Staying in the Workforce with Fibromyalgia

by

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Abstract

Remaining employed with fibromyalgia can be difficult in the increasingly precarious work world, where employees are expected to be healthy and able to consistently meet their job demands. Fibromyalgia also lacks medical legitimacy, which brings a risk of damaged workplace relationships and potential workplace discrimination for people with this illness, affecting mostly women. Their home lives may also impact their ability to remain employed, in conjunction with their impairments. Yet, despite varying degrees of pain, fatigue, and other health issues, 44% of Canadians with fibromyalgia remain in the workforce. How do they do it?

This thesis aimed to understand how, given the challenges of remaining employed, these women stay at work. It also considered other stakeholders in the women’s employment and what discourses underlie the accounts of all three groups. The thesis comprised two studies. First, a critical discourse analysis of fibromyalgia information materials found that they generally portray employment as incompatible with fibromyalgia and, when they very rarely mention work, employees are seen as responsible for self-managing their symptoms on the job. The second study sought the perspectives of women with fibromyalgia, their family members and workmates on how the women remained employed. That study found that employed women with fibromyalgia improvised disclosure dances to respond to everyday
disclosure risks in workplace relationships. They, their family members, and workmates portrayed the women as normal, valuable employees who had not ‘given in’ to their fibromyalgia. Social relationships, from empathetic to conflicted, figured prominently in these two identity-management strategies, through which participants tried to stop the stigma process. The thesis findings highlight the importance of workplace social relations to job retention for employees with invisible impairments. Implications for work disability literature, research using the triad/dyad data-collection method, workplace practice, internal and state workplace policy, and rehabilitation practice are discussed.
Acknowledgments

Doctoral studies changed my life very much for the better. I have so many people to thank for helping me along this journey. The first are all my thesis-research participants, who invited me into their homes and let me into their lives. Their experiential knowledge is the core of this study. Without them, I would have no data. I am grateful as well to the people and organizations who helped me find research participants.

My doctoral journey began in 2007, when Baraa Alghalyini, at the time a physician at St. Michael’s Hospital, invited me to speak at a grand round about fibromyalgia. Celia Schwartz, social worker at St. Michael’s Hospital, had given her my name. After the grand round, Baraa organized a workshop on fibromyalgia at the Family Medicine Forum, where I was on the panel, and together we wrote an article for Canadian Family Physician. In the process of our collaboration, I birthed a doctoral thesis topic. Celia and Baraa were my midwives.

The Rehabilitation Sciences Institute (RSI) turned out to be an excellent location for a social researcher to pursue a PhD in the health sciences. Although learning this new culture was a bumpy ride, there were so many who helped smooth it. Karen Yoshida initiated me into the disciplines of rehabilitation sciences and disability studies and taught me embodiment and feminist theories. Margaret MacNeill contributed her knowledge of critical theories and women’s health to my Program Advisory Committee (PAC), as well as her careful editing of the thesis. My other PAC member, Bonnie Kirsh, brought to the committee her expertise in employment and mental health, her helpful feedback, and her steadiness. Rebecca Renwick, Jan Angus, and Tanya Titchkosky, my comprehensive examiners, made me feel like a scholar for the first time. Through the years, the students who started their
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I returned to university to learn the qualitative research approach and social theory. My expectations were exceeded by my instructors in the Essentials of Qualitative Research Course Series: Ping-Chun Hsiung, Denise Gastaldo, Peggy McDonough, and Joan Eakin, and by presenters and attendees at seminars of the Centre for Critical Qualitative Health Research. Colleagues at annual conferences of the Canadian Disability Studies Association and the Canadian Women and Gender Studies Association Recherches feministes expanded my mind with their outside-the-box thinking. Reconnecting with Anne Braithwaite, Michelle Owen, and Laurence Parent is always a pleasure.

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Chapter 1
Rationale, Literature Review, and Research Questions

This chapter presents the rationale for the thesis, the policy context, and a review of pertinent literature and the thesis research questions. The rationale section begins with the issue of chronic illnesses in general and employment, then moves to fibromyalgia, the chronic illness that is the focus of this thesis, and my reasons for choosing to focus on this illness. I then describe the policy environment that impacts the ability of employees with chronic illnesses to stay at work. The literature review addresses the domains of workplace and home in relation to work ability as well as literature on fibromyalgia and employment. Problems with these literatures are discussed. The chapter ends with the thesis research questions and an explanation of the thesis organization.

Rationale

Chronic illness is increasingly common among employees in the aging workforce (Cooke, 2006; Foot & Venne, 2011). Impairments\(^1\) from chronic illness, such as pain and fatigue, tend to be invisible, a characteristic that has advantages and disadvantages. On one hand, employees can choose whether or not to disclose their impairments at work (Gates & Akabas, 2011). On the other hand, invisible impairments are difficult to prove when employees seek accommodations from employers, understanding from coworkers, or income-security benefits that enable them to leave the workforce (Lightman, Vick, Herd, & Mitchell, 2009; Tarasuk & Eakin, 1995). In particular, chronic-pain conditions are commonly misconceived as resulting from mental illness or as malingering (Noonan & Wagner, 2005), producing disbelief that they create legitimate impairments.

\(^1\) I use ‘impairment’ rather than ‘disability’ to describe physical or mental characteristics that reduce individuals’ ability to function. I use ‘disable’ in the sense of the social model of disability; that is, people are not disabled by their impairments but by their social environments (Oliver, 1996).
Pain is one of the invisible chronic conditions least likely to be believed by employers, family, and friends. Chronic pain is more prevalent among women than among men, and women have higher rates of pain-related impairment (IASP, 2007). Nevertheless, both women and men with chronic pain often have difficulty proving their impairments at work (Lightman et al., 2009; Tarasuk & Eakin, 1995). Women’s compensation claims tend to result from illnesses, the causes of which are difficult to attribute to work; whereas, men’s claims tend to result from injuries (Côté & Coutu, 2010), whose work-based origins are easier to prove.

Chronic pain generally impacts employed women’s home lives differently than men’s. Whereas employed men perceive pain as threatening their jobs, employed women with primary responsibility for housework, child, and elder care perceive pain as threatening not only their jobs but their families (Unruh, 1996). Family responsibilities also reduce the time women have for recuperating at home (Côté & Coutu, 2010), lengthening the time taken to return to work. Therefore, for women with chronic pain, the home environment is relevant to whether or not they stay at work.

There is a group of people with chronic illness that exemplifies the challenges described above: women with fibromyalgia. It is an episodic condition primarily defined by chronic, widespread pain (Wolfe et al., 2010) but also by extreme fatigue, non-refreshing sleep, cognitive difficulties and other issues. According to the latest figures, 520,000 Canadians report a diagnosis of fibromyalgia (Statistics Canada, 2015). Most of them are women (82%), and over two thirds (65%) are middle-aged (Statistics Canada, 2010; Statistics Canada, 2015). Like chronic pain in general, fibromyalgia is contentious and produces invisible impairments. Nonetheless, almost half of Canadians with the condition (44% or
273,000) are in the labour force (Statistics Canada, 2010). Some of those not in the labour force are retired, leaving only 21% of Canadians with fibromyalgia reporting that they are permanently unable to work (Statistics Canada, 2010). This is surprising, given that information on fibromyalgia contains little encouragement or advice for remaining in the workforce (Oldfield, 2011). Although a very small literature exists about staying at work with fibromyalgia, there is a need to expand this literature and to translate it into information that women with fibromyalgia and health professionals can use to help these women remain employed.

