

Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach

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Abstract

In this paper I employ data triangulation in order to investigate the complex nature of the altered lifeworlds and daily geographies of women living with fibromyalgia syndrome (FMS). More specifically, I use the findings of in-depth interviews and a standardized test (the Sickness Impact Profile [SIP]) in a mixed-method approach to understanding how women's lives change after the onset of FMS and how their changing bodies and locations in society and space shape such altered lifeworlds. These data were collected from 55 women living with FMS in Ontario, Canada. The experiential evidence shared during the interviews is used to qualify or explain certain phenomena observed within the SIP dataset. I focus on four specific experiences in the women's lives; these are the: (1) onset of mental haziness and fatigue; (2) development of disrupted sleep/sleep disorders; (3) removal from paid labour; and (4) withdrawal from social and recreational activities. It is found that changes in the women's bodies *precipitated* some of the most significant life changes experienced, including altered identities and diminished incomes, and that altered bodily realities facilitated or denied access to socio-spatial life. At the same time, the women's changing locations in society and space also played a role in bringing about such changes.

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Introduction

The onset of chronic illness can be a life-altering experience. Chronic illnesses generally intrude on a person's everyday life, such as by disrupting one's ability to perform paid labour, and can result in bodily impairment that is visible to others (Charmaz, 1995) or that is 'hidden' with no visible signs (Stone, 1993). Recent scholarship in the social sciences has helped to illustrate the extremely marginalized spaces in which chronically ill women

live (see, for example, Crooks & Chouinard, 2006; Dyck, 1995; Moss, 1997; Moss & Dyck, 2002). Studies have assisted not only in identifying common issues, such as systemic barriers imposed on these women's everyday lives by larger social and economic systems and institutions (see, for example, Russo & Jansen, 1988), but also issues specific to certain groups such as those who have 'hidden disabilities/illnesses' (see Stone, 1993), or those who experience fluctuations in ability levels or symptoms (see Rosenblum, 1997). Thus, we are beginning to understand how, as Butler and Bowlby (1997) suggest, both the physical and social environments in which chronically ill women live impact upon

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their abilities to engage in everyday socio-spatial life and roles, such as participating in recreational activities and/or being a worker. As a result, we can recognize that the onset of chronic illness plays a significant role in shaping women's lifeworlds and daily geographies, where the lifeworld is the "the taken-for-granted mundane experiences of daily life as carried out in particular spatio-temporal settings" (Dyck, 1995, p. 307) and daily geographies are the places, routes, and paths that women use to live out their lives.

In this paper I explore the altered lifeworlds and daily geographies of women who have developed a specific chronic illness: fibromyalgia syndrome (FMS). FMS primarily affects women (The Arthritis Society, 2002; Clauw & Crawford, 2003). Many uncertainties frame this illness, including its newness as a diagnostic category (Starlanyl & Copeland, 2001), the fact that some practitioners do not believe it is a real condition and will not diagnose it (Ehrlich, 2003), and reports that it is over-diagnosed (Fitzcharles & Boulos, 2003). Chronic pain and fatigue are its two main symptoms (Clauw & Crofford, 2003); they are devastating and can result in bodily impairments which diminish women's abilities to fully participate in society and space (Åsbring, 2001). Other commonly occurring symptoms include: exhaustion and fatigue; point tenderness; aches; depression; muscle stiffness; insomnia; and mental confusion also known as 'fibro fog' (see Starlanyl & Copeland, 2001, or Farhey & Hess, 2004 for a more comprehensive discussion). Comorbidity is also common; including: irritable bowel syndrome; arthritis; chronic fatigue immune deficiency syndrome (CFIDS); restless leg syndrome (RLS); lupus; multiple sclerosis; and depression (Farhey & Hess, 2004; Starlanyl & Copeland, 2001). FMS is diagnosed on the basis of exclusion (Barker, 2002; Schafer, 1997); meaning that, generally, all other diseases or illnesses must first be ruled out through objective tests such as blood work or MRIs prior to its diagnosis. The use of the (subjective) tender point test combined with evidence of widespread pain for at least 3 months has become a generally accepted diagnostic standard for FMS (Starlanyl & Copeland, 2001). More specifically, there are believed to be 18 tender points on a person's body, of which 11 must exhibit tenderness along with a history of widespread pain, for a diagnosis of FMS to be reached.

Doctors and medical researchers have not yet discovered the processes giving rise to the symptoms

of FMS, hence its designation as a syndrome. This puts it into a class of medically unexplained conditions or contested illnesses which includes CFIDS and RLS. These contested illnesses are similar not in that they share common symptoms—though some do—but in that they are all 'syndromes' whereby there is no clear understanding as to what causes them or what connects the symptoms to the broader condition. The lack of knowledge about the cause (or causes) of FMS and uncertainty over whether or not this syndrome has any biophysical basis, and is not exclusively mental or psychosomatic, has meant that some practitioners and allied health professionals have chosen not to recognize it as a legitimate diagnosis (see the arguments made by Ehrlich, 2003; Goldenberg, 2004; Hadler, 2003; or Hadler & Greenhalgh, 2004 for more detail about this debate). As Åsbring and Närvänen (2003) suggest, some of the problems associated with the FMS diagnosis that inform its contested status rest with the fact that it can *only* be verified using a patient's descriptions of his or her own symptoms. Another thing common to contested chronic conditions such as FMS is that they are much more prevalent among women and there is an important gendered dynamic to how they are experienced and also diagnosed (see Barker, 2005 or Crooks, 2006, for further discussion). The reality of contested illnesses, and chronic conditions classified as syndromes (Starlanyl & Copeland, 2001), is that there are no cures available and their symptoms are medically unexplained.

Here I take a methodologically innovative approach to examining the altered lifeworlds and daily geographies of women living with FMS through engaging in a mixed-method analysis. More specifically, a health-related quality-of-life survey instrument, the Sickness Impact Profile (SIP), is used to complement in-depth interview findings as a way of engaging in data triangulation for the purpose of complementarity (Yauch & Steudel, 2003). According to Adamson, Goberman-Hill, Woolhead, and Donovan (2004) and Sale and Brazil (2004), the mixing of qualitative and quantitative approaches within health research is becoming increasingly common. While the data collected in this study were primarily qualitative in nature, a quantitative component was added in order to get a preliminary and more standardized picture of the impact of FMS on daily functioning. Adamson et al. (2004, p. 139) argue that the "inclusion of standardized survey questions in qualitative interviews can

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