

# An embodied geography of disablement: Chronically ill women's struggles for enabling places in spaces of health care and daily life

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## Abstract

Using data gathered from 18 interviews with women who have developed arthritic illnesses we illustrate how becoming a chronically ill woman is a geographically uneven process. By examining changes in the spatial configuration of everyday life, performances of the ill female self in places, and relations with places of life important to these women, such as the health care clinic and workplace, we show how women's capacities to struggle effectively for enabling identities are challenged. Further, we argue that embodying illness involves women and others, including doctors, assigning meanings to their changing material, lived and represented places in the world.

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## Situating women's experiences of chronic illness and disability in society and space

Social scientific research is showing that women's experiences of chronic illness and impairment are outcomes not only of physically or mentally impaired bodies, but also of socially and spatially constituted barriers to inclusion and well-being. This challenges biomedical views of illness as the individualized experience of disease and disability as the inevitable consequence of impaired bodies and minds. Becoming an ill or impaired person has thus increasingly been viewed as a process of self-transformation: through which

we<sup>1</sup> contend not only with changing mental or physical capacities to negotiate places of everyday life, but also with how this situates us as particular embodied subjects. Although place helps to shape our capacities to cope with life-altering circumstances, few studies explicitly recognize the place-specificity and spatiality of becoming an ill and/or disabled woman. We argue here that becoming a chronically ill woman is a geographically uneven process of embodying, performing and representing ill female selves in and through place. It is a relational process of becoming *other than* normatively 'healthy' able female subjects who are valued as belonging and mattering in 'normal' places of life.

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<sup>1</sup>The term 'our' and 'we' is used at times throughout this paper when discussing the lives and life spaces of chronically ill women as one of the authors of this paper is chronically ill with a rheumatic disease.

The main purpose of this paper is to explore the spatiality of chronically ill women's disablement. More specifically, we examine how being embodied as ill and female in one space of life, particularly within places of health care, influences how women perform themselves in different places of daily life. We draw on data collected from 18 in-depth interviews with women living in Hamilton, Canada, who have been diagnosed with a rheumatic illness (including fibromyalgia syndrome (FMS), lupus, osteoarthritis and rheumatoid arthritis) to document and explain the changing geography of ill women's lives. We argue that embodying illness and even disability involves women and others assigning meaning to their changing material, lived and represented places in multiple spaces of life.

In the next section, we outline the ways in which becoming a chronically ill woman is a geographic process of embodying difference and negotiating disabling barriers to well-being. To put our approach in context, we discuss how it builds upon efforts made by feminist scholars and geographers to advance our understanding of these lived realities of illness and disablement as being outcomes of processes of embodiment and struggle. Then we discuss some of the key ways in which chronically ill women's lives are altered by processes of differencing. The four sections which follow outline the study itself, the participants, and the major findings, including the women's everyday lives with chronic illness, their experiences within places of health care and their struggles to overcome barriers to enablement and well-being outside places such as health care clinics. These sections are followed by a discussion and conclusion which outlines the implications of these findings for understanding ill women's lives and for future research.

### A feminist conceptualization of disablement

For the purposes of this paper, we conceptualize disablement to be an embodied process of becoming and being ill in place(s) and over time in ways that have disabling outcomes for individuals. This process can result in spatial deprivation (Driedger et al., 2004) and its outcomes are the result of changes to one's environment that are both within and beyond an individual's control (Verbrugge and Jette, 1994). It is through this relational process that ill women are situated (by themselves and others) in society and space, and their embodied selves and changing geographies of life are inscribed with particular meanings. Further, we conceptualize women's struggles in and against often disabling socio-spatial constructions of their ill female selves as having a spatiality or geography which involves negotiating and contesting multiple material, lived and imagined differences between disabled and able 'wo-

manly' ways of being and becoming in place. This differencing occurs on bases of class, gender, race, age, and sexuality, as well as differences in physical or mental abilities. Chronically ill women are thus caught up in relational processes of *differencing* in society and space (cf. Kobayashi, 1997) in diverse ways. As the geography of ill women's daily lives changes, for instance to exclude living in a private home or 'belonging' in places of paid work as a result of experiencing this process of disablement, other newer places and roles loom larger in women's lives.

Feminist disability scholars, although rarely explicitly concerned with the spatiality of women's lives, have helped to demonstrate that social differences such as gender and race influence how ill and impaired women are treated, and their needs understood, in places such as the health care clinic and rehabilitation center (e.g. Morris, 1991; Begum, 1996; Frank, 2000). This work shows how restrictive cultural images of the 'normal', attractive female body influence treatment and rehabilitation. Women with limb deficiencies, for instance, have tended to be constructed as negatively 'other' than able women and as therefore requiring material restoration through prostheses; even when they may in fact be more comfortable with their bodies, at least initially, as they are (see Frank, 2000). Such practices not only construct the impaired female body as 'lacking' in comparison to able ones, but also teach women with impairments to loathe their bodies and selves. Clearly such representations have profound implications for where and how women with bodily impairments live.

Feminist geographic accounts of disability and chronic illness (e.g. Valentine, 1999; Butler and Parr, 1999; Dyck, 1995) have helped to highlight the role of place and changing relations to particular spaces of life in struggles to come to terms with being ill and disabled, and to overcome socially and spatially constructed barriers to well-being and inclusion in society and space. Identities are understood as being forged through changing relations to significant places of life and people within them, such as workplaces and homes, and through struggles to deal with losses of one's places in the world (e.g. no longer being able to frequent valued places of social interaction outside the home). Furthermore, becoming an ill person involves losses in valued attributes of the self-associated with changes in where one has a presence and opportunities to interact in specific ways with others. Valentine (1999), for example, shows how the positive masculinity of a male self can be unsettled and threatened when that self is forced, through injury and impairment, to spend more time within the traditionally feminized sphere of the home than in masculinized places such as working class pubs and competitive sporting events. Butler (1999) explores tensions that arise within identities when places of life are disabling and/or heterosexist: she discusses how

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