*Personal reflection*

The topic of fibromyalgia and employment is of particular interest to me because I was diagnosed with fibromyalgia in the mid-1990s and, although impaired for the following decade, was able to stay in the workforce because I was self-employed. During the numerous rehabilitation programs I attended, I observed that women (including me) used phrases from the self-help books we were reading, as well as other information we were given in the programs, to describe our bodies and our fibromyalgia experiences. I also joined a fibromyalgia-patient-advocacy group and attended support-group meetings, where I noticed that women with fibromyalgia used remarkably similar phrases to describe their bodies. These observations led me to ask how fibromyalgia information materials portray the condition and what discourses underlie these portrayals. I set out to answer this question in the first study of my doctoral research, which is reported in Chapter 3 of this thesis. A key finding of that study was that the fibromyalgia-information materials I analyzed rarely mentioned employment. That finding alerted me to the need to start filling this gap by
studying how women with fibromyalgia stay at work. This became the objective of my second study, reported in Chapters 4 and 5.

**The Structural and Social Environments of Employment with Fibromyalgia**

For employees with fibromyalgia, staying at work depends not only on individual factors, such as the severity of impairment and the individual’s ability to manage it, but also on the environments of policy, the workplace, and the home. The next section covers literature on these environments.

**The policy environment**

A number of public- and private-sector policies, along with their associated programs, affect whether and how people with episodic conditions such as fibromyalgia participate in the workforce. These policies fall into two main groups: human rights legislation and income-support programs for people with impairments who leave the labour force. Although human rights legislation prohibits discrimination on the basis of disability,\(^2\) there is little evidence that it has increased employment of people with impairments outside the public sector (Jongbloed, 2009). One reason for the legislation’s lack of effectiveness is that it is enforced through individual complaints, which can be expensive to pursue and take many years to adjudicate (Tompa, Scott, Trevithick, & Bhattacharyya, 2006). Another reason is that the legislation tends to focus on the removal of physical barriers in public spaces (including workplaces) that prevent people with visible mobility impairments from accessing them. However, people with invisible impairments are prevented from accessing paid work through more subtle mechanisms, such as the organization and pacing of work (Davis, 2005).

People with episodic impairments who can work part-time, part-year, or intermittently do not readily fit the eligibility criteria for government and private disability-

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\(^2\) In human rights legislation, the term ‘disability’ connotes ‘impairment,’ so I use it here.
insurance programs (Lightman et al., 2009). These programs generally require that recipients be permanently incapable of working (McKee, Popiel, & Boyce, 2006). For employees with fibromyalgia, these criteria pose particular challenges: first, they must prove their invisible impairments; second, they must prove that they are completely unable to work. Canada Pension Plan disability benefits, for example, require that applicants have a disability that is both severe (“you have a mental or physical disability that regularly stops you from doing any type of substantially gainful work”) and prolonged (“your disability is long-term and of indefinite duration”), and it must prevent the applicant “from being able to work at any job on a regular basis” (Service Canada, 2015). This Canadian requirement is stricter than eligibility criteria in other OECD countries. In Denmark, for example, only a 50% reduction in work capacity is required to qualify for federal disability benefits (OECD, 2010). Thus, Danes can work part time and also receive federal disability benefits, but Canadians generally cannot. In Canada, some government income-support programs allow recipients to earn a limited income from paid work (CWGHR, 2009; Stapleton & Procyk, 2010). The Ontario Disability Support Program (ODSP) eligibility criteria are somewhat less stringent than CPP’s. ODSP requires proof that applicants have substantial impairments that are continuous or recurrent, expected to last for a year or more, and significantly limit their ability to work (ODSP, 2012). Benefits recipients can be employed and keep half of their monthly earnings, plus certain exempted costs such as child care (ODSP, 2012). Although ODSP benefits are low, they also include prescription drug coverage and dental services.

Some people who consider returning to the workforce full time can only find precarious jobs with low, insecure wages and no health benefits. This is more likely to be the case for women with impairments than for non-disabled women (Wilton, 2006). For the
former, low but stable income-support payments with health benefits are less risky than employment (CRSAO, 2012). To encourage benefits recipients to work, some income-support programs allow them to try out a new job for 3 months without losing their income support (Stapleton & Procyk, 2010). Despite this encouragement, recipients are concerned about having to re-apply for benefits if their new jobs are incompatible with their impairments or if their jobs end (CWGHR, 2009). For the above-described reasons, staying on income-support benefits can be simpler than working (Patel, Greasley, & Watson, 2007).

All of the above reasons present people with fibromyalgia with a dilemma: to struggle to continue working full-time with impairment challenges, to work part-time if possible, with a consequently lower income if they are sole or primary breadwinners, or, if they are able to surmount the difficult task of proving disability, to leave the workforce and face poverty.

**The workplace environment**

Since the 1970s, non-standard employment relationships (part-time, casual, contract, temporary, self-employment) have increased (Tompa et al., 2006). Although these forms of work have long employed women seeking to accommodate their family responsibilities, precarious employment has expanded into occupations that traditionally offered standard employment (Facey & Eakin, 2010). For example, Lewchuck, Vrankulj, and Laflèche (2014) report that, in their study of southern Ontario workers, half were employed in precarious work and 40% had no benefits beyond a basic wage. Canadians with impairments of all kinds are less likely to be in standard employment than other Canadians (Tompa et al., 2006; Wilton, 2006), and a higher proportion of women with impairments work in precarious jobs than men with impairments (Tompa, et al., 2006). Although more part-time work opportunities might enable people with episodic conditions to remain in the workforce, these
part-time jobs can increase their vulnerability as workers, because they have the drawbacks of precarious employment: lower pay and job insecurity as well as lack of benefits, access to training, union membership, and labour-law protection (Facey & Eakin, 2010; Tompa et al., 2006; Vick & Lightman, 2010; Wilton, 2006). As well, in precarious employment it is hard to build the supportive workplace relationships necessary to negotiate accommodations and to successfully implement them (Gates & Akabas, 2011; Wilton, 2006).

*Disclosure of illness or impairments.* Workplace disclosure is a particularly thorny issue for employees with chronic illnesses. I refer to studies specific to employees with fibromyalgia as well as studies about employees with other invisible conditions, such as mental health disorders and chronic pain. Employees with these conditions are at risk of similar stereotypes as employees with fibromyalgia if their conditions become known.

Because impairments from chronic illnesses are invisible, it is possible to ‘pass as normal’ and thus avoid the stereotypes that people with visible impairments face (Davis, 2005; MacDonald-Wilson et al., 2011). Not disclosing an invisible condition is in fact common; for example, Gignac et al. (2012) report that only half of their participants disclosed their arthritis to employers, and that the literature reports even less frequent disclosure by employees with less medically legitimate conditions (Gignac & Cao, 2009). There are several reasons why employees with fibromyalgia do not disclose their condition or impairments. First, disclosure can spawn moral judgement of these women: disbelief that they are truly ill and that they are responsible for causing their conditions (Hansen, 2008; Oldfield, 2013). Moral judgment can also lead supervisors to question the validity of impairment claims, regardless of medical or other evidence (Tarasuk & Eakin, 1995). Given this moral judgment, employees fear being seen as incompetent and thus losing promotion
opportunities, or even their jobs, particularly if they are precarious and accommodations are not likely to be offered (Gates & Akabas, 2011; Gignac & Cao, 2009; Hansen, 2008; MacDonald-Wilson et al., 2011). These risks are especially pressing for women who are the sole income earners in their households or have had earning gaps because of child-rearing responsibilities (Dyck & Jongbloed, 2000).

