimate way of being. Added to this, persons living with shifting disabilities do not have a language to intelligibly put this in-between embodiment into words. Thus, since our society does not "see" or acknowledge the embodied-ness of (in)visible illness let alone living in-between (dis)ability as a valid way of being, individuals remain wrongfully socialized in understanding disability as an embodied state in which one is only visibly and immutably impaired.

Without the conspicuous presence of her canes or walker, Lynda offers another illustration of the cultural legacy supporting "ability" and "disability" as mutually exclusive categories rather than mutable embodiments that are not part of the "true target population" of disabled people (Ferri & Gregg, 1998; Jung, 2002). Conveying the subtle physical and social exclusion of persons whose disabilities resist myopic cultural translations embedded within the ableist organization of the built environment, Lynda relays:

> *When I'm going around Loblaws with the cart there's nowhere to sit. That's a BIG PROBLEM. I've actually moved stuff off the shelf- laundry soap, and parked my butt down because there's nowhere to sit . . . . But the assumptions from a store management point of view is, well, have they ever listened? Have they ever asked? As a former business operator, I NEVER PAID ATTENTION . . . . I just assumed everything was fine for the disabled . . . . A HUGE, A HUGE assumption that everybody makes is that we look after our disabled citizens. We don't.*

Corroborating Lynda's comments, Ann Davis (2005) maintains:

> People who are not disabled may not recognize that something as basic as the configuration of the supermarket plays a role in making the lives of some disabled persons worse . . . . It may . . . exacerbate the individual's difficulties and deepen their invisibility (p. 58).

Lynda stresses how as a previous able-bodied person in management, she rarely paid heed to the needs of persons with disabilities because she assumed, as she implies many non-disabled people do, that our society equitably oversees the welfare of its vulnerable citizens. However, since persons living with (in)visible disabilities like Lynda are literally out of sight, so too are their accommodational needs. Ann Davis (2005) echoes this assertion claiming that when people are out of sight, they are also out of mind. Since societies are physically constructed and socially organized *as if* the majority of citizens are fully able-bodied, then there is no need to think beyond the inclusion of accessible ramps and doors for the minority with *obvious* physical disabilities.

Crediting Lynda and Davis's remarks within a broader geographical frame, Imrie (1998) and Kitchin (1998) confirm that ordinary spaces like the grocery store reflect landscapes of exclusion that materially partitions "same" from "other" bodies, the able-bodied "us" from the disabled "them" (Chouinard, 1997). Dear, Gaber, Takahashi, and Wilton (1997) maintain that this socio-spatial production erases the complex realities of corporeal difference, ultimately offering no room for more fluid identities and citizenship beyond the scenography of ordinariness (Michalko, 2002). To quote Rod Michalko (2002):

> Even though society is the place of disability, it [society] is reluctant to give disability a place. . . After all, society "built itself" only for those. . . [whose] "ordinariness" is fashioned within the imaginary of non-disability. Making a place for disability is out of the question; too much time, money, and energy have been placed into fashioning the artifice of society (pp. 151-152).

Yet as this study implies, it is imperative that we first stretch our minds beyond anachronistic thinking that equates disability exclusively with visible and mobility impairments to the plethora of (in)visible disabilities that are equally if not more disabling because of their complexity. Thus, the way we think about what constitutes disability as an embodied identity underscores the implications surrounding existing and future policy implications. In redressing such disabling inequities, Moss recommends framing accommodation policies within more elastic, fluid boundaries that accounts for the instability of the (un)settled body rather against constricting, illusive norms across time and place. Writing from the borders of her own institutional battle within the academy Moss stresses:

> [We need] to frame strategies toward accommodation in volatile terms . . . of accepting chronic illness in its own pattern of fluctuation . . . strategies need to be flexible. Various types of chronic illness manifest differently; therefore, the specificity of accommodation . . . must look different . . . . Accommodation strategies need to be redefined such that there is less . . . of a norm against which a person with chronic illness is measured and more of a notion of equitable access . . . Embracing volatility in policy opens up possibilities for reframing accommodation as a process . . . within spaces of ability and disability, but also in between spaces (2000, p. 292).

Broadening the bureaucratic flexibility Moss advocates, Imrie (2004) declares that we need more policies and usable resources (Lutz & Bowers, 2005) that recognize disability as a universal condition of the human species. He suggests that policies geared towards those with special needs[10] need not be based on the needs of a few but be flexible enough to encompass the world for many (p. 10). Advocating a radical politics of disability in the same vein as Moss, Price and Shildrick (1996) advise not a pluralizing of the conditions of disability as the notion of TABs or Temporarily Able-bodied intends but rather exposing the failure of (dis)abled norms themselves to encapsulate a definitive standard (p. 236). Ultimately, such misguided notions of visible, unchanging restrictions in bodies and bodily performance, the latter particularly related to rigid notions of ambulation, legitimize the rightfully and "regularly disabled" and "invisibilize" women with less familiar, (un)stable disabilities. I revisit the political implications associated with living with a fluctuating (dis)abled embodiment in the final chapter of this work.

Summary

Throughout this chapter, I examine the obstacles surrounding how (un)settled embodiment is forgotten and remembered by others in participants' daily lives. The central tension portrayed is that it is the shifting (in)visibility and (in)credulity associated with women's (un)settled bodies that causes the most difficulty in everyday life. Participants want to be recognized as (in)visibly disabled and stress the need for others to understand that their disabilities are always a part of their identity even though they shift from invisible to visible, and settled to unsettled. However, with a so-called "normal" appearance on most days, the women convey that living with an (in)visible disability is experienced as a constant struggle that evokes invidious suspicion and pervasive misunderstanding. As referred to throughout this text, since there is no particular "look" to an (in)visible disability and the

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[10] I find this to be an offensive phrase that requires radical revision.

women do not physically appear consistently unwell, they are not treated as such to the extent that their disabilities are sometimes forgotten either completely or temporarily. Even with a verifiable medical diagnosis, participants must repeatedly remind and convince family members, friends, partners, and colleagues that they frequently, but not always, experience disabling restrictions although their bodies defy this social reading.

Paradoxically, an unexpected twist derived from the women's accounts is that even when they visibly appear unwell in the presence of specific physical or behavioral signs, participants must still remind others about the validity of their (un)settled subjectivities. Exacerbations of pain and fatigue are especially under-recognized as indicators of (in)visible illness and are not properly understood as seriously disabling in the moment. A simplistic and flawed reliance on the visual dimension of bodily appearance critically impinges on the lives of women living with (in)visible disabilities. Since participants are not conspicuously nor habitually (dis)abled in the same ways across all contexts or in the ready-made ways our society visually naturalizes the identification of disabled bodies, their subjectivities elide social legitimation. As participants reveal, this lack of knowledge and the flawed assumptions it breeds is damaging to their physical, social, and emotional well-being.

This shifting social (in)validation of (in)visible disability once again transposes itself, shifting women back into a never-ending quagmire of (dis)belief. Feelings of humiliation, inferiority, and guilt mixed with personal misgivings conspire to make women mistrust their own judgment about how serious their conditions really are. The visual paradox of being (in)visibly (un)well widens the gulf between what is seen (health and ability) and what actually is (at times, disabling limitations), thereby adding to the burden of everyday life expectations (Vickers, 2001b). Similar to many individuals, participants are culturally sensitized to adhere to norms of healthy, able bodies and perceive themselves as partially fitting with these expectations because more often than not, they can perform like anyone else. Since they look "normal," there is social pressure to "act like" others and keep pace with the expectations of an able-bodied world. The dilemma surrounding this mentality is that by setting a precedent that they can "overcome" or successfully manage their bodily limitations in all situations, women in effect, personally and socially invalidate the reality of (in)visible disabilities and place themselves at greater risk for additional setbacks. Conversely, by disrupting the cultural logic of (dis)abled bodies by calling attention to their (un)settled-ness when they look so well, women risk being socially perceived as weak, inferior, and failing to successfully live up to cultural performance standards.

The ways bodies are visually and discursively (mis)interpreted in our society equally parallels the manner in which (in)visible disability is delegitimized and/or absent in workplace policies and public access. Societal metrics that conflict with self-definitions of (dis)ability lie at the core of women's organizational and political invisibility. Describing her place of employment and her relationship with her supervisor, Angela reveals that many women living with (in)visible disabilities who often look well are not considered "disabled enough" and institutionally "fall through the cracks." Culturally, individuals are expected to be fully able or completely disabled. Conceiving bodies as fitting between definitive spaces of ability and disability has not entered into collective consciousness. While Moss (2000) contends that there is a politics to claiming living in-between (dis)ability, this self-politicization is problematic precisely because of its shifting materiality. Rather than being permanently and predictably impaired, many women living with (in)visible disabilities like

Angela occupy several subjectivities sometimes independently and sometimes in tandem on the disability spectrum. Since their bodies resist definitive constructions as healthy or unhealthy and able or disabled, policies accounting for and ensuring that their needs are flexibly met remain on the wayside of organizational management practices. Since a woman's credibility as partially disabled is constantly in question, especially when compared with more visibly disabled colleagues as Angela illuminates, the question arises of whether this shifting "gray area" of living in-between ability and disability is even a valid way of ideologically constructing and accommodating the experiential realities of an (in)visible disability.

Lynda's story extends the socio-political invisibility of women living with fluctuating bodies to their exclusion within the built environment. Architecturally, the invisibility of (in)visible illness reflects crude classifications of ability and disability. As Lynda indicates, bodies must comply with compulsory able-bodied notions of space and performance rather than challenge the logic of these predetermined ideals. While accommodations such as scooters in grocery stores and ramps accommodate the needs of persons with obvious mobility impairments, significant barriers remain for many individuals whose disabilities like Lynda's are present but commonly "out of sight." Ann Davis (2005) reiterates this perspective indicating that as a society, we fail to address that there are many more subtle and pervasive mechanisms of inaccessibility and exclusion that can in fact, exacerbate a person's disability, and limit their participation in society. For example, some women like Lynda who appear able-bodied with MS experience shifting periods of disabling fatigue and need to sit down and rest while shopping and/or require the frequent use of a washroom that is both physically accessible and conveniently located. These forms of support escape consideration because the complexity of corporeal difference is culturally misunderstood. More to the point, if the primary identification of disabled bodies rests on the premise of visuality, then the diversity of bodily experience remains jeopardized. Accordingly, many women like Lynda suffer in silence and become exceedingly invisible in spaces that deny the more fluid parameters of human embodiment. Consequently, in not being seen and/or taken seriously as (in)visibly disabled, many women whose embodiments fluctuate struggle to defend their personhood, their rights as workers, and their public inclusion as citizens in relation to the way that (dis)ability is bureaucratically (mis)constructed and societally organized.

In the following chapter, I enrich this discussion by portraying the manner in which the women themselves move back and forth between forgetting and remembering the presence of an (un)settled embodiment in their own lives given their relatively healthy appearance and fluctuating cycles of bodily (dis)order.

(Un)Convincing Bodies Part V

Chapter 8

(Un)Forgotten Bodies Revisited: The Self in Flux

Paralleling having an (in)visible disability that is habitually socially forgotten because it (in)visibly fluctuates between periods of calm and unrest is that Angela, Angie, Helen, and to some extent Lynda, shift between forgetting or consciously denying their disability and remembering its presence in their lives (Charmaz, 1991; Langer, 1994; Olney & Brockelman, 2003; Sveilich, 2005; Telford, Kralik, & Koch, 2006). I explore this tension of forgetting and remembering as an extension of women's experience of being (un)convinced of the reality of their (un)settled bodies as opposed to its traditional treatment in the chronic illness literature as a coping strategy and/or state of active resistance (Hillyer, 1993; Langer, 1994; Livneh & Antonak, 1997; O'Neill & Morrow, 2001; Royer, 1998). Writing about the phasic nature of denial among persons with disabilities from a psychotherapeutic lens, Langer (1994) buttresses this (un)convincing friction noting that while denial provides hope to cope with illness, an observation shared by Schaefer (1995), individuals do show a fluctuating [in]attention to their disability. Angela's candidness encapsulates this friction of trying to convince others to acknowledge the (in)visible (un)settling reality of her MS at face value despite her often-healthy appearance, while personally aspiring to forget its presence in her life because she fears being disbelieved.

> *[It's about] convincing people it's a whole neurological thing . . . . You can't see it but if someone tells you it's there, it's there . . . . I'm always cognizant that my disability is not taken seriously because it's not readily identified by others . . . [Then there's] the denial thing, not dealing with it . . . I'm scared my self will be devalidated.*

I begin this chapter with a fitting anecdote reflecting Lynda's experience. In not looking or physically feeling impaired, Lynda sometimes forgets her MS exists within ordinary moments in her life. However, such forgetting quickly shades into a striking remembrance when Lynda's body fails to cooperate with her able-bodied intentions.

> *Just sitting here like this . . . I feel fine. I don't know I'm disabled until I stand up. Which is why I actually broke my fingers last year. When we moved in here last year, my cat Ted . . . he was attempting to express his displeasure about being moved to a new home. There was a pile of stuff in the corner and he went over . . . there and squatted and started peeing on stuff in the corner. And I started to run towards him . . . to make sure he stopped peeing and I FELL because I forgot I can't run. So I don't realize I'm disabled until I try to do something.*

Summarizing this self-forgetting in chronic illness, Becker (1997) eloquently writes:

> The body remembers. Embodied knowledge is shaped by memories. . . Long after bodily changes have occurred, people continue to experience their bodies as they used to be. People who can no longer walk may attempt to get up out of a wheel chair and walk, or they may say, "I'm fine just sitting here" and see themselves as unimpaired (p. 193).

Conceptually introducing the notion of self-forgetting as a "demented hope" or a hopeful turnaround in relation to the (un)settling character of MS Angie admits:

> *I think most of the time it's just totally invisible even to me. I'm in such an extreme state of denial . . . The process of disease with relapsing-remitting it's just like it comes and goes so you are always kind of hopeful I guess that you don't have MS or something. Or you're always hopeful that it won't come back . . . . There's the HOPE, the demented hope that like . . . you aren't sick, there's nothing wrong with you . . . These symptoms resolve themselves and then I can be like symptom-less for a while versus symptomatic all the time . . . . I still refuse to accept the fact that I have MS. I'm still hopeful that there's a way of turning it around . . . I can't believe that it's happening sometimes.*

In turn, this "distorted" sense of hope that their situation will change emanates from a prolonged adjustment period innate to relapsing-remitting disease in which many women like Angie do not have to immediately confront the truth of their bodies (O'Neill & Morrow, 2001). Angie reasons:

> *Like the key to this and it's probably very specific to this disease is that . . . there is something about the temporariness of it that makes it more, it makes it more manageable. The thing about MS, with relapsing-remitting is you're given a period of time where you can ADJUST . . . For a lot of diseases you aren't allowed to acclimatize yourself. Your life changes overnight.*

Adding to a prolonged disease process, Angie overlooks her physical limitations because she finds it difficult to accept the new, unfamiliar reality of her body's volatility in place of her formerly stable, enabled body. Elucidating her self-forgetful-ness Angie says:

> *It's just problematic for me to just admit that I need to slow down or I need to take a nap and it's because of MS. It's like admitting MS in terms of physical symptoms. And I'm like very reticent to admit limitations . . . . I just dismiss it. . . It's difficult to relinquish your previous ability level or admitting that you can't do something.*

Sharing Angie's thoughts, Angela comments that encouraging others to be mindful of her MS means regrettably remembering that her body is no longer one of the perfectly functioning, vital able-bodies our society values. In turn, this painful recognition conspires to remind Angela that her identity is also no longer intact.

> *It's that whole too, acknowledging something is wrong. Something is wrong with my body. It's really not always easy.*

Donoghue and Siegel (2000) maintain that the (in)visibly ill are caught between contradictory and I would add, (un)settled wishes: wanting clear, convincing, outward signs of their condition to validate it and wanting to maintain a healthy, normal appearance and identity. Reflecting on a photograph depicting the stark disembodiment of her cane, Angela refers to the strain of wanting to accept the reality of her MS by visually and publicly legitimating its presence and choosing to invisibilize it by positioning her MS out of sight and out of mind from others and herself.

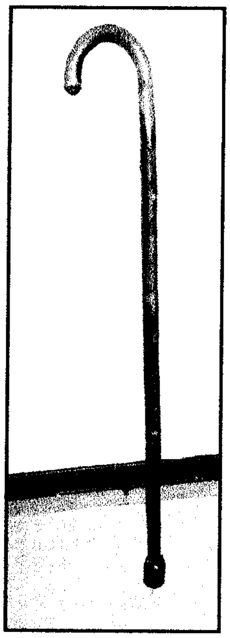

Figure 24. The cane: (In)validating the body

> *Sometimes I do think in a traditional sense [I'm] in denial. I'm pulling the wool over my own eyes . . . . The way I deal with my [in]visible disability, my reluctance to use my cane says it all.*
>
> *Something I struggle with every day is accepting the validity of my limitations and just being okay with that . . . it should be valid all the time [but] I guess it's just allowing yourself to accept it as being valid.*

The incongruity Angela describes in living with a fluctuating (in)visible illness that does not immediately render her "disabled" across all circumstances and accepting the reality of the limitations imposed by her body is thus a constant battle to ascribe credibility to the seriousness of her MS and legitimating its presence in her life.

As part of this tension, Charmaz (1991) indicates that the structure of one's life can mute the (in)visibility of intrusive symptoms (p. 59). Angela details how the coping mechanisms she employs such as pulling a wagon to carry her son and relying on a wheeled buggy to bring milk home from the grocery store encourages others to discount her disability because these strategies inconspicuously fit into ordinary life, thereby keeping her MS invisible. Writing about the seeming façade of (in)visible disabilities like multiple sclerosis, Fitzgerald (2000) adds that controlling the condition through sensible activity management works to avoid symptom exacerbation and also in effect, hides the condition from oneself.

> *The whole coping thing . . . I found I was taking and looking at pictures of things that were my coping mechanisms and I was like that's really interesting because that's keeping it as invisible as possible. I've developed all these coping mechanisms. My friend M-C when I was asking her and she's like "I don't notice anything because you have all these coping mechanisms that you just do and you never identify it as this is my coping mechanism right now. It's I'm going grocery shopping and I need the bundle buggy even though I'm just buying milk." They're so small that people don't question it . . . they fit into life . . . Sometimes you feel the trick is to keep it as invisible as possible.*

At the heart of this and the previous account, Angela struggles with the dilemma of wanting others to appreciate her disability but does not want to socially amplify its presence and elicit its memory. By visibilizing her disability with her cane, Angela vividly confronts the perceived reality of a flawed body and a socially undesirable persona that she would rather forget. Attesting to Angela's disinclination, Charmaz (2000) indicates that persons living with (in)visible disabilities can feel fundamentally flawed despite their relative lack of visibility on a day-to-day basis (p. 286). For example, choosing to use a visible assistive aid can symbolize taking on an identity as seriously disabled (Charmaz, 1991, p. 151), a reality that Angela eagerly seeks to avert. This double bind is also cited by Richardson (2005) who observes that women experiencing (in)visible conditions are entangled in a situation where to visibly express their condition warrants its contentious remembrance and simultaneously threatens their personal integrity by deflecting attention away from their identity as able-bodied women.

Tugging at the seams of self-forgetting for Angela are (in)visible reminders including concrete things and experiences that catapult her back down to the reality of her (un)settled embodiment. Such embodied reminders as Angela suggests, are always "*something you can see, feel, that makes it all so real.*" Although periodically forgotten by others and often choosing to forget her disability herself, Angela's (un)settled-ness reasserts itself through other's validation of it. Referring to her trip to London, Angela recounts:

Figure 25. Touring London with a friend.

> *The whole traveling thing . . . my friend . . . she was more concerned about the eight-hour flight and my fatigue. She was the one doing the "well, the first day there you're going to be tired so we have to do this" and it was like, "well let's not worry about it, let's just do it." She was the one who really constantly brought me back down . . . This friend I haven't seen in about two years and she spent the whole time doing the "are you okay?" "No." "Do we need to stop? Are you okay?" And it was like "no, I'm not okay. I'm really tired but I'm in London and we have a lot to see." And my friend M-C will often . . . do the "do we need to go sit down for a few minutes?" Somebody else picking it up and validating it in a sense. Doing the "oh remember, you have this THING to take care of."*

Making the (un)settled-ness of MS tangibly real also prompts self-remembering when Angela's youngest son calls attention to her (un)predictable, varying abilities.

> *We took this picture because I use to be able to carry Z on my back a lot. Now I can't. My line to him is always "sorry I can't because of my MS". . . But every once in a while I'll say do you want a piggyback? And he's like, "you can piggyback me but what about you're MS?" It's a real, that's the one thing that makes it really concrete.*

Figure 26. Piggybacking son at home.

Ultimately, remembering (in)visible disability, as Angela's examples illustrate, often depends on other's reminding women of its significant presence in their lives, validating its legitimacy in the moment, and expressing concern over whether a woman can feasibly endeavor to do what she chooses without exacerbating her condition.

Moving forward into Helen's lifeworld, Helen explains it is easier to downplay and neglect her bodily limitations because they are not directly visible and coupled with this, are perceived as less serious than difficulties associated with more visible, physical conditions. Stone (2005) mirrors this viewpoint commenting that even when vehemently defending their conditions as sometimes disabling, women accept the hegemonic belief that only those disabilities worth taking seriously are those that are always visible (p. 303). Commenting on this ghettoizing inherent to the disability movement in Canada, Dreidger (1999) writes:

> The disability movement does not like sick people. . . the "real" issues are of people in wheelchairs and to some extent, blind persons and then those with invisible disabilities. Sickness [or fluctuating disability] is denied in the movement. . . in Canada. . . there is an informal hierarchy of disability in the movement [and] the stars are those in wheelchairs (p. 321).

In keeping with Helen and Driedger's comments, Brueggemann and Moddelmog (2002) and Olney et al. (2003) refer to the practice of crip-casteing, a hierarchizing of disability that distinguishes the "real" disabled from the interlopers (Deal, 2003, p. 903). Sustaining this view in relation to living with the stigma of an (in)visible disability, Goffman (1963) denotes:

> The . . . individual exhibits a tendency to stratify his "own" according to the degree to which their stigma is apparent and obtrusive . . . . It is in his affiliation with, or separation from, his more evidently stigmatized fellows, that the individual's oscillation of identification is most sharply marked . . . . Presumably the more allied the individual is with normals, the more he will see himself in non-stigmatic terms (p. 107).

Any endeavor to convince oneself of the seriousness of a chronic condition commonly evolves into questioning one's self-identity. Simi Linton (1998) maintains that "the question of who 'qualifies' as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are" (p. 12). By optimally comparing herself to persons with more visible disabilities, whose limitations are more obvious and impairing, Helen convinces herself that her condition is not justifiably disabling, despite the extreme debility she periodically experiences. In this way, Helen does not legitimately deem herself among the "conventionally disabled" because she is only sometimes impaired and thus, relatively "better off" than persons who live with disability as a constant state (Royer, 1998; Wendell, 1996). According to Corbin (2003), there must be a marked acuity or significant interference with activities of daily living and social relationships before persons define themselves as ill. Equating the (in)visibility of her vulvodynia with her refuge in the world of the normal, Helen narrates:

> *If I had a more visible, physical condition or something more serious, I'd be like I can't do this. I don't see those limitations. There are those limitations but I don't see them because it's not physically visible so I just overlook those limitations.*

Reporting a comparable ontological conundrum, Gordon, Feldman, and Crose (1998) indicate that there is less impetus for women living with (in)visible chronic illness to view themselves as disabled because of the protracted, often-erratic nature of their functional limitations. Discussing the implications of their study further, Gordon et al. infer that:

> While many of the women had rather severe limitations in their lives due to chronic illness . . . [this] alone did not constitute a view of self as disabled. Due to the slow, progressive nature of may of the women's illnesses. . . they saw these limitations as more of an accommodation to illness, rather than the development of an awareness of self as a member of the [dis]ability community (1998, pp. 9-10).

It is also worth noting that by demoting the nature of her own (u)settled-ness and believing others are "worse off," Helen strives to avoid the shame and humiliation that an identification as disabled confers upon individuals in our society. Extending this argument, Wendell (1996) theorizes:

> I have heard other people. . . some of them in terrible circumstances, say they do not consider themselves disabled because "others are so much worse off than I am." I think it is sometimes a way of minimizing one's own difficulties in order not to feel frustration, grief, or shame. . . and to feel stronger, healthier, and more 'normal' (p. 27).

Picking up Wendell's argument, Vickers (2001b), and Donoghue and Siegel (2000) further substantiate that when disease is in remission to a greater or lesser degree, the individual feels healthy and normal, sometimes even phony for identifying as having an (un)settling disability (Gordon et al., 1998). Speaking to almost feeling like an imposter for participating in this research Angie implies:

> *Like I still have moments where I feel like there's nothing wrong. I feel pretty good. Like yeah, I could almost feel like a fraud participating in this study at all because I am perfectly fine, you know.*

Although threads of self-other stigmatization resurface in Chapters 10, 11, and 12, it is clear here that there are major obstacles with identifying as an (in)visibly (dis)abled woman. In fact, Corbin (2003) remarks that even when someone receives a medical diagnosis, an illness identity does not naturally ensue. For example, Lynda reveals that claiming disability as part of her identity developed through a gradual process of impending loss and greater physical visibility as a disabled woman.

> *I actually do label myself disabled and that was [a] capitulation. It took a long time. There was a long time when I couldn't say to someone on the phone "can you tell me do you have disabled parking? Is the washroom on the main floor because I'm disabled." But now I can say that and it doesn't phase me.*

While Marris (1996) contends that being a woman with a chronic illness is only part of one's identity and experience, she concurs with Shakespeare (1996) who articulates that "disability is a very powerful identity, and one that has the potential to transcend other identities" (pp. 103-104). Amplifying this viewpoint, Wendell (1996) remarks that accepting disability means making a deep change in identity and accepting the reality (though not the injustice) of the stigma of being chronically ill (p. 26). Adding to this, stereotypical images, particularly of women living with disabilities as inferior, weak, passive, dependent, and incompetent discourage some women like Angie, Angela, and Helen from conceptualizing and legitimately recognizing their own disorders as disabilities (Stone, 1995, p. 416; Wendell, 1996, p. 63). Given this disavowel, disassociating disability from one's self-concept safely maintains many women within self-imposed boundaries of the relatively but not always well, rather than the genuinely disabled.

In order to deepen understanding of the tension between self-forgetting and remembering, I steer the discussion back to Helen's narrative, drawing more extensively on the ways in which she associates self-forgetting with "shutting off" vulvodynia's (un)settled presence in her life. While shutting off is integral to blending in (un)settled-ness, a theme I address in Chapter 10, I offer an alternate interpretation here that focuses specifically on the contradictions inherent in the fluctuating rejection and recognition of an (un)settled body within the context of Helen's sexual identity.

Shutting Off: Helen's Story

Due to the physiological nature of her vulvodynia, Helen's (un)settled-ness is embodied in her sexual functioning and identity as a woman. While I am in no way suggesting that multiple sclerosis does not have physical, emotional, and social implications in relation to women's sexual selves (Kralik, Koch, & Eastwood, 2003), this facet of lived experience was not a focus of this inquiry nor a topic of conversation initiated or pursed among the other participants.

Helen shuts off vulvodynia in two incongruous ways: first, by stretching the physical boundaries of her body and second, by rejecting her sexual identity as a woman physically, socially, and emotionally. Intellectually, Helen is aware that her chronic condition exists but pushes past this embodied recollection by ignoring the urge to urinate and the accompanying pain she experiences while participating in social activities such as tree planting. Helen conflictingly recognizes the recklessness in self-sabotaging and dismissing her pain since such risk-taking precipitates illness exacerbations (Atkins & Marston, 1999; Hillyer, 1993; Langer, 1994; Sveilich, 2005), and circumvents the recognition that she is functionally different from her peers and should respect her body's (un)settled-ness.

> *I try to shut off vulvodynia in general. I just pretend it's not there, it's not happening. At times I make irresponsible choices because it's just I want to pretend its not there and go about my daily life. For example, a couple of years ago when I was tree planting and my symptoms were quite bad . . . and my partner at the time . . . he's like "quit, just quit. And I'm like "no, no, no, I don't want to quit." So it's kind of like just denying it . . . even though I am physically, acutely aware that its there. Mentally I'm just like "no, no, I don't know what you're talking about. This is fine. Life is fine." And its not, but I shut it out . . . So I do stretch the limits. [But] also, it's dangerous in that to shut it out . . . can make my symptoms worse. You know, I'm totally normal, I'm just going to ignore it. Then I do stupid things . . . because I think I'm just like everybody else and that has been a problem for me is that I keep thinking I'm totally normal . . . . I keep thinking I'm just like everybody else . . . . I have problems . . . realizing I'm not like everybody else. . . that I can't do everything* that *everybody else does. . . Being out with my friends and they're doing things or they're going places where I can't or I can but I shouldn't. That's the thing. I can but I shouldn't. And convincing myself that I shouldn't . . . [I need to] learn to accept that this is my life instead of constantly trying to fight it and deny the reality of it.*

Charmaz (1991) and Donoghue and Siegel (2000) highlight Helen's shutting off stressing that in ignoring signals from their bodies, and believing themselves to be (almost) like everyone else, individuals push themselves to test their endurance, to see how normal or close to normal functioning they can get. By stretching the body's boundaries in this way, (un)settled-ness is less visible and therefore, less real and easily forgotten for Helen. Angie similarly encapsulates this disregard explaining, "*half the time I'm quite able and capable but. . . sometimes I do things just to prove that I can when maybe I probably shouldn't.*" Angela quickly recognizes when she's "pushed it too far" stretching her body's limits stating "*my fatigue hits only when I've pushed it. . . my legs feel like. . . they've been dipped in lead. . . . I always know what's happening cause I feel like I can't do this but [if] I want to I'm going to.*" Clearly, because the women in this study are both (dis)abled to varying degrees, it is maddening as Helen implies, to convince oneself that despite a healthy appearance and a body capable of complying with their wishes albeit sometimes at a harmful price, that they are in fact, not quite so able or "normal" across all situations.

Alternately, Helen perilously stretches her bodily boundaries by psychologically disengaging herself from her physical pain to maintain a sexual relationship with her boyfriend. Within this context, the body, in its failure to respond sexually without pain for Helen is as Gadow (1980) writes, increasingly viewed as an embattled oppressor because it destroys possibilities. Angie similarly refers to this tormenting disconnection from her body upon the onset of her MS implying:

> *My body was MISBEHAVING and in my mind it was like, I almost had to DIVIDE the two just to deal with it. I was so ANGRY . . . I concentrated on my body as "other". . . It was not me anymore.*

Augmenting an understanding of this 'mind-body split' and its relationship to self-forgetting, Register (1999) denotes:

> When your body is defective and cannot be fixed, the idea that the mind and spirit are of greater value than mere matter has considerable appeal. . . .[when] your

> healthy mind balks at reconciling with a recalcitrant body. . . the easiest way out of that conflict is to ignore your body altogether.

Wendell (1999) speaks to this mind-body divide as a mode of transcendence in which individuals actively resist identifying with the pain and discomfort of their condition. However, a cerebral hiatus from the body's painful messages and the grin and bear it philosophy this implies embodies a delicate balance. Although Wendell (1996) acknowledges that it is important for an individual to demonstrate a vigilant respect for what is happening within their body at any given moment, I suggest that even with the best of intentions, this awareness can easily slide into a carnal silencing with self-injurious consequences rather than a corporeal emancipation. Helen relays how her self-forgetting mirrors this self-abnegation.

> *It seems that my body knows when I'm doing something stupid to it. When I'm pushing too far . . . . I feel like I can't say I don't like sex. . . . I just detach myself from it . . . At times I see my body as this TRAITOR who betrayed me because it's not doing what I want it to do. As though there's some mind that's separate . . . . I was trying to please [him]or fulfill HIS NEEDS.*

By pushing her body and conceding to the needs of her boyfriend, Helen risks another flare-up of knife-like pain and intense burning that Wendell (2001) verifies "means danger, risk of relapse, hospitalization [and] long-lasting or permanent damage to one's capacities to function" (p. 25). At the same time, stretching her body's limits enables Helen to assuage the guilt of being unable to sustain sexual intimacy with her boyfriend that she believes is part of being a "real woman" who lives in accord with the cultural, gendered scripts of female sexuality. I return to the significance of Helen's sexual identity in relation to the fluidity of (un)settled-ness in Chapter 10.

While a sophisticated analysis of the emotionality of (in)visible disability is beyond the parameters of this chapter, I pause here and draw the reader's attention to its place as an (in)visible facet of (un)settled embodiment and return to it again in Chapter 12 with a focus on Lynda's story. Writing about guilt and shame, Donoghue and Siegel (2000) contend that living with chronic illness often means living with a crushing sense of responsibility, discomfiture, and attempts at activities that can be ruinous. These feelings relate to the fact that as Ann Davis (2005) maintains, we assign considerable meaning to meeting able-bodied standards and in doing so, sometimes compromise or even sacrifice other things to attain the mere appearance of being healthy and able. Feeling at war with an oppressive body that demeans and humiliates by refusing to perform reliably (Gadow, 1980) and perceiving herself as a failure both sexually and as a woman, Helen sacrifices her body to sustain the well-being of her relationship with her boyfriend and her value as a woman. However, her culpability is often short-lived as resentment quickly follows along with another unbearable cycle of painful symptoms.

> *It got to the point where [in] my past relationships we'd have sex maybe a couple of times a year and this is when we'd live in the same city or in the same house. And I was like okay, we'll I'll do this for him . . . It was kind of a sacrifice but I'm like if I want to make this relationship work this is something I have to do. And then I would risk a flare-up or then it would be even more irritating because we had sex so seldom that there was more stretching and tearing and things going on.*
>
> *Like I should want to have sex with my partners. I should want to have a physical relationship . . . I did feel that guilt you know they're sort of "you never want to touch me. I feel you're rejecting me you know". . . So then once again, pushing myself to the limits where it would be okay let's have sex. I knew it was a bad choice to make but because of that guilt, I was like I want to make this situation right. And so I'd make bad choices for myself, and then end up in a lot of pain and resent it.*

Torn between not having sex and feeling like an unaffectionate girlfriend, and having sex and intentionally inciting a flare-up, Helen emotionally shuts off her sexual self. On this end of the continuum, the tension of remembering vulvodynia's magnitude in her life evolves into forgetting or neglecting her sexuality as a self-protective measure that safeguards Helen's body from physical pain and injury.