Employees with chronic illness who do not disclose conceal their impairments through self-accommodations, such as using vacation leave rather than sick leave (Dyck & Jongbloed, 2000; Gignac et al., 2012). Concealing impairments is easier if the person is relatively free of supervision at work (Dyck & Jongbloed, 2000). To free up time to rest at home, women with high incomes can buy services, such as housekeeping and childcare, to replace their unpaid domestic work (Crooks, Stone, & Owen, 2009; Dyck & Jongbloed, 2000). Employees who conceal their impairments may not disclose them until the severity of impairment visibly affects job performance and thus threatens a poor performance evaluation (Gignac et al., 2012). Finally, non-disclosure is more likely in non-unionized, private-sector, or service jobs than in public-sector or professional jobs (Dyck & Jongbloed, 2000).

Although changing jobs is one strategy for self-accommodating invisible impairments, because chronic illnesses and other episodic conditions tend to arrive in middle age, people feel locked into their jobs, not wanting to lose the seniority and benefits they have already earned (Gignac et al., 2012). There is also concern that age discrimination will hurt the chances of being re-employed (Patel et al., 2007).

For women with chronic illnesses, disclosing invisible impairments at work opens their bodies to scrutiny and threatens to construct them as unfit for their jobs (Moss & Dyck, 2002). Women with chronic illnesses internalize this stereotyping, feeling they must justify
their work ability and perform to a higher standard than non-disabled employees in order to be perceived as competent (Hansen, 2008). Yet, they are hampered in their job performance in ways that other employees are not: by pain and fatigue, and by the extra time needed to prepare for work and recover from it. On the other hand, disclosure can benefit employees with chronic illnesses, particularly if they sense that supervisors and coworkers will respond supportively (Gignac & Cao, 2009). Disclosure can end the need to struggle alone with pain, fatigue, and embarrassment and lower stress from concealing impairments. Disclosure can also open up possibilities for support from supervisors and co-workers in the form of creative thinking, empathy, and teamwork (Hansen, 2008; MacDonald-Wilson et al., 2011). This support can substantially enable women with invisible impairments to remain employed (Hansen, 2008).

Disclosure is a necessary step before requesting accommodations. After disclosing, employees with chronic pain need to establish credibility for their impairments: convincing employers, first, that they are not malingering (Eakin, MacEachen, & Clarke, 2003; Tarasuk & Eakin, 1995); second, that the pain impairs their job performance; and, third, that therefore they need and are entitled to workplace accommodations. Not surprisingly, good workplace relationships are key in negotiating accommodations for episodic impairments, because accommodations can require changes to work processes and tasks that impinge on supervisors and co-workers, as well as on employers’ productivity needs (Gates & Akbas, 2011). For accommodations to be effectively implemented, a collaborative climate of goodwill and trust among workplace parties is necessary as well as good communication among co-workers, supervisors, human resources personnel, and union representatives (Dunstan & MacEachen, 2012; Gates & Akbas, 2011; MacEachen, et al., 2006).
Aside from workplace relationships, women’s status at work and employer policies can help or hinder accommodations for episodic impairments. Women who have unique or special skills, jobs that give them more control over their work and more knowledge of resources, or who are high up in their organization’s hierarchy can be more successful at gaining accommodations (Crooks, Stone, & Owen, 2009; Dyck & Jongbloed, 2000). So can women who have worked with the same employer for a long time (Henriksson, Liedberg, & Gerdle, 2005). In contrast, women in precarious jobs can be less successful at gaining accommodations, because they are less likely to have long-term workplace relationships or workplace status to leverage. Negotiating accommodations tends to be smoother and the workplace environment more supportive when employers have policies concerning, and direct experience hiring, people with episodic impairments (Franche et al., 2009; Schultz, Milner, Hanson, & Winter, 2011). However, even with supportive policies and positive attitudes, supervisors may still lack strategies for accommodating employees with impairments (Schultz et al., 2011).

Employees with invisible conditions can be reticent to identify themselves as disabled, an identity implied in requesting accommodations. For example, Crooks, Chouinard, and Wilton (2008) found that women with fibromyalgia identified themselves as ‘disabled’ very selectively; for example, only when applying for disabled parking spaces. In another study, Parsons, Eakin, Bell, Franche, and Davis (2008) found that employees returning to work after cancer treatment did not identify as disabled, even though treatment effects that affect work and are similar to fibromyalgia symptoms (e.g., chronic pain, extreme fatigue, brain fog) can linger long after treatment ends.
The home environment

For most employed women who live in families, work does not end when they go home (Côté & Coutu, 2010). Although the proportion of employed women rose steadily over the last 30 years, a gender gap persists in housework, child and elder care within families (Statistics Canada, 2012). Even though men do more of this unpaid family work than they did 30 years ago, women employed full time still spend twice as many hours/week caring for children as employed men (50 vs. 25) and 1.6 times as many hours on housework (14 vs. 9). In addition, more women than men care for elders (14% vs. 9%) (Statistics Canada, 2012). Women’s unpaid family work can impact their employment; for example, women are 10 times more likely to work part-time to care for their own children than men (34% vs. 3%). Time-budget surveys often count only the physical tasks of family work (Bryson, 2013); yet, women’s nurturing includes emotional work (e.g., maintaining relationships and resolving conflicts), mental work (e.g., planning and scheduling), and spiritual work (e.g., coping with dramatic change and discrimination) (Eichler, 2008). Women’s household tasks are more time-sensitive than men’s. Women are more likely responsible for fixed, life-maintaining tasks (e.g., cooking, cleaning); whereas, men are more likely responsible for flexible tasks (e.g. home maintenance) (Liu, 2008). Because women’s unpaid family work is invisible yet essential (Eichler, 2008) as well as time consuming, it is important to study the home environment in any research on job retention.

Whether and how much unpaid family work is shared by other family members impacts the workforce participation of women with chronic illnesses. In single-parent families in particular (Côté & Coutu, 2010), children are too young to take on household work that otherwise could be shared by a partner, and single mothers in low-paid jobs cannot
afford to replace their household work by hiring household help. In contrast, having partners who are willing to share housework and not having children living at home can enable women with episodic conditions to stay at work (Crooks, Stone, & Owen, 2009). Finally, emotional support from family members enables women with chronic illnesses to remain in the workforce (Dyck & Jongbloed, 2000); whereas, lack of emotional support may make employment difficult.

For employed women with chronic illnesses, family work can take much longer than for non-disabled people, eating into time available to do the personal care tasks needed to prepare for the workday. For these women, personal-care tasks, such as getting out of bed, washing, dressing, and taking medications on a prescribed schedule, is time-consuming as well (Hansen & Philo, 2007). Despite these women’s need for paid help with household tasks, government-funded housework services are generally available to people with impairments who have left the workforce (Hansen, 2008). Of course, well-paid women can hire others to perform their domestic work (Moss & Dyck, 2002). However, for women who cannot, the extra time, effort, and energy that their double day requires makes balancing work and home life even more challenging than for women without impairments.

Unless women with episodic impairments are economically secure, highly motivated in their work (Crooks, Stone, & Owen, 2009), or derive self-esteem from it (Johansson, Hamberg, Westman, Göran, & Lindgren, 1999), staying at work depends largely on family responsibilities (Côté & Coutu, 2010). How important women’s family work is to their self-identity matters as well. For women with chronic illnesses who see being a good mother and a good wife as intrinsic parts of their identity, maintaining this identity is more important than remaining employed (Johansson et al., 1999). For working-class women in less
rewarding jobs, family responsibilities may take priority over employment (Johannson et al., 1997). Women who have a subordinate role in their families and responsibility for most of the domestic work have problems prioritizing their own rehabilitation needs and are less likely to return to work than men (Côté & Coutu, 2010; Johannson, Hamberg, & Lindgren, & Westman, 1997). As Johannson et al. suggest, women’s chronic pain persists because of their domestic work in the home.