> *Sometimes it's just a matter of completely shutting off the fact that I'm a sexual being. For me, it's just always been something I always want to go away . . . I wish I wasn't sexual. I wish it didn't exist. I wish I didn't have to do the sex at all . . . because of the vulvodynia. I want to hide and repress it and make it go away. In the past, when I was with my partners . . . I'll just get to the point where we really just have almost no physical relationship, maybe kissing now and then but it's just sort of that denial of my physical being.*

Helen's self-concept is strongly linked with being sexual and exuding a feminine sexuality. By framing her feminine identity within the confines of vaginal pain and agonizing intercourse, within a dysfunctional body that entraps rather than liberates, Helen is reminded of her invisibility as a woman who is sexually dead within a culture that openly encourages women to celebrate their bodies and sexual selves. Helen visibly acknowledges her feelings of un-womanliness and sexual self-erasure in the following passage:

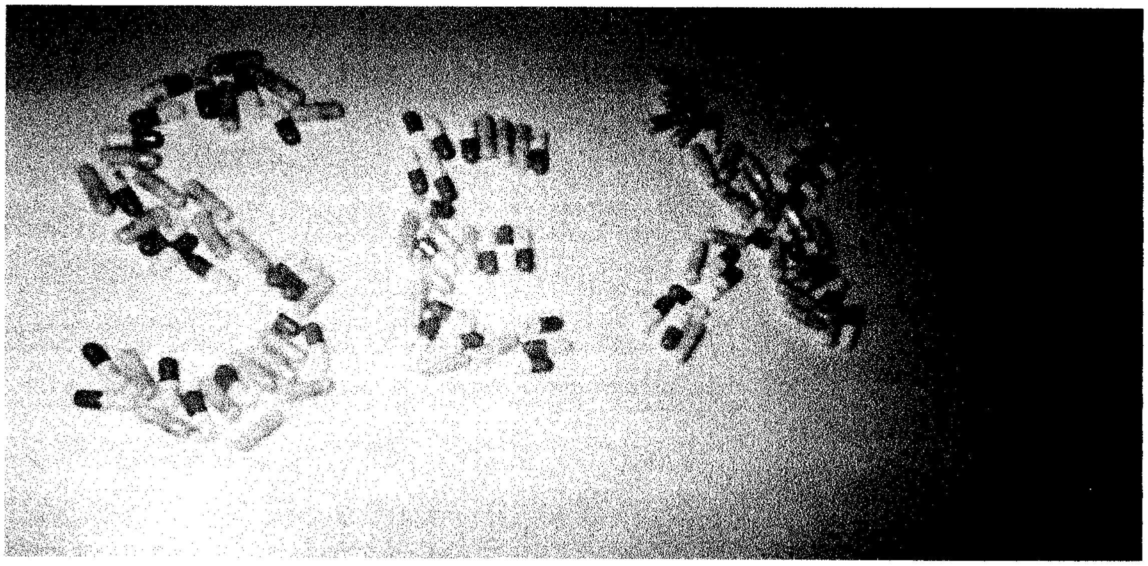

Figure 27. Medicating the body: Sexual (in)visibility.

> *I've written out [sex] here in the pills . . . my understanding and my self-image of what it means to be a woman is so tied into my experiences of vulvodynia and my experiences of pain and the medication I'm on . . . just being so uninterested in sex and sexuality, in my vagina, in just wanting it to go away . . . There is this part of me*

> *that I feel has died at times or is dying. My sexuality is shut off; it's dead to me. It's like I try and ignore it. I divorce myself from it. It's dead to me.*

Equally relevant, by shutting off her sexual self, Helen is reminded of her physical difference from her peers. Unquestionably, our culture's celebration of healthy, young, able bodies that are free of pain coupled with cultural expectations encouraging women's sexual attractiveness and sexual pleasure alienates Helen, making her feel like an outcast among her friends. Unlike her peers, Helen physically embodies a different culture, an alternate way of being because of the physical restrictions and fluctuating pain imposed by her vulvodynia. Given this corporeal cultural clash, living with an (un)settled body erects an (in)visible wall of painful silence hiding Helen's estrangement from her peers who often forget and/or misunderstand Helen's distressing reality. Illuminating this scenario, Ohman et al. (2003) claim that feeling alienated in chronic illness is akin to feeling like a social outsider. Helen eloquently elucidates her social and sexual invisibility within this social-cultural dislocation.

> *Being out with my friends . . . [if] we're talking about our relationships . . . I might say "oh you know, I can't really do that or have that or whatever." I'm just sitting there and I'm just not a part of the conversation . . . . There's this constant like my God I'm so different from other women. I'm so not normal. There's something wrong with me . . . I don't fit in. I'm not like everybody else . . . . Even though my friends know about my condition, I don't think they fully understand . . . I FEEL INVISIBLE at those times.*
>
> *I feel like I'm not there . . . [it's] so different from my reality. They're not talking about my world . . . They're sort of talking to each other and I feel kind of excluded . . . It's as though they're speaking a DIFFERENT LANGUAGE . . . and I can't enter that conversation . . . It's a totally different culture that I'm not familiar [with] and I can't be a part of . . . I feel like I'm the one who always has to try and enter that culture. No one's trying to enter my understanding.*

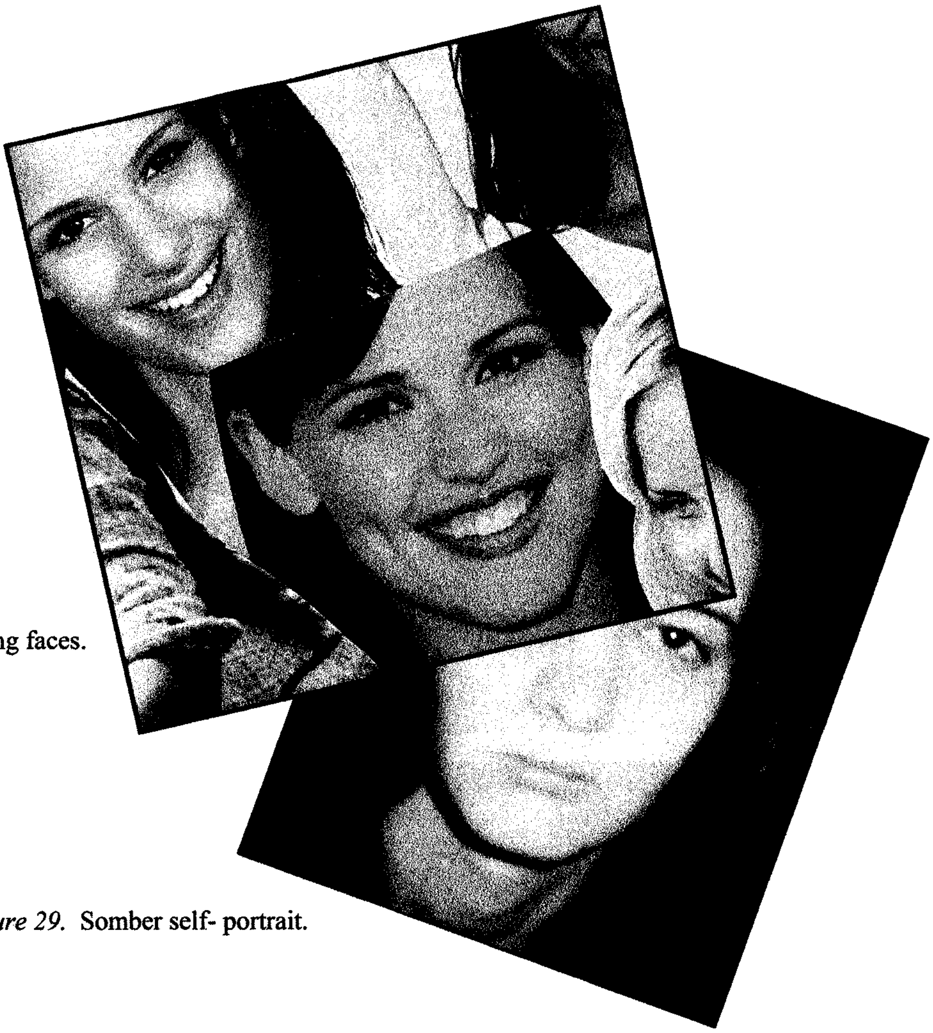

Figure 28. Smiling faces.

Figure 29. Somber self- portrait.

Helen further exemplifies her social invisibility in her visual portrayal by juxtaposing a somber self-portrait with a collage of women's jovial, vibrant faces. Opening with a small poem, she writes:

Smiling, happy vaginas.

Laughing vaginas.

Having a good time vagina.

Not my vagina.

Inviting us deeper into her embodied world, Helen conveys:

> *Smiling faces everywhere seem to say you're not one of us. You're different as they talk to each other in words I can't understand. Words like sex, pleasure, new jeans, road trip, biking, pantyhose, the pill, and jogging. Worlds that build a wall*

> *around me . . . until I'm invisible . . . they're shutting me out in this way. They can't see me and my lived experience.*

Helen poignantly expresses a language of sexual (un)settled-ness that her friends with their healthy, pain-free bodies cannot imagine let alone fully comprehend. Comparing herself with the unencumbered bodies and normal sex lives of her friends, Helen's sexual (un)settled-ness physically and socially disconnects her from her peers. Unwittingly forgetting Helen's vulvodynia as they embody a world in which buying new jeans, biking, and sexual pleasure are taken-for-granted experiences rather than unfamiliar pain-inducing events, Helen remains on the outside envisioning a world of possibility that she can never fully enter. Feeling invisible, excluded, and alone as she vicariously experiences the vitality and sexual freedom of her friends, Helen's carnal segregation stingingly reminds her of the person she would like to be and at the same time, the person and world she tries to forget.

Summary

Hand in hand with the tension of social others forgetting and remembering a woman's (un)settled embodiment is the never-ending friction between self-forgetting and remembering the presence of an (in)visible disability. This shifting (in)attention rests on the relapsing-remitting nature of (in)visible chronic illness and the manner in which it permeates participants' lives. As Angie illustrates, there is a demented hope or conscious denial that fleeting periods of calm and unrest will abate and return women to their former able-bodied selves and lives. It is this hope in returning to the world of the normal that sustains shifts in forgetting and remembering disability.

Since women outwardly appear like their healthy counterparts and their disabilities are not always limiting across all contexts, they do not always consider the legitimacy of their "sometimes flaring" conditions. As a result, participants tend to forget about their fluctuating identities. As Angela's narrative reveals, this shifting (in)validation revolves around the integration of coping strategies she employs that maintains the invisibility of her MS to herself and others. In not witnessing the physical limitations imposed by her MS, by camouflaging its presence, Angela's MS is easily forgotten. Similarly, Angela's attempts to discount her disability by leaving her canes at home when she travels offers another example of "invisibilizing" or forgetting the presence of her disability. This conscious albeit symbolic gesture erases the validity of disability from Angela's body and mind, ultimately securing her identity as still fitting in with the able-bodied world. Yet, although sometimes socially forgotten and often choosing to overlook her disability herself, Angela's MS quickly rematerializes through the spontaneous recollections of friends and her children. These remembrances concretize the presence of Angela's MS whether it is "acting up" or not, thereby justifying its visible place in her life for self and others.

Given the nature of our ocularcentric society, participants feed into their own self-forgetfulness and delegitimation by perceiving themselves as physically "better off," often downplaying their (un)settled subjectivities as "not really all that disabling" in comparison with individuals whose disabilities are always visible and unchanging. For Helen, forgetting, or what she refers to as "shutting off" her (un)settled body, is a complex event encompassing both a stretching of her body's physical limitations in the moment and a self-protective distancing of her sexuality. In battling her oppressive body and forgetting its presence in her life, Helen vividly describes how she physically sacrifices herself and risks exacerbating her condition by pushing beyond intense waves of pain to maintain sexual intimacy with her boyfriend. Forgetting vulvodynia in this context for Helen implies functioning as a "real woman" who is capable of meeting the cultural expectations of female sexuality.

From an alternate angle, shutting off vulvodynia for Helen means rejecting her sexuality to protect her body from harm. This decision does not come without serious costs to her relationships and well-being. Surrounded by healthy peers who are engaging in and talking about sexual activity, Helen's (un)settled embodiment is forgotten and/or misunderstood because she physically appears healthy and able-bodied. The silence of her physical difference, sexual invisibility as well as the cultural estrangement she experiences remains unnoticed until she reminds her friends of her (in)visible reality and the world of sexual freedom that they take for granted but that she cannot fully enter.

These interpretations do not suggest that participants resist the social validation of their (un)settling conditions. On the contrary, participants seek social validation of their disabilities but not at the stigmatizing expense of relying on visible aids to prove their disabilities or being (mis)perceived as ill all the time. Ironically, it is exactly these kinds of negative social valuations and self-reminders, the latter often derived from family and friends, that lures participants back into a recognition of their (un)settled lives. Stated differently, remembering an (in)visible disability means acknowledging and validating its presence as part of self-identity, an identification that is never painless regardless of its infinite recollection.

Having come to the end of the (un)convincing bodies movement, I steer the analysis to the fifth movement characterizing the fluidity of identity. As stated in the introductory commentary, I divide this second story into three chapters beginning with the secreting of fluid identities in chapter 9, blending-in fluid identities in chapter 10, and unburdening fluid identities in chapter 11.

The Fifth Movement

The Fluidity of Identity Part I

Chapter 9

Secreting Fluid Identities: (Im)Positions of Normalcy

This chapter directs the reader-viewer to the story of the fluidity[11] of identity in living with an (un)settled embodiment. Described in the second chapter and reappearing throughout the (un)convincing bodies movement, the embodied relation of living in-between (dis)ability transgresses conventional boundaries of being *either* healthy or ill, or able or disabled. Consequently, the manner in which any one identity is expressed at any given moment is never finite but in constant flux. It is within this existential milieu that many women struggle to maintain control over defining self-images (Atkins & Marston, 1999; Beatty, 2004; Hilbert, 1984; Michalko, 2002; Miller, 1997; Richardson, 2005; Sveilich, 2005).

Negotiating the fluidity of identity within this chapter translates into learning about stigma, especially (though not exclusively) its internalized significance for the women in this study. Though not stigmatized in obvious ways as persons with visible disabilities, women with (in)visible disabilities are subject to forms of rejection, humiliation, and social disapproval (Charmaz, 1991; Coleman, 1997; Davis, 2005; Goffman, 1963; Greene, 2000; Murphy, 1990; Thomas, 1999). Jacoby (1994) observes that stigma is not an automatic result of possessing some discreditable attribute but is only relevant if the person perceives potentially discrediting traits as weighing heavily and shamefully on their self-identity

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[11] Throughout Chapters 9 and 10, I interchange the terms "fluidity" and "(un)settled-ness since each denotes the fluctuating and/or sometimes synchronous nature of living with an (in)visible (dis)abled body.

irrespective of whether others know about such attributes (Goffman, 1963; Schneider & Conrad, 1983, pp. 34-35). Hence, what a woman thinks about herself in relation to her (dis)ability as well as what others think regardless of whether such perceptions actually exist, guides how women choose to portray their fluid selves (Schneider & Conrad, 1983, p. 152). Indeed, Stone (1995) affirms that it is the disrepute of disability that most people think about in deciding whether to acknowledge their own disabilities. Echoing this sentiment, Goffman (1963) contends:

> [S]he who becomes stigmatized in later life . . . has thoroughly learned about the normal and the stigmatized long before [s]he must see [her] himself as deficient. . . [s]he will have a special problem in re-identifying [her]himself and a likelihood of developing disapproval of self (p. 34).

In the first part of this chapter, I introduce the notion of fluidity as taboo, a private, closeted subjectivity. Moving in tandem with the idea of closeted subjectivity, I then illuminate the fluctuating comforting-danger of secreting (un)settled-ness. Closely resonating with this chapter, I follow-up in Chapter 11 focusing on Angela's narrative and Helen's story more exclusively to present the struggles these women experience in being visually seen as able-bodied alongside the manner in which they "play up" and (dis)claim the (dis)abled side of their identities. In Chapter 11, I explore the unburdening of fluid identities. Subsumed within each of these chapters, I emphasize how the women's stories disturb culturally given templates of health, illness, ability, and disability.

It is important to mention from the outset that there are discrete subtleties that experientially distinguish secreting from blending-in in relation to the women's accounts. Although each way of contending with fluidity serves to preserve an able-bodied identity, secreting the fluidity of (un)settled-ness is associated with strategically avoiding disclosure and rejecting the legitimacy of (un)settled-ness. In contrast, blending-in is a *working with* rather than against the fluidity of (un)settled-ness in a way that epitomizes health with illness and ability with disability in accord with a woman's identity in the moment. Yet taken together, both sets of circumstances experientially resemble an interminable obstacle course in managing the disjuncture between a woman's lived experience and its social (re)presentation, between how a woman is seen through cultural filters of (dis)ability and how the fluidity of (un)settled-ness experientially punctures societal (mis)perceptions.

Fluidity as Taboo

Originally conceptualized within homosexual subculture and popularly described by Eve Sedgwick Kosofsky (1990) in *Epistemology of the Closet*, one of the first instances of theorizing the secreting of (in)visible disability appears in Schneider and Conrad's (1980) work of people living with epilepsy. The metaphor of the closet reflects how people keep secret what they perceive as potentially discreditable attributes about themselves (Goffman, 1963). Although Sedgwick Kosofsky (1990) argues that the closet is not symbolically relevant to disability because it is a visible stigma whereas homosexuality is not, I agree with Tobin Siebers (2004) that the reality of (in)visible disability presents a persuasively alternate set of circumstances precisely because of its changing visibility and (un)settled notions of self.

Secreting a chronic condition that is not readily identifiable may seem upon initial reflection to the reader to be at odds with a traditional conceptualization of passing, a process which when successful, is literally invisible (Hillyer, 1993). However, as Vickers (2001b) attests, "(in)visible illness is frequently but not always hidden" (p. 111). Stone (1995) reports that when it is possible to hide the true extent of a disability, women are more prone to hiding (p. 420). This propensity to secret an (un)settled body evolves around the compulsory nature of able-bodied-ness in our society (Kafer, 2003; McRuer, 2003, 2006) and conceptions of illness as a private matter (Beatty, 2004; Charmaz, 1991; Hilbert, 1984; Olney & Brockelman, 2003; Vickers, 2001b; Ware, 1992). To be in the closet for women with (in)visible disabilities means to be a secret and to preserve this silence. Writing about impression management, Goffman (1963) refers to "dark secrets" which consist of facts about a person which she/he knows and intentionally conceals because they are incompatible with the self-image they want to project. Unquestioningly, women living with (un)settled bodies are fundamentally aware that they are secretly different from others (Lennon et al., 1989) because they live in-between states of (dis)ability, thereby defying the blueprint for a fixed, non-impaired carnality. As a result, such women are encouraged to secret their (dis)abling conditions, especially those not culturally recognized as familiar disabilities like paraplegia or blindness (Hughes, 2002; Stone, 1993; Sveilich, 2005).

Within this work, societal pressure among women to revere the silence of (un)settled-ness derives from the cultural mandate that we hide less-than-perfect, problematic bodies that "fail" or almost fail to live up to standards of normality. Such standards include conformity in body size, movement, gesture, speech, emotional expression, appearance, scent, and control of internal bodily functioning (Charmaz, 2000; Stone, 1995; Sveilich, 2005; Wendell, 1996, 1997; Vickers, 2001b). Since our proximity to such standards are important to our self-identity, social acceptability, and self-respect (Wendell, 1996, p. 88), maintaining the secrecy surrounding any deviation from these ideals becomes a part of portraying a credible self in day-to-day life (Charmaz, 1991, p. 116). However, in striving to adhere to disciplinary practices of physical normalcy, Wendell (1996) warns that such compliance culminates in an elevated enshrinement of these ideals.

> When the ideals of physical health, appearance, and performance become more difficult to meet, the social standards of normalcy follow suit, threatening more of us with the possibility of falling below the minimum required for self-esteem and social acceptability. Moreover, for many people, falling in the 'normal' range is not enough, especially when they are constantly pressured and encouraged to try to meet the ideal. By pursuing the cultural ideal, people can raise the standards of normality (p. 89).

Richardson (2005) emphasizes that any expression of pain while necessary for legitimating women's experience, is forbidden, socially undesirable behavior (p. 37). Donoghue and Siegel (2000) purport that it is embarrassing to talk about stigmatizing symptoms and most people would rather not hear about them (p. 40). This tabooing of illness talk (Werner et al., 2004), especially associated with women's conditions such as endometriosis, premenstrual syndrome (Donoghue & Siegel, 2000, p. 43) and I argue vulvodynia, is in part derived from gendered attitudes that tacitly imply women have a biologically natural, greater resilience towards pain and consequently, their pain need not be taken seriously (Bendelow & Williams, 1998). Exploring gendered perceptions of pain, Bendelow (2000) contends:

> Most people perceive that women have a superior capacity to men for coping with pain . . . female hormonal and reproductive functioning and the role of motherhood equip[s] girls and women with a 'natural' capacity to endure pain, whereas no such biological preparation is identified for boys and men (p. 118).

For Wendell (1997), such cultural dictates more broadly stem from the impermeable fears that we as a society harbor towards a person's inability to control their body and I believe, from a ubiquitous disinterest in and discrediting of the lived experience of (in)visible chronic illness. Angie strikingly reveals how this disabling aversion to talking about illness among the healthy is an incontrovertible form of oppressive silencing among women living with (in)visible disabilities.

> *The culture in which we live, like I mean, disability is completely, it's just like non-existent. Its hidden right? It's uncomfortable. It's not the norm. The norm is like completely able-bodied people, you know, feeling good. . . Health is like a very important tenet of our culture. Anything that isn't healthy has like a negative connotation or discomfort or it's not the thing that you want OUT front and center. The weird offshoot of that is that we don't talk about illness and disease because they're too like scary right . . . . People don't educate themselves to diseases unless they have it . . . I mean, I didn't know anything about MS until I had it and I don't know anything about most other diseases and until I have them, I probably won't be interested in knowing about them.*

Angie further reflects:

> *People that have illness or disease they can go on and on for hours and days about their symptoms and their histories and how they're feeling. And I just think those are stories that are probably more interesting to people who are going through it themselves than people who aren't. And the people who aren't don't want to hear it and that is like a silence.*

As Angie suggests, since chronic illness significantly pervades one's quality of life, women often (un)consciously turn inwards, evincing a self-immersion in its ongoing trajectory. In essence, this connective engagement while effective in helping women cope and elicit social support can in turn, alienate others by inspiring apathy and social withdrawal. Equally relevant, cognizant of being socially (mis)perceived as whiners and complainers, (Donoghue & Siegel, 2000; Charmaz, 1997; Richardson, 2005; Sveilich, 2005), women living with (in)visible disabilities self-suppress any inclination towards illness talk, especially with others who are disinclined to empathically enter their (un)settled worlds. Acknowledging her own silent immersion, Helen admits:

> *No one likes being a downer all the time. When I'm out with my friends, I don't want to be the one complaining being like "God I'm in pain again today just like I was yesterday and like I'll be tomorrow." Because no one would want to hang out with me, you know. But it's such a pervasive thing in my life. . . But if that's all I do, no one would want to hang around me so it's something I have to keep quiet.*

Angela links this cultural silencing to the invisibility of her MS and the misinterpretation of seeking sympathy.

> *It's a struggle to talk about having MS without feeling like a sucky, whiny baby, especially when it's such an intangible thing to other people.*

In the end, the cultural tabooing of illness talk fosters as Angie and Helen exclaim, a rampant silencing of real bodies and real lives, thereby increasing the invisibility of (in)visible illness and the knowledge this can offer us about living successfully with chronic disease (Wall, 2000). In order to evade the potential for social estrangement, Angie and Helen emphasize how women living with (in)visible disabilities often suffer in silence to protect their self-image and to emotionally albeit misguidedly, shelter others from worlds of illness where mythic fantasies of the perfect, invulnerable body can continue to speciously flourish. At this juncture, I move to discuss the secreting of fluidity in women's everyday lives as both a comfort and a danger.

Secrecy: The Comforting-Danger

Passing as an act of secrecy requires others to see women in particular ways that as Kimpson (2000) suggests, keeps disability invisible (p. 323). Joining Kimpson, Munson (2003) and Samuels (2003) cite that passing which pertains to instances of secreting and blending-in for this research, is experienced as a privilege and/or may engender a sense of misrecognition and internal dissonance. Given our society's tendency to repress and disbelieve embodied differences that are not overt (Siebers, 2004), Angela, Helen, and Angie experience secreting their (un)settled-ness as both a comfort and a danger. I unpack this tumultuous (dis)comfort beginning with Angela. In living in-between (dis)abled worlds, Angela slips between passing or secreting by default (Samuels, 2003; Sherry, 2004) because her MS is not always physically obvious and deliberately secreting her (un)settled-ness. Echoing the words of Elaine Ginsberg (1996), passing in the broadest sense of the term depends on a presumed, unexamined binary logic of identity as healthy/unhealthy and able/disabled that presupposes a distinction between essence and appearance, the real person and the persona. By materially and discursively crossing the borders of health, illness, ability, and disability situationally and contextually, Angela both secrets and indirectly reveals the (in)stability of her identity rather than conveying any one particular sense of self (Moss & Dyck, 2002; Samuels, 2003). Angela appears healthy and is functionally able-bodied in most situations, but is also functionally limited and disabled in others despite her appearance of wellness. Unpacking this ontological standpoint further, Moss and Dyck (1999b) contend:

> Individuals have multiple identities and they manifest differently at different times and in different places . . . identities themselves fluctuate. Any one identity is mobile and impermanent, and coalesces around the circumstances of a particular setting. Individuals hold contradictory identities simultaneously (p. 163).

In alignment with Moss and Dyck's (1999b) vision, living with an (un)settled embodiment *is* contradiction incarnate among the women in this study. In being cognizant of this, fluidity need not be culturally seen or interpreted as speciously disjointed, but embraced more openly as another layer of human diversity. Yet, this invitation to stretch our understanding beyond comfortable epistemic confines within the common scenes of our everyday lives remains the elemental challenge that many women like Angela repeatedly battle.

Angela experiences great comfort and pride in being able to (un)intentionally shroud her MS in secrecy. By appearing and being partially able-bodied, Angela physically fits in with able-bodied culture despite the fluid presence of MS in her life. By situating herself in part as belonging to the "able-bodied world," Angela embodies a "smugness" knowing that in secretly inhabiting the "disabled world," she can evade unwanted detection and devaluation because on most occasions, her body belies this social reading (Charmaz, 1991, 1997; Olney & Brockelman, 2003). Writing about the dynamic secrecy surrounding "age passing," Cooper (1985) relays that when we pass with ease, we are exceedingly comforted that we do not have to identify with others who are "not passing," who are different. Stone's (1995) words typify the refuge Angela experiences in secreting her disability. She emphasizes that "in a world in which people with disabilities are objectified as "other," it makes sense to work at passing for normal; to pretend that one has nothing in common with the 'disabled'" (p. 421). Enlightening us on living in-between (dis)ability and its comforting secrecy Angela relays:

> *It's like having a secret the whole passing thing. You feel almost SMUG that hey, you don't know. . . . I have this DISABILITY . . . Like you're holding something over someone . . . When you think of that whole concept of disability and I don't know, it's almost, I'm so proud of myself I am able to pass in the able-bodied group. . . . When I'm in the MS clinic, that's where I get my smug, I don't look as disabled as you people. I met a man in the waiting room and he was like "oh, are you one of the nurses? Do you work here?" And it was just like "nope, I'm a patient." And I felt really good about it . . . that I could pass.*

Although Angela lives with MS and periodically experiences its circumscribing (un)settledness, her able-bodied appearance and ability to function reasonably well fractures this sometimes-disabling reality. For Angela, representing herself as non-disabled reflects not only embodying a secret identity, a fluidly (un)well persona that no one suspects given her appearance, but experientially transgresses and interrogates conceptions of ability and disability as rigid, inflexible embodiments. Here, Ginsberg's (1996) work strikes a resounding chord with Angela's account.

> The possibility of passing challenges a number of problematic and even antithetical assumptions about identities, the first of which is that some identity categories are inherent and unalterable essences. . . passing forces a reconsideration of the cultural logic that the physical body is the site of identic intelligibility (p. 4).

Similarly addressing the incongruity enveloping the faith we place in the visual reading of bodies and the misreading of healthy looking albeit (in)visibly disabled bodies, Titchkosky (2001) ascertains:

> For those with non-readily apparent disabilities . . . everything about us can be made to signify normalcy. . . [in]visible disabilities are made invisible by something and that something is the taken-for-granted appearance of normalcy. . . Disabilities are covered over, and are made invisible, by the structures and assumptions of normalcy . . . people who 'come out'" understand their experience of disability has been organized in relation to the structures of normalcy (p. 133).

Reminiscent of Angela's fluid embodiment, Georgina Kleege's (1999) autobiographical text *Sight Unseen* conveys how being "imperfectly blind" complicates the boundaries between ability and disability as highly arbitrary and easily denaturalized (Mintz, 2002).

> I am legally blind. . . . The sighted imagine blindness as a state between life and death, an existence encased in darkness, an invisible coffin. . . . At the 1992 Matisse exhibition in New York's Museum of Modern Art, a man said to me, "You're standing to close to that painting. You have to stand back to really see it" . . . . He was right. I was standing about a foot from the canvas large enough for most people to view comfortably from a distance. I perform a slow minuet before each painting, stepping forward and back, sweeping my gaze from edge to edge. . . . I didn't get a chance to tell him that I am blind. I suspect that it would have stopped him in his tracks. . . . To such people there is a right way and a wrong way to see. . . I see what I sense is there, what I know is there, what I hope is there, not necessarily what actually is. For the sighted, seeing is both instantaneous and absolute . . . The sighted can be so touchingly naïve about vision (Kleege, 1999, pp. 9, 93-96).

Complementing Angela and Kleege's accounts, Ann Davis (2005) states those who are visibly disabled assume that the difference between themselves and anyone who is able-bodied must be visibly obvious. When someone looks like an able-bodied person yet claims disability from the position of being in-between (dis)ability and sometimes occupying both conditions as Angela does, it shatters this taken-for-granted assumption. Exemplifying this ambiguity in situ, Price and Shildrick (1998) comment:

> In any illness or disability, discontinuities continually erupt, queering any imagined correspondence between bodily form, appearance, function and ability; the man with

> locked-in syndrome, who writes a best-selling book . . . the visually impaired woman who trains as a film director. Such unexpected disruptions not only contest the apparent limits of an impaired body, but mark the instability of the normative identities of those who are blind. . . disabled, and so on (p. 241).

Far from being easily intellectually entertained, situating disability as an indeterminate fluid identity that encapsulates ability *intermittently with* disability and disability *intermittently with* ability dismantles the very fabric of conceptualizing bodies in society. Given this, Angela is (mis)perceived as a non-disabled person rather than as a fellow patient with MS in her earlier example because the essence of living with a fluid (un)settled body enables women to successfully present and claim another sphere of identity other than disability in the moment (Charmaz, 1997). In turn, this self-presentation bestows Angela with a sense of corporeal superiority in knowing that she can "still pass" as someone whose bodily difference is primarily indecipherable and by extension, (in)directly demonstrate that living with MS does not preclude a more open, combinatory embodiment.

Clandestine Misgivings

Rivaling the reassuring secrecy of an (un)settled embodiment is that some women experience misgivings about verbally concealing something that is integral to their lives (Hilbert, 1984). While the spotty (in)visibility of (un)settled embodiment allows individuals to participate in mainstream society *as if* they are only able-bodied, from the perspective of women living with (in)visible disabilities in this study, such a variable embodiment is a mixed blessing (Stone, 1999, p. 308). Vickers (2001b) implies that the pain of silence associated with an (un)settled embodiment inspires feelings of deception and a divided sense of self because of the refusal to reveal the true nature of one's in-between lived reality (Hillyer, 1993). Angela's self-confidence in portraying herself and being perceived as non-disabled among her staff at work deeply conflicts with feeling dishonest in secreting her “real” (dis)abled identity (Browne, Connors, & Stern, 1985; Stone, 1995). Yet this apparent ontological duplicity offsets Angela’s intense desire to preserve a valued, able-bodied, professional image as an MS educator. Conveying this reality while discussing a staff training session, Angela contends:

> *None of my front-line staff knows I have MS. . . When I was doing that meeting on Thursday, I had kept it. It wasn’t me. It was me talking about this neurological disorder. You’re DISHONEST with yourself and in a sense with other people. . . I did not disclose [and] it was taken very seriously. . . .When I presented the information I felt very confident and very much like I was educating, informing. . . . I had someone come up after and go “wow you know a lot about MS. You were really able to educate us a lot.”*

For Angela, secreting her MS in this instance is an act of self-preservation (Wall, 2000). Secreting enables Angela to retain her identity as a detached, credible professional with an “official” expertise rather than as a woman living within the shifting borders of (dis)ability whose subjectivity, emotionally laden knowledge, and identity risks institutional discrediting and devaluation. Accentuating this scenario, Charmaz (1991) indicates an intellectualized stance frames information for others in a more serious manner because it is detached from personal subjectivity, provides respite from emotions, and minimizes the chance of eliciting other’s sorrow, shock or pity. Conveying the need to maintain this secrecy, Charmaz (1997) asserts “ill people face immediate interactional risks [in] being rejected and stigmatized for disclosing and for having an illness (Ponse, 1976, 2), being unable to handle others’ responses, and losing control over their emotions” (p. 113). In this way, secreting (un)settled-ness eludes the “clouding” of a woman’s identity as exclusively disabled, a theme I develop next.

Clouding Identity

The propensity to secret living in-between (dis)ability derives not only from a cultural imperative that encourages the (in)visibly (dis)abled to present themselves as well but to the notion that revealing a fluid embodiment may negatively "cloud" or overshadow other people's judgments about a woman's identity (Charmaz, 1991; Lutz & Bowers, 2005; Sveilich, 2005; Royer, 1998; Vickers, 1997, 2001b). Since women commonly fear that their conditions will dominate their interpersonal relationships, the way others view and respond to women with (in)visible chronic illness has an important effect on how they perceive and construct their self-identity (Asbring & Narvanen, 2002; Kralik et al., 2001). Attesting to the tension between Angela's private, fluid subjectivity as a woman living with MS and her outward professional credibility as a seemingly non-disabled woman, Susman (1994) and Vickers (1997) declare that this friction underlies the fear of the social equation of disability with an overarching or "master status" that inundates all other aspects of identity. By revealing her MS, Angela ventures being solely (mis)identified and devalued as a "disabled person," or more pertinently, *the* disabled colleague in her previous example rather than as a knowledgeable, professional, (dis)abled woman who lives with the disease of MS and its shifting subjectivities (Coleman, 1997; Charmaz, 1997, 2000; Goffman, 1963; Stone, 1995; Tighe, 2001). Royer (1998) supports this observation indicating that chronically ill people want to be treated as whole persons and known for attributes other than their illness (p. 64). This assertion is especially valid when a woman's disability is not culturally understood as being in flux. Revisiting her staff meeting, Angela explicates this rift revealing:

> *Would I feel that way if I disclosed to them? I may not have been able to keep myself at that level, like almost detachment . . . because it would in a sense shadow or CLOUD people's interpretations of what I was saying. . . . It would make a difference. The staff I'm presenting to would be "OH DEAR, POOR ANGIE, I*

> *DIDN'T' KNOW THAT!" Which in turn, is going to affect everything else I'm saying to them.*

When people believe they are susceptible to or will assuredly lose status and self-esteem, they sidestep disclosing illness (Charmaz, 1997, p. 113). Fearing professional and social discrediting in the eyes of others by divulging their disabilities that are not readily believable, many women like Angela prefer to safeguard the secrecy of their MS (Charmaz, 1997; Moss & Dyck, 2002). Espousing this view, Matthews and Harrington (2000) attest to Angela's hesitancy in revealing her MS stating:

> As soon as a disability is recognized . . . the disabled individual becomes "labeled." For those with invisible [or (in)visible] disabilities, though, as long as their disability remains invisible, it simply does not exist for the other and therefore provides no basis for labeling. This confers a "normal" status to the relationship between the disabled and able-bodied others. The person with the disability, therefore, can be seen as a person not just "first" but "only." This provides strong motivation to keep knowledge of an invisible disability concealed (p. 411).

For Angie, clouding identity occurs within an interpersonal climate of unsolicited and overly dramatized sympathy from family and social others. Invitations of support are experienced in demeaning ways, culminating in the negation of her right to self-determine how she feels at any given moment given the complexity of her fluid embodiment. Angie narrates three interrelated examples.