In summary, literature on employed women’s home responsibilities reveals that a gender gap persists in unpaid household work; women still do more of it than men. For employed women with chronic illnesses, home responsibilities impinge on the time and energy they have for paid work and their ability to rest at home from their jobs. Preparing for work can take much longer than for non-disabled employees. In households where family members share household and caring work and where women with chronic illnesses receive emotional support, they are more likely to stay in the workforce.

Having illuminated the policy, workplace and home environments that influence participation of women with fibromyalgia in the labour force, I now turn to literature pertinent to staying at work with fibromyalgia.

**Remaining employed with fibromyalgia**

The literature specifically on fibromyalgia and employment comprises only a few studies, which are discussed in this section. To supplement this very small literature, I also discuss studies from the small literature on the illness experience of fibromyalgia that included some employed participants.

The few existing studies specifically about employment with fibromyalgia describe multiple reasons why participants with fibromyalgia remain employed. These studies suggest
that participants found their work meaningful through the satisfaction and recognition it provided. Working helped them feel ‘normal’ and that they were contributing to society (deVries, Brower, Groothoff, Geertzen, & Reneman, 2011; Palstam, Gard, & Mannerkorpi, 2013). Not only was work meaningful for participants, it was therapeutic. By providing daily structure and socializing, work distracted them from pain. Not surprisingly, participants stayed at work because they needed the income (deVries et al., 2011; Palstam et al., 2013).

Furthermore, participants’ work environments were enabling. The working conditions were flexible, giving employees control over work hours, work pace, and work location. In addition, participants’ work tasks suited their health, in that they were not strenuous or ergonomic aids were available (deVries et al., 2011). Lastly, their work and non-work environments were supportive. Being appreciated by supervisors and co-workers was important for remaining at work (Henriksson, Liedberg et al., 2005). They also received support outside work from health care professionals, family, and friends (Palstam et al., 2013). Together, these individual, work, and social conditions helped women with fibromyalgia remain employed.

Participants of fibromyalgia-illness-experience studies who remained in the workforce reported spending less time managing pain or negative emotions, and more satisfaction with their lives than women who left their jobs (Liedberg, Hesselstrand, & Henriksson, 2004). In contrast, women who left their jobs were likely to focus more on their health problems (Liedberg & Henriksson, 2002). In a longitudinal study of women with fibromyalgia, Wigers (1996) found that collecting a full disability pension predicted negative health outcomes (pain, lack of energy, and lack of work capacity) among people who had similar levels of symptom intensity at the beginning of the study.
The two literatures report some strategies that women with fibromyalgia use to stay in the workforce. First, participants prioritized paid work over other activities, reducing their leisure and social activities to allow more time to rest for work (Crooks, 2007; Crooks, Stone, & Owen, 2009; Liedberg & Henriksson, 2002; Löfgren, Ekholm, & Öhman, 2006; Sim & Madden 2008). At work, they prioritized tasks so that they could work at their own pace (Bossema et al., 2012; Sallinen, Kukkurainen, Peltokallio, & Mikkelsson, 2010). Second, they used self-care practices, including exercise, relaxation, and stress reduction (Löfgren, Ekholm, & Öhman, 2006; Werner, Sissel Steihaug, & Malterud, 2003). Third, they negotiated accommodations, such as changing their work schedules (e.g., starting later in the day, varying work hours, taking days off without pay or using vacation leave) as well as working at home, modifying the type of work they did, getting adjustable chairs and tables, having fewer physical demands, and frequently changing positions (Henriksson, Liedberg et al. 2005; Liedberg & Henriksson, 2002; Löfgren, Ekholm et al., 2006; Sallinen et al., 2010). Negotiating changes at work required support not only from supervisors and co-workers but also at higher levels of the organization (Liedberg & Henriksson, 2002). Fourth, some women with fibromyalgia changed their occupations (Rakovski, Zettel-Watson, & Rutledge, 2012). Augmenting the strategies women with fibromyalgia reported, participants in Bossema et al.’s (2012) study identified desirable working conditions for employees with fibromyalgia: jobs that preserve energy for home and leisure, reasonable workloads, clear agreements with management, development opportunities, and help from colleagues. Many of the strategies that women with fibromyalgia used to remain employed involved manipulating time to fit their impairments.
As discussed in the Background section above, negotiating accommodations requires disclosing impairments, which not all employees are willing to do. Even if employees with fibromyalgia disclose their impairments, disclosure does not necessarily guarantee accommodation. They may face the same disbelief that they face when trying to convince doctors, family, and friends that they are chronically ill (Schaefer, 1995). In high-stress workplaces, women with fibromyalgia can feel guilty asking colleagues for help or asking supervisors to adjust work tasks and hours, because they do not want to increase the workload of their colleagues (Liedberg & Henriksson, 2002).

The fibromyalgia-illness-experience literature also reports that support at home affects whether women with FM stay at work. When family members did not share domestic work, or did not believe that the women were impaired and still expected them to carry a full load of domestic duties, women with fibromyalgia typically had neither time to recover from paid work, nor enough energy left from work for family life (Henriksson, Liedberg, & Gerdle, 2005; Liedberg & Henriksson, 2002). Therefore, they were more likely than others to leave the labour force (Henriksson, Liedberg et al., 2005; Liedberg & Henriksson, 2002; Liedberg, Hesselstrand, et al., 2004). Conversely, when family members shared family work and women with fibromyalgia received emotional support from family members, the women were more likely to stay at work (Liedberg, Hesselstrand, & Henriksson, 2004; Löfgren, Ekholm, & Öhman, 2006).

In summary, from the literatures on fibromyalgia illness experience and employment with fibromyalgia, we learn that, to remain employed, women with FM adopt various strategies to control their pain and fatigue, including self-accommodations and accommodations negotiated with employers. They have multiple reasons for staying in the
workforce other than financial. Their workforce participation is affected by the amount of emotional and instrumental support they receive at work and at home, and by how much family members share household and caring work.

I now draw on Golden-Biddle and Locke’s (1997) literature-assessment framework to critique literature on remaining employed with fibromyalgia in terms of whether it is incomplete (has gaps), inadequate (has oversights), or incommensurate (needs an alternative theoretical perspective).

My review of fibromyalgia-illness-experience studies that include employed participants suggests that this literature is incomplete. Given that few fibromyalgia-illness-experience studies look at employment, this literature pays little attention to paid work, despite employment being a central aspect of daily life for many women in the industrialized world, including women with FM. This literature tells us little about how the structures that constrain and enable these women’s participation in the workforce and how they use their agency to negotiate these structures. Second, FM illness-experience studies that do address employment rarely examine the perspectives of key players who shape women’s employment possibilities: their family members and workplace parties.

The FM illness-experience literature is inadequate (i.e., has oversights) in that, first, although the interaction of workplace and home environments is discussed to a limited extent, women’s unequal responsibility for unpaid domestic work is very rarely questioned. Second, all but a few of the studies in both literatures recruited participants from clinical settings or, in even fewer cases, support groups. Women who seek help from clinicians or support groups are more impaired by fibromyalgia (Rusu, Gee, Lagacé, & Parlor, 2015) or
more disabled by their social and physical environments. Recruiting from these sources limits representation of women who stay at work in the FM illness-experience literature.

The FM illness-experience literature is *incommensurate* (i.e., needs an alternative theoretical perspective), first, in that it is rooted to a large extent in two theoretical concepts that generally frame chronic illness (and by extension fibromyalgia) as a largely negative experience. Many of the studies use as their theoretical basis one of two concepts from the sociology of chronic illness: Bury’s (1982) concept ‘chronic illness as biographical disruption’ and Charmaz’s (1983) concept ‘loss of self’ due to chronic illness. Both concepts come from the sociology of chronic illness, which generally focuses on suffering and dependence. Second, most of the illness-experience studies take a phenomenological approach, describing women’s daily lived experiences but not questioning the structures that can disable women with FM.