> *There's a connotation of weakness or diminished ability . . . Like I'm a weak woman. Like I remember once, I was over at my parent's house and my mom was telling me how tired I looked. . . She had just gotten home from work and was like "I'll make you dinner" and its like "you're probably more tired than I am. Like I did not work all day" . . . She assumes there's a pattern across MS, and I personally don't feel the fatigue thing and on her part, its like assumed.*
>
> *And my sister, like any fucking time we do anything she's constantly like "well I don't want to make you tired." THAT really pisses me off. . . I'll decide when I'm MS'Y and when I'm not. Like don't ASSUME anything. I'm sure she's expressing it from a place of concern . . . but it's an ASSUMPTION.*

> *Like every time you say you're tired is it MS? You're setting a precedent. . . . But that's the PROBLEM right? The second you're diagnosed with a disease, EVERYTHING wrong with you is MS . . . My legs are shaky- MS. I feel a little sick today- MS. I need to nap- MS. . . . And suddenly, the next time I'm at hockey and I don't want to walk to the end of the platform just because I'm LAZY, does that mean my friend will automatically not give me a hassle about it because she thinks its MS?*

Within these examples, clouding identity emanates from an absence of information or more appositely, misinformation about the nature of the fluidity of an (un)settled embodiment. As Angie relays, an inexorable interpersonal pattern develops in which it becomes exceedingly challenging to distinguish the fluctuating eruptions of (un)settled-ness from a woman's nearly ordinary state of health It is then impossible to persuade others that one is not tired, weak, or feeling MS'Y as Angie states, even though a woman may not physically look well.

The counter side of interpersonal clouding is that since MS is such a significant part of Angie's identity, it becomes the self-imposed nexus of her lifeworld. Since the presence of MS is constant despite its erratic flares, Angie's MS clouds or socially colors her own assumptions and relationships. Clarifying this intrapersonal clouding, Angie observes:

> *Sometimes people offer to help and it has nothing to do with MS. They're just being kind of nice. And sometimes I jump to the conclusion that its MS. . . . Like it can EASILY TAKE OVER . . . . You know, when someone volunteers something out of generosity, it's like oh it's because I have MS or oh, you think I'm tired. Because you make it too much of a deal. You make it ALL THE DEAL all the time. . . . MS is part of me, its part of who I am. To someone maybe I am like THAT GIRL WITH MS. . . . So it's a constant. It transforms all your relationships.*
>
> *I talk about being the "MS Girl" . . . . because it takes over so much of your life. Like I think it's something that's happening to me. . . . [but]. . . . I don't want that identity to take over. . . . [like] I'm that one-dimensional characteristic . . . . MS is not me. Or I am not MS or I don't want it to be. . . . I think that's totally weird and unhealthy and I don't want to be all caught up in it. I don't want it to define me. . . . It's like a label. It's a label I'm rejecting.*

While offers of social support are sometimes welcome, Angie often misconstrues others' intentions because they are an unwelcome, demeaning reminder of her embodied difference. Given that MS is an all-encompassing aspect of her identity, it is exceedingly difficult for Angie to dissuade herself that others are treating her "normally" rather than as "offensively special" because of her disability. Cognizant of this self-clouding, Angie disclaims MS as the sole feature of her identity, noting its negative impact on her emotional well-being and social relationships.

Inversely, Lynda illustrates the "vicarious clouding" her husband experiences because of the pervasiveness of her MS. Addressing this courtesy stigma, Goffman (1963) observes that the person with an (in)direct stigma carries a burden that is not really theirs. More simply stated, because the (un)settling limitations of Lynda's MS imbue every aspect of her life and her marital relationship, her husband similarly embodies the constraints of living with an (un)settled body.

Figure 30. Spousal clouding.

> *Looking at D, you wouldn't know that my husband also has an invisible disability and that disability is me . . . . All aspects of his life are affected by my limitations. My parents are in Barbados. . . they invited us down. . . there's no point me going because I can't walk. I mean the last time we were there I could barely make it to the beach. I wouldn't even be able to do that now. . . So I said "D why don't you go and stay with my parents?". . . He said he doesn't want to go if I don't go. . . . My existence in his life disables him in a number of ways . . . [It] impacts his life as though he were disabled because there's a lot of things he can't do even though he's not disabled. In some respects he might as well be.*

Having shed light on the manner in which having a fluid (dis)abled body can (in)directly encroach on a woman's self-concept and the nature of her relationships with others, I reorient the reader back to an examination of the secreting of fluidity focusing on

Helen's narrative. For Helen, sustaining the secrecy of vulvodynia reflects a two-tiered dilemma. On one level, akin to Angela, there is an enduring sense of comfort and security in embodying an on again off again condition that no one can see or is sensitively attuned to see. However, as Kimpson (2000) and Stone (1995, 2005) remind us, in secreting their fluid conditions, Angela and Helen allow others to sustain erroneous beliefs that disability must always be visible and that to be able-bodied or disabled in a fixed way is normal. Yet, aside from this solace, there is also an omnipresent danger for Helen to be "constantly on" for fear of being "found out" (Goffman, 1963), to maintain a partial façade of health and able-bodied-ness in the midst of her disabling pain. Articulating this double-edged secrecy and the psychic mobilization required to sustain it Helen exclaims:

> *It is something I really keep hidden, like a secret. . . . It gets TIRING . . . trying to keep this a secret. I think its something you have to PSYCH YOURSELF UP FOR like "okay, c'mon, here we go, let's do this" kind of thing. That's the conversation in my head. . . . I can pass. . . But sometimes it takes a bit of work. I think it's a comfort certainly that I can have my condition and no one has to know. It's this kind of protection. But at the same time too, it's also a danger in the sense that I seem so normal to everyone. It's frustrating. I AM LIKE EVERYONE, why can't I be like everyone else?. . . So there is that comfort that no one has to know but then there's the danger of I'm totally normal. I keep thinking I'm totally normal. . . I WANT TO be like everyone else. I WANT TO fit in.*

Although physically akin to so-called normal others, Helen's close to normal corporeality experientially distinguishes her from others. Helen is able to portray an able-bodied self because the nature of oscillating better and worse periods of pain fosters this flexible self-presentation. At the same time, such secreting necessitates engaging in "emotional work" (Hochschild, 1979). While consciously working on managing one's inner feelings is integral to blending-in, a topic I discuss in Chapter 10, I draw specific attention to its magnitude here in relation to Helen's experience of striving to portray an unchanging embodiment within the ontological presence of a secret, fluid one. Conceptually pioneered by Arlie Hochschild (1979), emotional work refers to the management of one's emotions, both bodily displays and subjective states, to conform to the demands of a social situation (Freund, 1999, p. 473). To "work on" an emotion or feeling refers to the effort to shape or manage inner feelings (Hochschild, 1979, p. 561). Hence, secreting (un)settled-ness as Helen explicates, necessitates psyching herself up, what Hochschild (1983) refers to as "deep acting" or what I conceive as molding a mindset to garner the physical and emotional strength Helen needs to present herself in a settled way despite her body's resistance (Strauss & Corbin, 1984). While physically and mentally exhausting to sustain over time (Freund, 1990), this stressful emotional work preserves a normal, desired persona and a sense of belonging for Helen. Paradoxically, the consolation secrecy offers in enabling Helen to envisage herself "like everybody else" is detrimental to her welfare and belies the gravity of her condition to herself and others.

Shameful Bodies

Clandestinely living with an (un)settled embodiment entails living with felt stigma (Jacoby, 1994; Scrambler & Hopkins, 1986). Congruent with clouding, felt stigma entails feelings of shame, guilt, and insecurity associated with a loss of dignity in being unable to meet standards set by oneself and society and having an (un)settled body that distinguishes one from ordinary peers (Asbring & Narvanen, 2002; Donoghue & Siegel, 2000; Flesner et al., 2003; Sveilich, 2005; Vickers, 2000; Wilde, 2003). Goffman (1963) purports that possession of discrediting information weighs heavily and shamefully on a person's identity because individuals "have something" others don't understand and it is this lack of understanding that is the impetus for fearing and avoiding potentially negative reactions from others (Schneider & Conrad, 1980). Adopting this same position, Ann Davis (2005), Sveilich (2005), and Vickers (2001b) cite that it is an absence of understanding about the [in]visible condition and its effects rather than the condition itself that makes exposure a risky endeavor for women. This reality is especially true for "unmentionable" disorders associated with sexual or excretory organs including I argue, vulvodynia (Lazare, 1992, p. 233; Hillyer, 1993; Myers, 2004). As an academic living with inflammatory bowel disease, Myers (2004) admits, "the average person isn't reluctant to hear about chest pain resulting from a chronic heart problem, but few are equally predisposed to stories involving a person's excretory organs" (p. 24). Taking us further into the comforting-danger of secreting her vulvodynia Helen admits:

> *There very much is this face I put on for the public world . . . partly out of shame because I don't want people to know, not shame but embarrassment. I don't want people to know my vagina hurts. I don't want people to know that I have to pee all the time. So partly there's embarrassment and then just partly I want them to think everything's okay you know?*

Sustaining the secrecy of a chronic condition is troublesome especially when it flows in and out of (un)settled-ness. Helen reveals how suppressing her urge to repeatedly go the washroom during class because she fears her classmates will assume something is physically "wrong" with her is rarely tolerable. Helen claims:

> *I worry its rude you know, if I'm walking out in a lecture when the professor's talking or when the class is really small or when someone else is giving a presentation or something. I feel bad [because] I don't want to interrupt the class and be like "excuse me, can I go the bathroom?" . . . . The worst for me is our class ends ten minutes before the hour . . . so I [am] always counting that ten minutes before the hour and when classes would go a little bit longer I was going INSANE. I'm like do I get up right now? Even though I know the class is going to end in two minutes. Or do I try to wait which is really tough. I go before the class, I go in the middle of class, and I go after class and I feel like my classmates, if they run into me on my multiple trips to the bathroom that they're thinking, "what's wrong with her? Why is she so weird? Why is she always in the bathroom?" I think it's seen as a weird thing if you're always going to the bathroom. It's abnormal, there's something strange or wrong or unusual . . . . It's EMBARASSING.*

Clearly, as Helen suggests, women living with (un)settled bodies do not want to appear physically different from others or invite unwarranted social speculation that something may be carnally amiss. Vickers (2001b) encapsulates the nature of secreting proposing that individuals like Helen circumvent acknowledging perceived flaws and weaknesses because it diminishes their self-esteem. For Helen, it is the secretive albeit natural plasticity of (un)settled embodiment that experientially enables her, albeit with a modicum of physical discomfort, to function and socially present herself in valued, ordinary ways consistent with other's physical ability and academic competence (Charmaz, 2000; Davis, 2005; Sveilich, 2005; Taub et al., 2004; Wilde, 2003). In this way, moving with the ebb and flow of her urinary pain enables Helen to elude being perceived as "odd" or deviant. This "moving with" the fluctuation of fluidity is a theme I return to in chapter 11.

Fragmented (Dis)Guises

Women living with (in)visible disabilities exercise some choice in determining how they want to represent themselves to others. The antithesis of secreting vulvodynia for Helen is that she feels fragmented or torn as a person because she is intentionally presenting a contrived identity performance that does not mirror her real, (dis)abled self. Freund and McGuire (1999), Greene (2000), Hillyer (1993), and Jourard (1971) confirm that when lived experience and its social presentation are paradoxical, the individual experiences dissonance in hiding their true self. Conveying this logic, Helen concedes:

> *I [feel] fragmented in terms of I can't WHOLLY be myself with people that I haven't told about my condition because I feel like I'm always lying or have to put on a good face or whatever.*

Clair et al. (2005) refer to Helen's sense of fragmentation inferring that people experience a feeling of authenticity when they can be fully themselves in public and harbor feelings of disingenuousness in portraying someone other than their true selves (p. 79). In *The Presentation of Self in Everyday Life,* Goffman (1959) explores the self as a series of facades erected for different audiences. Metaphorically paralleling the calculated secreting of identity with a dramaturgical performance in which actors don "masks" and "get in character" Goffman declares:

> In everyday life . . . there is a clear understanding that first impressions are important. By acknowledging they are keeping secrets from others, [individuals] maintain a show of being only the character they project and this is just a show.
>
> When an individual plays a part [s]he requests [her]/his observers to take seriously the impression that is fostered before them . . . . They are asked to believe that the character they see actually possesses the attributes [s]he appears to possess . . . and that in general matters are what they appear to be (1959, pp. 11, 17, 177).

In drawing metaphorically on dramaturgic expression, I am not arguing that the pain and limitations associated with an (un)settled embodiment and the fluidity of identity (un/healthy dis/abled) this implies are inauthentic, mere performances that are always voluntarily under one's control. What I am venturing is that because some women like Helen consciously strive to regulate aspects of their appearance and performance in ways that enhances their self-esteem, social approval, and credibility (Schlenker, 1980), they can sometimes determine *how* their identities are habitually stylized based on the fluid nature of their bodies in the moment (Diedrich, 2007; Reissman, 2003). Articulating a view that is germane to the partial performance of a fluid identity, Charmaz (1997) insinuates that the chronically ill develop a dialectical self that engages in an ongoing internal dialogue with their body's carnal messages as a way of strategically containing illness. This communion between body and self expresses the fluidity of embodiment in ways that stretch the possibilities for living with (in)visible illness.

In her poststructuralist text *Gender Trouble,* Judith Butler (1990) destabilizes the notion of a naturalized, coherent gender identity in a way that partly sparks the sense of flow and movement in the negotiation of a secret (dis)abled embodiment. While Butler's emphasis on corporeal performance and the denaturalizing of identities equally applies to blending-in which I discuss in the subsequent chapter, I elaborate its significance here in relation to the social presentation of self in living with the secrecy of an (un)settled embodiment. Articulating the manner in which gender is a performative relation, an ensemble of embodied acts, Butler writes:

> Gender is not a noun, but neither is it a set of free-floating attributes. . . gender is performatively produced and compelled by the regulatory practices of gender coherence. . . . In this sense, gender is always a doing. . . .There is no gender identity behind expressions of gender; that identity is performatively constituted by the very "expressions" that are said to be its results (1990, pp. 24-25).

While I dispute Butler's elision of the lived experience of actual bodies in place of the body as nothing more than a sum of its cultural significations, discursive practices, and power configurations, the notion that gender is a fluid, corporeal style intriguingly resonates with the fluidity of (un)settled-ness as a sometimes-stylized performance whose effects obfuscate (dis)abled norms. Akin to gendered identities that exist through a stylized repetition of acts, bodily gestures, and desires that produce the illusory effect of a stable embodied core (Butler, 1990, pp. 33, 136-141), the fluidity of a (dis)abled identity is (un)intentionally culturally enacted in ways that subverts and displaces naturalized and reified notions of health, illness, ability, and disability. Integrating a Butlerian perspective into their own work, Shildrick and Price (1996) claim that illness and disability are performative acts that serve to produce effects of identity coherence, control, and normativity while simultaneously destabilizing the body by revealing that which exceeds imposed normativities (p. 107).

However, unlike Butler and Shildrick and Price's demarcation between discourse and materiality, I suggest following the phenomenological scholarship of Bigwood (1991) and Gendlin (1962, 1992), that fluidity is an essential part of the body's pre-discursive, biological core within which cultural constructions of health, illness, ability, and disability are socially absorbed. Articulating this point further, I call upon the words of Millward and Kelly (2003) who posit:

> To be human is to engage with the world in a physical sense. To be human is to live in a world of physical experiences that are mediated through the body and its underlying biology. . . Culture may be thought of as the system of meanings, which render the physical and social worlds understandable. However, their roots, both the social and the cultural, have a physical material reality. . . . Experiences of the body have an existence that, in their basic functional forms are somehow independent of social interaction (pp. 159-160).

Taking these divergent yet complementary readings together, Helen covertly steps onto the social stage of her everyday world as someone whose appearance and manner is to some extent, culturally performed. On one level, Helen physically appears and enacts a healthy, able-bodied identity among other "regular" persons. Yet, it is exactly within this context where the fluidity of (un)settled-ness demonstrates its migratory complexity. What I am striving to convey is that fluidity paradoxically conceals Helen's unsettled-ness or in the words of Siebers (2004), "masquerades" while it simultaneously reveals its pliable, corporeal essence. Expanding this view, Siebers conjectures:

> The masquerade counteracts passing, claiming disability [or (dis)ability] . . . as a version of itself . . . . The masquerade shows that disability exists at the same time that it, as masquerade, does not exist. (2004, pp. 4,15).

In this respect, (dis)ability is partly an enfleshed performance of oscillating body stories (Ekins & King, 1999) derived from a fluid ontology of equally compelling true selves in the moment.

Alternatively, this ostensively impossible way of being embodies a biological elasticity, a metaphysics of fluidity and flow (Young, 1990) that naturally exists beyond its intentional cultural practice. Hence, "putting on a good face" for Helen is a partial façade that superimposes the fluidity of (dis)ability by physically masking her bodily pain while successfully drawing on the depths of this same mutability to physically and socially enact a healthy, functioning self. In this way, "switching faces" thus implies choosing among equally true selves, blurring the boundaries between accurate self-presentation and self-misrepresentation (Royer, 1998; Schlenker, 1985). Here I again pay homage to Siebers (2004) who purports that because social prejudices about [dis]ability are rigid, the fluidity of a (dis)abled identity exposes misguided assumptions by rendering identity as provisional, insecure, and always something more than is culturally envisaged. I return to this observation in a different context in my discussion of blending-in in chapter 11.

(In)Excusable Bodies

Charmaz (1991) purports that since the chronically ill often refuse to grant their illness the legitimacy it deserves, secreting reinforces feelings of guilt and shame when contemplating disability as an "excuse" or cop-out to garner special privileges (Charmaz, 1997; Schneider & Conrad, 1980). Given Helen's tentative reluctance to define her vulvodynia as a "bona fide" disability, she is averse to making any allowance for its presence in her academic life and therefore, chooses to conceal it. Comparing herself with more pardonable bodies Helen declares:

> *Would I refer to my condition as a disability? I don't know . . . I don't want to use it as a crutch . . . as an excuse for things. So I'm hesitant to be like "I have a disability." It's a tricky word to navigate because in one way, I don't want to identify myself as disabled not because of negative stigmas attached to disability but because I don't want to use it as an excuse and to imply that this is somehow*

> *equivalent to other forms of more visible disability like someone whose paraplegic or something.*

Reflecting on Helen's use of the word "crutch" symbolically, this identification blithely insinuates the unspoken assumption that persons living with disabilities are dependent, disadvantaged, and "less than" everyone else. Supporting this reflection, Asbring and Narvanen (2002) report that women with chronic illness are commonly perceived as less than a whole person, less well functioning as, and of less value than others (p. 157). Moreover, Watson's study (2002) of disabled people's notions of self-identity reveals that their own perceptions of people with disabilities as weak and disempowered are potent images that participants chose to distance themselves from (p. 521). In this sense, identifying oneself as disabled is an excusable or justifiable basis for eschewing one's responsibilities only when it is considered carnally equivalent with more visible, impairing conditions. Thus, while Helen refutes it, I question whether her disinclination to claim disability (or (dis)ability) as a part of her identity (un)consciously relates to her own biases and fears of being unduly perceived as well as disbelieved. Since the nature of fluidity shields and exonerates women from having to reveal their periodic disabled selves, I surmise that it is less controversial to claim any apprehension in disassociating the stigma ascribed to disability from one's own shifting reality. Stated differently, it is easy to refute the claim that disability is something you fear because of its cultural stigma when it is not (always) visibly noticeable or behaviorally distinguishable in relation to your own circumstances.

Closely aligned with the felt stigma associated with having an (in)visible disability for Helen is the fear of drawing attention to herself and arousing gratuitous sympathy (Joachim & Acorn, 2003). Beatty (2004) reveals that people living with (in)visible illness do not want differential treatment since illness is a part of their everyday lives. Helen interrogates the delicacy in distinguishing whether divulging her vulvodynia credibly warrants an academic extension or whether it is more advantageous to valorously withstand her pain, evade sympathy from her professor, and preclude the stigma of being perceived as a whining, ineffectual student giving into the infirmities of her body.

Figure 31. In the bathtub.

> *There's a fine line between I could get away with using this as an excuse versus I have no choice you know? . . . . And I know in my body when it's like I HAVE TO GO INTO THE BATHTUB RIGHT NOW and I can't read because I can't focus versus I'm in pain but if I can just bear it for a couple of hours, I can get this done. I don't want people thinking I want PITY . . . I don't want this to be an EXCUSE for anything . . . . I think partly in thinking about using it as an excuse is a matter of like toughness though not toughness. . . I feel as though if I asked for an extension for my paper for example because of my vulvodynia and explained it to my professor, I'd feel kind of wimpy or something . . . . I'd feel like I'm just being a SUCK because sometimes I'm in pain and I have to go to the bathroom and I can't get my paper done . . . . So that way, in terms of using it as an excuse, it's like I'd be judged as being a suck or being a wimp or something like that.*

Taking up this scenario, Olney and Brockelman (2003) observe that post-secondary students with (in)visible disabilities express concern that others may believe they are exploiting their disability to obtain unfair advantages. The interpretive subtleties Helen exemplifies between knowing she can endure her pain and complete her work versus conceding to her body's inklings and potentially arousing pity is aptly observed by Tighe (2001):

> The act of pitying is a product of a non-disabled's [or a (dis)abled's] person's conception of disability as an undesirable state of neediness, unproductivity and dependence. An individual with a disability is put in the position of refuting this view by demonstrating to the non-disabled . . . that disability doesn't really mean that at all in their case- just look how well they are coping and achieving in society *despite* having a [dis]ability (p. 522).

Conveying the (un)settling nature of her MS Angela says:

> *A lot of the times, I'm hesitant to use the word "disability" when I'm telling people about my MS. I'll say it's a neurological disorder. . . . I don't always have the disability.*

Here, Corbin's (2003) words resound with Angela:

> It doesn't matter if one has cancer, AIDS, multiple sclerosis, or Parkinson's disease; as long as one "feels good" and "can do" what one wants, then one might not necessarily see oneself as ill (p. 266).

Charmaz (1997, 2000) states that although people may acknowledge that illness affects their lives, they often resist its effects upon the self, preferring to conceptually package it as a "condition" rather than as a "disability" as Angela does to evade stigmatizing repercussions. As Tighe (2001) asserts, Helen and Angela believe that drawing on their disabilities will elicit unwanted pity and misunderstanding from others, and consequently supersede the able-bodied side of their personas. Stressing the (un)conscious implications of Helen and Angela's convictions, Wendell (1996) insists:

> Disability carries a stigma that many people want to avoid, if at all possible . . . They may be in the habit of thinking of disability as total, believing that people who are disabled are disabled in all respects. Since they know they are not themselves disabled in all respects, they may resist identifying themselves as people with disabilities. They may fear, with good reason, that if they identify themselves as disabled, others will see them as wholly disabled and fail to recognize their remaining abilities. . . . It is hard to describe the [in]visible reality of disability to others without feeling that you are constantly complaining and asking for sympathy (pp. 25-27).

With the exception of Lynda who is visibly disabled, Helen, Angela, and Angie are hesitant to self-identify as women living with (in)visible disabilities. To say "I am [dis]abled" is a personal statement of self-categorization, labeling, and identity (Swain & Cameron, 1999, p. 77). Living with chronic fatigue syndrome, Dorothy Wall (2005) admits:

> "I'd never thought of myself as disabled, never would have attached that word to myself. Was I? Ill, yes. Exhausted, yes. But disabled? I slid the word around in my head for months . . . knowing that on some level it fit. In some ways, in some contexts, I was" (p. 137).

Clearly, no one wants to be socially (mis)judged as constantly ill rather than invariably so in a society that provides no other options for a more flexible understanding of health and illness. Yet given my own standpoint in living with and articulating (in)visible disability as a fluid (dis)abled embodiment, as a legitimate form of corporeal diversity, the participants' hesitation echoes a somewhat surprising and unanticipated observation.

Writing about identity politics, Barnes and Mercer (2003) confirm that many individuals with impairments (whether visible, invisible, or (in)visible I argue) do not identify themselves as [dis]abled people (p. 129). While a range of experiential standpoints and alternate identities exists across the experience of disability, claiming a fluctuating, (dis)abled identity is problematic in this study primarily because of a woman's more or less healthy appearance coupled with mainstream views of chronic illness and disability as physically obvious and habitually impairing. Living with the (in)visibility of diabetes, Marris (1996) implies that "people prefer us to have a definite rather than indefinite identity (can walk or can't walk) and stick to it" (p. 78). This reflection sparks the question of the legitimacy of an array of subjectivities that are sometimes enabling, sometimes disabling, sometimes both. Since the nature of (un)settled embodiment is provisional and plural, and participants are not always noticeably impaired, conceiving oneself as (dis)abled is an alternate self-identification that counteracts dominant cultural tropes and expectations of persons with disabilities as visibly tragic, weak, dependent, and consistently suffering rather than living with an unpredictably evanescent embodiment. Angela, Angie, and Helen claim a shifting embodiment of (dis)ability rather than mainstream, exclusive notions of ability and disability, and health and illness. By living in-between (dis)ability, these women frustrate material and discursive identifications as always able, always healthy, always disabled, or always ill. Yet, while Angela, Helen, and Angie acknowledge their fluctuating disabilities and consider themselves "not able" sometimes, integrating and accepting the permanency of this (in)stability into their self-identities is a vacillating reality akin to the erratic nature of their bodies. However, such splintered and momentary acknowledgements as able, disabled, in-between, neither, or both is what makes (in)visible disability a uniquely fluid rather than resolute embodiment. Rather than striving to eliminate contradictions in claiming any one identity over another, what Angela, Helen, and Angie (un)consciously demonstrate is that complexity and provisional selves are the expected canons not only for their volatile bodies but also for all human bodies.

In an alternate vein, I am captivated that participants were not averse to self-identify as living with an (in)visible disability upon entering this study. While Angela, Angie, and Helen perceive themselves as more or less able-bodied with shifting illness, I conjecture that my use of the phrase "(in)visible disabilities" and "(un)settled bodies" sparked an innovative and alternate sense of identification for them. For example, never having considered the concept of (in)visible disabilities prior to her participation in this research, Angela's photographs visibly depict both a normalized version of self in fluctuating illness and more faintly, depictions of her struggles as (un)well across ordinary life scenes. Angela readily articulates the tensions of (in)visibly living with the shifting realities of multiple sclerosis, voicing her sense of belonging as both able-bodied *and* disabled in relation to this research.

> *I thought about definitions of disability and ability and I don't fit into either of those . . . I identify with the able-bodied because I've BEEN there for such a long time . . . I belong there because I still look like I belong there . . . And I've MOVED. At this point, I feel I belong more in this disabled population. . . . When I first saw your thing [study announcement] it gave me a sense of there's a group of us . . . . I had never thought about it and it was like, hey, I fit in there!*

Perhaps, as Angela implies, it is safer to embrace one's identity with a fluctuating chronic illness as a vacillating, variegated embodiment within the confines of a (dis)ability-positive research project rather than risk the personal vulnerability of this thorny identification in a culture that neither existentially equates nor legitimizes (in)visible disability with chronic health conditions. In keeping with this discussion, I revisit the issue of self-identity as I contemplate the implications for this research in the final chapter of this thesis.

Summary

A significant part of managing a fluid (dis)abled persona is maintaining the privacy of an (un)stable illness. As participants' accounts reveal, to closet (in)visible disability means to live in secrecy with an (un)settled body and to preserve this silence whenever possible. Indeed, ours is a culture that is myopically fixated on healthy, perfectly functioning, able bodies. There is societal pressure to comply with norms of physical appearance, comportment, movement, performance, and internal bodily functioning and sanctions against any deviation from these compulsory ideals. Tightly woven around this cultural orthodoxy is the experience of felt and enacted stigma in the form of rejection, humiliation, and social disapproval associated with chronic illness whether visible, invisible or shifting, that precludes women from coming out as (in)visibly disabled. Striving to sustain these principles of normality thus becomes a fundamental part of credibly portraying the healthy, able-bodied side of women's identities.

Intimately connected with the shame ascribed to bodies that fail to live up to societal and self-imposed expectations of normalcy is the cultural tabooing of illness talk. As the participants' statements demonstrate, there is a pervasive cultural aversion to talking about illness that silences the voices of women living with (in)visible disabilities in this project. This silencing of real bodies and real lives further entrenches the invisibility of (in)visible illness and the knowledge our society requires to recognize and understand it. Throughout their accounts, participants comment that it is embarrassing to talk about illness in the company of others because they fear being misperceived as whiners and complainers or cunning manipulators seeking sympathy rather than empathic understanding and validation of their conditions. Coupled with this, since participants' bodies denaturalize the fixity of cultural scripts of (dis)ability because they neither occupy one way of being to the exclusivity of the other, a complex web of social misunderstanding commonly ensues. Accordingly, it is often easier for the women to perpetuate the secrecy of (un)settled-ness and maintain a positive self-image rather than struggle with the emotional burden of convincing others that the presence of chronic illness in their lives is visible and invisible, stable and unstable, predictable and unpredictable.

In many ways, living with an (in)visible disability is a conflicting experience. Participants express a contradictory sense of freedom and oppression or a "comforting-danger" in secreting their (un)settled bodies. Given the cultural proscriptions surrounding illness talk, participants convey feelings of security and pride in being able to thwart suspicions of illness and the social devaluation it commonly entails because they typically look well and present themselves when possible, in accordance with able-bodied performance standards. Fearing that their (un)settled bodies will "cloud" or overshadow other personal attributes as well as their lives and relationships, participants often choose to safeguard the secrecy of their (in)visible disabilities because they want to be treated as full members of society rather than arouse unwanted sympathy and misunderstanding that they are always rather than periodically unwell.

Paired with this consolation and the silence of self-preservation is the lingering danger of feeling deceitful with oneself and others because of the refusal to reveal the true nature of one's in-between lived reality. Angela's intense desire to preserve a valued able-bodied professional image at work deeply conflicts with her desire to blur the boundaries for her colleagues between ability and disability, to enable them to perceive her both as a credible professional and as a woman living with the (in)visible, (un)settling realities of MS. For Helen, secreting reflects a sense of fragmentation, a disingenuous self that conveys a partially fabricated social presentation that contradicts her internal embodiment. In many instances, secreting for Helen is a kind of cultural performance in which she must "put on a good face" to mask her bodily pain and enact a healthy, functioning self in the moment.

The irony of secreting, which is regrettably unseen by others and that reappears in sharper focus with blending-in in Chapter 10, is that it sustains the invisibility and incredulity of (un)settled embodiment as a legitimate feature of human diversity. Participants in this study are (in)visibly 'living out" what we believe to be contradictory and unbelievable subjectivities. In passing as able-bodied, these women are coping with being healthy, ill, able, and disabled in various degrees and combinations within a diversity of scenarios. Yet this lived-in complexity remains beneath our notice, promulgating flawed constructions of (dis)ability as strictly visible, permanent, and predictable. Yet, it is exactly the elasticity of an (un)settled embodiment that invites us to reconsider the logic of how we interpret the physicality of bodies and the identities of those who embody them. At this juncture, I turn primarily to Helen's narrative to illuminate the dynamic of blending-in, an active "melding with" the body to sculpt a fluid presentation of self.

The Fluidity of Identity Part II

Chapter 10

Blending-in Fluid Identities: (Im)Positions of Normalcy

The secrecy of (un)settled-ness imperceptibly shades into laborious efforts at blending-in the fluidity of a (dis)abled identity. Commonly referred to in the chronic illness literature as normalization or pretending to live *as if* normal (Charmaz, 1997, 2000; Register, 1999; Robinson, 1993; Strauss & Corbin, 1984; Vickers, 2001b), women living with an (in)visible (un)settled body strive to go with the flow of their bodies by blending into able-bodied culture. Blending-in occurs when women's bodies are relatively calm as well as when their bodies are acting up with unsettling intrusions. Charmaz (1995) considers blending as akin to struggling ***with*** illness rather than *against* illness, to keep life as normal as possible by minimizing its consequences (Clair et al., 2005; Joachim & Acorn, 2000b; Register, 1999). Bury (2000) and Kelly and Field (1996) avow that to be acknowledged as competent social performers, we must give the impression of exerting some degree of control in relation to the strategic style or performative aspects of illness management. Since women living with (un)settled bodies lack control over the erratic nature of fluidity, they become highly inventive and skilled at interpreting and handling their bodies and (re)constructing their identity(s). Endorsing this view, Moss and Dyck (2002) affirm:

> Expressing a specific body (whether ill/well) through relearning their bodies and environments is heightened for women with chronic illness because they are in effect forced to restructure their everyday life in order to accommodate their chronic illness (p. 161).

A recurring thread within this study is that Helen, Angela, and Angie have a desperate need to be and be seen as normal given the (dis)continuity of their (un)stable bodies (Joachim & Acorn, 2000b; Vickers, 2001b). Angela introduces and encapsulates this need for normalcy and the inherent tensions in presenting a stable self in light of a fluid, (un)settled body.

> *I really like the idea of having an [in]visible disability. That I can pull the wool over people's eyes . . . . You can pass through . . . some people just don't notice . . . it's the normalization. You look normal . . . Sometimes it's really nice to look normal . . . But again too, I like the idea of God I wish people knew so they could give you a seat on the bus sort of thing or "boy you look really tired, why don't I help you carry your groceries home."*

While appearing and functionally enacting an able-bodied persona permits Angela to retain her self-worth and sense of normalcy in fitting into able-bodied society, the corollary of blending-in, like secrecy, "invisibilizes" the very essence of fluidity. Garland-Thomson (2002) reminds us that our culture offers profound disincentives and few rewards in identifying as disabled to any extent (p. 22). Accordingly, as Charmaz (1987) and Tighe (2001) propose, in rejecting any identification with negative images of disability, women living with (un)settled bodies construct a valued identity by believing they must consistently and fully meet the standards of normalcy because they are able to do so *most* of the time. The disquieting issue surrounding this mentality is that blending-in, while a propitious method of moving through and being in the world (Michalko, 1998) for Angela sometimes places her physical well-being in jeopardy. By visibly maintaining the values of the privileged (able-bodied) group (Hillyer, 1993), Angela further conceals her disability from personal and cultural awareness. Calling attention to this heroics of normalcy, Morris (1991) remarks:

> The standards of the able-bodied are not superior and the only ones available. 'Normal' does not equal 'right, good and positive.' Fighting to fulfill some ideal of normalcy gives power to the nonsense that to be average is to be better than that which is not (p. 188).

Equally momentous, women living with (un)settled bodies are culturally entrapped within normalizing institutional discourses. Angela emphasizes how societal pressures associated with the cultural imposition of normalcy espouse standards of autonomy, independence, and physical strength that women are expected to meet. Becker (1997) comments that hegemonic discourses of normalcy mediated by social institutions are not simply layered onto the experience of disruptive chronic illness but play a vital role in the shaping of people's everyday subjectivities. Sadly, the reality of living with(in) a body that is flaringly (un)well is overshadowed by hegemonic dictates that stress physical self-reliance at all costs and that quells alternative ways of interdependent living with the body's shifting materiality. Angela explains:

> *You read the literature . . . . and it's keep your life as normal as possible, keep working as long as you're able, do as much for yourself as possible. And I don't know, it would really be nice to have it the other way around. Hire a maid, have someone come in and do all of your cooking, conserve your energy for the important things in life. But that's what you get in all the literature. That's the information from your doctor, your neurologist, the MS Society. Work as hard as you possibly can and do as much for yourself as possible. And it's interesting because when I was newly diagnosed I read and believed all that. But that's the only advice that's out there. Like this is the literature people are getting and there's no options. Yeah, so keeping it all nice and normal.*

Underlying Angela's account is the implicit and blatant rejection of disabled bodies and disability as part of any idealized lifestyle. Women with (un)seen chronic illness are encouraged, especially given the altering (in)visibility and severity of their disabilities, to sustain dominant ideals of physical attractiveness, good health, the endurance to "keep up" with so-called normal others, and to defy wherever possible, inscriptions as ill, deviant, and abnormal (Moss & Dyck, 2002, pp. 96-97; Sandahl, 2003; Vickers, 2001b). Periods of calm and greater ability enable many women like Angela to believe that they must meet these often-unrealistic expectations if they are to fit in with able-bodied society. Exemplifying the stress of living in accord with cultural edicts that serve to discipline and normalize (un)settled bodies, Angela remarks how she conserves her energy throughout the day to closely approximate these ideals.