My review of the very small field of literature about employment with fibromyalgia suggests that it is *incomplete* in that it does not include the interaction of the policy and home environments with employment. These two other environments affect the participation of women with fibromyalgia in the labour force. It also does not take account of precarious employment, a growing trend in Western countries. This literature is *inadequate* for the Canadian policy context, because many of the studies are from Scandinavia and Holland, where it is possible to work part-time and also receive partial disability pensions. This combination may make it easier for participants in these studies to remain employed than it is for Canadians, who generally must prove that they are incapable of working before being granted disability pensions. Finally, the literature on employment with fibromyalgia is *incommensurate* in its focus on identifying facilitators and barriers to employment for
women with fibromyalgia without examining the power relations underlying these women’s work, paid and unpaid. Although identifying facilitators and barriers highlights women’s agency and to some extent the structures that employees with fibromyalgia contend with, the literature on employment with fibromyalgia has not yet looked at how women and others around them manage the women’s identities to help the women remain employed. At present, we know nothing about how women with fibromyalgia negotiate discourses about FM and use these discourses to remain employed.

**Addressing Problems in the Literature**

To address the problems identified above in fibromyalgia-illness-experience studies that address employment and research that specifically studies employment with fibromyalgia, we need to know more about how and why women with this condition stay on the job, particularly when they do not disclose their invisible impairments to employers. To expand the literature on fibromyalgia illness experience into the employment domain, a key area of women’s lives, participants need to be recruited from the general community, rather than from locations where women seek specialized help. These are the recruitment sources of previous fibromyalgia-experience studies: rheumatology clinics, pain management programs, and support groups. To understand how women with fibromyalgia stay at work, we need to understand how women negotiate the structures that enable and constrain their workforce participation and what role social relationships play in these negotiations. To produce a fuller understanding of how women with fibromyalgia stay at work, we need to know the perspectives of their family members and workplace parties, key actors in the work and home environments. Finally, we need to know more about discourses on fibromyalgia, particularly
in relation to paid work, as well as how employed women with fibromyalgia, their family members, supervisors and coworkers negotiate these discourses.

The fibromyalgia illness-experience literature, using the concepts ‘chronic illness as biographical disruption’ and ‘chronic illness as loss of self’, has done important work in documenting the daily suffering of women with fibromyalgia as well as the ways that they cope with their impairments. The limited attention in the literature about employment with fibromyalgia has initiated an understanding of job-retention facilitators for women with the condition. To complement these literatures and to better understand how women with fibromyalgia find ways to remain in the workforce, there is need to expand the research lens beyond the women themselves to the structures and people in the environments that affect their ability to remain employed: policy, home, and workplace. Such an approach challenges the dominant focus in fibromyalgia-illness-experience research by applying an empirical lens to the lived experience of employed women with the illness and by questioning their working conditions as well as the extent of their women’s responsibility for unpaid domestic work, which appear to be structures that affect participation of women with fibromyalgia in paid work.

**Research Questions**

This thesis addressed the problems identified in the literature by posing two questions. The primary research question was: Given the challenges of remaining employed, how do women with fibromyalgia stay at work? With this question, I aimed to gain an understanding of how these women remain employed through the perspectives of women themselves, their family members, and their supervisors or coworkers (i.e., their workmates).
The secondary research question was: What discourses underlie the perspectives of these groups, and how do they negotiate these discourses?

The thesis comprised two studies. The first study, the findings of which are reported in Chapter 3, aimed to produce an understanding of how information materials about fibromyalgia portray the condition. A key finding of this study was that information materials generally portray employment as incompatible with fibromyalgia. However, in the course of doing the study, I found statistical data revealing that a large proportion of Canadians with fibromyalgia remain employed. The contrast between these data and the key finding of the first study led to the second study. It was informed by first study’s findings concerning narratives about fibromyalgia and employment. The second study’s findings are reported in Chapters 4 and 5.

**Organization of Thesis**

In this introductory chapter, I presented the background to the thesis topic, reviewed pertinent literature, and posed the thesis research questions. In Chapter 2 I explain the theoretical framework, the methodology and methods, and reflect on my research journey. Chapters 3 to 5 comprise three manuscripts that cover the findings of the thesis and their discussion. The manuscripts, their publication location and status are as follows:


**Chapter 4** - Oldfield, M., MacEachen, E., Kirsh, B. & MacNeill, M. (accepted with minor revisions April 2015, resubmitted in August 2015). Impromptu everyday disclosure dances:
How women with stigmatized chronic illnesses respond to disclosure risks at work.

*Disability and Rehabilitation.*

Chapter 5 - Oldfield, M., MacEachen, E., MacNeill, M., & Kirsh, B. “You want to show that you’re a valuable employee”: A critical discourse analysis of portrayals of employed women with fibromyalgia. To be submitted to *Social Science and Medicine.*

Finally, Chapter 6 synthesizes the three manuscripts and discusses the implications of the thesis findings for policy, practice, and future research. There is a list of all the publications and presentations that resulted from this thesis in Appendix 1.
References


https://tspace.library.utoronto.ca/bitstream/1807/35223/1/12.1.Oldfield.pdf


Chapter 2
Conceptual Framework, Methodology, and Reflection

This chapter begins with an explanation of the thesis conceptual framework, followed by a description of the methodology, critical discourse analysis. Then I summarize the methods of the first and second studies that comprise the thesis, and discuss some methodological issues not raised in Chapters 3, 4 or 5. The chapter ends with a reflection on my research journey.

Conceptual Framework

To enable answering the thesis research questions outlined at the end of Chapter 1, a guiding conceptual framework was assembled. It combined an ontology attending to both structure and agency, with a critical disability perspective, and the concepts of stigma and managing identity.

Ontology

Within the three key environments of policy, workplace and home, several structures are in operation, including how policies address the needs of people with episodic conditions, social relations in the workplace, the division of family work in households, and discourses about fibromyalgia and work. These structures may enable and constrain participation of women with fibromyalgia in the workforce. However, attending to structures alone allows only partial understanding of how women with fibromyalgia stay at work. An ontology that addresses both structure and agency was needed, one that recognized that women with fibromyalgia navigate and negotiate the structures that enable and constrain their workforce participation. Family members and workmates, key actors in the women’s social environments, also navigate and negotiate structures. Individuals’ ability to exercise agency
varies, of course, according to the resources available to them, which are affected by their class, occupation, education, income, and other social differences.

**Critical disability studies**

I took a critical disability studies perspective in the thesis (e.g., Barnes & Mercer, 2005; Garland-Thomson, 1997; Zola, 1972) to re-examine existing notions of fibromyalgia illness experience, and fibromyalgia and employment. This critical, questioning approach also enabled identifying discourses about fibromyalgia and work as well as understanding how discourses about fibromyalgia shape the actions of employed women, their family members and workmates, and thus influence the participation of women with fibromyalgia in the workforce.

The thesis was also guided by a modified version of the social model of disability, the foundation of critical disability studies, which I now describe. Briefly, the social model of disability sees disability as arising not from individuals’ impairments but from societal attitudes and structures that marginalize and exclude people with impairments from public life and spaces (Oliver, 1996, 1998). Disability scholars created the social model to counteract the still-dominant perspective on disability, the medical model, which locates disability in individuals’ impairments (Williams, 2000). The medical model of disability was inappropriate for this thesis because it does not look beyond the individual. Similarly, the human rights model of disability focuses on individual rights; for example, to workplace accommodations. This individual focus made it inappropriate for this thesis. In contrast, the social model regards disability as being socially constructed and is therefore more comprehensive in its attention to social contexts than either the medical or human rights models of disability.
The social model of disability has been critiqued by a number of disability scholars. They argue that the social model ignores people’s experiences of impairment as well as social differences, such as those based on gender, ethnicity, class, and age (Barnes & Mercer, 2005). They also argue that the social model dichotomizes disability and impairment, making the former the concern of disability activism and the latter an individual concern (Shakespeare, 2006; Thomas, 2007). This leaves impairment open to the jurisdiction of the medical model of disability, which the social model opposes. To solve this conundrum, Shakespeare proposes an alternate model of disability: “people are disabled by society and their bodies” (2006, p. 2).

Disability scholars of chronic illness have “brought the body back in” to disability studies (Hansen & Philo, 2007). They argue that, in distancing itself from the medical model by insisting that disabled people are not sick, the social model excludes people with chronic illnesses, who are largely women and whose impairments are invisible (Driedger & Owen, 2008; Wendell, 2001). In addition, the social model does not account for the fluctuations between health and illness that are common with chronic conditions (Wendell, 2001). Although disability scholars of chronic illness argue that the social model insufficiently explains the experiences of chronically ill women, it is still relevant because these women face many social barriers, particularly in remaining employed (Driedger & Owen, 2008). Therefore, I chose the modified version of the social model, as critiqued by disability scholars of chronic illness, to guide the thesis. It considers both the social domain as well as the individual embodiment of impairments.
Stigma

Although the concept of stigma is frequently addressed in reports of research about people with impairments, what researchers mean by stigma is often undefined. For this reason, I explain here the conceptualization of stigma used in the thesis. Goffman (1963) defined stigma as an “attribute that is deeply discrediting” but “is neither creditable nor discreditable as a thing in itself” (p. 4). He added that, instead, stigma “is really a special kind of relationship between attribute and stereotype” (p. 5). Later, Jones, et al., drawing on theories of deviance and labelling developed since Goffman’s 1963 book, proposed the term ‘marks,’ which they defined as “inferred conditions of deviation from a prototype or norm that might initiate the stigmatizing process” (1984, p. 8).

Goffman’s concept of stigma as an attribute, and to a lesser extent Jones et al.’s concept of marks, were widely taken up in subsequent research. However, this research has been critiqued as limiting its consideration of the social to impacts of stigma on the stigmatized person through individual discriminatory acts (Link & Phelan, 2001; Yang et al., 2007). Instead of conceiving stigma as an individual attribute or mark, Link and Phelan define it as a social process with four interrelated components. First, human differences that matter socially are labelled as such. Second, labelled people are linked to socially constructed, negative stereotypes (sets of undesirable characteristics). For example, at work, the cultures of individual workplaces may influence whether differences are linked to negative stereotypes and whether stigma ensues (Kirsh & Gewurtz, 2011). Third, negative labels separate ‘them’ from ‘us,’ reifying differences. Fourth, labelled people move downward in the eyes of others in their status hierarchies and experience discrimination. Link and Phelan distinguish between individual discrimination (others’ behavior toward a labelled
person who has lost status) and structural discrimination (accumulated practices that
disadvantage labelled people even without individual discrimination). An example of
individual discrimination relevant to this thesis is people with fibromyalgia reporting
compromised health care and unmet healthcare needs because a considerable proportion of
physicians stereotype them as not physically ill but psychologically troubled (Hayes et al.,
2010; Rusu et al., 2015; Skop, 2015). An example of structural discrimination is the general
requirement of Canadian disability income-security programs that applicants be permanently
and consistently unable to work, mentioned in Chapter 1.

In Link and Phelan’s conceptualization, “stigma is entirely dependent on social,
economic, and political power” (2001, p. 375). For example, Link and Phelan use the term
‘label’ to connote that human differences do not result in stigma unless the perspective of a
dominant group has the power to link labels with negative stereotypes, producing the other
components of stigma: separation, status loss, and discrimination. Link and Phelan dispute
portrayals of stigmatized groups as helpless victims, pointing out that labelled people
actively use available resources to resist negative stereotypes promulgated by powerful
groups. One example relevant to this thesis is the efforts of patient-advocacy organizations to
convince physicians that fibromyalgia is a medically legitimate (i.e., bodily based) disease, in
order to improve access to healthcare of people with the condition. One way in which
labelled people demonstrate their agency is in managing their identities to mitigate stigma. I
turn to this topic next.

**Managing identity**

Goffman described several ways in which discreditable people, those with a “secret
differentness” (1963, p. 81), control information about themselves to avoid stigma. These
ways include ‘passing’ as ‘normal’ (the latter being, in Goffman’s terms, people who are not discreditable). Ways of passing as normal include, first, not disclosing discrediting information about oneself; second, avoiding symbols that draw attention to a discredited attribute (such as using adaptive aids); third, presenting signs of a less discredited attribute; and fourth, telling only a small group of people. These may be people who have the same attribute and can help each other pass. Concealing discrediting information can have negative consequences when the person is “called to a showdown by persons who have now learned of his [sic] secret and are about to confront him for having been false” (p. 85). Goffman points out that the same strategies for concealment may not work in all situations, and new strategies need to be invented. This insight helped me understand how women with fibromyalgia tailor their disclosure strategies to changing circumstances.

More recently, scholars in organization studies have studied how employees construct and manage their identities at work in relation to discourses in their work environments. They may accept, reject or modify these discourses in constructing and managing their identities (Watson, 2008). Organizational studies theorists recognize that the existence of out-groups is salient to managing one’s identity with a group, such as a work team (Alvesson, Ashcraft, & Thomas, 2008). In Link and Phelan’s terms, the separation of employees into in-groups (‘us’) and out-groups (‘them’), a component of the stigma process, may be key to managing identities at work, particularly in workplaces where employees compete with each other to keep their jobs. Organizational studies theorists also recognize that identities are managed in negotiation with discourses that proscribe “who one can be and how one should act, some of which enjoy stronger institutional and material support than others” (Alvesson et al., 2008, p. 11). Identities are not static but, rather, continuously
managed in response to competing and contradictory discourses (Watson, 2008). Identity management may also be prompted by everyday stresses or intensified by crises (Alvesson et al., 2008). Toyoki and Brown (2014), based on their study of prisoners, add that stigmatized-identity management strategies are effects not only of agency but of power. People contest their stigmatized identities by “deform[ing] and divert[ing] for their own purposes the relations of power in which they are caught” (p. 730). Together, the concepts of stigma and managing stigmatized identities helped me understand how people demonstrate agency in response to power underlying the stigma process.

**Methodology - Critical Discourse Analysis**

A discourse is a scaffold for understanding and talking about a phenomenon, and a way of representing the social world (Cheek, 2004; Fairclough, 2003). It can also be thought of as a web of taken-for-granted assumptions that enable certain ways of thinking about phenomena and marginalize alternative understandings (Cheek, 2004; Phelan, Wright, & Gibson, 2014). Dominant discourses tend to be the ones advocated by powerful social groups and thus come to be seen as the most valid forms of knowledge (Fairclough, 2003). Through this linking of knowledge and power, dominant discourses gain the authority of ‘truths’ (Hall, 1997). Discourses are assembled, in turn, to create narratives; in other words, stories about the social world. These narratives are socially constructed representations, and they may spawn counter-narratives. One such example is the social model of disability (described earlier in this chapter), which counters the medical representation of disability as an individual deficit in need of fixing.