> *For me, it's like a glass of water- my energy throughout the day. I have to make sure I drink it the right way so that the water lasts me the whole day. If I drink too much at one time, then I'm feeling like shit for the rest of the day . . . . If we are going over to the island for the day, I plan it in such a way that I'm NOT going to be walking for a long time. We're going to Hanlan's Point, we're going to swim, and then we're going to walk back to the ferry. Where five years ago, we would go to Hanlan's Point and swim, then we'd walk over to Centerville, and then we'd walk home. I wouldn't do that now.*

Portraying the work life narratives of men and women living with (un)seen chronic illness, Vickers (2003) posits that because they look normal, want to be normal, and strive to render themselves as non-disabled, blending-in (un)settled-ness perilously camouflages its fluid essence and I argue, accentuates its "movement." As a matter of course, Helen routinely sacrifices the real, fluid nature of her body because of her desperate need to "hang onto normality" (Charmaz, 1991; Moss & Dyck, 2002; Vickers, 2001b). Although Charmaz (2000) stresses normalizing reduces the disruption of fluidity by confining illness to private experience, Vickers (2001b) affirms that the excruciating desire to maintain one's sense of normalcy at all costs, a process Royer (1998) refers to as "supernormalizing," eclipses the limitations surrounding (in)visible chronic illness. Charmaz (2000) notes that because the chronically ill are judged by conventional standards, they blend-in their discomfort when their bodies allow them to function in ordinary ways. However, such fused discomfiture as this study demonstrates, can inflame an already compromised body. Rather than risk the shame and humiliation of being seen as "not normal," Helen struggles to physically blend-in and "cover up" (Goffman, 1963; Robinson, 1993; Royer, 1998) her urinary urgency, moving with and acting as if her pain does not exist. Helen explains her self-applied pressure to blend-in with the able-bodied culture of the graduate classroom where everyone appears well and the (in)visible fluidity of chronic illness is muted.

> *For me it was hardest because things started getting really bad when I was doing my M.A. I think the hardest was trying to function NORMALLY and pretend everything was okay and trying to get a degree while feeling like CRAP all the time . . . Our lectures were three hours and we had a break in the middle but basically those whole three hours I felt like I had to go to the bathroom and I was just in a lot of pain . . . It was too much to be HIDING . . . It was really hard to have to have to be so quiet. Well, I guess I didn't have to be but I was quiet and private about it.*

Sharing Helen's pressure to blend-in as a normal, healthy woman in academia, Christine Overall (1998) comments:

> I . . . experienced from many people whom I encountered, a strong pressure to pass for normal. I define passing as the concealment of a stigmatized identity, often through the assumption of a counterpart non-stigmatized identity. Despite my disabilities, I was urged to play the role of the non-disabled person. I experienced pressure not to be ill, not to show weakness or exhibit pain (p. 156).

Charmaz (1997) and Gibson, Placek, Lane, Brohimer, and Lovelace (2005) affirm that blending-in illness safeguards a normal definition of self and eludes the alienation and isolation that can come with being (in)visibly (dis)abled. For Helen, presenting an outward appearance of normalcy in one sense does not require a deliberate effort because she is physically indistinguishable and functions comparatively well in relation with her healthy peers. Yet, there are moments where stoically blending-in waves of urinary unsettled-ness demands an almost inconceivable, Herculean effort to circumvent the shame and embarrassment of others witnessing this humiliating embodied difference (Jackson, 2005; Robinson, 1993; Royer, 1998; Tardy, 2000; Wilde, 2003). Since Helen appears in good health and can calmly "be with" her pain, any attempt to visibly and convincingly puncture this embodied tension in the classroom is rarely actualized.

(Dis)Claiming Normalcy

Chronic illness momentously impacts a woman's life in significant ways and has specific resonance with a woman's sexual identity (Kralik, Koch, & Eastwood, 2003). In our western culture, women learn from a very early age that their physical attractiveness and value resides in their bodies and are encouraged to conceal their imperfections because they are cause for shame (Stone, 1993, p. 3; Wendell, 1996). The relationship between (un)settled embodiment and sexuality is a deeply profound concern for Helen whose volatile body is intimately tied to the (dys)functioning of her genitalia and the construction of her sexual self (Kralik et al., 2003). Since there is no subculture that exists that supports a fluid, (dis)abled identity (Schnieder & Conrad, 1980), blending-in for Helen necessitates a kind of "cooperative resistance" that transforms her erratic, fragmented, painful body into one that is sexually responsive and pain-free. Rosenfeld and Faircloth (2004) define this "embodied fluidity" as enacting a physical flexibility across time and space that enables individuals to produce themselves as competent social actors by sacrificing the demands of their bodies to meet able-bodied expectations. Juxtaposing a heightened awareness of her "abnormal," broken body with a collage of an ideal, flawless, female form whose body harmoniously unites physically and sexually, Helen reasons:

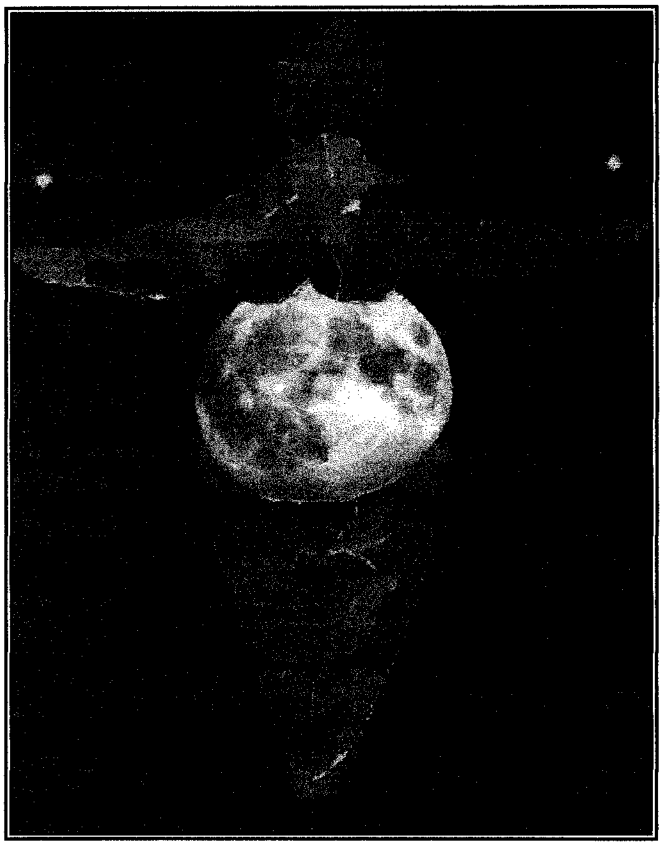

Figure 32. Embodied harmony: The complete woman.

> *This is an image I use in a lot of my artwork . . . cutting out the female form and piecing it back together. [It's] the idea of the fragmented self being pieced together as a whole. But it doesn't quite align . . . . That's what I feel often. I am this unnatural woman. I'm not supposed to be this way. I'm abnormal. . . . Like my body's NOT WORKING properly. It's broken, there's something WRONG, the parts aren't quite right. Like a radio or something that's broken.*
>
> *If we look at the symbol of a woman as eternal life, as reproduction . . . I have concerns about do I ever want to get married . . . ? Could I ever . . . commit myself to loving someone for an extended period of time when I know that my physical health is going to be a problem? . . . And that connects to me not wanting to have children which goes back to my self-conception as a woman . . . So do my concerns about not being a mother, not wanting children, or not getting married make me less of a woman?*

Artistically the process of collage, characterized by shredding various materials into fragments and (re)fashioning each piece together to create an intact representational form, mirrors the fluidity of Helen's (un)settled embodiment. Despite vacillating painful flare-ups alongside episodes of calm where the promise of cure exists on the fringe of Helen's consciousness, there are "missing pieces" that biologically circumvent the reconfiguration of a healthy, sexual self. In her exploration of the meaning of health and disability among women with physical impairments, Tighe (2001) alludes to the manner in which the discipline of normality dictates that a "normal sexuality" for women is heterosexual, sexually active, and defined by male acceptability (Bartky, 1990). Addressing this position further, Marris (1996) stipulates:

> We each have our own idea of what it means to be a woman formed in line with, and in opposition to, the ideas of womanhood offered to us by society. To be a woman may mean to be pretty, sexy, nurturing, independent- all qualities that can be undermined or changed for us by illness or disability. . . . As women we are defined as sexual beings. The outside world defines and judges us both as a potential object of male desire and according to how much we can satisfy that desire. At its most basic . . . it is about have[ing] ordinary sexual intercourse (pp. 101-102).

Clearly, since nurturance is associated with womanhood across cultures and because fecundity is a basic and embodied expectation for many women, sexual dysfunction assaults one's core sense of self (Becker, 1997, p. 84). Since Helen's identity is intimately entwined with the physical limitations imposed by the fluidity of her vulvodynia, she feels incomplete and inferior in her "womanly unnaturalness." In their study of the (dis)continuity of the embodied self in infertility, a condition the authors define as an invisible disability, Clarke, Martin-Matthews, and Matthews (2006) stress that the "failed" infertile body, which I extend to the vulvodynic body, compels women to feel deficient as adult women, calling into question their sense of being womanly, female, and feminine. Emotionally torn inside and out, unable to put all the shredded pieces together to physically heal and become whole again, Helen feels like a failure in being incapable of fulfilling the cultural norms of what it means to be a healthy, sexually responsive, fertile, "real woman." Given this, Helen questions whether having a body that resists conformity with such gendered expectations will morally and socially devalue her essential worth as a woman.

While molding fluidity within social prescriptions of normalcy reflects one layer of how women portray their identities, I propose that the framework of "possible selves" as described within the context of Alzheimer's Disease by Cotrell and Hooker (2005) offers another viable conduit for situating an understanding the fluidity of an (un)settled embodiment. Developing the construct of possible selves, Cotrell and Hooker imply:

> The possible selves concept captures the dynamic, goal-oriented aspects of the personality, focuses on domains of greatest value to the individual, and is sensitive to significant life transitions and events, such as parenthood, care giving, and illness (Hooker, 1999). The possible selves concept extends self-concept . . . to include ideas about what an individual would like to become or fears becoming (Markus & Nurius, 1986). . . . Construction of possible selves may offer one strategy whereby [one] can maintain a positive sense of self and life satisfaction (2005, pp. 285-286).

Matthews and Harrington (2000) insist that most people whether visibly or [in]visibly disabled, experience their conditions as a defect or personal inadequacy. Fearing the shameful inability to maintain a performatively intact sexual self, Helen describes her "addiction" to normalcy as the pressure to conform to the sanctity of social expectations by "prescriptively blending" her body into a sexually accommodating, idealized one. Here, blending-in creates a version of a hoped-for possible self that socially validates rather than denigrates Helen's identity as a woman.

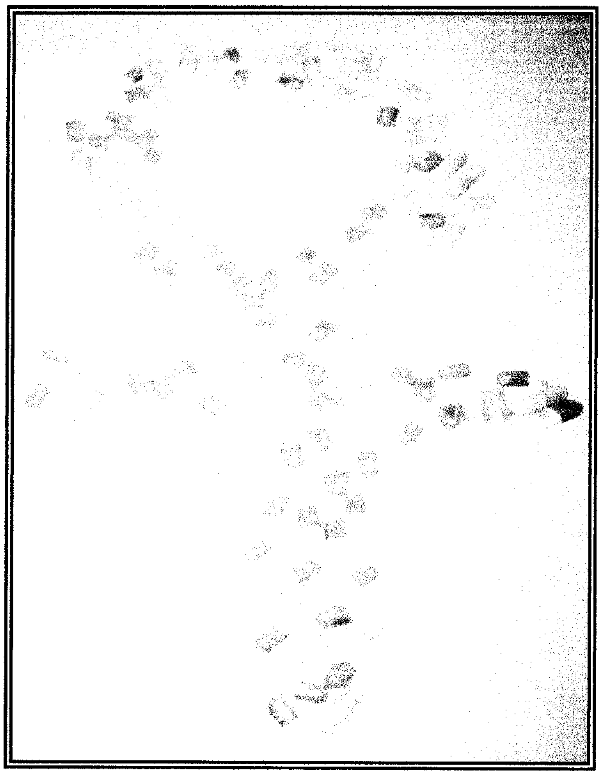

Figure 33. Restoring womanhood through medication.

> [My] *pills ALLOW ME TO FUNCTION AS A WOMAN, if we understand woman to be about sex and sexuality and stuff like that . . . . I have to take these pills to maintain some sort of NORMALCY in order to make sex sort of even possible . . . These pills allow me to be a woman. I NEED these pills to be normal you know. It's like an addiction [to be at] a level of where I'm functioning normally. . . without these pills I'm not whole, I'm not myself . . . without them . . . I do become invisible.*

Chiefly poignant is Helen's belief that without her pills to biologically restore a sense of normalcy and functional harmony she is nonexistent, her inferior personhood shattered in a culture that reifies bodily perfection and women's sensuality. In this sense, taking medication carnally blends-in Helen's fluidity into another more acceptable, hopeful body in which she is partly capable of resuscitating a healthy, sexual persona. Ultimately, such medical transmogrification enables Helen to enact the fluidity of her body by restructuring definitions of normality, health, illness, and womanhood in the moment, thereby (re)configuring the fluidity of an (un)settled embodiment on her own terms.

Twisting Fluidity

Blending-in the fluidity of possible selves into our society of wellness situates Helen within what she defines as a "double life" (Clair et al., p. 82; Wall, 2005, p. 145). While medically blending-in the fluidity of vulvodynia enables Helen to sexually function in a tolerable capacity and portray a possiblized self that is immune from the vagaries of sick, noncompliant bodies, this (re)presentation experientially belies the "painful erratica" of vulvodynia and Helen's real self. More simplistically, this twin or double embodiment reflects the incompatibility of what is seen and unseen, of coexisting worlds of health and illness and ability and disability that are at experiential odds with their fabricated (re)construction. Speaking to the embodied incongruity between the "felt privacy" of her pain and its public portrayal, Helen relays this double vision:

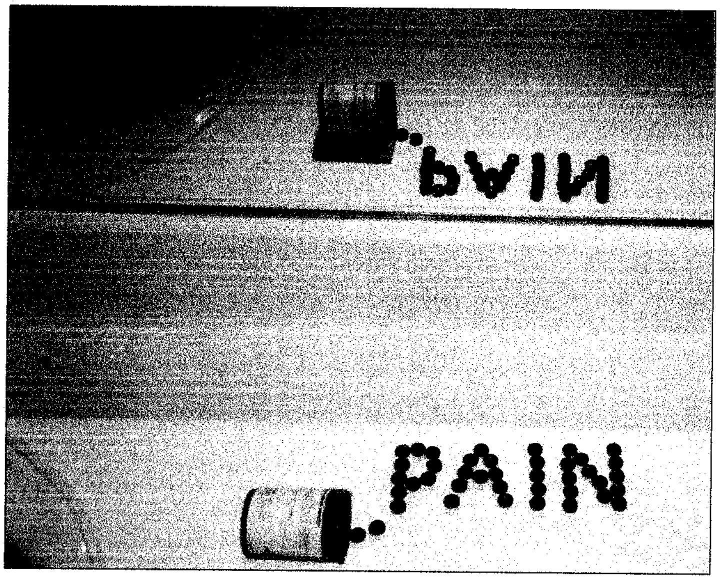

Figure 34. Mirror reflection: The double life of (in)visible pain.

> *I don't realize how much of a DOUBLE LIFE I'm leading sometimes . . . Like what I'm experiencing versus what other people think I'm experiencing . . . . A private life and a public life . . . . There's quite a discord between the reality of how I'm feeling and the image I'm projecting . . . . You look in the mirror and you see the pill bottle, you see the sink, you see the words but that's not what it looks like in reality. In reality, it's different.*

Research into the lives of individuals living with (in)visible disabilities confirms that much of our supposed understanding of "reality" or what we believe to be true is in actuality, often an image of reality (Vickers, 2005, p. 83). In essence then, the notion that "seeing is believing" (Fitzgerald and Paterson, 1995, p. 14), symbolically reflected in the mirror image of Helen's pills, muddles any connection between appearance and representation. By medically regulating her body, Helen physically reveals fluidity as a controlled, blended carnality while concurrently exposing its social distortion in masking her pain. Helen takes us a step further commenting that while medication offers some bodily control over fluidity, she often feels out of control in having tried various remedies to alleviate her pain. This facet of her life remains publicly unseen and unknown, further reinforcing the duplicity of a double life. Helen exclaims:

> *I've lost control of it in that there's so many things I've tried and nothing seems to work . . . So it's an attempt to gain control but at the same time, I feel it sort of slipping out of my hands . . . . And that's why I feel it's controlling me . . . And it comes back to this kind of abnormal/normal thing.*

In referring to her double life, Helen ultimately compels us to appreciate that an uncritical, reliance on what we think we see and know is often illusory as it relates to the fluidity of an (un)settled embodiment. Presentational identities are not always what they seem to be. Looking well as Helen illuminates, does not imply bodies that are pain-free and free of functional limitations. Clearly, the essence of understanding the lived experience of (un)settled embodiment is not about what we see, cannot see, or need to see to be convinced but different ways of looking, noticing, thinking and believing how women's lives are lived.

Charmaz (2000) observes that the chronically ill eventually come to take their (un)settled way of being in the world for granted (p. 283). The norm of embodied stability unravels as the body's natural rhythm cultivates a flowing cadence that becomes predictably precarious. Speaking further to the incongruity between appearance and reality, between the private experience of (un)settled-ness and her public mirage of wellness, Helen stings us into reconsidering the manner in which we see health and able-bodied-ness in our society and conventionally conceive of normality in ready-made, orthodox ways (Titchkosky, 2003; Vickers, 2005; Watson, 2002).

> *I want to challenge THAT IDEA of normalcy . . . People looking at me might think oh she's totally normal and then if they were to see something like this portrayal they'd think whoa, no she's not! [But] I am normal. This is my normal everyday life. This isn't exceptional for me . . . it isn't extraordinary. This is normal. So just twisting what we think of as normal . . . getting people to look at the ordinary or the everyday in a different way . . . forcing us to look again. To question what we're seeing and to say okay wait a second, we've totally accepted this as normal but how normal is it really? Like I said, how I appear as normal day to day on the street and getting people to think again about that and be like what is normal? And what's behind that normalcy? . . . . I guess eliminating some of that distinction between my normal and other people's normal . . . . For me normal is having pain or having these really inhibiting problems.*

Helen defines herself as a normal woman with a sometimes-disabling condition that is integral to her biography. While Helen observes that her reliance on medication is "not normal" in terms of how bodies are supposed to biologically function and in relation to the way society envisions naturally functioning bodies, moving with and reconfiguring the fluidity of her body with medication is a habitual way of life and a customary part of her embodiment. Thus, for Helen, living with the pain of an (un)settled body is a natural, ordinary experience albeit one that complexifies the manner in which we understand health, illness, and (dis)ability.

In twisting conceptions of (ab)normalcy and inscribing normality *with* illness rather than *over* illness, Helen is in effect, bending the rules of representation (Siebers, 2001) by re-articulating what it means to be (un)well. Reiterating the view that living with a fluctuating (un)settled body creates a space for competing readings of ill bodies, Moss and Dyck (2002) insist:

> Women appropriate familiar scripts like that of health and re-work them to make them apply to *their* experiences of *their* bodies. This involves de-linking chronic illness from its regularized, normalized, and naturalized meanings and re-linking illness to more enabling, notable meanings- alternative meanings that incorporate fluidity; meanings that make new inscriptions more meaningful for women's *specific* bodies and their embodiment (p. 102).

In this way, as Becker (1997) reasons, the struggle to come to terms with discourses on normalcy involves the reshaping of notions of normality within the parameters of "what is normal for me." Given the nature of her (un)settled body, Helen reinvents what it means to be physically and sexually normal by partially resisting in effect, the "normalization of normalcy." This finding aligns with those cited by Watson (2002) in which persons with physical disabilities restructure what normalcy means in the context of their identities and lives. By carnally re-inscribing normalcy with/as fluidity, Helen embodies several carnalities at once- healthy, ill, normal, and painful, each of which is fleetingly permanent in the moment and forever in transition. Helen's fluid embodiment transcends who people think she is with how she experientially lives her body in relation to its materiality at any given time. Advocating this reasoning and expanding its subjectivity, I again emphasize the work of Moss and Dyck (2002) who insist:

> Women with chronic illness seek out discursive categories through which to make sense of their fluctuating bodies and experiences of an unpredictable disease process. Even with the fluidity of inscriptions. . .women find some solace in being able, at least temporarily, to "fix" their body discursively, the utility of which gives texture to their lived [experiences] (p. 103).

What is most salient in conjunction with the fluidity of Helen's physicality is the manner in which her bodily mutability allows her to (re)fuse fixed and counter-hegemonic self-inscriptions that bypass static ontologies in place of seemingly contrary subjectivities.

While we live in a society that seeks normalcy through the pharmacological intervention of bodies, Helen urges us to "look again" and reexamine the universalizing assumptions of health, illness, normalcy, and abnormalcy that discursively structures the curative purview of medicine and our own cultural (mis)understanding. Appealing to our reliance on visual cues, on what we see and how we see, Helen invites us to interrogate the (un)familiar and the (extra)ordinary, to broaden our "vision" and imaginations beyond monolithic, visible presumptions of human bodies as (ab)normal and (un)well. As Helen intimates, it is only by stretching our receptivity into the crevices of indeterminable-ness that characterizes (un)settled embodiment that we can begin to support more fluid constructions of all bodies and lives. Mirroring Helen's intentions, Lennard Davis's (2002) notion of dismodernism highlighted earlier in Chapter 2, electrifies a new way of thinking that begins from the premise of wounded subjectivities in which we are all nonstandard bodies (p. 32). I cheer and applaud Davis's gumption to invert the template of ability with disability, a way of seeing that intellectually tethers Helen's vision that underneath it all, we are all disabled in normalcy.

Summary

The complementary intentions of Chapters 9 and 10 orient the reader-viewer's attention to the ways in which women secret and blend-in their fluid selves within ordinary life scenes. It is clear that while participants prefer to secret and performatively camouflage their (un)settled bodies, it is the very nature of a fluid embodiment that is never one way of being or another that permits such corporeal liberty and the credible enactment of pliable identities. While secrecy offers both protection and peril in concealing the legitimacy of (un)settled embodiment, a working against the exposure of (in)visible disability, blending-in, as Helen's narrative aptly demonstrates, is a subtly different carnal partnership in which women rely on the variable nature of their (dis)abled subjectivities to negotiate a habitable fluid presentation of self in the moment. More specifically, blending-in health with illness or more adroitly, as illness, implies a strategic listening and responding to the body's (un)settling cadences. It is a flexible working with the mutability of the body for the expression of potential or possibilized selves (Cotrell & Hooker 2005).

Akin to the legacy of able-bodied normalcy supporting the secrecy of (in)visible disability, blending-in is partially ensconced in institutional and cultural discourses that prescribe how bodies and identities should be. Given the (dis)continuity of their (un)stable bodies, participants experience a heightened sensitivity to being and being perceived as normal. They want to keep their lives as normal as possible and this often means blending-in with illness rather than against it. At the same time, this carnal collaboration is not always opportune because it can jeopardize a woman's physical welfare as she sacrifices her own health to "keep up" with so-called normal others in relation to standards of appearance, autonomy, and functional performance. While it is argued that normalizing discourses and practices that shape participants' lives safeguard a woman's self-image by easing the disruption of a fluid embodiment (Charmaz, 2000), this form of identity management also occludes how women live with the shifting realities of an (in)visible disability and the (in)credulity of their identities. Since there is no sub-culture to support the fluidity of a (dis)abled identity (Schneider & Conrad, 1980) despite its legitimate presence in women's lives, Angela and more considerably Helen, weave a web in which they silently (dis)claim normalcy and (dis)ability.

Similar to secrecy, blending-in both accentuates the material uniqueness of bodies and socially censors (in)visible disability. A vital part of Helen's narrative focuses on this tension in relation to her feelings of inferiority, incompleteness, and feminine unnaturalness in living with the shifting sexual fragility of her body. Bringing the reader-viewer inside the physical and emotional depths of her (un)settled body, Helen exemplifies the way she (dis)claims normalcy with/as illness by molding the shifting contours of her (un)well body as an ordinary part of her everyday life. Through a combination of vividly textured artistic and photographic images, Helen details how she both "works with" and transcends the demands of her episodic pain-infused body by blurring the boundaries between the carnally (im)possible. For example, we witness Helen pharmacologically blending-in the plasticity of (un)settled-ness to "make her normal," to make sexual relations possible, and to unveil the presence of (un)settled-ness in shaping identity.

Paralleling this, Helen directs our attention to manner in which blending-in complicates the reality of living with an (in)visible illness by muddling the borders between what is and what is given, between how bodies are and how they are socially presented. With this in mind, Helen urges us to "look again" by twisting how we visually interpret bodies by (re)inscribing the ways that fluidity agitates cultural tropes of normalcy, abnormalcy, health, illness, ability, disability, visibility and invisibility. Disclosure or unburdening a woman's fluid identity similarly disrupts the common ways we see and understand disability in our society. It is to this dynamic and the tensions surrounding it that I now direct attention to.

The Fluidity of Identity Part III

Chapter 11

Unburdening Fluid Identities: Dialectical Tensions

In the preceding chapters I explore how women secret and blend-in (un)settled-ness as ways of moving through the world to portray a convincing, able-bodied self. The inverse of concealing a hybridized body that (in)visibly shifts between the lifeworlds of (dis)ability is that participants are misperceived as *always* healthy and *always* able-bodied. These misperceptions can place participants at risk for exacerbating their conditions. Given that (in)visible disability is essentially a private and unnoticed experience (Richardson, 2005), the reader may even wonder why anyone would choose to self-identify as living with an (un)settled (dis)abled body (Brueggemann & Moddelmog, 2002). Rather than revealing personal information to convince others of the legitimacy of their fluid embodiments, a more frequent relational event is that many women obviate opportunities to unburden themselves because of concerns related to personal privacy, autonomy over information, and the potential for stigma, distrust, and misunderstanding that accompanies life with an (in)visible disability (Afifi & Guerrero, 2000; Rosenfeld, 2000). Yet despite a woman's preference to conceal fluidity, there are situations that demand one's social visibility and validation as (dis)abled.

Derlega, Metts, Petronio, and Margulis (1993) stress that self-disclosure is not a "one size fits all" decision but serves different functions for different individuals in their relationships with others. As a core element of shaping social impressions, of claiming identity(s), disclosure refers to the process of verbally revealing authentic and intimate personal information to others (Derlega et al., 1993). While disclosure does not always occur verbally, my focus in this chapter is on the verbal communication of one's fluid embodiment rather than its shadowy behavioral manifestations. Augmenting this focus, Rosenfeld (2000) endorses the view that:

> Self-disclosure is a scary notion! It can explain our existence, reveal who we are to ourselves and others as we disclose and engage in an act of "becoming," and, more fundamentally, allow us to exist in the world. It can help us to "heal" ourselves and, simultaneously, serve as an indication of the intimacy of our relationships. Paraphrasing Jourard (1971), self-disclosure requires courage, not only the courage to *be*, but the courage to be known, to be perceived by others as one actually is (p. 4).

Differing from persons whose disabilities are permanently visible, individuals living with (un)settled bodies have greater choice over information control (Goffman, 1963, p. 113) because by living in-between, they dually inhabit the worlds of health and illness. Irrespective of this self-determination, Clair et al. (2005) contend that (in)visible disabilities place a greater burden on individuals even though they are routinely unnoticed by others. All in all, the tension surrounding the unburdening of an (un)well identity resides between the need to protect one's self worth as predominantly able-bodied and the desire to live authentically and credibly with an (un)settled embodiment. Although Angela, Helen, and Angie prefer to privately shoulder and blend-in their (un)settled-ness on a daily basis, there are specific circumstances and contexts that inspire them to reveal the truth of their mobile subjectivities (Lowton, 2004; Petronio, 2002). Unburdening (un)settled-ness in these instances reflects dynamic and contextual considerations including evaluating the emotional risk in disclosing, assessing the potential for negative social evaluations, skepticism, and misunderstanding alongside the obligation to educate others and liberate a more authentic self.

Dynamic Foundations: (Un)Necessary Tellings

Akin to secrecy and blending-in, unburdening (un)settled-ness or "coming out," a phrase originally derived from gay liberationist politics, involves a never-ending set of complex negotiations in determining how a woman's self-presentation is publicly conveyed within the context of fluidity (Charmaz, 1997; Olney & Brockelman, 2003; Vickers, 2001b). Since our western culture fails to tell sufferers how to cope with their chronic conditions (Hilbert, 1984), Angela, Helen, and Angie are not simply "in" or "out" of the closet but alter the logic of the closet by moving through a revolving door congruent with the fluidity of their (un)settled-ness (Conrad & Schneider, 1980; Siebers, 2004; Vickers 1997). Underpinning this standpoint, Moss and Dyck (2002) observe that the unpredictability of bodily being does not equal stability in the expression of self, but involves a complacency with being in an ongoing unstable transition (p. 143).

Angela, Helen, and Angie stress specific relational and contextual considerations that motivate them to unburden their fluid identities or refrain from revealing the privacy of their embodiments. Although Angela considers MS a private issue, divulging her commotional embodiment evolves around the interfusion of exercising autonomous choice in what she substantively chooses to tell, the necessity of revealing her (un)settled-ness, and evaluating the nature of her interpersonal relationships. Petronio (2002) contends that since people believe it is their right to self-determine what others know about them, they make disclosive judgments in relation to their own particular motivations. Expounding these considerations, Angela remarks:

> *When I'm ready to disclose to somebody, I really have to think WHY, why am I doing this? Why is it important to me? Why is it going to be important to my relationship with them? . . . . It's having a CHOICE of who you're going to share with and why you're going to share it . . . . It's sort of a necessity for telling some people . . . At*

> *work, I did the this is a part of me and I may need to ask for a bigger computer screen, I may need to take a lot of time off to go to appointments and that's what I say.*

Angela continues:

> *Being single for the past five years, and I've dated a few people and a few people I've just chosen not to tell . . . I knew I didn't really want a relationship with that person. It wasn't going to AFFECT our relationship. They don't need to know.*

Rosenfeld (2000) posits that people give varying degrees of boundary access to social others as a way to control the entrée to private information (p. 11). Derlega et al. (1993) refer to such boundaries as dyadic parameters within which it is safe to disclose and across which self-disclosure will remain confidential (p. 67). Reinforcing this perspective, Beatty (2004), Charmaz (1997), Clair et al. (2005), and Derlega et al. (2000) maintain that because the sensitive nature of illness disclosure spurs the risk of incurring callous social ascriptions, people tend to share confidential information about themselves within a relational milieu of psychological safety.

Within the bounds of this study, Angela and Helen reveal the fluidity of their conditions to individuals they can confide in and who are intimately involved in their day-to-day lives rather than with unfamiliar acquaintances in offhand, cursory ways (Afifi & Guerrero, 2000; Jourard, 1971; Lowton, 2004). Analogous to Angela, Helen negotiates revealing her (dis)abled identity by distinguishing whether someone is a part of an "in" or an "out" group. For Derlega et al. (1993), distinctions between in and out groups reflect the degree to which an individual is an appropriate or inappropriate disclosure recipient. These authors purport:

> Individuals might be *appropriate* as disclosure recipients because of their acceptance of the discloser, skill in understanding the discloser's message, motivation to help, and discretion. . . However, some individuals might be *inappropriate* as disclosure targets because they are indiscreet or untrustworthy (Derlega et al., 1993, p. 85).

With close friends, partners, and family members who characterize Helen's intimate social circle, Helen is candid about her condition without fearing unsupportive, discrediting responses. Helen describes how she justifies these (un)necessary tellings.

> *There's kind of an "in" and an "out" group . . . In the in-group . . . . with my closer friends or my partner and with my family I can be more open and honest. . . I know they're not gonna think I'm weird or shy away from me . . . . With the out-group, it's like you don't get anything . . . . they're not part of my private life so I hesitate bringing people inside unless I know them well. You know some people, if you don't know them that well and you hear about some UNUSUAL problem they have or they start talking about genitals with you, you might kinda think uh this person's got some issues or problems and they can just deal with it on their own.*

The salient point worth reiterating here is that because living with an (un)settled body is an unfamiliar reality among many individuals in our culture, women risk exposing themselves to misunderstanding and negative evaluations from others who are outside their intimate lifeworlds. What women crave in living with the (un)predictability of their bodies then is the consistency of support and understanding of others who know them best.

Getting It

Unburdening (un)settled-ness is more than just revealing oneself; it is a dialectical relationship between individuals (Petronio, 2002). As with any decision to reveal private information about oneself, individuals living with (in)visible disabilities are particularly vulnerable to the reactions of social others. Identifying MS as an intimate part of her identity that she rarely discloses, Angela, is more apt to reveal this aspect of her life with empathic others in her social world like Helen as well as with other individuals living with disabilities. Angela accentuates the importance for both (non)disabled others to "get it," to be empathically amenable and intellectually curious about the (un)settled-ness of her MS rather than feeling awkwardly silenced and reservedly sympathetic. Since Angela considers her disability a private part of her life, she distinguishes between revealing this aspect of herself to trusted family and friends who will reciprocate with faith and understanding as opposed to others who casually pass in and out of her life and are less likely to comprehend the reality of a fluid disability. Angela says:

> *I don't mind talking a lot about it with people who "get it." I guess it comes from an idea of INTIMACY. . . . Am I willing to give that intimate part of me away? . . . I'm not willing to share it with people who you know, I see on the street but if I'm out with my friends . . . its part of me and they know and understand but the average Joe on the street doesn't know and understand.*

Sveilich (2005) notes that people will seek out others who are suffering with similar symptoms in order to validate their own (p. 93). Angela expresses an emotional affinity with other women with disabilities who share the physical and social experience of (un)settled-ness in their daily lives. Derlega et al. (1993) stress this kind of reciprocal kinship noting:

> To reciprocate means to give something back that matches something received. . . In self-disclosure research, *the norm of reciprocity* refers to the tendency for recipients to match the level of intimacy in the disclosure they return with the level of intimacy in the disclosure they receive (p. 33).

Yet despite a natural, almost effortless affinity with a disabled woman in her co-op, not all "wise others" are considered safe others who will understand and validate an (in)visible disability (Goffman, 1963; Schneider & Conrad, 1980, p. 38). Angela alleges:

> *One of my good friends in this co-op, she's a paraplegic and she gets it . . . It's funny because I do feel . . . very comfortable talking to her about my MS as opposed to other members of the co-op who I know on the same level as her but I've never disclosed with . . . It's not really just because she has a disability. It's because emotionally she's gone through everything I'm going through . . . She gets it more. That whole concept of getting it is so important to me.*
>
> *I find there's a lot of people with disabilities that live in this building and there are two women in particular who have a dog and I spend a lot of time talking to them out in the courtyard when they bring their dog out. I WANT TO TELL THESE WOMEN RIGHT? I have no idea what their disabilities are but then like why? I don't know*

> *them intimately . . . Why? Because they have a disability like I do and I want to tell them you know. The other day I helped them dig out their van and they were like "oh you're so great" and it was like that's because I UNDERSTAND.*

While seemingly empathic, Angela is hesitant to reveal herself to her neighbors because her MS is not readily visible and these women are not a part of her intimate social network. In not looking disabled, Angela risks misunderstanding, devalidation, and even possible rejection from her neighbors since persons living with disabilities themselves are not prima facie, compassionately responsive towards all persons with disabilities, especially individuals whose disabilities are not readily apparent.[12] Addressing this view, Lowton (2004) and Petronio (2002) purport that revealing private information can be risky, both for the person who does the disclosing and for those who hear and may reject the validity of the disclosive message. Illustrating this latter dynamic, Angela alludes to the difficulty her parents have in "getting" her MS. Since the bodily signs of her MS are not always visible, Angela's parents, despite their knowledge of their daughter's condition, are startled to witness its presence and only recently embrace any discussion about it.

> *My parents are supportive but don't quite "get it". . . Six years after my diagnosis, they are finally starting to be able to talk to me about it. They are affected by the invisibleness of my disability. Because they can't see it, they assume all is well. When they do see an indication of the MS, they are always taken aback. . . . It's hard to have others understand something you can't see.*

Thus, "getting" or believing the fluctuating, (in)visible nature of MS is problematic for Angela's parents because when it lies dormant, Angela appears healthy and normal. Yet, when the unexpectedness of MS rears its embodied presence, Angela's parents confront an

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[12] In making this assertion, I am not implying that all persons with disabilities fail to empathize with individuals living with visible, invisible or fluctuating (in)visible disabilities. On the contrary, what I am suggesting is that because (in)visible disabilities are not always evident, women like Angela may not be considered "genuinely disabled" to warrant this supportive identification.

astonishing reality because they have difficulty comprehending that a disability does not always have to be visible to permanently exist in their daughter's life.

Decisions surrounding how to retain control and credibly present the fluidity of their (dis)abled selves while maintaining a positive self-image is sometimes experienced indirectly through what I define as "vicarious disclosure." This kind of protective telling (Derlega, et al., 2000; Charmaz, 1991; Schneider & Conrad, 1980; Vickers, 2001b) assuages the pressure to sustain the secrecy of MS along with the discomfort of demeaning pitying reactions that Angela, Helen, and Angie fervently seek to avoid. Enhancing this observation, Joachim and Acorn (2000b) cite that the emotional trauma of disclosure relates to beliefs that the responses of others will elicit unwarranted pity as well as unwelcome speculation, insensitivity, and judgments concerning their character (Hilbert, 1984; Lowton, 2004; Vickers, 1997). Detailing the vicarious unburdening of her MS through her son, Angela admits:

> *E's friend's mom said to me "oh E told me you have MS. Is that true?" That was easy for me . . . because I didn't have to do it . . . the gate's been open and often times that person has had their few minutes to process . . . It's more valid because they've had the opportunity instead of it being on an emotional level it comes on an intellectual level. I get to reach them when they're on the intellectual level instead of still working at that "oh I'm so sorry!" or "oh really?" THAT LOOK . . . . I don't want people to feel like I'm so sorry or it's so bad.*

Angela believes that allowing her son to reveal her MS on her behalf makes telling less threatening and more credible because it emotionally disconnects her identity as a woman from the disability or condition, something she lives with rather than *the* dominant characteristic defining and overriding her identity. Attesting to this reflection, Afifi and Guerrero (2000) comment:

> Individuals not only seek to present positive images of themselves; they also hope to disassociate themselves from undesirable identities. . . In fact, some have argued that

> this desire to distance ourselves from identity-threatening information is more motivational than is the desire to be linked with positive impressions (p. 173).

By permitting her son to reveal her MS in a detached, impersonal way, Angela is able to maintain her integrity as a person. Conrad (1980) notes such preventive disclosures reduces the risk of morally disreputable interpretations that might be applied by naïve others and controls how the self is seen and understood (p. 41). Documenting similar findings, Derlega et al.'s (2000) work on disclosure among persons living with AIDS and their partners reveals that indirect disclosure about the diagnosis provides protection from being hurt or rejected and minimizes the potential for negative consequences (p. 62). Directing attention to the problematic aspects of disclosure, Greene (2000) and Susman (1994) highlight Angela's reasoning claiming it is not the functional limitations but the social responses to it that poses the greatest problem for persons living with (in)visible disabilities, especially those that are unconvincing in their physical appearance.

Offering another example typifying the protective potential of vicarious disclosure in relation to her former husband's girlfriend, Angela recollects:

> *I went on a school trip with Z . . . to an apple farm . . . S. was dating this woman L. and her son was in school with Z and she has a few invisible disabilities. She was the one when we were at the farm who [said] "I wanted to tell the teacher you have MS because I was scared she was going to ask you to run across the field and look for some kids and you wouldn't be able to and I didn't want you to get fatigued." i I never had anyone say I want to disclose for you so you weren't asked to do something that you wouldn't be able to do.*

When others know about the secret of (in)visible disability, the possibility for disclosure exists (Hillyer, 1993; Lowton, 2004). In this instance, the offer of vicarious revelation serves to prevent the potential for misunderstanding between Angela and her son's teacher as well as to safeguard Angela's physical welfare. "L's" attunement to the invisible aspects of living with a chronic illness and her willingness to disclose on behalf of Angela is a preemptive strategy to shield and justify the fluidity of Angela's MS and to indirectly educate others about the nature of the disease. Yet despite this caring camaraderie, such vicarious disclosure also runs the risk of violating a woman's privacy and sense of psychological safety. Communicative acts carry a degree of responsibility in recognizing the potential impact of their knowledge on the recipient and others (Petronio, 2002). Derlega et al. (1993) comment that if individuals know personal information about us, they may (un)intentionally divulge information to people we do not know, like, or that we would choose to confide in (p. 66). In this instance, the balance of power over the ownership and control of intimate information drastically shifts and may inadvertently amplify personal vulnerability by creating social impressions of women living with (in)visible (dis)abilities like Angela that can be emotionally wounding rather than compassionate.

Queer studies theorists Barbone and Rice (1994) distinguish between "coming out," whereby one admits to having a debilitating fluid condition without actually appearing disabled and "being out," in which one's fluid embodiment indicates some degree of deviance from the norm of health (pp. 92-93). Differing from Angela and Helen, Angie indicates that disclosing the (un)settling story of her MS depends on whether the fluidity of her flare-ups culminates in a visibly (un)happy ending.

> *It's not something I can hide- it's not something I'm willing to hide . . . but I bet if I had an obvious, overt physical indication of my MS, I wouldn't tell anyone . . . . The only time I'm comfortable with it is when nothing is happening to me. That's when I'm like "oh yeah, I have MS" to people. Cause it's like dormant or it's not bothering me. When I'm LEAST likely to talk about it or to acknowledge it would be when it IS bothering me . . . . Like when I talk about MS when I'm not going through it, I'm more flippant, I'm funnier about it, I joke it off and I'm probably less emotional about it. Because when it's happening, and if I try to talk about it when it's happening, oh my God, I'm a mess of tears and snot and I'm just too close too it right? It's not in the past . . . Like if I told you about my MS attack two years ago where I look really fine. . . it's a happy ending because I got through it . . . I regained feeling in my face and I'm not drooling out of the corner of my mouth . . . I*

> *can tell that story . . . because I'm okay. There was nothing left behind. But if I was still drooling or I still couldn't feel my face it would be a painful story to tell . . .and it wouldn't have a happy resolution . . . That's why it's easier for me . . . . it has a happy ending kind of.*

This conscious choice to reveal a (dis)abled identity emanates less from Angie's identification and acceptance of her (un)settled embodiment than it is from not outwardly appearing disabled, at least in the familiar ways our society visually and socially constructs disabled identities. In her doctoral research exploring the relationship between (in)visible chronic illness and disclosure, Beatty (2004) reports that features of the illness experience including appearance, severity, and intrusiveness of symptoms influence participants' choice to disclose their (dis)abled identities. When Angie's body is "settled down," disclosing MS is shrouded within a corporeal invisibility that safeguards her from the emotional trauma and stigma of identifying as an (un)well, (dis)abled woman. When such (un)settling episodes of MS leave no residual traces, Angie's story is one of bodily redemption and triumph (Frank, 1995), a story she is comfortable telling because she successfully survives the ravages of her volatile body. Exemplifying Angie's logic, Charmaz (2000) avers, "the teller can claim a heroic self who emerges victorious despite poor odds. A good story of a past crisis does not pollute the present" (p. 281). In leaving nothing behind, the story of (un)settled-ness is less daunting and seemingly less real because mirroring its fluid essence, it restoratively transforms the body back to a familiar version of itself. It is this confidence that makes telling comfortable for Angie. Mirroring Angie's outlook, Kimberly Myer's (2004) decision to "come out in the abstract" and claim a debilitating disease and a (dis)abled identity when feeling well during her attendance at the 2002 National Endowment for the Humanities Summer Institute mitigates the threat of this revelation.

I was fortunate to be able to come out while I was seemingly normal. As in my case,

> coming out is often easier when one is able to do so "in the abstract"- that is, when one's disease is well-managed and does not significantly compromise personal or professional life. . . When the degree of disruptiveness is low, so is the threat of stigmatization; a person can more safely admit to having a debilitating disease because she does not actually appear disabled (p. 260).

Connecting our culture's preference for these restitution narratives to the issue of disclosure, I recall Frank's (1995) assertion that these "disclosive narratives" in which the individual can eventually return to be "as good as new" or closely approximating the status quo, are triumphantly exonerating because they expose a stigma-free, settled self in the moment.

When disability is not readily apparent to others, it is often preferable to remain closeted (Myers, 2004, p. 257). Differing from Angie, Helen refrains from unburdening her vulvodynia unless it significantly interferes in her life in a behaviorally problematic, socially visible manner. Noting this, Hilbert (1984) states that disclosure is often warranted when pain forces people to behave in unusual ways or change their habits in ways subject to misperception (p. 371). As Helen admits, exposing her vulvodynia is typically an "all or nothing" phenomena in which the presence of fluidity either engulfs her functional performance to the point where it is socially conspicuous or remains just elusive enough to circumvent its expression.

> *I wait until I ABSOLUTELY NEED TO TELL SOMEONE . . . . With me its sort of ALL OR NOTHING is a bad way to put it. I either NEED to disclose it and I do or I don't need to and I don't . . . . It's still very much IS a private issue. Like no one in my PhD program knows about it and my professors don't know about it just because AT THE MOMENT . . . it hasn't affected my schoolwork to the point that they would notice something was wrong.*

When Lynda initially began walking with a cane at work, her decision to disclose her MS, following Helen's inclination, was less a matter of personal preference than one of incontestable necessity. Downplaying the gravity of this self-revelation to her co-workers to preserve her self-image as a competent, productive worker, Lynda reflects:

> *I didn't make a formal announcement. People would see me with a cane and say "what did you do to your leg?" And I'd say, "I have MS." But I'd say, "don't worry and stuff. I'm fine. I'm still walking around." And just change the subject . . . If people looked kind of perplexed by it I would say, "Do you know any people with MS?" And actually everybody seemed to . . . but that's not necessarily a good gauge of what they know because they'd judge you on the poor bugger who lived next door to them that's incapacitated in a wheelchair. But I would just tell everybody I'm following a fairly benign course. You don't want the people you're working with to assume you're not up to the job.*

Both Helen and Lynda's accounts illustrate that disclosing an (in)visible disability is dependent upon how visibly noticeable and intrusive it becomes in everyday life. Each of these women wants to fit-in in ordinary ways in the classroom and the workforce. However, unlike Helen whose complications from vulvodynia remains beneath the notice of others, Lynda's body takes on a more visibly disabled identification with the use of her canes and consequently, she no longer has the option of determining the level of necessity in informing others about her MS.

Bewildering Silences

Unburdening a fluid embodiment frequently incites a bewildering silence. Beatty (2004) and Sveilich (2005) propose that this awkward social silence relates to the "un-discussable" nature of illness and disability in our society, insufficient knowledge about chronic disease, and a lack of awareness regarding how to appropriately respond to this kind of disclosive intimacy. Angela observes the manner in which this humiliating, painful silence results in well-intentioned albeit vacuous platitudes.

> *That actual initial moment of disclosure is really difficult. The first minute that you turn to someone and you're like "I have MS." That minute afterward and their response is SO, SO DIFFICULT . . . The most common sort of response is "I'm so sorry". . . . That's not really what I want from you. I just want you to go "oh, okay. Tell me about it" or something like that.*

Referring to the actual moment of disclosure and the ensuing unnerving silence is for Angie, akin to metaphorically laying down an unrivaled "trump card." This occasionally spontaneous and equally silencing revelation abruptly dumbfounds other people who are misinformed about the corporeal expression of (un)settling illnesses like MS and ultimately suspends communication.

> *There are people in your life who you don't know very well and you tell them oh I have blankety, blank disease . . . It's just like silencing almost . . . it's like this weird silent moment . . . there's no follow-up except an expression of like concern or condolence or something . . . . I don't think that people understand disease that much unless somebody in their family or they are afflicted with something. I don't think we're that educated to diseases or health problems . . . . If somebody told me . . . they had cancer I wouldn't be like "hey that's great!" I would probably be completely silenced by that too. . . It's like a pretty big TRUMP CARD. It's like I have a major disease, what have you got? It's SILENCING. Like once somebody lays a doozy down like I've got MS it's kind of like a challenge . . . . Try to trump, try to do better than that.*

Confronted with patronizing, apologetic responses and/or impenetrable silences, Angela and Angie point to the painful difficulties surrounding the unburdening of their (in)visible disabilities. Rather than encouraging thoughtful, sensitive responses that encourage women to explain the nature of (un)settled-ness in their lives, such revelations emotionally overwhelm others and in effect, shut down a willingness towards understanding. Akin to the individual who holds the winning hand or card in a card game, other players, in this case the non-disabled, are literally out of the game because they cannot compete with the explosive nature of such a matchless disclosure.

Although Angela declares she is receptive to talking about her MS, she elaborates the complexity associated with appearing normal and sharing this intimacy and in turn, the psychic energy it takes to cope with the ignorance of others in light of the ambiguity of a fluid embodiment. Following Vickers (2001b), I appreciate Angela's comment that it is easier to pass when you "look normal" rather than endure the emotional aggravation or "botherment" (Lowton, 2004) just to ensure others understand and believe you.

> *I don't have issues sharing the whole concept of MS with people. I don't like the idea of them going "oh what's up with that girl? Why is she carrying a cane?" Because I could see a neighbor saying, "so what's with the cane Angela?" Then I have to deal with the I have MS and most of the time you're not dealing with a good understanding of the disease and having to go into a long lengthy explanation and deal with whatever their response is . . . . There are some people where you know what? It's not worth my time dealing with me and their reaction . . . I'm passing because I'm not going to go into this. I'm choosing not to reveal to you. It's nice to have that option.*

Since the process of telling never ends, individuals who choose to unburden their (in)visible disability continually place themselves at risk for disbelief, insensitivity, stereotyping, and prejudice. However, Angela feels fortunate in having the option to decide whom she discloses to and under what circumstance to avert the potential for negative social valuations and misunderstanding (Beatty, 2004; Charmaz, 1997; Davis, 2005; Sveilich, 2005; Vickers, 1997, 2001).

Transgressing Normalcy

Secreting (un)settled embodiment requires women to expend a significant amount of energy and may harm one's physical and psychological health (Derlega et al., 1993). James Pennebaker (1989) writes "to actively inhibit one's thoughts, feelings, or behaviors requires physiological work. . . . Over time . . . inhibition serves as a cumulative stressor on the body" (pp. 96-97). Within the confines of this research, women who typically look healthy and able-bodied must decide to partially refute the assumption of normalcy (synonymous with able-bodied-ness) as part of revealing the (un)settled-ness of their identities. Titchkosky (2001) reflects the challenge innate to coming out of normalcy and into the fluidity of (dis)ability:

> Coming out as [dis]abled, in the absence of what a culture typically envisions as disability's typical presence, seems a slightly different matter. . . It is the very visibility of normalcy that must be silenced, ignored, denied. It is the person's assumed and apparent stance in normalcy that makes coming out as, and passing into, disability a different matter for people whose differences do not readily appear to others who unquestioningly assume, and thus "see" only, the structures of normalcy (p. 3).

Disclaiming normalcy as Angie believes, is seldom desirable and more often than not, inspires pervasive anxiety about having to consistently explain the dissonance between reality and representation, between the lived-in-ness of fluidity and presumptive appearances of non-disability. This tension serves as a steady, aggravating reminder of disability's legitimate existence in women's lives as well as conjures up feelings of humiliation in being "not what one seems to be." Envisioning herself as primarily able-bodied, Angie juxtaposes the renunciation of the disabled side of her identity with feeling emotionally empowered in sanctioning a more genuine, fluid self by unburdening the shame she ascribes to her disability.

> *It's like a bad . . . SECRET. . . . you don't want to admit to . . . you don't want to admit you can't do stuff especially when you consider yourself VERY ABLE-BODIED or capable like everyone else . . . .It's like a WEIRD SHARING of I don't want to admit it. I don't want to tell them because then they know too and it's like doubly admitting it. . . It's a CONSTANT reminder, A CONSTANT having to deal with It . . . You're constantly reminded that you have MS . . . .[but] It feels good to tell people and not feel ashamed. It feels good to share it. It's kind of empowering to let people know. It's like a step to get away from shame you know.*

Unburdening the fluidity of identity as Angie alludes to, is therapeutic (Clair et al. 2005; Schneider & Conrad 1980) or cathartic (Derlega et al., 1993; Rosenfeld, 2000), enabling women to cope more effectively by diffusing the emotional stress and self-stigma accompanying the encumbrance of concealing their (un)settled selves. Directing further attention to this reality, Derlega et al. (1993) believe:

> The act of self-disclosure may relieve feelings of guilt and shame over difficulties

> previously kept hidden. The act of disclosure may help persons see themselves more positively because they have divulged the information . . . persons who have not disclosed to anyone . . . may feel worse and more ashamed about themselves because they infer from the act of concealing that the information is negative (p. 96).

Moreover, as part of this self-catharsis, disclosure legitimizes and magnifies the cultural understanding of (in)visible disability thereby ascribing more global credibility to the fluidity of (in)visible disabilities (Derlega et al., 1993; Schneider & Conrad, 1980, p. 40; Vickers, 1997). While achieving the psychological emancipation Angie mentions typically demands a receptive, nonjudgmental audience (Schneider & Conrad, 1980), my reflections from this research suggest that the sheer act of such self-catharsis when deemed appropriate inspires more authentic living for women.

Politicizing Fluidity

Many (in)visible illnesses according to Vickers (2000) impede disclosure beyond the privacy of bodily experience to a socio-cultural injunction against its open dialogue. The decision to reveal the fluidity of (un)settled-ness arises as women grapple with the unspoken compulsion to resist such social quarantine in place of raising cultural consciousness or as Helen states, "of making the private public" (Afifi & Guerrero, 2000; Clair et al., 2005; Derlega et al., 2000; Joachim & Acorn, 2003; Schneider & Conrad, 1983; Thomas, 2002; Vickers, 1997, 2001b). Sustaining Helen's outlook, Bill Hughes (2002) maintains that if oppression is embodied, if it is lived and felt by [dis]abled people in the course of their daily lives, then we must collapse the distinction between private troubles and public issues (p. 68). Elucidating this struggle as an opportunity to inform and defend the legitimacy of (un)settled embodiment, Helen ardently claims:

> *As much as I have become more comfortable talking about my body with other people there is still that kind of social taboo. I mean do your professors want to*

> *know about your vagina? Does your co-worker want to know about it? . . . I keep it a secret because of the shame and embarrassment.*
>
> *It's sort of like okay, we don't want to talk about infirmity, we don't want to talk about you know, how reliant we our on our bodies to function like this perfect little machine. I think it frightens people to think that things can go wrong . . . I'm gonna tell you things can go wrong! You can't hide me away any longer . . . You're going to have to get over it that things go wrong with our bodies and that it could happen to you and that you can't make people feel ashamed about it once something does.*
>
> *That's why I was interested in getting involved in your study partly just to make the PRIVATE PUBLIC . . . . that idea of dismantling taboos because I think those taboos can be very DEBILITATING or DISABLING in themselves in the sense that I don't feel comfortable talking about certain things in certain contexts . . . . I think understanding how CLOSETED it's been has made me more open about it . . . . rather than feeling that I need to ashamed and that I'm a dirty little secret . . . It's like the more people know about it, the more free I can be.*

Unequivocally as Helen indicates, our society inculcates its members to aspire to ideal albeit rarely realized notions of attractive, healthy, perfectly functioning, normal bodies (Hughes, 2002). These unattainable carnal mores, emanating from social practices and discourse perpetuates the myth of bodily perfection (Stone, 1995) that our bodies are invincible and that "bad things" like chronic illness will not happen to us if we assume responsibility for our health and well-being. Helen comments that women who "deviate" from such fantastical standards of social acceptance become "rejected bodies" (Wendell, 1996) and "rejected others," inspiring deep-seated fears because they are constant reminders to people who (falsely) believe they are currently measuring up that they might slip outside of these ideals (Davis, 2005; Stone, 1995; Wendell, 1997). Bolstering this view, Atkins and Marston (1999) hold that fear and distancing from the unwell relates to the trepidation of becoming ill and/or disabled. They infer, "everyone may, at any moment, become disabled. And most people, if they do not die young, will become disabled. To avoid confrontation with the vulnerability of the body, those not yet disabled [fear and] stigmatize those with disabilities"

(p. 12). Illuminating the importance of giving voice to the subjective experience of disability as a way of eroding societal ignorance and misunderstanding that colludes in the oppression of chronically ill and disabled women, Morris (1991) offers:

> The experience of ageing, of being ill, of being in pain, of physical and intellectual limitations, are all part of the experience of living. Fear of all these things, however, means that there is little cultural representation that creates an understanding of their subjective reality. . . to deny the personal experience of disability, is in the end, to collude in our oppression (p. 183).

In a riveting paper, Norah Vincent's (1999) cutting commentary reminds us that disability rather than ability is a better measurement for what is normal since life is but a brief window of ability between the natural states of disability. This ideological inversion serves as the radical foundation for an embodied politics that we need to build a more tolerant cultural legacy.

Ware (1992) argues that in carrying the burden of (un)settled-ness, women deprive themselves of talking about what is most on their minds and being supportively affirmed in their experiences (p. 353). Striving to bring such dialogic healing into the wider socio-political circle, Helen's words pave the way for debunking the tabooing of fragile, porous bodies like the vulvo-urodynic body that traverses the boundaries of appropriate containment and provokes feelings of aversion and anxiety (Kristeva, 1982; Shildrick, 1999). As a way of palliating cultural fears, Helen adamantly believes that women living with chronic illness and disabilities are responsible for educating others about the nature and implications of living with fluid bodies (Joachim & Acorn, 2003; Lowton, 2004; Vickers, 1997). Sharing Helen's vision, Pamela Moss (1999) contends:

> I sometimes think about giving in to ME [myalgic encephalomyelitis] and FM [fibromyalgia], and permit them to take over my life. . . . But I do not. I persevere

> [because] it is vital for me to assist in politicizing chronic illness as a disabling condition so that there is no dismissal based on otherness and no coercion to conform (p. 164).

Such libratory learning demands creating greater public consciousness of the psychic damage perpetuated by an extensive cultural ignorance of (un)settled bodies and the shaming associated with women's "body talk." In coupling the personal with the political (Stanley & Wise, 1993; Thomas, 2002), the intimacy of her everyday bodily experience with the social, cultural, and institutional structures and practices oppressively enveloping it, Helen equates how this destructive cultural silencing and mystification of more fluid forms of embodiment is a far worse fate to endure than illness itself.

> *What I want [others] to notice in looking at the photos and looking at me . . . is that PRIVACY is something you CAN talk about. For me, it's important MAKING IT VISIBLE. In the sense of not necessarily VISUAL but something you talk about, something you hear about, something people know about . . . . By creating all these taboos, by not letting people talk about it . . . you are HARMING ME . . . And so I want to say, get over the fact that you don't want to see a picture of a vagina. Here it is! If we're afraid to talk about our bodies and afraid to talk about what's happening, there's not going to be [any] support. Not only are people harming individuals with these conditions but I think ultimately, in the long run, they're harming themselves.*

Advocating the transformative power of photography as a medium for taking control of the representation of (in)visible disability including its negative aspects, for bringing her personal experience visually and conversationally out of the closet and into the public eye, Helen endeavors to pierce society's carnal valhalla and the harmful attitudes that sustain her shameful secrecy. Here, (in)visible disability is exhibited not as a voyeuristic spectacle but as an illuminative gateway that asks us to question our habits of seeing and thinking about the cultural signification of bodies.

> *I think for me, this experience, the vulvodynia, has been about SEEING THE UNSEEN or you know, paying attention to what we tend to ignore . . .we can't ignore these problems and these issues. This is something that has to be more*

> *visible. This is something that needs to be discussed more. This is something that needs to be researched more.*

Joining Helen in igniting different ways of noticing, of making (in)visible disability more socially visible, Lynda imparts her own vision urging the reader-viewer to transcend their own myopic, stereotypic thinking about disabled bodies in favor of embracing a pluralized conception of human embodiment. Since women living with (in)visible disabilities occupy a range of subject positions just like anyone else, it is important, as Lynda stresses, to remember that identity simply cannot be read off the body in a simplistic manner.

> *I hope that people will see people in a wheelchair or with a cane or a walker and look beyond that and say to themselves . . . that person has a whole other dimension. We do, or I used to, see someone who is disabled and just think they're disabled. To recognize they have a lot beyond the label. That's the whole purpose of doing your PhD thesis is to get people to think critically about the issues. Anything that opens people's eyes and makes them question their premises is a very, very viable thing.*

Silencing (un)settled-ness and marginalizing those who have the courage to speak out about its alternating presence in their lives sustains embodied divisions between (un)healthy and/or (dis)abled persons in society. By remaining culturally wedded to fictitious assumptions and illness-related fears, we deny others the truth of their subjectivities rather than fostering a climate for compassionate understanding and opportunities for wider support for all individuals living with (in)visible disabilities now and those who will experience disability in the future.

Building on Helen's standpoint, Angie believes that educating others by dismantling the cultural tabooing of disability talk through photography paves the way for creating an alternate, less daunting space for connecting bodies and lives together beyond words. By relying on visual expression to entice the reader-viewer beneath the skin of MS, Angie candidly explicates the phenomenal carnality of an (un)settled embodiment without the threat of hurtful reprisal.

> *I think that people have predetermined ideas about disease and disability. If you say like "MS," and free-associate with like thirty people, you'd probably come up with very similar words . . . like it's a disease, probably brain, I think you can't walk maybe . . . Or my mom had MS.*
>
> *For a lot of these (in)visible or transient diseases, it's like people are relying on you describing in words what you're going through. And sometimes you just don't connect to that and maybe a photo will speak in a way that you weren't able to use language . . . . it speaks for itself where maybe you can't or you're too afraid or you have no words or it's taboo.*

Most notable in lieu of Angie's thoughts is that her visual portrayal, unlike the self-works of the other participants, is a visually anonymous albeit gripping personal, sensory depiction of her experience with multiple sclerosis. However as Angie infers, it is exactly the innocuous magnetism of photography, its antithetical propensity to both statically capture and resist capture of the mobile essence of her (un)settled body that harbors an equally disclosive and transformative power. Clearly, it is Angie's intention for the reader-viewer to assume responsibility to fill in the absences, to imbue her images with meaning, physical sensation, emotion, and "lives lived." It is a call to move beyond the realm of insipid, sterile language and rigid cultural constructions and into the uncharted waters of a visceral, connected body-to-body knowing.

Summary

To review, living with an (in)visible disability is a private reality that is not willingly shared among study participants. While Angela, Angie, and Helen prefer to shoulder the burden of secrecy, there are particular moments that demand the disclosure of their shifting bodies. As a form of identity management, unburdening the fluctuating realities of living with an (un)settled embodiment is not a finite decision but rather an ongoing process of deliberation about who, when, and how to reveal seemingly (un)convincing information about oneself as dually inhabiting and moving between the worlds of health and illness. Rarely a welcome experience because of a primarily healthy, able-bodied appearance that often contradicts the severity of shifts in the material body, coming out of the revolving door of (in)visible disability exposes women to bewildering silences. These silences suspend interpersonal communication and hold the potential for stigmatization, social rejection, cultural misunderstanding and many times, unsolicited commiseration. Consequently, "coming out" as (un)well takes place within the context of supportive others including family members, partners, close friends, and at times, other women living with disabilities who can empathize and validate a woman's shifting embodiment.

In different ways, the women's portrayals convey that it is important for both (non)disabled others to "get it," to be willing to understand that which is not always readily visible, that fluctuates, that (un)expectedly appears in one situation but disappears in another. This does not imply that other people in the participants' lives are not privy to disclosure but rather relational dynamics, temporal concerns, and context play significant roles in determining the degree of boundary access the women grant others about their lives. Other factors also influence the variable nature of disclosure. For instance, Angie relays how unburdening the reality of her (un)settled body depends on whether her flare-ups culminate in a "happy ending." When cyclic flare-ups leave no evidentiary traces of disability, disclosure is a welcome opportunity because the moral of the story is a promising one. This differs from Helen who depicts disclosure as an "all or nothing" determination that hinges on how notably her pain behaviorally interferes in her life or the extent to which it is socially visible.

As Angela's story evinces, unburdening an (un)settled embodiment is also characterized by indirect or vicarious disclosure. Angela describes how her son (un)intentionally reveals her disability to others and how this indirect telling serves to preserve her dignity and minimizes the fear, shame, and emotional trauma of self-claiming a partially disabled identity. This form of unburdening an (un)settling disability emotionally distances Angela as a person from the condition of MS. In this vein, the disclosure of MS is more a factual declaration rather than a risky undertaking in arguing a credible (dis)abled self. Equally relevant, unburdening the secrecy of an (un)settled embodiment does not always rest directly with personal choice. Others who live with invisible disabilities themselves and have knowledge of a participants' disability can vicariously disclose with the intention of protecting their physical welfare and assuaging the potential for misunderstanding. At the same time however, this kind of solidarity can (un)intentionally violate a participants' personal privacy and psychological safety.

Akin to secreting, non-disclosure protects participants' self-worth as "more or less" normal and able-bodied despite fluctuations in health. Within the context of this study and as reported in the wider chronic illness literature, disability, especially when it is invisible or in this case, shifting in degree of visibility and severity, is perceived as a private matter. The same cultural tabooing of disability talk enveloping secrecy similarly manifests itself in relation to disclosure decisions. On the other side, given that a fundamental challenge for the women in this study is the crediting of their (dis)abled subjectivities, unburdening an (un)settled embodiment is experienced as an empowering personal catharsis for divesting feelings of guilt, shame, and dishonesty that wreak psychic havoc on a woman's health. By revealing their true selves in all their complexity, participants defend the legitimacy of their (un)settled bodies and position themselves for leading more authentic, effectual lives.

Equally significant, disclosing a fluid embodiment, as Helen implies, joins the privacy of personal experience to its wider social recognition. Helen indicates that it is the responsibility of women living with (un)settled bodies to conversationally take (in)visible disability out of the closet, educate others, and eradicate the shaming silence of (un)seen illness. By speaking openly about their bodies and lives and making them visible through photographic portrayals, participants foster a cultural and political awareness of (in)visible disability as part of the larger diversity of all bodies in society. Equally relevant, by socially sanctioning the credibility of bodies that (in)visibly orbit inside and outside of (dis)ability, participants destabilize wounding stereotypes, attitudes, and flawed assumptions that oppressively infiltrate their lives and that kindles the misunderstanding surrounding (in)visible disability.

While secreting, blending-in, and disclosing one's identity is contextually paramount to living with an (in)visible disability, there are many facets of (un)settled embodiment that remain unseen and unspoken. In the final interpretive chapter, I draw in-depth on Lynda's narrative to illustrate the (in)visible emotional world of an (un)predictable embodiment as progressive loss.

The Sixth Movement

Chapter 12

(In)Visible Wounds

In chapters 9 and 10, I explore the ways in which women living in-between periods of health and illness manage and enact their fluid identities by secreting and blending-in their (dis)abled selves across ordinary life moments. I then examine the interpersonal dynamics and contextual considerations that impel or dissuade women to unburden their fluid selves. In this final interpretive movement, I expand my analysis into the (in)visible emotive world of the volatility of (un)settling illness as loss and touch on its impact for self-identity. In doing so, I draw chiefly on segments from Lynda's narrative. Differing from Angela, Angie, and Helen who live with less visible, remitting phases of illness, Lynda's MS unfolds into a visibly incessant cycle of loss and mourning given its slow but steady progression. No longer requiring a strategic presentation of self, the essence of Lynda's experience piercingly illuminates the (in)visible "emotionality" or self-feelings (Denzin, 1984, p. 3) of living with the progressive losses associated with an unsettled body. While Lynda must continually adapt to a visibly disabled body and identity, my focus is not on negotiating somatic alterations but is concerned with its hidden "felt" dimension. Giving voice to the emotional interiority of unsettled-ness as loss, Lynda relays:

> *When I think of (in)visible disability, I think about the things you don't see when you say this person has MS . . . . To me it's all EMOTIONAL . . . . Disability is not really what happens to you; it's how you deal with it. So obviously, I don't deal with it all that well which is, that's okay. I'm not going to beat myself up because I don't deal with it well. Because nobody's handing out awards for dealing with it well. I don't care. I don't deal with it well. Who does?*

Pointing to the silence surrounding the visible and invisible emotional world of an unsettling disability and my interest as a researcher in this lived experience, Lynda comments:

> *A lot of things I've never really articulated . . . It's such an unusual experience to just sit and ramble and you're not asleep on the floor . . .You're the only person who ever asked.*

Reiterating this shadowed dialogue, Angie exclaims:

> *Its things like this that people don't talk about. That fact that a physical ailment can have SUCH, can lead to such HUGE changes in your MENTAL LIFE, your relationships with other people. People talk about the physical ramifications and they don't really talk about (short pause) they talk LESS about the OTHER STUFF which is personally, way more interesting.*

For Lynda, the essence of her progressive MS reflects a gradual fading away of familiar, valued selves and the perpetual grieving from a socially visible existence to an invisibly "invalid" one (Lubkin, 1986). Since emotions are integral to our being (Freund, 1990), (in)visible chronic illness is a threat not only against the body but the embodied self (Toombs, 1992). Attentive to this relationship, the heart of this chapter invites the reader-viewer to witness how unsettledness emotionally stalks the human spirit. Cognizant of the Dickensian bleakness our society ascribes to disability coupled with Frank (1995) and Wall's (2005) assertion that one of our most difficult duties as human beings is to listen to the voices of those who suffer, I present Lynda's account mindful that some readers will fear her story, tucking it into the back of their minds, and that others will compassionately listen and remember.

Basing my analysis within the emotive world of (in)visible disability, I organize this chapter in relation to three cohesive themes: woman interrupted, lost opportunities, and (dis)connections. Each of these themes highlights the (in)visible emotive world surrounding an (un)settled embodiment as loss. While many of these themes exemplify issues related to adjustment, coping, and the reconstruction of identity, these areas, while extensively documented in the chronic illness literature (Charmaz, 1995, 1997; Corbin & Strauss, 1988;

Dewar & Lee, 2000; Miller, 1992; Pollock & Sands, 1997), are beyond the interpretive scope of this chapter. Following Carol Thomas (1999) who believes that any introspective study of disability must tap the inner landscapes of our interior worlds, I present this chapter not as a comprehensive analysis[13] but as an enlightening portrait touching on the subjectivity of private suffering and its oppressive socio-cultural bedrock.

Woman Interrupted

Loss is a silent unending experience that is an inherent part of the lived experience of being-in-the-world with chronic illness (Michael, 1996; Schaefer, 1995; Stone, 2007; Vickers, 2001b). This is particularly evident for a number of women like Lynda inhabiting the "downward phase" of the illness trajectory (Corbin & Strauss, 1988). In their text *Unending Work and Care*, Corbin and Strauss (1988) discuss this downward trajectory as the nexus of loss among the chronically ill.

> By definition, bodily deterioration is the chief physical feature of a deteriorating phase. Translated into bodily limitations and then into behavioral and interactional limitations in performance, this deterioration leads the ill . . . to modify or cut back on or cut out certain activities (p. 255).