In managing identities, people may accept discourses in their entirety (Dickson, 1990) or take them up to varying degrees (Sturken & Cartwright, 2001) to suit different situations.
An example of the first response is the term ‘fibromyalgia patient’, part of the representation of fibromyalgia that patient-advocacy organizations construct, drawing on biomedical discourse to legitimate fibromyalgia as a medically recognized and therefore ‘real’ disease (Oldfield, 2013). An example of the second response is Crooks et al.’s (2008) finding that women with fibromyalgia did not label themselves ‘disabled’ unless they needed to; for example, to obtain disabled parking permits. In critical disability scholarship, identity has been approached through analysis of how people with impairments are portrayed and ignored (e.g., Yoshida & Shanouda, 2015). Scholars such as Hardin and Hardin (2004) have also examined whether and how people with impairments take up the labels offered by media portrayals.

Critical discourse analysis (CDA) assumes that language shapes society, and society is shaped by language (Wokak & Meyer, 2009). In CDA, researchers examine the use of language in existing texts such as policy documents or in produced texts such as interviews, to understand how discourses influence what people think or do (Sykes, Willig, & Marks, 2004; Wokak & Meyer, 2009). CDA does not assume that research participants’ words directly reflect their inner reality; instead, it sees interviews as performances in which both participants and interviewers present themselves in certain ways using the discourses available to them (Atkinson & Delamont, 2005; Kvale & Brinkmann, 2009; MacEachen, Polzer, & Clarke, 2008; Rapley, 2001). For this reason, contradictions and inconsistencies within interviews are expected (Nikander, 2012).

Critical discourse analysis aims not only to understand social phenomena, but to understand the power relations within them by questioning taken-for-granted representations, ideologies, and power (Phelan et al., 2014). Although participants may consider these
assumptions too ‘natural’ to reflect upon (Lazar, 2005), they nevertheless shape how participants present themselves. Assumptions can also be revealed by what participants do not say (Powers, 2002), particularly in the talk of people who know each other, such as the participants in this study: employed women with fibromyalgia, their family members and workmates. Examining assumptions and omissions within participants’ talk can reveal the power relations that participants reproduce when they draw on discourses (Kvale & Brinkmann, 2009).

Critical discourse analysis aims to understand not only discourses as structures that enable and constrain the possibilities for people’s lives, but how people use their agency to navigate discourses in their daily lives (Fairclough, 2003). In this way, CDA is congruent with the ontology of this thesis, a combination of structure and agency. CDA is also an appropriate methodology for addressing how employed women with fibromyalgia, their family members, and workmates negotiate discourses related to fibromyalgia and employment as well as how they manage stigmatized identities at work. In addition, CDA is sensitive to assumptions and omissions in interview talk and therefore helpful in analyzing why the people who inhabit a joint situation have different perspectives on it, and how they manage not just their own identities but those of others in the relationship (Adams & Gardiner, 2005). Tracing similarities in participants’ talk across interviews through CDA—similarities in their claims, assumptions, and rationales—can help identify discourses as well (MacEachen et al., 2008).

**Study Designs and Analysis Processes**

To investigate information about fibromyalgia in the first study, I turned to the Internet, the information source accessed most often by people with fibromyalgia (Daraz,
MacDermid, Wilkins, Gibson, & Shaw, 2011). I collected Web-based texts that women newly diagnosed with fibromyalgia in two cities were likely to encounter from the following types of websites: patient-advocacy organizations, health-education organizations, and rehabilitation programs. Whereas texts on the health-education-organization and rehabilitation-program websites were written by professionals, the patient-advocacy-organization texts included people’s lived experiences of fibromyalgia in the form of ‘patient testimonials,’ as these websites call them. I used four criteria to analyze the collected texts: what I understood the materials to say about fibromyalgia; what appeared to be assumptions underlying these statements; what appeared to be implications embedded within the statements about fibromyalgia; and what I found to be missing from the information materials. I began data analysis with a reading of each text, looking for key messages and statements to illustrate the messages and any mention of paid work. I then grouped these messages under headings that expressed their commonalities, to create a list of six main messages. Next I grouped these main messages into two categories: messages about FM in general; and messages about FM and work. Within each of these two categories, I arranged the main messages in the general order in which they appeared across texts. For more on the methods of this study, please see Chapter 3.

In the second study, multiple perspectives on the situations of employed women with fibromyalgia were elicited through interviews with participant triads or dyads comprising women with fibromyalgia, family members, and supervisors or co-workers (i.e., workmates). The study received ethics approval from the University of Toronto’s Health Sciences Research Ethics Board (see Appendix 2). A total of 26 participants were interviewed: nine
women with fibromyalgia, seven family members, six workmates, and four additional managers. (For participant characteristics, see Tables 1 and 2.)

I wrote two sets of field notes immediately after each interview: interview summaries and research context notes. First, the interview summaries helped me reflect on how participants’ experiences of fibromyalgia differed from mine. In them, I compared the interview just done with previous ones in the same triad/dyad and outside it. Later on in the interviewing process, I began noting emerging patterns (similarities and differences) among the interviews. Second, I wrote research-context field notes, which I began writing before the interviews when I recorded pre-interview interactions with participants. These notes helped remind me of the interviews long after they were done. In addition, while listening to the audio-recordings as I read each transcript after it was returned to me to check its accuracy, I visualized the participants and our contexts during the interviews.

The data were managed through coding, during which analysis began. In collaboration with my supervisor, I developed a mixture of deductive and inductive codes. The deductive codes (e.g., Disclosure, Work Relationships) came from the literature review in the thesis proposal and the interview guides (see Appendix 6). The inductive codes (e.g., Hard Worker) were new topics that emerged from the data, or surprises (MacNeill & Rail, 2010). While coding, I produced summaries of emerging themes for discussion at biweekly meetings with my supervisor. We refined these themes as I continued coding and later produced code and narrative summaries. The purpose of the code summaries was to compare interview data across the triads. Because it was not possible to summarize all the codes, I selected nine based on their potential for answering analytical questions and their relevance to the emerging themes. For each code, I compiled the coded material for each participant
group (women with fibromyalgia, family members, workmates and, where relevant, employer representatives), read through the material taking copious notes, and then distilled them into dimensions within each code.

To compare interviews within the triads/dyads, I reread the transcripts for each triad/dyad and their field notes, and then wrote narrative summaries (Mauthner & Doucet, 1998), noting in particular performances, tensions, assumptions, and power relations. The narrative summaries reassembled and re-contextualized the interviews, after their fragmentation in coding. Writing the summaries prompted analytical memos, enabling further development of the themes. For the manuscripts that comprise Chapters 4 and 5, I chose the two themes with the most potential for making new literature contributions: impromptu everyday disclosure dances and participant portrayals of the employed women with fibromyalgia. I used relational diagrams (Clarke, 2005) to connect dimensions from the code summaries (see Appendix 7) and also drew on the narrative summaries, further developing the two themes into concepts. I continued reading literature related to the two concepts and looked for theories to explain the findings. Throughout the writing process, my supervisor critiqued drafts, and we periodically met to discuss them. In summary, the data analysis, interpretation, and writing processes were parallel and iterative: going back and forth between the concepts, the data, literature, theories, and discussion.

In addition to field notes, I wrote analytical memos on the transcripts, whenever I thought of a connection, a pattern, a similarity or difference in the interview data and while listening to the audio recordings. Analytical memos also flowed from discussions with colleagues about the emerging findings and recorded my working-through of ideas. These analytical memos proved useful in the construction of code summaries. In addition to
analytical memos, reflective memos recorded my interaction with participants, how the research was affecting me, and how I was affecting the research. Finally, methodological memos tracked decisions throughout the research process as well as reflections on ethical and methodological issues that came up in the research.