Although the intensity of loss varies, an (un)settled embodiment produces a barrage of unpredictable and unwanted physical, functional, and social changes that biographically disrupts a woman's customary way of life, plans, and expectations (Asbring, 2000; Boeije, Duijnstee, Grypdonck, & Pool, 2002; Bury, 1982; Charmaz, 1997; Ohman et al., 2003; Stone, 2007). Pioneered extensively through the work of Michael Bury (1982, 2000), the idea of biographical disruption, introduced earlier in chapters 2 and 4, involves the onset of cataclysmic bodily disorder that corrupts an individual's self-identity and self-worth

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[13] I develop this chapter as a starting point for further investigation into the emotive world of (un)settled embodiment.

(Charmaz, 1983; Paterson & Hughes, 2000). Taking us further into the meaning associated with an (un)settled embodiment as biographical interruption, Charmaz (1983) notes:

> Chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones. The experiences and meanings upon which these ill persons had built former positive self-images are no longer available to them . . . Over time, accumulated loss of formerly sustaining self-images without new ones results in a diminished self-concept. . . As they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and futures, affected individuals commonly not only lose self-esteem, but even self-identity (pp. 168-169).

Moving from a very active to a very passive way of life in living with an (un)settled body has an omnipresent emotional as well as existential basis. The more fulfilling a woman's life prior to the onset of illness, the more emotionally devastating the trajectory of (un)settled embodiment (Asbring, 2000; Kralik, 2002). Considering the explosive magnitude a shifting embodiment entails, women living with steadily degenerating bodies amidst periods of protracted stability emotionally "feel" the variability of their bodily losses (Charmaz, 1995). Sustaining this point of view, Denzin (1984) denotes that emotions have a lived realness that constitutes an interior essence or core that radiates through our inner and outer streams of experience. Denzin posits, "the feeling person, the person in emotional consciousness, feels his[her] self in emotion. Feelings disclose the person to him[her]self" (1984, p. 51). It is the emotional pain (Bendelow, 2000) or hidden psychic aspects of living with the loss of abilities that comprises an (in)visible form of suffering among persons living with chronic illness (Charmaz, 2000; Morse, 2000; Olsson et al., 2004; Vickers, 2001b). Ohman et al. (2003) define suffering as the emotional response to an anticipated future that is lost or destroyed or to a changed expected present. Corroborating this contention, Corbin and Strauss (1983) stress:

> When a severe chronic illness comes crashing into someone's life, it cannot help but

> separate the person of the present from the person of the past and affect or even shatter any images of the self held for the future. Unless the illness is mild or its effect on activity is relatively negligible, who I was in the past and hoped to be in the future are rendered discontinuous with who I am in the present (p. 49).

Granting this conceptualization, Cassell (1992) and Stark and McGovern (1992) reason that suffering is a private, subjective experience unique to the individual that typically occurs within a milieu of silence. While the nature of emotional suffering shifts with the experience of chronic illness from simple transitory discomfort to extreme anguish or despair (Michael, 1996), it is often an all-encompassing experience (Starck & McGovern, 1992, p. 27). Freund and McGuire (1999) stipulate, "loss make[s] an illness experience profoundly disruptive. People actively grieve because the loss of functioning represents a loss of integrity- the wholeness of the person and being robbed of the future" (p. 140). Describing an imminently failing body that is beyond her control, Lynda expresses how the uncontrollable, increasing functional losses associated with her MS reflects an endless state of mourning and by extension, a heightened self-consciousness that she is no longer the person she once valued and knew.

> *For the person trying to understand disability, it's a constant mourning process. You're in mourning constantly and being reminded constantly of what you can't do. . . . I keep losing abilities day-by-day . . . Most days it feels like I can't do as much as I did yesterday. . . Its losing ground I call it. Losing altitude. I'm like on a plane that's falling out of the sky.*

Coinciding with what Lynda refers to as "losing altitude" or witnessing a plummeting bodily wreckage, Charmaz (1983, 1995, 1997, 2002) reinforces that the body once taken for granted in health dramatically spirals out of control in chronic illness, shattering the unity of one's prior embodied self. Given that mobility is a major marker of independence in our society (Becker, 1997, p. 96), the physical "loss of doing" (Michael, 1996) and the inability to control one's self and life in ways hoped for erodes self-esteem and self-identity over time (Lubkin, 1986; Reynolds & Prior, 2003). Confirming this reality among women living with (in)visible chronic illness, Marris (1996) claims that we live in a society which values good health, physical fitness, and wholeness, a society which values people for doing rather than for existing, for being active rather than passive (p. 19). Indisputably, as Lubkin (1986) and Pollack and Sands (1997) confirm, the loss of independence attests to a form of grief and suffering among women living with an (un)predictable deteriorating body.

One of the main definitions of normality in our culture that is an essential part of one's biographical intactness and self-identity is the ability to engage in paid labor (Marris, 1996). As a former business manager, Lynda's identity was physically and socially woven around a mobile, fast-paced lifestyle of organizing events and socializing with clients. Lynda juxtaposes her previously meticulous, productive, dynamic self with her progressive bodily decline and efforts to retain control over the scattered remains of her functional independence and self-worth.

> *I was a business executive and I had a daily agenda and a daily "to do" list and did ongoing strategic planning and I was, a million details and I was controlling all of them. That is a big part of you if you are a business operator or a business manager that you like to control, you like to oversee details and you like to create order in the universe. That's displaced. Now what do you control? Now what do you organize?*
>
> *It's an important concept- control and self-worth. Grocery shopping is pretty much the last thing I do outside the house that gives me any sense of self-worth. I dread the day when I will be inevitably, maybe forced to relinquish the job to my husband on a permanent basis. I actually enjoy the task despite the challenges. . . . It gives me a last vestige of control . . . I'm stubbornly hanging onto it until it becomes impossible for me to do it. . . . Once that's gone, it's one of those very few things that make me feel I have value . . . . this is my only regular excursion outside of the house that gives me any sense of accomplishment.*

Given that the social expectation and personal experience of control is so strongly valued in our culture, loss of control over one's body as Lynda avers, is a direct assault to her sense of self as a valued and valuable person (Freund & McGuire, 1999). Echoing Lynda's sentiments, Miller (1997) and Kralik (2002) insist that women fear that if they do not maintain some independence and normalcy in their lives that they will lose ability to do so altogether when faced with the (un)settling trajectory of MS. The struggle for control in chronic illness is thus a struggle between combating further losses and feeling controlled by one's condition (Charmaz, 1997, p. 260). Lynda's words clearly depict the chaos of a body, personhood, and universe that are no longer self-determined but rather existentially precarious and spiraling out of control. While constantly reminded of all the activities she can no longer accomplish in the course of daily life and the crushing feelings of sorrow and defeat associated with this, remaining activities such as grocery shopping buffer the painful endurance of endless physical decline and Lynda's increasing invisibility from the social world and from herself.

Illuminating a further example of how her gradual loss of mobility and functioning is (in)visibly wounding as it radically impacts her sense of accomplishment and personal value, Lynda reveals:

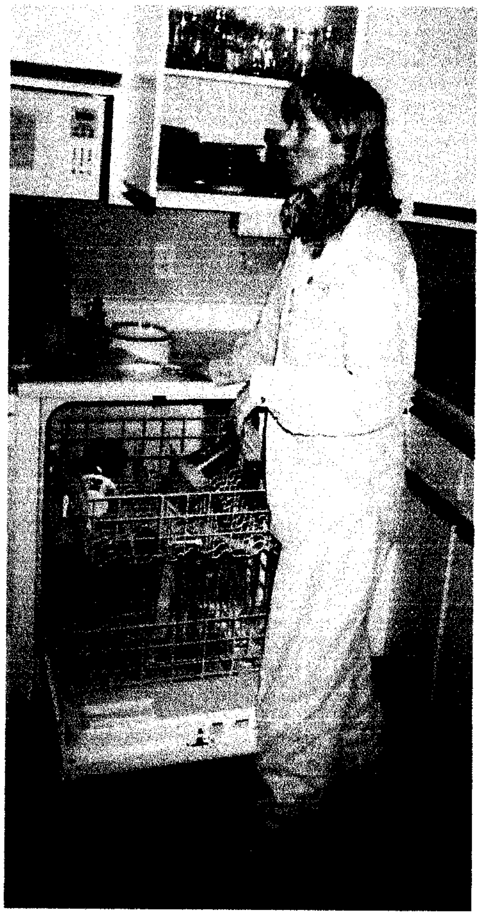

Figure 35: Kitchen duties.

> *I no longer walk very much but at least . . . kitchen duties make me feel useful. Cooking doesn't require that much squatting and bending and there's counters to lean on and all that kind of thing. I have to take a lot of sits, a lot of rests . . . . Anybody seeing me in the kitchen or cooking just wouldn't realize how desperate I am to keep doing it because there's just so little I can do . . . I mean all this stuff is so invisible. These things tear me up. Anything that you can do physically becomes SO DESIRABLE.*

Maintaining her ability to shop and prepare meals provides Lynda with a sense of routine, normalcy, and usefulness in contributing to the care of others. Although keenly aware of her impending functional losses, being able to grocery shop, plan, and cook meals instills a sense of pride and enables Lynda to exercise autonomy and control in her life in the midst of her degenerative disability. Whether in the grocery store or in the kitchen, Lynda occupies a visibly significant "place" in the world where she resists the ravages of (un)settling illness.

The significance ascribed to these activities not only instills a sense of calm over a chaotic body but also bestows momentary coherence and connection in Lynda's everyday life. It is these ordinary moments and their emotive import within the scenes of Lynda's everyday life that otherwise go unnoticed in the flow of our own lives and in the lives of those with (in)visible disabilities.

The centrality of the body lies in its capacity for action. Envisioning the inevitability of losing one's physical capacity to function as an autonomous adult is a frightening experience. We depend on our bodies to functionally perform in desired ways. Trusting our bodies and exercising the freedom to live our lives the way we choose secures our individuality. Prematurely incurring the harrowing experience of physical degeneration, of having one's life interrupted by illness, is something that we believe naturally occurs in old age rather than in the prime of adult life. As a cultural value, Sveilich (2005) comments that physical dependency is associated with human failure (p. 54). Our culture teaches us that if we can no longer physically do things, we no longer matter as people. This socially enshrined way of thinking has colossal affective implications for living with a progressive chronic disease.

With a continual loss of functional mobility, Lynda increasingly perceives herself as a "burden" because of her mounting physical reliance on others. This shameful self-conception and the feelings of vulnerability and powerless it denotes strips away Lynda's self-worth day-by-day, standing in stark contrast to the way Lynda wishes to be perceived based on her former able-bodied identity and roles (Charmaz, 1983; Galvin, 2005). In their work on women living with breast cancer, Meyerowitz, Chaiken, and Clark (1988) maintain that disabilities are particularly adverse when they disrupt a woman's actual or perceived abilities to perform important, self-defining social roles. Stressing the significance of this loss, they endorse the view that "not only must women deal with the immediate fears, emotional reactions, and physical impairments that typically accompany a life-threatening, disabling disease; she may also face an unexpected sense of rolelessness and a sudden assault to self-esteem" (p. 73). Mindful of this scenario, the gradual loss of mobility and functional abilities consequently necessitates the negotiation of new and often undesirable roles in relation to others (Dewar & Lee, 2000; Dyck, 1995; Freund & McGuire, 1999; Lubkin, 1986; Robinson, 1988).

As a woman who should be healthy and capable of independent care, one of the most humiliating and emotionally devastating facets of living with MS for Lynda is becoming exceedingly reliant on her aging mother (Donoghue & Siegel, 2000, p. 67; Charmaz, 1983). Relaying the disgrace and personal mortification she feels but that remains unseen by those around her given her pictorial cheery countenance, Lynda declares:

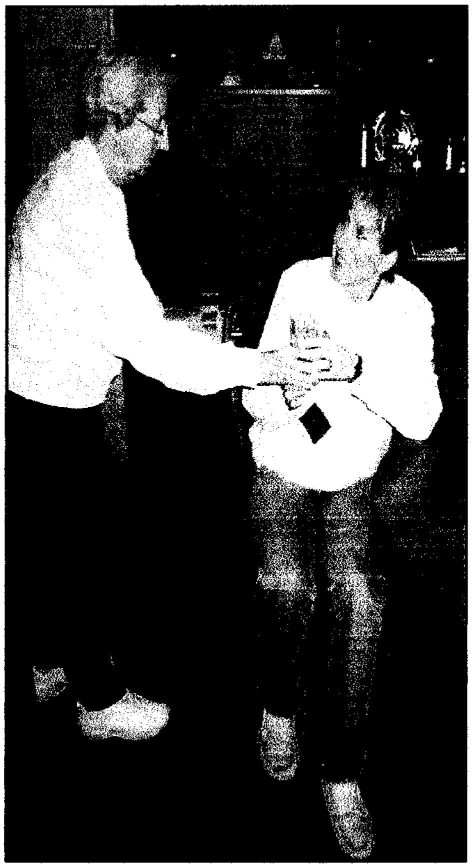

Figure 36. Being served.

> *This is a big part of [in]visible disability. That's my mother . . . WAITING ON ME. And that's just an awful part of my disease. I mean my mother's seventy-five years old and it used to be that I had lots of energy and I waited on my mother . . . . At this point in our lives, I'm supposed to be waiting on her. . . . SHE'S SERVING ME. . . I hate it. I just hate it.*

The loss of physical functioning and control over her body is a direct assault on Lynda's personhood because of the meaning she invests in being self-sufficient and participating in equally valued ways in significant relationships (Freund & McGuire, 1999). Robinson's (1988) seminal research on the lived experience of persons with multiple sclerosis indicates that physical dependency not only demands a restructuring of social roles but more importantly, undermines the reciprocal value of relationships (p. 63). This reversal of roles is demeaning to self-identity because many women like Lynda have little control over their bodies and their disease progression (Charmaz, 1983). Lynda insinuates how guilty, "shamefully useless," and vulnerable she feels in being physically powerless to help her elderly mother as she did when she was able-bodied (Charmaz, 1983; Driedger, Crooks, & Bennett, 2004; Raheim & Haland, 2006). This self-deprecation, similarly cited by Olsson et al. (2003) in their study of women living with multiple sclerosis, is deeply rooted in ableist discourse that equates full humanity with wholly functioning, perfect bodies. Moreover, inculcated cultural expectations among women (and daughters) in our society to nurture and care for others is antithetical with the experience of a progressively unsettled embodiment.

The feelings of personal inadequacy and indignity that Lynda reveals are also concealed manifestations of disablism (Thomas, 1999) that envelop some individuals like Lynda in a web of silencing despair. Similarly observing his own experience in living with quadriplegia, Robert Murphy (1990) proclaims:

> Whatever the physically impaired person may think of [her]himself, [s]he is attributed a negative identity by society, and much of [her]his social life is a struggle against this imposed image. . . The greatest impediment to a person's taking full part in [her]his society are not [her]his physical flaws, but rather the. . . myths, fears, and misunderstanding that society attaches to them (p. 113).

Following Murphy, Jenny Morris (1991) discusses the nature of damaging cultural ideals and representations that influence this kind of insufferable condemnation:

> We receive so many messages from the non-disabled world that we are. . .considered less than human. . . . A physically different body, or a body which behaves in a different way, means an incomplete body and this means that our very selves are similarly incomplete. . . Non-disabled people's judgments about disability undermine our very existence (pp. 26-27).

It is acutely evident from Lynda's narrative that the ways our culture negatively constructs disability as a tragic, dependent existence that offers little promise for any kind of quality of life sears the flesh, leaving visible scars and familiar memories of a better, more productive life. Such reprehensible thinking, still evident in our society today, preserves the despair and hopelessness some women like Lynda experience in their daily lives.

At the same time, scholarly and activist indictment encouraging persons with disabilities to renounce culturally ingrained images and norms when physically and emotionally suffering the exigencies of disease "in the moment" is also I believe, dangerously glib. Unquestioningly, the place of emotions, of the feeling and meaning-making individual, is endemic to that which constitutes us as human and has particular importance in the lives of many women living with disabilities. It is important to acknowledge and validate the hidden and painful aspects of (in)visible disability because these are part of the realities of many women's lives. Indeed, as Denzin (1984) reminds us, this emotional meaning is commonly hidden or distorted by scientific understanding and I believe is further stifled because the (non)disabled reject its place and significance in fostering attitudinal and social change. Attentive to the emotive world of (in)visible disability and building on Denzin's argument, Morris (2001) raises an analogous concern that within our society there is neither room for celebrating different bodies nor recognizing the negative aspects of impairment without undermining the value of the lives of persons with disabilities. She insists, "I worry that if we do start talking about the painful (and valuable?) aspects of living with impairment and illness, non-disabled people will turn around and say, "there you are then, we always knew that your lives weren't worth living" (p. 10). While Morris's fear is valid, I believe that glossing over the profundity of emotional experience in women's lives as Lynda's narrative demonstrates, sustains the personal as private and the experience of suffering as unutterable and apolitical.

Lost Opportunities

Grieving a body that is calm one moment with its present limitations and unsettled the next with increasing incapacity connotes not only living with the (un)certainty of physical and functional loss but with a more global attenuation of control over life circumstances and choices (Charmaz, 1991; Kralik, 2002; Miller, 1997; Vickers, 2001b). Since our society emphasizes what we do rather than who we are, individuals who cannot perform conventional roles and meet social obligations consequently lose the very means needed to sustain a personally meaningful life (Charmaz, 1983, p. 191; Donoghue & Siegel, 2000). This is especially evident as Asbring (2000) indicates in relation to how an increasingly unsettled embodiment encroaches upon a woman's sense of self as defined by her occupational identity. This traumatic alteration from a recognizable to an unrecognizable self is enmired in the privacy of emotional suffering. Here, advancing disability interrupts participation in the daily round of life, crushing a woman's sense of self and social identity. Former ways of life and anticipated opportunities are replaced with new routines, revised expectations, and an altered albeit not necessarily accepted identity that accounts for increasing disability (Charmaz, 1991; Michael, 1996; Moss & Dyck, 2002).

Given the nature of some progressive disabilities, biographical recasting is sometimes impossible because of the lack of control over one's illness trajectory (Corbin & Strauss, 1988). Lynda describes how living with the anguish of her unstable body bespeaks a deep-seated chronic sorrow that Flesner et al. (2003) and Hainsworth (1994) correspondingly identify among persons living with multiple sclerosis. Originally coined by Olshansky (1962) in his work with parents of children with intellectual disabilities, chronic sorrow is a permanent, periodic, and progressive state characterized by feelings of sadness, anger, frustration, guilt, and fear (Hainsworth, 1994, pp. 237, 240). Complicated by feelings of envy, reminders of unfulfilled life goals activate this (in)visible pervasive sadness for Lynda in relation to the unconstrained, upwardly mobile lives of her non-disabled friends.

Figure 37. **Left behind: Visiting a friend's design studio.**

> *I live with envy and it's very much a part of the invisible disability . . . I don't even know if envy is the right word . . . I wish things were different. So I guess envy is what it is but its not. It's not that I covet what [others] have; I just covet their choices.*
>
> *This is my friend's interior design studio in Oakville. I wanted this photo because it's representative of how my friends have sped ahead. Now they're all in their forties, in their peak earning power and at the height of their careers . . . and I'm out of a career altogether and that's an invisible part of it that is agony. It's just agony. It's very painful to stand by and watch them continue to climb the career ladder while I*

> *can't. They're heading on up and I'm . . . heading on out to no-man's land watching everybody succeed . . . It's hard to swallow your ambition . . . . I'm not the one going anywhere when I was always the one going places.*
>
> *It's really a defeatist train of thought to think about what would have been or what could have been . . . But in my situation, there are a lot of opportunities to be grateful for what I have and there's a million, zillion opportunities to be miserable over what I don't have.*

The poignancy of this account evinces the manner in which MS shatters Lynda's lifeworld and occupational identity as a highly motivated professional and destroys all possibilities for a rewarding anticipated future (Moss & Dyck, 2002). Although Lynda endures her limitations, she grieves her previous invincible able-bodied self and the loss of activities and social worth associated with them (Asbring, 2000, p. 317; Asbring, 2001; Kralik, 2002). Buttressing this reflection, Galvin's (2005) study exploring the self-perceptions of persons living with acquired disabilities suggests that the imperative to work is fuelled less by the need for income than the vital mode of identification it provides (p. 404). Shedding further light on this observation, Royer (1998) posits:

> The ability to be productive is a highly valued trait in our culture. The chronically ill are like most people, socialized and wishing to have purpose and meaning in their lives; they want to contribute in some meaningful way. . . Having a chronic illness does not change internalized values and goals acquired by lifelong socialization processes. On the contrary, it causes reflection on life's accomplishments and an acute realization of the temporary nature of earthly existence (p. 147).

Most problematic is the manner in which the meaning associated with life-changing disabilities and its bearing on personal identity are culturally and discursively constituted. We live in a society in which one's ability to engage in paid labor (or not) is often a crucial determinant of social membership. While many activist-scholars (for example, Oliver, 1990) advocating a social theory of disability argue that a greater majority of disabled people could work if certain societal barriers were eradicated, this ideology further ingrains feelings of sorrow and oppresses many persons with disabilities like Lynda whose physicality regardless of accommodations, circumscribes their participation in paid labor (Galvin, 2005). Interrogating this attitude and exposing its toxic ramifications, Paul Abberley (1999) insists:

> It is certainly *not easy to challenge the imperative* to work because the expectation that everyone *should* work, both to earn a living and to define themselves, is so ingrained that to suggest that it is possible to develop a meaningful and pleasurable life outside it seems akin to heresy. It is vital to do so, however, or there will be many people who will remain 'disabled' by expectations which are unrealistic whether they are held by people inside or outside a social model view (cited in Galvin, 2005, p. 406).

What is less tangible and equally damaging in relation to women living with (in)visible disabilities and inherent in Abberley's address are the feelings of grief, sadness, and marginalization that claw the human spirit because of the experiential magnitude associated with such vanquished opportunities and the normative values they espouse. Reminded of the scope of her physical difference, progressive decline, and her isolation from the once familiar able-bodied working world, Lynda is not the person she ever envisioned herself to be. Instead, she has in essence, "lost herself." Picking up on this idea, Corbin and Strauss (1988) assert that when illness brings about a failed body and people are unable to perform tasks associated with various aspects of the self then certain parts of the self become lost (p. 65). Perceiving herself as someone no longer productively engaged in the world and missing out on life, Lynda is, in her words, a "woman interrupted." Resonating with Lynda's anguish, Boeije et al. (2002) reveal that lost plans and mundane wishes are commonly destroyed by the progression of MS. Life as previously experienced comes to a crashing halt and individuals must deal with what remains. Describing herself as hovering on the borders of a "no-man's land" in which she is alone and disconnected from a vibrant life of hopeful possibilities like her healthy friends, Lynda sinks into the oblivion of disability where she hovers between suffering and enduring her grief. Feeling empty and without meaningful direction, Lynda's words clearly attest to the (in)visible torment an (un)settled embodiment can entail. This agony as manifest in her everyday life, is very much an invisible and silent reality.

(Dis)Connections

Illness as Marris (1996) exclaims, is a solitary experience (p. 9). Living with increasing disability and the unpredictability of loss this inspires often incites social isolation and feelings of loneliness (Charmaz, 1997; Gulick, 2001; Lubkin, 1986; Royer, 1998). This alienation, and by implication, one's felt and tangible invisibility from the social world, is a veiled form of suffering of life with an (un)settled body (Asbring, 2000; Charmaz, 1983; Robinson, 1990). Royer (1998) refers to social isolation as a negative state of aloneness [and] or diminished participation in social relationships that incites feelings of being psychically alone in illness (pp. 65, 67). Reflecting on Lynda's narrative, I suggest that imminent bodily loss and the reality of a familiar life being torn apart as Lynda intimates, are inexorably bound with feeling socially, emotionally, and spatially isolated. Asbring (2000), Ohman et al. (2003), Olsson et al. (2004), and Royer (1998) confirm that loss of independence, autonomy, and the inability to participate in the workforce and other life activities precipitates feelings of despair in which one feels like an outsider who no longer belongs in the world, who is both alone and lonely in illness.

Charmaz (1991) maintains that as illness progresses, the individual feels confined within a shrunken world that exceedingly loses personal meaning and engulfs one in solitude.

> [The chronically ill] live narrow, restricted lives, which contrast sharply with the lives of other adults, who have more possibilities for constructing valued selves. . . . they suffer loss of friends and often drastically alter their lifestyles (Charmaz, 1991, pp. 172, 175).

While once inconceivable, Lynda attributes her social disconnection or "dys-placement" and the personal torment this implies to being "housebound" (Charmaz, 1991; Driedger et al., 2004; Kugelmann, 1999). Commenting on the physical isolation and desolation that living on the fringes of society evokes, Lynda contends:

> *Housebound is another key concept in my story. I'm pretty much housebound. It's a huge paradigm shift for a person who was never a homebody to become a virtual shut- in . . . . This is not the person I intended to be. I never, ever intended to be a stay-at-home person . . . . I don't work anymore, I don't do things anymore, I don't go places anymore. I don't even travel anymore . . . So all those things, all those dimensions in my life are not there anymore . . . my world is very narrow.*

Offering another illustration of the (in)visible narrowing of her social world, Lynda refers to her inability to shop in stores because she no longer has the mobility, physical coordination, and endurance to keep up with the frantic pace of crowds.

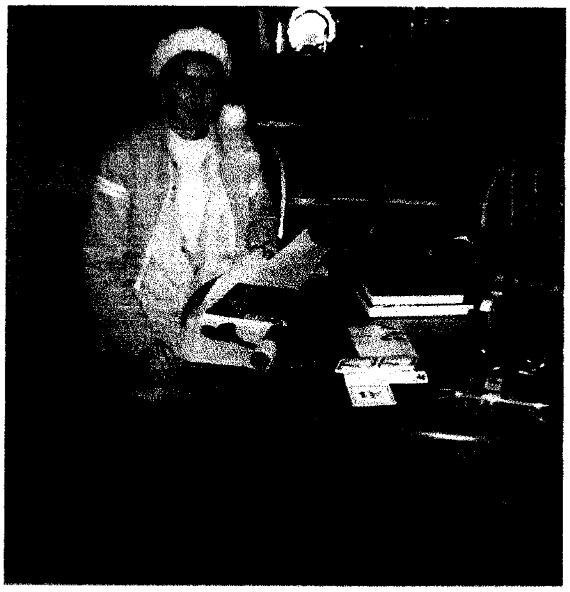

Figure 38. Christmas shopping on-line: Limited steps.

> *Shopping in many cases is out of the question. I usually give books as gifts because shopping on-line at Chapters requires no steps. That's another issue of [in]visible disability . . . . I can't go out to the stores and battle any kind of crowds. I can't handle the stress of crowds at all. To be with crowds you have to be coordinated. You have to be able to move and you have to be, you can't go slow. I can't get in and out of the stores in ten minutes. This is the first year I didn't go shopping in any stores at all . . . I wonder if people notice that there used to be a lot more trouble that went into getting their Christmas gifts.*

With a restricted number of steps available to her each day, Lynda's presence in the world is one of growing absence (Lubkin, 1986). Given her escalating physical decline and social invisibility, Lynda questions whether family and friends who receive books as Christmas gifts will attribute a lack of care and concern to such an "impersonal gift." In spite of the incongruity between Lynda's smiling expression in her photograph and the emotional intensity of her dwindling social participation, visually depicting her sense of "homelessness" (Kugelmann, 1999) from the social world makes this reality visible or knowable to family and friends who rarely, if ever, acknowledge this aspect of Lynda's world. Hence, it is only when this censoring and silencing of Lynda's isolation comes to the fore that the (in)visible emotionality of her life acquires sharper focus. By joining word and image, we enter into the color of Lynda's lifeworld, bearing witness to the hidden affective reality of (in)visible disability. The inevitability of bodily adversity and our impending mortality as human beings is something that we as a society ardently strive to keep in abeyance. Conveying this scenario as a form of disablism, Thomas (1999) insists that both the (non)disabled may consider the consequences of being impaired as private troubles (p. 48). Given this cultural inclination, keeping feelings private exacerbates personal suffering and estranges Lynda from receiving the emotional support she desperately needs in living day to day with her disability. Hence, it is not only the feelings of grief but also the intangibility of damaging social attitudes that silently plagues the lived experience of disability and strickens its presence from the world.

Lynda's physical decline breeds not only a withdrawal from social life but also an overall lack of spontaneity that further emphasizes her invisibility (Asbring, 2000; Marris, 1996). Unable to exercise the freedom to manage life, plan, and act as she pleases, Lynda must constantly acquiesce to the limitations of her body. Previously routine, unconsciously performed tasks become self-sabotaging, energy-sapping ordeals, findings similarly reported by Schaefer (1995) among chronically ill women and in Royer's (1998) work with individuals experiencing chronic illness. Elaborating this interpretive thread, Freund and McGuire (1999) concur that enormous attention surrounding mundane worries such as the location of restrooms, accessible entryways, and related issues are commonly at the forefront of (un)predictable illness and are constant reminders of the impact of disabling chronic disease on identity. Gibson et al. (2005) indicate that extensive planning surrounding the nature of illness in effect, weakens one's sense of mastery over a situation, reinforces feelings of being different, and constrains leading a normal life (Charmaz, 1991; Donoghue & Siegel, 2000; Michael, 1996; Royer, 1998). Delineating her sense of confinement and the alienation she experiences in being involuntarily at the will of her body, Lynda concedes:

> *Housebound to me is that if I didn't plan on it, I can't leave the house . . . So house-bound in the sense that I can't even leave the house . . . I'm not exactly a shut-in. I think of a shut-in as somebody who never gets outside. Housebound is you're pretty much confined to the house . . . . There's no spontaneity in my life anymore. And so a person unfamiliar with MS wouldn't appreciate that you cannot do something spontaneously. If it wasn't planned I can't do it because it means I didn't plan my food intake . . . [or] fluid intake. So I can't just get up and go. I can't be away from a bathroom . . . Those things that other people wouldn't think about. If I have anywhere to go, I have to know the day before because I couldn't leave the*

> *house now after all the coffee I've drank. It's all planned. I can't do any activity spontaneously.*

Charmaz (1997), Hakim, Bakheit, Bryant, Roberts, McIntosh-Michaels, Spackman, Martin, and McLellan (2000), Marris (1996), and Vickers (2001b) all document how alternations in social relationships unfold as the social world of the ill person increasingly narrows. The loss of interpersonal connections and the personal meaning invested in them, which was formerly a habitual part of Lynda's everyday work life, directly translates into an increasing state of loneliness and depression as her disability intensifies. This loss of social camaraderie and lack of belonging that Lynda identifies reflects one of the most (in)visibly calamitous aspects of living with the unsettled-ness of MS.

> *I don't have much in common with my friends anymore because I mean what we had in common was complaining about work . . . Now it becomes one sided "well tell me about your work" and I'm listening you know. Yeah, it's frustrating not to be able to contribute to the dynamic, the group dynamic like you once did . . . . Do these people that have bypassed you with success and experience, do they feel you even have anything in common with them anymore?*

Speaking directly to the intimate subjectivity of loneliness, Lynda describes her reliance on and fondness for her cats as embodying an alternate support network.

> *Loneliness goes part and parcel with being housebound. I've become excessively dependent on my feline companions for company. I'm alone most days . . . I don't think anyone who has a life outside the house can appreciate how important these pets are.*

Figure 39. Feline companions combat loneliness.

> *Any of us who stay home, shut-ins or whatever you want to call it, you have to have a cat. You can't have a dog because you can't take a dog for a walk. These cats, I talk to them all day long and they answer me back. I mean these cats keep me sane. If I didn't have these cats I probably would be lonely but I'm not because I've got these guys . . . they're my little microcosm, my good friends.*

While Lynda emphasizes that her feline companionship offers great comfort from suffering the vagaries of her disconnection from the social world, she also relays how the media, specifically reading newspapers and accessing the internet, makes her feel socially alive by vicariously connecting her with the external world. Beyond this connectivity, Ohman et al. (2003) indicate that activities such as reading a daily paper is a way of enduring or "getting through" the emotional distress of chronic illness. Lynda elucidates how the media is a vital conduit for curtailing feelings of social isolation and bridging her world with the lives of others.

Figure 40. Connecting through the media.

The information age has made it bearable for me. Staying connected via the internet mitigates feelings of isolation. Consuming two daily newspapers also does a lot to make me feel more a part of the world out there . . . . a daily newspaper is one of my greatest joys . . . . [it] keeps that experience of isolation away. Being in school or being at work generally keeps you connected to everything . . . especially if you're in business, it's your job to keep your ear to the ground and to talk to people and network and interact with everybody. Talk to your customers, talk, and talk, and talk, and talk . . . And all of a sudden bang! You're at home.

I'm not extrapolating any information from anybody . . . there's no interaction.
So . . . If I didn't have newspapers and the internet I would miss the interaction a lot more than I do. I don't miss it as much as I thought I would but these make a huge difference. The computer connects you and makes you feel part of things . . . . Because you're reading the same columnists everyday and they get to be your friends and that's a substitute for my interaction. You're still getting through the newspaper, through email, that emotional um, having the stimulation that keeps you from being a Zombie.

While Charmaz (1995) cites that people can find value in their restricted lives, I disagree in relation to Lynda's struggle for self-worth and meaning given her increasing disability. A considerable part of Lynda's social disengagement from the world, apart from her declining mobility, is a volitional form of negotiating a visibly escalating disabled identity. Supporting this view, Lubkin (1986) and Plach, Stevens, and Moss (2004) observe that social isolation may reflect a loss of self-esteem rather than the ability to participate in the social world (p. 89). Clearly, the way many women living with disabilities feel about themselves physically and socially as human beings has grave ramifications for the way they experience their identities and choose to live their lives. Since our feelings affect our thinking, Lynda's damaging self-appraisals as "decrepit," "pitiful," and "tragic" coupled with the emotional stress of relating to others who have a negative or misinformed attitude regarding MS reinforces her proclivity to domestically confine herself. In turn, this "invisibilization" sustains unrelenting feelings of loneliness, physical difference, unacceptability, and personal suffering (Boeije et al., 2002; Cassell, 1992; Gibson et al., 2005). Such evolving and enduring internment preys heavily on the soul[14] where Lynda's former able-bodied self is memorably alive while her identity as a woman living with a deteriorating disability becomes oxymoronically, a "living death."

"I Wasn't Always Like This": Being (In)Visible

As the root of one's personal and interpersonal identity, the body is the medium through which conceptions of the self are emotionally lived and formed (Corbin & Strauss, 1983; Denzin, 1984; Livneh & Antonak, 1997; Lubkin, 1986). Although it is beyond the intent of this chapter to fully capture the significance of body image within the context of

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[14] In this chapter, I refer to the word "soul" as equated with an inner self, the essence of our human being-ness.

disability-related loss and change, I do want to point to its emotional weight in being and feeling (dis)connected from the larger social world.

Visible changes in physical appearance, functional performance, and the visibility of mobility devices inspires shame and embarrassment among women living with the downward spiral of progressive multiple sclerosis because they violate the very essence of the self (Boeije et al., 2002; Lazare, 1992). Specifically, the nature and degree of bodily changes and the negative social appraisals they often promulgate acutely influence a woman's self-feelings and body image, defined here as the mental representation or schema of one's own body (Livneh & Antonak, 1997; Lubkin, 1986). Denzin (1984) reminds us that the emotions we feel are in many respects, a part of our imagined attitudes and judgments of social others across situations. Lynda repeatedly underscores the significance she assumingly ascribes to others' mournful perceptions of her as a decrepit, feeble, incapacitated woman in relation to the visibility of her canes and reciprocally, the ways these debasing observations reinscribes her negative self-image.

> *A lot of the disability issue for me is always what other people are thinking about me. I probably flatter myself to think that anybody even pays attention but I CAN'T HELP IT. I can't help thinking what will people think . . . . When I was able, when I was not disabled, it never occurred to me that I was so concerned about what other people thought . . . Its human nature.*
>
> *You see somebody all decrepit and useless and isn't that sad but you can't even imagine it. Five years ago, they were skiing, they we're running down the street . . . . I ASSUME people are looking at me and remembering me in the way I used to be cause I'm remembering the way I used to be. Every time you meet new people, you want to say, "I WASN'T ALWAYS LIKE THIS!"*

As Robert Murphy (1990) declares, in losing and mourning one's old self lost to disability, individuals like Lynda feel different, changed in their own mind, self-image, and in the basic conditions of existence (p. 85). As Lynda implies, negative self-perceptions and defeatist self-talk are both invisible to others and equally emotionally debilitating.

Figure 41. The party: Judgment day.

> *At this one party, there were people I hadn't seen in a long time and I knew they were going "Oh I wonder how much worse Lynda is from the last time we saw her? Oh look, she has two canes!" Even though maybe they weren't . . . I can't help thinking that they are making judgments . . . . You imagine that they feel sorry for you. Everyone knows you're "poor Lynda." So that's an invisible disability Anything that um, any thoughts that weaken me, any thoughts that you know, are disabling.*

Echoing the self-conscious, emotive acuteness Lynda describes within the scenes of his life with quadriplegia, Murphy (1990) comments:

> I cannot remember ever before thinking about physical disability, except as something that happened to other, less fortunate, people. It certainly had no relevance to me. With the onset of my own impairment, I became almost morbidly sensitive to the social position and treatment of the disabled, and I began to notice nuances of behavior that would have gone over my head in times past (p. 86).

Grounding Lynda's and Murphy's experience in its larger socio-cultural heritage, Thomas (1999) purports:

> [Our] 'inner world'. . . is closely bound up with socio-cultural processes which generate negative attitudes about impairment and disability, and sustain prejudicial

> meanings, ideas, discourses, images and stereotypes. These impact upon disabled people in diverse ways and can lodge themselves in their subjectivities, sometimes with profoundly exclusionary consequences by working on [one's] sense of personhood and self-esteem (pp. 47-48).

For Lynda, appearing before others with a disability that has deteriorated to the point where she needs to use two canes at a party magnifies her vulnerability in relation to the spectacle of disability. Within this context, culturally ingrained notions of disability as a pathetically debilitating experience seep into Lynda's consciousness in ways that become emotionally and socially paralyzing regardless of whether others actually think and hold these attitudes.

Taking another example, while exuding an upright posture visibly signifies the normal, autonomous, competent, moral template of able-bodied-ness and social belonging in our society, utilizing a mobility device as Lynda denotes, presages a spoiled identity that taints social contact by deeming her disabled embodiment as less than fully human (Diedrich, 2001; Goffman, 1963; Coleman, 1997; Michael, 1996; Toombs, 1995). Lynda explains:

> *To a person that's always seen herself in a certain way you just have never seen yourself as a person in a wheelchair . . . . The way I always perceive someone with a cane or in a wheelchair is that they're not able-bodied . . . . It's just a prejudice you develop over time. We pass judgment on people with mobility aids.*

As Sartre (1958, 1982) portends, when the (disabled) body is on display to the social gaze of the (non-disabled) other, it becomes a fallen object, experiencing shame and humiliation in its own objectivity (cited in Hughes, 1999, p. 162). Cementing this reality further, Garland-Thomson (1997b) comments that the non-disabled stare sculpts the disabled subject into a self-conscious spectacle, thereby "naturalizing" its visual field as it reinforces the difference between self (same) and other (different) (Hevey, 1993; hooks, 1995). While Lynda believes that using a scooter to shop socially magnifies her bodily difference, it paradoxically erases her disabled presence and more broadly, her value and identity as a human being. Laying claim to this observation, Zitzelsberger (2005) highlights how women's bodies are rendered hyper-visible with the use of adaptive equipment and their personhoods shunned or ignored (p. 394). It is only by embodying an erect posture upon exiting the store that Lynda engages with the non-disabled at "eye level," that her presence as a human being is "visible" and thereby personally and socially valid.

> *Being in a wheelchair, everybody treats you like you're invisible. When I'm in a wheelchair or on a scooter, I don't look anybody in the face because I don't want to see them look away. And I don't want to know that they're looking at me . . . I don't look anybody in the face when I'm on a scooter. Don't look at anybody's face. Then I don't have to feel bad that they're looking at me with pity or they're looking away cause I catch them looking at me or whatever . . . . It's that apparatus (the scooter) that conveys DECRETPITUDE . . . . I go through a whole store and don't look at anybody in the face except at the end when I stand up and cash out. Then all of a sudden, I'm looking at the cashier in the eye because I'm eye level. So I exist.*

Contemplating the loss of upright posture in her own life with multiple sclerosis, Kay Toombs (1995) reveals:

> Self-esteem is the easiest thing to lose with multiple sclerosis. . . . This is a culture which places great value on physical fitness, sexuality, and youth. The person who staggers, wears a brace, uses crutches or a cane is far from the ideal. No matter how much one tries not to "buy into" this cultural imperative, the negative response of others is hard to ignore (p. 16).

Analogous to Linda and Kay Toomb's social erasure, Nancy Mairs (1990) comments:

> I had to adjust to the most outward and visible sign of all, a three-wheeled electric scooter. . . it shouts to the world "Here is a woman who can't stand on her own two feet." At the same time, paradoxically, it renders me invisible. . . . I want to shout "Down here! There's a person down here!" But I'm not . . . quite a person anymore (p. 89).

Culturally linking stigmatizing constructions of bodies characterized by discernible stigma symbols such as wheelchairs as weak, misfortunate, dependent, shameful, vulnerable, and incompetent (Goffman, 1963; Tighe, 2001) to a cultural ocularcentrism, a visual aesthetic scaling of bodies (Young, 1990), Hughes (1999) purports:

> The 'gaze' is a carnal point of view. . . of the seer, not the seen. Vision is an act of judgment. . . . When a person with an impairment encounters a discriminatory gaze- be it institutional or personal- she encounters- not a pure look-but an act of invalidation . . . the non-disabled gaze is disfiguring yet it assumes itself to be an act that identifies disfigurement. . . . The 'condition' is visualized as an abnormality, a dysfunction, a pathology, a flaw, a fault, a deficit, a lack (of wholeness). . . It spills into the language of disorder and the judgment of tragedy (Oliver, 1995, 1996). . . . It is a profoundly cultural act, constituted by a particular 'scopic regime' or way of seeing and knowing but also constitutive of social and cultural relationships, including patterns of oppression, discrimination and exclusion (pp. 163-166).

This insidious specular positioning that is unnaturally reflective of the observer and structured by rigid (mis)constructions of (dis)ability maddeningly persists in infecting our society. The consequence of such virulently constructed perceptions is that many women with visible physical disabilities like Lynda are discounted and assume they are discounted as "invalid other" because they fail to meet "normate" standards of appearance and functioning (Butler & Bowlby, 1997; Hughes, 2000; Overboe, 1999; Paterson & Hughes, 2002; Shakespeare, 1994; Thomson, 2002; Wendell, 1996). For Lynda, this visible social devaluation is so emotionally scathing that it necessitates evading the wounding gaze of the non-disabled as part of negotiating her disabled identity and protecting the remnants of her dwindling self-worth.

Summary

In summary, it is the profundity of embodied physical change and the concomitant feelings of shame and despair visually and experientially branded within Lynda's flesh that remain an unseen, unbearable part of the emotive world of loss within the context of a progressive disabled embodiment. Alterations in physical appearance, mobility, and functioning echo transformations in self-image and inspire feelings of inferiority or what

Goffman (1963) coins an "other-consciousness." Substantiating this perspective, Michalko (2002) and Shakespeare (1994) claim that the experience of physical disability as a negative identity occurs within social relations where the "body-of-functions" with the ability to do things like everyone else is privileged over the "broken down body" leading to feelings of social rejection and lowered expectations (Coleman, 1997). Charmaz (1995), Stone (1995), and Wendell (1996) imply that disabled women are especially vulnerable to this aesthetic and social invalidation since their self-worth and wholeness as human beings is allied with bodily standards of physical perfection. Consequently, the internalization of negative self-feelings and the social aversion Lynda experiences ubiquitously pervades her everyday experience, ultimately sustaining her invisible world of isolation and marginalization. It is only by rendering this reality more visible and emotionally palpable that we begin to see and grasp the magnitude of the unseen emotive world of (in)visible disability.

In witnessing the unsettling progression of Lynda's MS, we not only glimpse her physical suffering in an increasingly disabled body and exclusionary world but we are privy to the intimacies of the human soul. The emotive world of (un)settled embodiment is silent and invisible and we are eager to keep it from view. We rarely notice the diminished opportunities, altered life roles, shrinking social world, and layers of grief, guilt, and humiliation baked into these losses accompanying the biographical interruptions of many women with (in)visible disabilities. Such changes are not glaringly obvious when we see and engage with women living with disabilities in our lives nor do we want to stop and acknowledge the implications of human frailty and the possibility of disability in our own lives. As Lynda poignantly portrays, disability happens when we are living our lives, making plans, dreaming dreams, and moving along at full speed. Lynda removes the veil of silence smoldering around her life and the naïveté surrounding the normalcy of our own lives by pictorially capturing common scenes that throw us into the whirlwind of the body's instability. While I initially did not understand how a woman with a gradually worsening, visible disability could claim a shifting embodiment in relation to this study, Lynda altered my ways of recognizing (in)visible disability as more than an erratic physical embodiment but as a hidden emotive one as well.

Throughout the interpretive chapters I narrate the story of (un)settled embodiment around the two intertwined movements of (un)convincing bodies and the fluidity of identity. I then move on to illuminate a third story that depicts how an (un)settled embodiment is emotionally and socially experienced in visible and invisible ways. I now turn to the final chapter inviting the reader to reflect on what we have learned and to consider the contributions of this thesis within the larger scope of academic scholarship. I also suggest some practice and policy implications for social work and offer scholarly directions in continuing this journey.

Closing Movement

Chapter 13

(Re)Weaving Tensions: An Invitation for Reflection

In this final chapter, I offer an overview of the research focus, objectives, and questions informing this study. I then revisit the "thematic tensions" conveyed in the women's portrayals. Since I interweave an analysis and discussion of the study's themes throughout the interpretive chapters, my intent here is to provide a closing summary rather than an extensive review of the issues considered. Following this, I emphasize the substantive and methodological contributions of this work including commentary on the value of working with photography as an interpretive tool and as a transformative personal process. I close with some recommendations for social work and illuminate prospective paths for continued scholarship.

Situated within a visually informed phenomenology, this research explores how women living with (in)visible disabilities experience (un)settled bodies, bodies that visibly and invisibly shift into and out of episodes of calm or "settled-ness" and unrest or "unsettled-ness." Taking the (un)settled body as the central premise of this text, I combined in-depth conversational interviews with approaches to (non)art photography to illuminate how four women, three living with multiple sclerosis, and one living with vulvodynia, experience their fluctuating bodies materially, socially, and spatially across everyday moments. In doing so, I developed a more fluid understanding of disability and embodied identity beyond what ordinarily meets the eye.

The objectives informing this research work in tandem to reveal an understanding of an (un)settled embodiment that stretches the boundaries of the experience of disability.

Specifically, this research invites dialogue that glides back and forth between image and text, between lived experience and its visual expression to evoke alternate ways of noticing, thinking about, and legitimating (in)visible disability as another tier of our human diversity. Second, this research relies on participants' photographic portrayals to disturb dominant cultural constructions, assumptions, and myths surrounding health, illness, ability, and disability in favor of illuminating identities that fluidly move inside, outside, and in-between these experiential and discursive borders. By denaturalizing the cultural maps that guide how we make sense of (dis)abled bodies, this research aims to break free of rigid ways of thinking by validating multiple possibilities for embodiment. Last and equally vital, this research has sought to transform the gaze of the viewer by unsettling habitual ways of "seeing" (dis)ability, thereby expanding how we interpret bodies in society.

In addressing the lived experience of women living with (un)settled bodies, I began with several initial questions including what are the different ways women experience and ascribe meaning to the (in)visible (un)settled-ness of their bodies? In what ways does this episodic (un)settled-ness enact itself across ordinary life moments, settings, and temporal frames? In what ways does living in between shifting periods of (un)settled-ness enable women to negotiate passing into and out of a (dis)abled identity in ordinary moments, situations, and contexts? In what ways is an (un)settled embodiment experienced as an (in)visible disability and a (dis)abled identity? A secondary focus asked how practices of (non)art photography can give expression to and transform our understanding of (un)settled embodiment. In reaching for a starting point to unpack this protean embodiment, I return to the "lived tensions" and address their significance within the initial questions posed.

Lived Tensions

(Un)Convincing Bodies

I interpret the main question of how women experience and ascribe meaning to their (un)settled subjectivities around three storied movements: (un)convincing bodies; the fluidity of identity; and (in)visible wounds. Before proceeding, I want to comment on the background of the participants in light of the discussion ahead. While the experience of (in)visible disability encompasses many forms of chronic disabling illness, this study is limited to the experiences of four women with two forms of (in)visible disability, namely multiple sclerosis and vulvodynia. These women share similar socio-demographic profiles. They are all white, middle class, and university educated. With the exception of one participant, the women are single, live in the city of Toronto, have an income well above the poverty line, and work full-time. Two women identified as heterosexual, one self-identified as queer, and another defined herself as "sexually open." While sexual orientation influences the experience of women living with (in)visible disabilities, participants did not focus on this aspect of their identities nor was this facet a focus of the research. Prior to this research, the participants never had an opportunity to discuss their disabilities and this fact may have influenced what they perceived as significant to their lives at the time of the study. The participants share similar institutional experiences, particularly within the health care system, and social experiences in negotiating their disabilities in the community. With these characteristics in mind, themes should be interpreted with care given the absence of greater participant diversity and the exclusion of other kinds of social and institutional encounters.

Based on the women's accounts, this research suggests several considerations that warrant attention. A crucial thread reappearing throughout this inquiry is that understanding and legitimating an (un)settled embodiment need to begin with the flesh and blood experience of real bodies. As participants insist, the interruptive cycling of erratically (dis)appearing signs of illness or what I refer to as "carnal whisperings" and "fluid sightings" are privately experienced events. These ephemeral episodes sometimes leave convincing, residual traces on the body and at other times, frustratingly evaporate like the thick mist of a dream. This contradiction between what feels so real and what seems too phantasmic to be experienced echoes the phenomenal essence of an (un)settled embodiment in this project.

The (in)credulity spiraling around a woman's volatile body while initially biographically alarming and perplexing, becomes an expected way of being and having a body for participants during the onset of illness. Since participants commonly look "perfectly fine" during these (sur)real flares, they defy medical and cultural scripts that denote what it means to be normatively healthy and ill. Bodily changes (de)materialize with such rapidity that it is *almost* impossible for the women and others to witness even the most insignificant albeit legible sign of disorder. Given the albatross of their (in)visible suffering, participants carry the burden of substantiating their altering claims of (un)settled-ness. A tension unfolds that, in the end, rivals a woman's faith in the integrity of her body against her mounting skepticism of what feels like an imaginary subjectivity (Donoghue & Siegel, 2000; Jackson, 1992; Lillrank, 2003; Moss & Dyck, 2002; Vickers, 2001b).

Although Dorothy Wall (2005) cautions against romanticizing the voice of the body because it can mislead us, I propose, in relation to the women in this study, that the body is a woman's oracle of truth- it tells her when something is looming or desperately wrong. It is a voice that participants honor yet struggle to privilege in the early stages of (in)visible illness.

Yet, I agree with Wall (2005) that early warning signs can be misread and dismissed as part of ordinary life stressors. This disregard as the women's stories reveal, continues until their physical distress worsens or until new fleshy clues of (un)settled-ness surface. At this critical juncture, participants crusade to defend the infallibility of their shifting bodies by embarking on a journey towards medical diagnosis (Sveilich, 2005; Vickers, 2001b).

(Dis)Credited Bodies

Obtaining a medical diagnosis is the hallmark for legitimizing an (un)settled embodiment (Moss & Dyck, 2002; Sveilich, 2005; Vickers, 2001b). While the search for medical validation bestows long awaited relief, it is also an agonizing battle for participants (Asbring & Narvanen, 2002; Jackson, 2005; Wall, 2005). Underlining this partially demoralizing and triumphant struggle is the manner in which medically legitimizing illness rests on explicit signs of disease. Although a reliance on technological imaging is the primary means for verifying pathology (Asbring & Narvanen, 2002; Cooper, 1997; Rhodes et al., 1999; Vickers, 2001b), early signs of (un)settling illness among the women initially escape diagnostic capture because they sporadically shift in and out of sight. Repeated attempts to tangibly prove their confounding subjectivities often fails in the early stages of illness, leaving participants and many women like them at a crossroads (Asbring & Narvanen, 2002; Koopman & Schweitzer, 1999; Reid et al., 1991; Richardson, 2005; Ware, 1992). Desperate for answers, participants become more resolute in their diagnostic quest as their symptoms intensify. At the same time, the women oscillate between feeling (un)convinced about the trustworthiness of diagnostic imaging and their own confidence in justifying their body's inner chaos. Ultimately, an ontological and epistemic battle ensues that pits scientific rationalism against the phenomenal "lived-in-ness" of the body and women as credible constructors of knowledge.

While a formal diagnosis bestows personal credibility, it is also emotionally traumatic for participants on several levels, a perspective widely reported among women living with many forms of (in)visible chronic illness (Chircop & Keddy, 2002; Jackson, 1992; Lillrank, 2003; Vickers, 2001b; Wall, 2005). When organic disease is not evident or clinical findings are inconclusive despite a participant's testimony, they are perceived as "suspect cases." On an alternate level, diagnosis is alarming when the veracity of disease contradicts periods of wellness (Charmaz, 2000; Kugelmann, 1999; Moss & Dyck, 2002). This rupture breeds a vacillating (mis)trust between doctors as faultless experts and women like Angie, Lynda, and Helen as psychologically flawed (Jackson, 1992; Vickers, 2001b).

Despite the experiential testimony rooted in a woman's body, physicians frequently dismiss such carnal evidence (Jackson, 2005; Sturge-Jacobs, 2002; Wall, 2005; Wendell, 1996). Yet, the pulse of this research persuades us to believe that participants' shifting bodies are real simply because they are lived. Lending credence to this position, Arthur Frank (1995) insists that the testimony of seeing is more of believing. In this sense, women's bodies and lives *are* their living testimonies. Accordingly, the struggle to legitimize an (un)settled embodiment in the beginning stages of illness should not be characterized by who defines and what constitutes reality, but that reality however settled or unsettled, is what participants feel and believe it to be.

As a patriarchal institution, the medical establishment has yet to embrace a rightful place for women's voices, especially in relation to the phenomenal body (Mathieson, 1994; Munson, 2000; Wendell, 1996). Coinciding with their gendered standpoint as patients, this research implies that the soundness of women's ways of knowing their bodies carries less authority than the omniscient lens of biomedicine (Chircop & Keddy, 2002; Griffin, 2000; Jackson, 2005; Wendell, 1996; Werner et al., 2003). Not only do doctors and the women in this study inhabit different bodies and different worlds, they value different forms of knowledge and modes of expression. Speaking to this rift, Dorothy Wall (2005) argues that although biomedical discourse gives authority, shape, and realness to people's experience, it simultaneously resists and discounts alternate forms of language that are "softer," experientially based, and empirically "groundless."

Expanding currents of thought in other inquiries, this research proposes that it is not just an absence of language but also that avenues for sharing out-of-the-ordinary, more poetic meanings are shutdown (Wall, 2005). Indeed, Angela, Angie, Helen, and Lynda exemplify that "body talk" is important talk (Mathieson, 1994). To cast out the "carnal semantica" of the body is to disconfirm the very basis of human existence among participants. As Wall (2005) comments, "to be stripped of voice is a wound in itself" (p. 37). Hence, this research impels us to rethink the importance of women's embodied ways of knowing in crediting personal subjectivities rather than trivializing this wisdom within the context of biomedicine. Such ontological and epistemological splintering dehumanizes women's bodily distress, ultimately denying many women the ability to define the experiential essence of their lives. This is a moral assault to the integrity of the women in this project and speaks more broadly to the lives of women living with (in)visible disabilities (Asbring & Narvanen, 2002; Jackson, 1992, 2005; Lillrank, 2003; Vickers, 2000).

(Inter)Personal Frictions

Women who ostensibly meet able-bodied ideals of physical appearance and functional performance can have medical problems that are serious but not always socially obvious (Davis, 2005). A disquieting concern articulated among the women is that the contradiction between looking "normal" and claiming (in)visible illness incites skepticism among friends, colleagues, social others, and within one's family (Davis, 2005; Marris, 1996; Moss & Dyck, 2002; Stone, 1993, 2005, 2007, Sveilich, 2005; Vickers, 2001b). In harmony with Moss and Dyck, (2002), Stone (2005), Sveilich, (2005) and Vickers (2001b), this study vividly reinforces that the non-disabled have tremendous difficulty imagining that someone who appears able-bodied can have fluctuating disabilities and commonly perceive them as insignificant (Stone, 1995). Thus, while participants want to be recognized as (in)visibly disabled, they want others to understand that even though their disabilities may not be visible at any given moment, they are always present, waiting for the "right moment" to make their fleshy debut. Even when Angela, Lynda, and Angie visibly appear disabled, they continue to justify their (un)settled selves because the variability of their limitations are minimized or are temporarily forgotten (Case, 2003). What I found incredibly surprising is that this inconceivability is not only characteristic among many non-disabled people, but sometimes exists among women living with (in)visible disabilities themselves. For example, Angela indicates that she often forgets about her boyfriend's arthritis because it is not always noticeable and changes in intensity from day to day. Given that little is known about how (in)visible disability may be forgotten in relation to others who also live with them, further investigation is necessary.

The discord characterizing others' forgetting and remembering a woman's (un)settled embodiment stems from prevailing cultural assumptions that are visually (mis)read off the body's outward appearance, ultimately (mis)informing our interpretation of bodies. Bodies that appear healthy and so-called "normal" but that are also periodically impaired unsettle the cultural canons of (dis)ability and thwart our comfort zones of understanding. Since others demand tangible evidence that a woman has real, imposing limitations, the subjectivity of a woman's shifting body and its impact on her life is discounted (Fitzgerald, 2000; Jung, 2000; Moss & Dyck, 1999a; Stone, 1995, 2005; Sturge-Jacobs, 2002; Vickers, 2001b).

The endemic skepticism surrounding the incongruity of not "looking disabled" but being fluidly (dis)abled culminates in damaging assumptions that physically, socially, and emotionally plague many women's lives (Kimpson, 2000; Peters, 1993; Stone, 1999; Vickers, 2000). Participants confront enormous societal pressure to fit in physically, occupationally, socially, and sexually as women, to be capable of accomplishing what any other able-bodied woman can because their bodies largely allow them to do so. Since participants often present themselves as able-bodied to avoid the stigma of illness, social others (wrongly) believe they can surmount their difficulties if they just try hard enough. Consequently, the women continuously self-impose able-bodied standards that stretch the boundaries of their bodies and that sacrifice their health to meet these implicit ideals. In turn, participants are (mis)perceived as always well rather than transiently (un)well (Marris, 1996; Stone, 1993; Sveilich, 2005; Vickers, 2001b).

Women in Flux

Juxtaposing the institutional and social (in)validation of (in)visible disability are personal moments among the participants of forgetting or "consciously denying" and recollecting the presence of disability in their lives. This twist, paralleling the work of Stone (2005), expands an analysis of the (in)credulity surrounding a shifting embodiment. With a relatively healthy appearance and the relapsing-remitting nature of their disabilities, it is a perpetual battle for Angie, Helen, and Angela to remain convinced of the legitimacy of their volatile subjectivities. Angie implies that there is a "demented hope" that her disability will disappear altogether and return her to the world of the "normal." Looping out of their social (in)validation, the women are similarly mired in social beliefs that the only forms of disability worth taking seriously are visibly stable ones (Stone, 1993, 2005; Vickers, 2001b). As a result, the instability of (un)settled-ness thus makes disability seem "less real" and less convincing since participants consider themselves as "better off" than persons whose disabilities are self-evident and do not fluctuate.

While the women want to be socially accepted as (in)visibly disabled, they refrain from seeking this recognition at the expense of having to persuasively "look disabled" and endure being (mis)perceived as ill all the time. Reminding others about their disabilities means validating and remembering the presence of disability in their lives, a painful admission that participants seek to avoid. No longer socially defined as "perfectly healthy and normal," Angela, Angie, and Helen want to forget they are no longer exclusively part of the able-bodied world. At the same time, their efforts to "shut off" their disabilities become upsetting reminders that they are physically different from their healthier peers.

(Re)Considering the Fluidity of Identity: The Comforting-Danger of Secrecy

Within the second storied movement of the fluidity of identity, women negotiate their combinatory embodiments as able, disabled, ill, and well across different life scenes. The proclivity to secret an (un)settled embodiment derives from the compulsory nature of able-bodied-ness in our society and a (mis)conception of illness as a private concern (Beatty, 2004; Charmaz, 1991; Kafer, 2003; McRuer, 2002; Myers, 2004; Vickers, 2001b; Ware, 1992). Women living with (in)visible disabilities want to be and be seen as "normal" (Moss & Dyck, 2002; Sveilich, 2005; Vickers, 2001b; Wall, 2005). Since living with the fluidity of a (dis)abled identity is not always physically legible and is a culturally unfamiliar experience, Angela, Angie, and Helen take comfort in preserving the silence of their (un)settled selves. Yet, juxtaposing the luxury and freedom of secreting is the inherent danger of this silencing (Kimpson, 2000; Vickers, 2001b; Wall, 2005). Fearing that their (un)settling disabilities will "cloud" other aspects of their identities, participants often choose to guard the secrecy of their disabilities because they want to be perceived as equal members of society rather than inspire unsolicited sympathy and misunderstanding. Simultaneously, with the exception of Lynda who is visibly disabled, participants also feel insincere, fraudulent, and experience a sense of fragmentation in portraying someone other than their "real selves" (Hillyer, 1993; Stone, 1995; Sveilich, 2005; Vickers, 2001b). This partial deception cements erroneous stereotypes that one has to "look disabled" to be disabled and that to be able-bodied or disabled in any absolute way is normal. By secreting their fluid selves, participants allow this illusory mentality to flourish, thereby precluding any opportunity for expanding our understanding of the plurality of human embodiment.

Blending-In

Subtly different from secreting, some women with (in)visible disabilities strive to blend-in the fluidity of their (dis)abled selves by inscribing normalcy with illness rather than over illness (Moss & Dyck, 2001). Drawing extensively on Helen's narrative, I depict blending-in as a "melding" with the body, an "enfleshed" partnership in which a woman actively works with the elasticity of her pain-infused body to present possible versions of the self. This strategic malleability, shaped by medical and cultural discourses that prescribe how bodies and identities should be, reflects a fine-tuned listening to the body's (un)settling rhythms. Through a combination of photographs, collage, and painting, Helen depicts how she complicates the reality of living with(in) an (in)visibly (dis)abled body by blurring the lines between the carnally (im)possible. For example, mirroring the self-applied pressure to conform to the cultural dictates of female sexuality, we observe Helen blending-in the plasticity of (un)settled-ness by pharmacologically altering her body's sensory paths to make sexual relations possible.

Together, secreting and blending-in forces a reconsideration that the physical body is the "sight" and site of identic intelligibility (Ginsberg, 1996). More so than secreting, blending-in accentuates the "liquidity" of the (un)settled body (Hughes, Russell, & Paterson, 2005), a carnal mobility that bypasses static ontologies and hegemonic categories in favor of fluid and contradictory subjectivities. In both instances, a number of women like Helen twist the rules of representation by (re)appropriating what it means to be (un)well in ways that (in)directly heightens their fluid selves (Moss & Dyck, 2002).

(Un)Burdened Bodies

While participants preserve the privilege of anonymity by secreting and blending-in their (un)settled bodies, there are moments that demand the unburdening or disclosure of an (in)visible disability. This scenario calls forth the legitimacy of an (in)visible disability as shifting and contextual rather than justifiably static. As a form of identity management, unburdening an (in)visible disability is a continuous cycle of negotiations surrounding who, when, and how to reveal seemingly incongruous and often misunderstood information about oneself (Beatty, 2004; Sveilich, 2005; Vickers, 1997). Participants are neither in nor out of the "disability closet" but live in a constant state of unstable self-expression (Moss & Dyck, 2002; Vickers, 1997). Living with an (in)visible disability is an intensely private matter for Angela, Helen, and Angie that is not readily shared. Revealing this intimate aspect of the self for these women occurs more willingly among trusted, empathically supportive family members, partners, and friends as well as other women living with disabilities rather than with acquaintances and unfamiliar social others (Afifi & Guerrero, 2000; Derlega et al., 1993; Lowton, 2004). Sharing the reality of living with an (in)visible disability is also easier when the outcome of cyclic flares as Angie indicates, culminates in a "happy ending," when no remnants of her MS remain in marking her body as visibly different.

Another point of interest is that unburdening an (in)visible disability means more than exposing the self as (un)well but accents a woman's exposure to the awkward silences that confound others and suspend communication when a physical appearance of health subverts this revelation. On the whole, it is not the chronic illness but the lack of knowledge, pity, suspicion, and social rejection of others who simply do not "get it" as Angela asserts, that poses the greatest dilemma for participants to "come out" as (in)visibly disabled (Beatty, 2004; Greene, 2000; Susman, 1994; Sveilich, 2005). At the same time, mollifying the discomfort of disclosure also occurs vicariously through others who have knowledge of a woman's disability as evident in Angela's life. This event, while aiming to protect the physical welfare of a woman and avert misunderstanding, can also threaten a woman's personal privacy and sense of psychological safety (Charmaz, 1991; Derlega et al., 1993; Hillyer, 1993; Lowton, 2004; Schneider & Conrad, 1980; Vickers, 2001b).

The inverse of unburdening an (un)settled embodiment is the catharsis participants experience in divesting feelings of guilt, shame, and dishonesty that plague their emotional well-being (Clair et al. 2005; Derlega et al., 1993; Rosenfeld, 2000; Schneider & Conrad 1980; Vickers, 1997). By revealing their fluid selves in all their complexity, participants create opportunities for leading more genuine, effectual lives. Coupled with this personal liberation, disclosure permits an un-silencing of subjugated voices that is tantamount to "making visible" how the privacy surrounding (in)visible illness and the tabooing of "disability talk" is shaped by our larger socio-political climate. For Helen, conversationally taking (in)visible disability out of the closet, creating awareness, and educating others is pivotal for eroding the silence encasing (un)seen illness and demystifying the opacity of more fluid conceptions of human identity.

Taken together, passing into and out of (dis)ability involves enacting a set of strategies to negotiate a particularized version of the self in the moment. These strategies including secreting and blending-in, are invisible themselves since others are unaware that participants are (dis)abled to begin with. Since living with an (in)visible disability is a fluctuating reality for Angela, Helen, and Angie, self-identifying as able-bodied and disabled is never a clear-cut decision. Each of these women both conforms with and destabilizes mainstream conceptions of (dis)ability by self-identifying as one or the other, neither, and both depending on the physical condition of their bodies, the situations they encounter, and the environment in which they find themselves. In this vein, self-identifying as (dis)abled is a conditional matter of personal choice rather than an uncomplicated identification. Supporting this outlook, Dorothy Wall (2005) writes:

> With an invisible illness . . . nothing is so clear. . . When things are not black-and-white, but marbled and shifting, how and when do you accept an identity as an ill person? Where is that clear-cut point of delineation, a line you cross, a specific moment you say, there's a new me here I have to acknowledge? (p. 138).

(In) Visible Wounds

Within Lynda's portrayal, we witness how living with an (un)settled body emotionally haunts the human spirit in (im)perceptible ways. Over time, diminished bodily capacities that make walking and any physical movement increasingly arduous, an absence from the labor force, a dwindling circle of friends, increasing social isolation, and the inability to control life in hoped for ways erodes Lynda's self-esteem and self-identity (Charmaz, 1983; Lubkin, 1986; Reynolds & Prior, 2003). The familiar normalcy of a once routine life silently recedes, spiraling Lynda into an (in)visible web of mourning, despondency, indignity, humiliation, and guilt for not being the person she once knew, longs for, and that society physically demands. Consequently, some women like Lynda become socially "invisible" because they cease to exist in valued ways in the world and to themselves as human beings (Asbring, 2000; Charmaz, 1983; Murphy, 1990; Robinson, 1990).

Lynda's narrative can be read more politically because it emphasizes how ableist cultural attitudes and popular images of persons with disabilities as tragic victims, invalid persons, and nonproductive "human failings" are a concealed form of disablism (Thomas,

1999) that pervades Lynda's life in multiple ways. For example, whether at the grocery store or at a Halloween party, Lynda's social participation is encumbered more by the expectation of demeaning cultural judgments that are emotionally "paralyzing" than by her bodily limitations. Equal to this, Lynda comments on how the inaccessibility of the built environment that does not want nor expects her disabled presence (Michalko, 2002a) sustains her isolation as "housebound." The existence of wounding attitudes, harmful ideological constructions, and exclusionary surroundings are a breeding ground for sustaining the cultural intolerance of persons with disabilities. The effects of this devaluation and oppression are branded into Lynda's flesh and left behind closed doors.

Persons living with disabilities are not ascribed an equal and just place in our society. Their marginalization as citizens is attributed to their functional limitations rather than to the ways society structures disability and the bodies of persons with disabilities as a "problem" in need of a "solution" (Titchkosky, 2007). Qualifying this perspective, Titchkosky (2007) states, "to think about disability is to think of some individuals with some functional problem; it is not to think about how the notion 'functional' is a socially organized term" (pp. 55-56). Throughout her narrative, Lynda expresses a deep sense of shame, inadequacy, and indignity in "failing" to meet ideals of healthy, perfectly functioning, "whole" bodies and expectations of autonomy and independence within our neo-liberalist climate of individualism. No longer able to participate in the once-cherished roles of productive professional, co-worker, and independent citizen that provided a sense of meaning and belonging in her life, Lynda is silently consigned to the (in)visible world of "rejected bodies," personhoods that no longer matter (Wendell, 1996). What Lynda's story awakens us to is how this personal experience of disability and the meaning ascribed to her experiences are a public reflection of disability that remains socially and politically conspicuous in ways we do not always "see" but that are intimately felt. As long as women's social and emotional worlds remain unseen, we cannot change the role society plays in the cultural conditions that envelop it. It is here that a transformation in the way we think about and respond to the (in)visibility of lives in context heralds its presence.

Having provided an overview of the main themes characterizing this research, I veer the discussion to the conceptual and methodological contributions of this work. As part of this discussion, I comment on the value of working interpretively with photography and state its transformative potential among the participants.

Conceptual and Methodological Shifts

Conceptual Shifts

By conceptually and experientially pairing an (in)visible disability with an (un)settled body, this research deepens an understanding of shifting bodies within the scope of chronic disabling illness in more sophisticated, nuanced, ways. Since there is no established language and ways of articulating the shifting complexity of (in)visible disability in everyday conversation, I develop a vocabulary rooted in the fiber of women's bodies that substantively sheds light on how bodies and identities contract and expand across material, social, emotional, and spatial locations. I offer new words that we do not yet have, words that stretch the imagination, words that cannot be statically or statistically interpreted, words that make the seemingly incredible more credible. I lay particular claim to the phrases "(un)convincing bodies" and "(un)settled bodies/embodiment" to denote that a woman is neither always healthy, ill, able, nor disabled but (in)visibly transitions between a mélange of subjectivities. Being introduced to these unfamiliar expressions publicly through my study announcement invoked a sense of personal connection among the participants in ways that resonated with the namelessness of their (un)settled selves.

Equally important, by interpretively working with concepts like "(in)visible," "(un)convincing," "(un)settled," "in-between," and "fluidity" that straddle the experiential and the social, I bring the reader into a qualitatively different relationship with participants' lives in ways that supplant naturalized notions of bodies with suggestions of contradiction, flux, partiality, and fluidness that complexify embodied identity.

Methodological Shifts: (En)Countering Images

Complementing this work's substantive contribution, this research is the first within social work scholarship to integrate a phenomenology of (in)visible disability with photography-as-communication (Weiser, 2001). The images the women create are nonverbal self-expressions that were not produced to reify the visual, but to more forcefully convey on both a cognitive and emotional level, what it "looks like" and means to live with an (un)settled body. Commenting on the impactfulness of her own photographs, Helen emphasizes:

> The photos I chose to include . . . I mean they're not all brilliant photos . . . the way the composition is. But they have a lot of significance to me. It really speaks very accurately to my experiences and hopefully in a way that communicates to the viewer not just sort of in a rational . . . intellectual way but hopefully the images will capture people on an emotional level as well.

The (un)remarkableness of the photographs and the artistic pieces appearing in Helen and Angie's portrayals jolt us into the immediacy of an (un)settled embodiment as it shifts across material, social, spatial, and institutional locations. It is through this unique corporeal engagement and the accessibility of these "(in)visible moments" that makes this research "come to life" and "come into our lives" in deeply personal, textured ways.

In *Inhabiting the Off-Frame: Social Workers as Connoisseurs of Ambiguity*, Allan Irving (2007) enchantingly lures readers out of the sinister woods of Enlightenment thought or what he refers to as the photographic "in-frame," towards a postmodernist (re)visioning from the margins of the "off-frame." For Irving, the in-frame metaphorically reflects dominant places of intellectual certainty and conviction whereas the "off-frame" denotes spaces and texts that are absent, ambiguous, that encourage us to wander, and that have no closure. Despite the lyrical elegance of his arguments, I was struck by the idea that a rupture between inner and outer interpretive lenses reproduces to some degree, modernist intellectual divisions that are counter-intuitive to understanding the mosaic of (in)visible disability. Differing from Irving, I believe that the ambiguity surrounding the off-frame *is* or *becomes* the in-frame within the context of an (un)settled embodiment. What I am positing is that what is absent, fragmentary, nameless, unfamiliar, and beyond our notice in the off-frame subtly transposes itself onto/as the in-frame. Writing about her life with breast cancer, Joe Spence believed that photographs, like identities, should always conjure debate and direct viewers to situations that exist outside the photographic frame (Bell, 2002, p. 11). I argue that many photographs in this text raise questions, present alternatives, and challenge the viewer to think beyond "central frames" and reasoned certainties of how bodies should appear and "be" by asking us to suspend our convictions as we contemplate alternate versions of "lives lived." I offer two brief illustrations.

The photograph of Helen's body floating in the bathtub (Figure 31) intentionally brings the "off-frame" or the invisibility of the body's (un)settled-ness into "view" within the centrality of an ordinary moment that would be in any other circumstances, unknown to us. The power of this image quietly situates an absence or the "fleshy otherwise-ness" of (in)visible disability into our awareness by connecting us to the lived-in-ness of Helen's pain and to the vulnerability of her body in the privacy of the moment. A different rendering of the in/off-frame appears symbolically in Figure 34. This mirror image, in which Helen spells out the word "pain" with her pills, ontologically sabotages what is seen in place of what is unseen, what is privately experienced in place of how lived experience is socially represented in relation to the body. Within the in-frame, we see the familiarity and the certainty of the pill bottle, the pills, and the word "pain." The dominant text symbolizes a medically contained, pain-free, "normal" self that Helen credibly portrays and that others "see." The off-frame or what is "masked" but that superimposes the in-frame, appears in the illegibility of the word "pain" spelled backwards. This distorted image reflects what is unseen and invisible beyond Helen's social presentation- a body in pain, its medical containment, and ways of living with fluidity that enable Helen to (re)inscribe "normalcy" as volatility.

Cultural interpretations of human bodies and the sets of assumptions governing how and what we see experientially conflicts with identities that fall within the interstices of the (in)visible, the (un)settled, and the (in)credible. Alexa Wright's (2001) portraits of persons with disabilities remind us that, "while the self is located in and expressed by the body, the body is not always an adequate representation of the self" (p. 507). This statement has particular resonance with a volatile body that disturbs tidy classifications. Several of the images in this work are, as Angie implies, "conversational pieces" that counter or "shoot back" ways of visually decoding bodies by twisting the unfamiliar as familiar, the unconvincing as convincing, and the unsettled as settled in women's lives. By provoking our gaze, participants distort constructions of ab/normalcy, health/illness, dis/ability, and in/visibility by showing us that possibilities for embodied identity are fluid, "always in the making," and never self-evident. In doing so, participants not only alert us to the ways their bodies fluctuate inside, outside, and between the material spaces of health and illness but how constraining categories perpetuate the unconvincing character and misinterpretation of their (un)settled subjectivities.

Exemplifying this material-discursive fracturing is a photograph of Angela sitting on the stairs in her apartment (Figure 17). While the viewer absorbs the seeming ordinariness of this capture and the "normalcy" of Angela's physical appearance, we fail to take in alternate ways of interpreting Angela's body as (un)well. We remain visually and intellectually wedded to the supposed certainties of what we see rather than thinking about what we see. We do not notice how sitting on the stairs is, in fact, an (in)visible strategy Angela routinely employs to cope with the fatigue of MS. We do not appreciate what lies behind the enactment of seemingly "normal" and "ordinary" bodies in relation to (in)visible disabilities.

Adopting a different lens, many of this study's images give voice to the experience of an (un)settled body in ways that medicine cannot capture. Angie pairs an image of a stone sculpture (Figure 10) signifying the disembodied credibility of medical imaging in detecting her MS against a photograph of flashes of lightening symbolizing the embodied "neural chaos" firing inside her brain (Figure 11). Angie juxtaposes the convincing ontological powers of medicine that resides outside of the body in its abstraction of her subjectivity against the unconvincing voice of fluidity residing inside her body. Here, the shifting materiality of the body (as subject) rivals disciplinary practices of statically inscribing bodies (as object) as normal or abnormal, diseased or healthy. These photographs among others blur the experiential horizons between how bodies are lived and how we make sense of them institutionally and socially. They bring the seeming impossibilities of human embodiment to the fore and attempt to make them more familiar, believable, and culturally intelligible.

Transformative Meaning-Making: Working with Photography

Working creatively with imagery provided participants with alternate conduits for expressing indigenous, multiple ways of knowing and offered a unique platform for the un-silencing of their marginalized voices (Dykstra, 1995; Gorman, 1993). "Making meaning" with photographs made the research questions "come alive," challenging the women (and myself) to think in different voices and "with different eyes" about the shifts, contradictions, and seeming impossibilities of their everyday worlds in living with an (un)settled body. By turning the photographic lens on themselves, the women engaged in self-dialogue in ways that enabled them to see the personal as more political in the mundane-ness of their lives and on a larger socio-cultural scale. Participants expressed their own prejudice about disabled bodies, challenged homogenized representations of health, illness, ability, and disability in light of their own malleable subjectivities, and reflected on the language and politics of a (dis)abled identity within the larger social landscape.

Moreover, working with photographs was an empowering experience among the women. For the first time, each woman was able to speak out about her life in ways that were personally meaningful and emotionally liberating. Imaginatively piecing their lives together and interpreting their visual portrayals allowed the women to, as bell hooks (1995) asserts, "transgress" by pushing past the barriers of verbal communication to focus on the "unspoken-ness" and "uncut" versions of their bodies and lives. This kind of transformative inventiveness and self-awareness is something I believe contemporary phenomenological scholarship has not been able to do with equal intensity with regard to (in)visible disability.

New Movements: Implications for Social Work

The women's narratives bring to the fore several recommendations for social work practice including crediting women's embodied ways of knowing, cultivating professional awareness of (in)visible disability, embracing fluid constructions of bodies in place of inflexible paradigms for service delivery, and politicizing alternate ways of conceptualizing disability that debunk categorical imperatives inherent in organizational guidelines and social policies.

Creating Knowledge: Making the Unfamiliar Familiar

One of the primary tenets of social work is that intervention at any level cannot occur without understanding and validating the experiences of the client populations we support. In claiming and practicing a professional ethos dedicated to the physical, social, and emotional well-being of all persons, we need return to the roots of our calling. This invitation, as the women in this project propose, begins with a willingness to engage in an empathic way of being in which we non-judgmentally trust and believe in the embodied experience of all people. While this may seem fundamentally obvious to a profession dedicated to human welfare and social justice, its enactment is, I believe, an entirely different matter with persons whose disabilities fluctuate and are seemingly (un)convincing as they ebb and flow from moment to moment. Paralleling this work, Carl Rodgers (1995) insists that an empathic way of being implies "moving with" the fluidity of embodied lives. He states:

> An empathic way of being means entering the private perceptual world of the other and becoming thoroughly at home in it. It involves being sensitive, moment by

> moment, to the changing felt meanings which flow in this other person. . . temporarily living in the other's life, moving about in it delicately without making judgments. . . . to experience the meanings more fully, and to move forward in the experiencing (pp. 142-155).

Arthur Frank (1995) states that to deny an individual's story is to deny the person telling the story (p. 109). A chronic thread woven throughout this research is that the shifting (in)credulity surrounding women's (un)settled subjectivities presents the most maddening barrier in their lives. Given their "healthy" appearance on many occasions, participant confound others and evoke skepticism because their bodies invert the legibility of cultural codes that deem bodies as able, disabled, healthy, and ill. Consequently, participants carry the "burden of persuasion" as they strive to convince others that their indeterminable subjectivities are real.

Since social workers cannot always "see" or know whom the (in)visibly disabled are, we need to be attuned to creating affirming relationships that honor all voices as testimony in their own right. We need to think about ways that support and validate women's experience regardless of whether we can "see" their pain and limitations and regardless of whether they have an (in)conclusive diagnosis attached to their subjectivities. As the women in this study vehemently claim, we must be willing to believe what we cannot (always) see, that shifts, and that loosens our comfortable premises about human identity.

In harmony with embracing bodily experience, this research invites us to consider how we can translate this embodied knowledge into the academy, into the broader arena of helping professions, and within society. Traditionally and in the post-modern climate of the social work classroom, an awareness of chronically ill individuals whose identities (in) discernibly move into and out of health, illness, ability, and disability is markedly absent. What the participants reveal in light of this absence is that (in)visible disability poses challenges to constructing knowledge in the first place because there is no common language that honors its splintered temperament. Yet, by validating the experiential import of the (un)settled body and its sensate expression, we open ways for acknowledging, talking about, and advocating for the legitimacy of (in)visible disabilities. Bringing this understanding and language into academic consciousness could take several paths. For instance, integrating (in)visible disability as a distinct focus of human diversity within faculties of social work and developing advanced training for practitioners working in the field, places (in)visible disability more centrally in our professional lives. Disseminating knowledge and establishing a rightful place for (in)visible disability in the academy could also occur through scholarly writing in the professional literature, conference presentations, workshops, and other forums of collective scholarship. A further possibility for advancing professional recognition of (in)visible disability could include creating interdisciplinary alliances that promote research initiatives and public awareness campaigns within the academy and in the (non)disabled community.

Institutionally, I believe the role of social work has a place in the collaborative training of doctors, medical students, and allied healthcare providers. This recommendation is highly significant given the women's early institutional dismissal as "controversial bodies" and their continuing struggle to defend their diagnoses, shifting limitations, and changing needs against the empirical lens of biomedicine and reigning paradigms of (dis)ability. Angie and Helen vie to be seen and heard as credible patients in relation to their liminal bodies. The sensual and metaphoric expressions they use to describe their mutable bodies are considered too "soft" and irrelevant in contrast with the evaluative precision and hollow language of pain scales. Consequently, their integrity as female patients wanes in their attempt to herald an unorthodox voice within the "factual" confines of biomedicine (Wall, 2005). Within this context, social workers are in an advantageous position to enlighten physicians and healthcare workers to understand that while the language of medicine assists in diagnostic evaluation, the voice of the body is equally if not more important, especially when illness does not initially present in "typical" ways but follows its own carnal agenda. Such understanding is invaluable because it opens up spaces where we can talk about shifting disabilities in ways that do not deflect from their shifting volatility. Advocating for expanded awareness and therapeutic protocols that account for contradiction, interruption, and the permeability of bodies can also serve to legitimate more medically controversial conditions such as environmental illness, chronic fatigue syndrome, fibroymyalgia, and nonspecific chronic pain conditions (Chircop & Keddy, 2003; Jackson, 1992; Gibson, 1997; Gibson et al., 2005; Munson, 2000; Sturge-Jacobs, 2002; Ware, 1992). By peeling away the layers of finite terms such as ab/normalcy, sickness/wellness, and real/unreal illness that govern institutional regimes and inscribing bodies with ways of understanding and communicating illness in person-centered ways, we can widen the scope of human compassion and support those most in need.

"Undoing" Disability: Categorical Dilemmas in Practice

The manner in which social services define clients and the ways the parameters of assistance are structured are barriers many individuals living with (in)visible disabilities confront. Professional practices, organizational guidelines, and the development of social and wider public policies are marred by archetypal constructions and cast-iron discourses of bodies as (ab)normal and (dis)abled. What this work makes clear in relation to how we identify and provide service to clients at all levels is that we cannot assume that someone who appears (dis) abled is invariably so across all moments and situations. Sharon Dale Stone (1999) reminds us that even though others cannot [always] see a person's disability, it nevertheless remains with them. The "known about-ness" of an (in)visible disability is, as the study participants repeatedly maintain, more of a sensitivity to different ways of being embodied than anything else.

Rather than rendering "disability" as an immutable construct marked by visible "abnormalities," behaviors, and adaptive aids, this research implies that we need to break free from resolute "either/or" ideas of bodies and embrace more contingent, fluid identifications in our work. However, this appeal as Rose Galvin (2003) points out, begs the question: how do we avoid exclusionary practices that create binary identifications in the first place? While perhaps raising more issues than answers, there are ways of considering this question that may be useful.

As the women's narratives convey, understanding (dis)abled bodies as residing within and between notions of health, illness, ability, and disability implies adopting a more sophisticated understanding of bodies beyond simplistic conceptions and notions of having "good" and "bad' days. Being attuned to how bodies simultaneously inhabit different dimensions of (dis)ability and that such fluctuations can have life-altering repercussions reframes the kinds of decisions we can make in relation to service access, intervention plans, and community support for persons living with (in)visible disabilities. Rather than drawing a definitive line between persons as *either* healthy or ill and able or disabled as we continue to do, we should reconsider situations where fused, fleeting, and multiple subjectivities are the norm and establish more inclusive and equitable practices that account for these pluralized embodiments. Abandoning customary assumptions about (dis)abled bodies, the rigidity of classifications that sustain them, and advocating for an expanded understanding of disability as a complex, evolving, elastic, indeterminable way of being offers a sound beginning.

Amplifying this way of thinking from a social work standpoint, Allan Irving (2007) refreshingly argues that we must embark on alternate journeys where sacred, stable meanings slide into the province of scattered meanings, fluid subjectivities, worlds of contingency, and fragmentation. Resonating with the currents of this dissertation, Irving asks us to see ourselves not as science practitioners seeking universal truths but as "connoisseurs of ambiguity" (p. 6). Echoing Tangenberg and Kemp (2002) who embrace the physical contours and meaning-richness of human being-ness, Irving's philosophy rattles our storehouses of wisdom, imploring us to embrace a more visceral social work that expects uncertainty, unresolved-ness, and moments of clarity as the only assurances we can begin to act from and that resuscitate our human connection. This philosophy, speaking in a different voice than the vogue of evidentiary "best practices," is where I believe the cycle of knowledge and social change can flourish.

Bodies of Controversy: An (In)Visible Politics

Ours is a society that has yet to embrace porous blueprints for bodies and identities that fluster the material and discursive spaces of ability and disability and the normative ideologies that support them. Visually and intellectually, Angela, Angie, and Helen institutionally baffle the "look of disability" and socio-politically frustrate "either/or" classifications and expectations of appearance and functioning as able or disabled and sick or well that doctors, employers, administrators, city planners, and policymakers rely on to authenticate bodies and orchestrate resources for human welfare. While it is not my intention to discuss the numerous inequities that contextualize the lives of persons with (in)visible disabilities, I do want to touch on the "problem of [(in)visible] disability" (Titchkosky, 2007) in a more politicized way in relation to matters such as disability insurance benefits, workplace accommodations, social assistance, and accessible transit. I relegate the majority of my remarks to the lives of women living with (in)visible disabilities given this study's focus on women, and revisit a few examples from the participant's narratives since there is little knowledge about how policies affect women's lives (Chouinard & Crooks, 2005).

Lewis, Hughes, and Saraga (1998) indicate that although social policies reflect embodied human beings, they are developed and applied in a "generalized way" or in the words of Ervelles (2001), with an "add-and-stir recipe" that fails to recognize the uniqueness of bodily experience.

Given that public officials materially and inscriptively define what it is to be healthy and ill, it is important to consider how language informs policy and the implications this embodied translation has for the authenticity of an (un)settled self. As I have reasoned throughout this thesis, it is important to rethink the logistics of categories themselves that govern the meaning of (dis)abled bodies and in tandem with this, reexamine what constitutes convincing "evidence" that bolsters these constructions. While classifications serve to organize meaning and structure decision-making, they equally immobilize progressive thinking in relation to human bodies.

I begin by drawing on the personal accounts of Vera Chouinard (1995) and Pamela Moss (2000) whose stories bare the injustices of negotiating income benefits and terms of employment in their identification as (dis)abled faculty members. Chouinard and Moss demonstrate how homogenized categories and ableist models of the "ideal academic" preclude the realities of persons who live in-between that which is taken-for-granted and that which is not granted at all. Chouinard and Moss demonstrate how individuals who breach naturalized categories that socially define what it means to be healthy, ill, able, disabled, employed, and unemployed, battle to secure equitable salaries and maintain their teaching positions. Their stories emphasize how an individual is expected to be either completely able-bodied and carry out "normate" standards of performance (Thomson, 1997a, b) or be completely disabled and unable to perform according to these ideals. There are no institutionalized conceptions of how bodies (workers) occupy in-between spaces. Being sometimes ill and sometimes healthy poses dilemmas for salary revisions in relation to an altered workload. As Moss (2000) insists, there is a presumption that one is not "equal" with a restructured workload that accommodates fluctuating disability. Since others witness these women performing academic duties in "able-bodied" ways, administrative and collegial suspicion arises when claims of illness and the need for equitable compensation compete with this representation. Indeed, Moss (2000) asserts that while there is a politics to claiming shifting identities, such self-politicization becomes fiercely controversial precisely because of its fluctuating materiality. I would also stress that such self-politicization is entangled within the societal frame of ableism that expects healthy and productive bodies to work at "full capacity" in relation to rigorous schedules and deadlines rather than individuals whose bodily rhythms demand a modified or "doable" pace. For Moss and Chouinard, seeking accommodation in relation to carrying out tasks in altered ways and their need for greater environmental accessibility discursively resides outside the confines of policies because there are no official categories within academia for persons who are both sometimes healthy and sometimes ill to fit in (Moss, 2000). Policy wise, this example illustrates that the gulf between the lived experience of (in)visible disability and its bureaucratic construal is wide. Speaking to this rift, Rosemarie Garland-Thomson (1997a) insists that there is always a gap between one's subjective experience and the cultural identity of having a disability, between any actual life experience and any imposed social category" (p. 140).

Within this study, participants remain intellectually trapped within the same sticky classificatory webs that Chouinard and Moss describe. What I want to reiterate is that because that there is no formal recognition of (in)visible disabilities through language nor any formalized way of talking about them conversationally, women are unable to articulate the fluidity of their disabilities within these intransigent constructions. Adding to this, participants identify a cultural taboo and a social aversion to talking about illness that makes claiming a partially disabled identity and seeking accommodation when one looks "normal" a shameful breach of social mores (Stone, 2007; Vickers, 2000). In keeping within the academic milieu, I illustrate with an example from Helen's narrative. Helen's self-interrogation surrounding the intensity of her recurring vaginal pain and the possibility of securing an extension for a school assignment ultimately culminates in the self-perception of her disability as an "invalid excuse" rather than a justifiable request. Since Helen's pain is not always impairing and because it is primarily invisible to others, she vacillates between (dis)believing in the credibility of her personhood and defending her rights as a student with a fluctuating disability. Differing from Moss and Chouinard's circumstances then, Helen moves between (in)validating herself as partially disabled and (dis)counting the manner in which ableism structures her life (Wendell, 1996).

As another case in point, while the Canadian Human Rights Code guarantees "reasonable"[14] accommodation under the Employment Equity Act, many persons with fluctuating disabilities struggle to secure employment accommodations (Vickers, 2001b). Adaptations requested by persons whose disabilities are "indefinable" and variable are often disbelieved among employers (Driedger, 2003; Moss, 2000). Within Angela's narrative, we witness the controversy surrounding her occupational invisibility as a (dis)abled employee. Angela's request for a larger computer screen and the frustration she experiences in not having her work schedule modified are two examples that demonstrate her inability to persuade others about the legitimacy of her MS and the absence of workplace ethics that are attuned to the needs of persons with (in)visible disabilities. Since Angela looks no different from her "able-bodied" colleagues, the crushing fatigue she experiences in conducting too many community assessments and her request for specialized computer equipment because of her fluctuating visual difficulties are not perceived as legible markers of disability. Unlike a coworker whose arthritis is visually certified by the use of her cane, Angela's limitations remain in doubt because they belie pronounced signs of a "disabled body." In this instance, the cultural logic of disability that partly resides in the visibility of physical difference translates into how it is organizationally defined and accommodated. For Angela's supervisor and her colleagues then, disability exists when it is self-evident. This mistaken mind-set is buoyed by inflexible codes governing many workplaces that equate disability with "visible inability" under all circumstances rather than appearing in some situations but not in others. Thus, a person with multiple sclerosis is thought to be restricted

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[14] What is considered "reasonable" accommodation in relation to "undue hardship" within current legislation remains open to debate in relation to (in)visible disability and beyond my intentions for this discussion.

in their activities in the same manner each day and under the same conditions rather than interchangeably so. Consequently, many women like Angela who are not completely able or completely disabled "fall through the cracks" and face employment discrimination within the larger disability population (Davis, 2005; Driedger, 2003; Moss, 2000; Vickers, 2001a, 2001b).

While it is difficult to maintain the legitimacy of an in-between identity in the labor force (Chouinard, 1995; Moss, 2000), some options exist that employers and policymakers might consider. Workspace modifications such as specialized equipment and ergonomic furnishings and personalized adaptations including reduced workloads, flexible hours, a quiet place for rest, job partnering, and the ability to work at home would no longer rely on medical authentication, quantifiable measures of physical functioning, and "normative competencies," but would rest on pliant protocols that anticipate the changing needs of individuals. Although disabilities need to be identified in some way, we need to ensure that we do not impose disclosure because it is a delicate matter of personal choice. As cited earlier in relation to Angela's narrative, it is important that policies are established from the outset so that individuals can recognize the legitimacy of their rights as (dis)abled and self-identify on their own terms if they choose. The ideal situation would be to have protocols in place and offered to all workers or at the very least, openly discussed with new employees upon hire. Ultimately, such strategies might motivate more people to identify as having an (in)visible disability and can help erode their exclusion and discrimination in the labor force.

From an alternative lens, neo-liberal social assistance initiatives such as the Ontario Disability Support Program (ODSP) have tightened the reins on definitions of disability and eligibility criteria that make it almost impossible to identify as having a disability "sometimes" (Chouinard & Crooks, 2005; Peters, 2003). While this program accounts for the "able-disabled"[15] (those who can "overcome" their disabilities and work) and individuals with "recurring" disabilities,[16] there is I believe, a veiled proviso that insinuates that chronic conditions must present as impairing in predictable ways across time. Consequently, persons who are periodically unwell or have undiagnosed, contested, or "dubious diagnoses" associated with for example, nonspecific chronic pain syndromes (Dumit, 2006; Jackson, 2002), may have substantial difficulty accessing support because their bodies defy the dichotomized inscriptive packaging of persons as able/disabled and employable/unemployable.

Calcified bureaucratic constructions are also evident in government policies pertaining to transit service accessibility. This scenario is evident in the denial of Angela's application to the Toronto Transit Commission's (TTC) Wheel-Trans service. Although Angela experiences debilitating fatigue and pain when walking, the fact that she is capable of ambulating at all for short distances restricts her entitlement. In contrast with more visible, stable disabilities, Angela's MS-related fatigue and pain defy measurement in gross, rudimentary ways because they subjectively fluctuate. Since Angela physically appears "able-bodied" and seemingly meets the expectations of "able-bodied-ness," her fluctuating *need* for assistance is not credibly assessed but denied. Here again, the volatility of the body that rubs against rather than neatly resides within bureaucratic service mandates is discredited and invisible. Thus, the politics of inhabiting a body that is anti-identarian

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[15] Tanya Titchkosky (2007) examines this bureaucratic representation of persons with disabilities as an act of "normative violence" in her text *Reading and Writing Disability Differently: The Textured Life of Embodiment.*

[16] Recurring disabilities cannot be "solved" under the normative logic of "overcoming" them given their unpredictable and shifting nature.

(McRuer, 2006), that occupies a "gray area" because it is physically capable one day, requires accommodation another, and is incapable the next, exceeds set taxonomies and becomes an "unimaginable problem." In this regard, persons whose disabilities alter their physical capacities and energy levels, whose bodies and needs change in different ways and across settings, do not register in the minds of administrative officials and policymakers with any credibility because they are not "rightfully disabled" and thus, hang on the fringe of the populace as "invisible citizens."

In summary, each of the situations addressed elicits several questions that necessitate further reflection. How can the experience of (in)visible disability be recognized when its shifting materiality is socially and politically questioned? How can we eradicate the dividing line between "deserving" and "undeserving" bodies? Are ways of conceiving bodies as (un)settled, in-between, fluid, and indeterminate legitimate categories? What are the alternatives to categorically constructing bodies? What this study reveals in light of these questions is that health, illness, ability, and disability are a continuum of experiences and (un)stable identifications rather than definitive positions. Titchkosky (2007) declares, "claiming to know disability, while not experiencing a need to reflect upon the assumptions, organization, and consequences of this knowledge is a common [and] oppressive social practice" (p. 40).

These examples demonstrate that bodies that agitate the boundaries of divisive classifications necessitate flexible characterizations within policies that redefine persons not in terms of seamless categories of human being-ness ("able" or "disabled"), but more porously as reflecting libratory subjectivities. We need to move away from standardized ways of cataloguing bodies and canonical practices that assess bodies against calculable deviations from mythical norms and more towards the objective of equitable access (Moss, 2000). Equal to this, regulatory bodies that determine requisite conditions for income benefits and accommodations require mandates that evolve with the needs of fluxing bodies and that account for volatility as expected, routine, and "normal" rather than unthinkable. Our profession in its varied capacities can work to (re)conceptualize an understanding of (in)visible disability within these framings rather than as a "problematic embodiment" (Titchkosky, 2007). Given that people are living longer and that chronic illness is becoming a part of everyday life for many (Driedger, 2003), we can improve the opportunities, abilities, and well-being of all individuals by advocating for the plurality of human identity.

Prospective Paths

While (in)visible disability is increasingly saturating scholarly consciousness, sustained commitment is essential. My experience in planting and nurturing the embryonic seeds of this dissertation suggests some paths for continued work. Since this research provides "pictures of possibility" that may resonate with the lives of others rather than "generalizable findings," future work should consider how age, race, ethnicity, education, socio-economic status, sexual orientation, geographical region, disability diversity, and the wider scope of personal, institutional, and social experiences contours the experience of an (in)visible disability. Studies exploring the lives of men with (in)visible illness are also appallingly sparse in the literature and demand attention. Scholarship invested in the place of gendered embodied knowledge, particularly its (in)significance in the physician-patient relationship, and the ways language informs institutional practices and policies are other ripe areas for further exploration. I also believe that cultivating arts-informed inquiries that vocalize and politicize the experience of (in)visible disability offers much promise.

A Final Voice

This research is a living testament of what it is like to live with(in) a body that is (in)visibly (un)settled, that is (un)convincing in its volatility, and that culminates in landscapes of emotional suffering in (un)seen ways. In writing these final words, I remain overwhelmed by the complexity of giving textual shape to the shapelessness of (in)visible disability, to convince others what it is like to experience an (un)settled body, a body that is relatively healthy, pain-free, and calm one day and intolerably incapacitated and chaotic the next. I believe the conversation of (un)settled embodiment must continue. There must be a willingness to embrace what we may doubt and what seems impossible. Given that disability is inevitable in our lives, we can no longer afford to ascribe to "visions" of it as forthrightly evident, as woodenly embodied, as never more than meets the eye. As a society we need to redefine ways of seeing, knowing, and understanding not with our eyes but through language, actions, relationships, and ordinary moments. It is my fervent hope that this dissertation reflects an indelible footprint along a road less traveled, bringing us a step closer to embracing the (un)settled-ness in all of our lives.

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Appendix A

Working Interview Guide

Introductory Guiding Questions

I'd like us to begin by talking about how you knew that something was "not quite right" with(in) your body, that what you were experiencing was "the beginning of something."

- What kinds of things stand out for you that reflect this time as you look at the photographs you have collected?
- In what ways do your photographs begin to talk about and show this time?
- Let's pretend your pictures can talk to us. What would they say about what you were feeling, thinking, and experiencing?
- What remains hidden? Silent? Invisible?

First Main Research Question

1. What are the different ways you experience and think about your body as it (un)predictably changes in visible and invisible ways?

***Guiding Questions*:**

- What is it like to live inside your body?
- What is it like to live with a body that keeps on changing?
- In what ways do you experience these changes/shifts in (in)visible ways?
- What do the changes feel like? How do they come about in your everyday life?
- In what ways do the pictures you have collected/produced capture this? (in visible and invisible ways?)
- If someone else were looking at your photographs what do you think they would they see? Feel? Experience?
- What would not be obvious? Would people miss? Assume?

- What would you want someone to see, feel, experience when looking at your photographs?

Second Main Research Question

2. In what ways does an episodic, (in)visible unsettledness enact/present itself in ordinary life moments, situations and contexts?

Guiding Questions

- What situations, settings, and moments in time give rise to your experiencing this unsettledness?
- What about these situations, contexts, settings and time frames triggers the more visible or invisible side of your condition/disability?
- When you find yourself in different situations, contexts and moments, what kinds of things do you find yourself doing as your body moves back and forth between periods of calm/unrest?
- In what ways do your pictures evoke this visible and invisible shifting between periods of calm/unrest across different life moments and contexts?

Third Main Research Question

3. In what ways do negotiating shifting periods of unsettledness enable and or prevent the individual from passing into and out of a (dis)abled identity in ordinary moments, situations, and contexts?

Guiding Questions

- What does it take to pass as healthy? "Disabled?" Both?
- What do you do to create a personal 'comfort zone' that allows you to pass?

- To disclose your disability/condition?
- When does passing not work? Under what circumstances does it prove difficult or challenging?
- In what contexts or settings is passing as healthy/disabled easier? More difficult?
- What happens when you find yourself caught in-between certain contexts or moments when you can pass either way as healthy/disabled?
- How do you manage the tension between being believed at times and disbelieved at others in relation to the (in)visibility of your condition/disability?
- If these pictures could talk, what would they say about how you experiencing passing back and forth between periods of calm/unrest? Health/illness?
- If someone else were looking at your photographs what would they see? Feel? Experience? Miss?
- What would you want someone to see, experience, understand when looking at these photographs?

Fourth Main Research Question

4. In what ways is (un)settled embodiment experienced as an (in)visible disability? A (dis)abled identity?

Guiding Questions

- When you think about your everyday life, in what ways does your condition present itself as an invisible/visible disability?
- In what ways do you experience your condition/disability as reflecting 'the real you'?

Secondary Research Focus: Photography and (un)settled embodiment

5. In what ways can practices of inquiry using photography give voice and transform our understanding of (in)visible, (un)settled embodiment?

Guiding Questions

- What was it like for you to begin to tell your story by collecting and take pictures for this project?
- How did you decide what pictures to include that really seemed to both show and tell your story?
- What made you decide to leave certain pictures out?
- What made you decide to select the photographs you chose for your final portrayal?
- In what ways did your photographs help tell the story of your experiences?
- In what ways do you think your pictures expand an understanding of (in)visible disability?
- What specific images, issues, questions, and concerns do you think your photographs convey that lead to a fuller understanding (in)visible disability?
- What kinds of things stand out for you in relation to collecting/taking pictures as a participant in this project?

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Appendix B

Study Information Letter

Unsettled Bodies: A Political Phenomenology of Women Living with (In)Visible Disabilities

June 30, 2004

Dear Interested Participant,

My name is Andrea Vick and I am a PhD student at the Faculty of Social Work, University of Toronto. I am conducting a research project that explores the everyday life experiences of women living with the visible and invisible effects of chronic, often disabling, health conditions as the thesis component of my degree requirements. This letter invites you to take part in this study and includes important information about your participation.

What Is This Study About?

Living with a chronic, often disabling health condition is poorly understood in our society. The purpose of this research explores how living with a chronic condition such as multiple sclerosis, fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, interstitial cystitis, Crohn's disease, ulcerative colitis or environmental illness presents itself as shifting in visible and invisible ways in your everyday life.

When and Where Will The Study Take Place?

I am inviting five women to participate in this study. Women will be recruited from the local Toronto area and from disability-related organizations in Toronto. The study is being carried out from August 2004 to the early spring of 2005.

What Does My Participation Involve?

This research relies on the use of photographs to both show and talk about what it is like to live with a chronic condition in ordinary life moments. You will be asked to share photographs from your own personal collections and take photographs that reflect a range of your experiences in different settings such as at home, with family, friends, at work, school, in local community places such as shopping malls, places of recreation and entertainment, in health care, social service and treatment settings and other places, events and activities of importance to you. Even after you have chosen and taken photographs, you may change your mind at any time and decide not to use certain pictures that reveal some or all of your identity.

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Appendix C

Informed Consent Form

Unsettled Bodies: A Political Phenomenology of Women Living with (In)Visible Disabilities

This consent form, a copy of which you will keep for your records, gives you an overall idea of what this research is about and what your participation will involve.

This research explores the everyday life experience of women living with the shifting visible and invisible effects of a chronic health condition such as multiple sclerosis, fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, interstitial cystitis, Crohn's disease, ulcerative colitis or environmental illness.

I understand that my participation is completely voluntary. I will take part in three to five conversational interviews in total each lasting around one and a half to two hours over a four to six week period. With my permission, the interviews will be audiotaped and transcribed. Since this research seeks to create new ways of seeing and experiencing disability using photography, I will be asked to select pictures from my own personal collections and take pictures that reflect a range of my experiences in different settings such as at home, with family, friends, at work, school, in local community places such as shopping malls, places of recreation and entertainment, in health care, social service and treatment settings, and other places, events and activities of importance to me. I will self-determine the nature of my identity in all photographs and in all written components of this project. Even after I have chosen and taken photographs, I may change my mind at any time and decide not to use certain pictures that reveal some or all of my identity. I understand that even though I may identify myself in photographs during the study, there is a risk that I may change my mind at a later date. If I change my mind once photographs are published in the dissertation, it will be too late to protect my identity.

I will not incur any expenses for creating my photographic portrayal. Costs for disposable cameras, film processing, photo duplication, and related supplies are provided by the researcher to a maximum amount of $150.00

I am under no obligation to participate in conversational interviews, may refuse to answer any interview question, stop the interview at any time, and withdraw from the study at any time. I have the right to refuse the audio taping of interviews. I am under no obligation to share or discuss any photographs. I understand that I may experience some emotional distress while talking about sensitive issues related to my chronic condition and everyday experiences. Should this happen, I will have access for a referral to ongoing counselling and if I wish, the researcher will help me make this initial contact.

I understand that my photographic portrayal will be made public and that my identity will not be revealed in any report, presentation or exhibit without my consent. All information