Field notes, analytical memos and reflective memos contributed to data interpretation. My supervisor and I discussed my reports on emerging findings, along with the field notes as I produced them. Based on these discussions, new topics were added to the interview guides. These discussions also led to two REB amendments (see Appendix 2). The first amended the information sheet and interview guide for workmates to ask general questions about managing employees with chronic health issues, rather than about fibromyalgia specifically. Although employed women with fibromyalgia had been eager to join the study, their supervisors were more difficult to recruit. In order to increase participation of supervisors in the study without damaging the workplace relationships of women with fibromyalgia, we amended the interview guide and information sheet/consent form (see Appendices E and F).

The second amendment expanded the protocol to include interviews with employers who did not employ the women with fibromyalgia but had managed employees with chronic illnesses, in order to expand my understanding of supervisors’ perspectives. Conceptualizing occurred during meetings with my supervisor, where we discussed the field notes and code summaries, and with my full thesis committee, where we discussed the concept-relationship diagrams (for an example, see Appendix 7). Data interpretation and conceptualizing continued in the writing of Chapters 4 and 5 and in reading of related empirical and conceptual literature.
Several measures enhanced research quality in the second study. Procedural changes made during data analysis and interpretation were tracked in methodological memos, yielding an audit trail. The research involved three kinds of crystallization: multiple participant viewpoints on shared situations, multiple analytical methods (coding, code-dimension summaries, narrative summaries), and discussing data interpretations with others (Mays & Pope, 2000; Richardson, 1994). The research findings offer a lens through which readers can look at how women with fibromyalgia stay at work. These are “cues for seeking similar qualities in other situations…ideas or images through which other situations can be more effectively investigated” (Eisner, 2004, p. e-6). For more details on the second study’s methods, please see Chapters 4 and 5.

**Reflection on My Research Journey**

Reflection involves sensitivity to how the researcher’s personal characteristics, assumptions and experience before beginning the research, as well as the research process itself, shape the data and its analysis (Mays & Pope, 2000). Reflection occurs at every stage of the research project, from reviewing the literature and deciding on the research question, to choosing a theoretical stance, to analyzing and interpreting the data and conceptualizing from it, and finally to writing up the findings. Because the researcher is the primary instrument in qualitative research, researchers need to reflect in particular on how their own positions and experiences are woven into their interpretation of participants’ experiences, which may differ from their own (Olesen, 2005; Sandelowski & Barroso, 2003).

One of the issues that my Program Advisory Committee and I discussed when I was planning the second study was how to approach my insider status during recruitment and interviewing. This is the situation in which researchers share with participants an experience
of the phenomenon under study (Corbin Dwyer & Buckle, 2009). Insider status has advantages and disadvantages. On one hand, being an insider helped me understand the context of participants’ experience, as well as what it feels like to have fibromyalgia. On the other hand, I did not want my insider status to harm my ability to attend to accounts in the data that differed from my own illness experience. Having expected to encounter such differences, I wanted to leave myself open to a plurality of data interpretations (Kvale, 1996).

Specifically, there were ways in which my fibromyalgia experience may have differed from my participants’. After joining the Ontario Fibromyalgia Association, from whose newsletter I learned about programs and fibromyalgia specialists, I obtained referrals to the specialists, joined professional and lay-run support groups, and an aquafit program for people with fibromyalgia, and read self-help books (before the World Wide Web, books were the medium) on the condition for several years after my diagnosis. I concluded that they all of these resources fed into an illness culture, which I needed to escape into order to get well. And so I did, concomitantly rejecting many fibromyalgia narratives and embracing the notion that my bodily experiences stemmed from middle age, not fibromyalgia. Over the course of the following decade, I worked at healing and slowly “got better,” as rheumatologist Jack Reynolds (renowned for his support of women with fibromyalgia) put it when I met him in 2008.

Returning to planning the second study, my supervisor and I considered the possibility that, if participants knew that I “got better” from fibromyalgia, that might prompt them to change or leave out some of their stories. Therefore, my committee and I decided that I would not disclose my insider status to participants unless they asked whether I had personal experience with fibromyalgia. If they did, I would tell them that I had had the illness
and then emphasize that it was the participants’ perspectives I sought. This stance is what Kvale calls “deliberate naiveté,” in which “you want to gather descriptions of relevant themes of the interviewee’s life world that are as rich and presuppositionless as possible” (1996, p. 33).

If participants wanted to hear about my experience, we decided that I would offer to tell them about it after the interview ended. Although I tried in this way not to influence participant’s accounts, I was still a co-producer of knowledge in the interviews (Kvale & Brinkmann, 2009), bringing to them—and later to the data interpretation and conceptualizing—my choice of research topic, conceptual stance, research approach, and personal experience. As it turned out, I disclosed my past fibromyalgia in three interviews, with different consequences. At the end of an interview with a woman with fibromyalgia, in telling my own story I pointed out where it was similar to hers. My telling seemed to validate her experience. However, with two other participants, one a woman with fibromyalgia and another a family member, disclosing my fibromyalgia had a different effect. Both women with fibromyalgia had been diagnosed in the last 2 to 4 years. When I tried to reassure the participants by saying that that I had gotten better from fibromyalgia over time, they did not seem any less upset after I disclosed than before.

As well as being an insider due to my past fibromyalgia, I was also an outsider. First, as a white woman born in Canada, my life differed substantially from two of the women with fibromyalgia who were Hispanic immigrants. Second, for much of my career has been in self-employment, so my recent experience of being supervised is limited to the doctoral degree. Even that experience differs from being supervised on a day-to-day basis in the same worksite as one’s manager.
It turned out not to be necessary to disclose my fibromyalgia before the interviews in order to build rapport, an advantage noted in literature on insider status (Corbin Dwyer & Buckle, 2009). It seemed enough for me to reassure participants of my belief that fibromyalgia is real. I tried to build rapport with participants by taking on their points of view and by not critiquing what they said, even in my mind let alone my speech. In interviews with family members and workmates, I was challenged by knowing what the women with fibromyalgia in the triads/dyads had already said about their situations and sometimes about their family members or workmates. In some situations, there were intra-triad conflicts. Initially I felt uncomfortable about them, but hearing at least two perspectives on a conflict shared within triads turned out to be very useful data. These contrasting perspectives pointed me to silences in participants’ accounts as well as differences.

In my decades of disability activism—for family members, myself when impaired by fibromyalgia, and as a member of disability and cooperative-housing organizations—I have put into practice the strengths-based model (Saleeby, 2005). This approach builds on individuals’ personal assets and strengths to solve problems in their lives and counters the medical and tragedy models of disability, which both emphasize individuals’ deficits. In the second study, I wanted to counter what I felt was a negative fibromyalgia narrative about employment by looking at how women stayed at work rather than why they left. This approach very much influenced my research objective for the second study.

I have also been a feminist since my teenage years. In my undergraduate degree and afterwards, I was exposed to many non-academic texts from the women’s movement. During my master’s degree in urban planning, I discovered academic women’s studies and arranged to do my thesis at the Ontario Institute for Studies in Education (OISE) on women
teleworking while caring for their toddlers. The thesis was informed by my supervisor Margrit Eichler’s work in family sociology and by Meg Luxton’s writing on the gendered division of household labour, which was seen as a major factor in women’s oppression and economic dependence on men. Another influence was Pat and Hugh Armstrong’s writing about women’s employment. These writings would fit into what is now called feminist political economy. Outside of academia, liberal feminist issues of concern at the time included promoting the entry of middle-class women into the paid workforce to increase their economic independence. Knowing that middle-class women had only been in the workforce in large numbers beginning in my generation, after major efforts to have women accepted in male-dominated occupations and spaces, I felt it was a great loss that so many women with fibromyalgia were being pushed out of the workforce in mid-career. This concern influenced my choice of a PhD research topic.

As I went through the interviewing, my assumptions about fibromyalgia began to change. I had expected they would, once I learned more about other women’s experiences. There were several surprises: first, how ill the women with fibromyalgia were; yet, they were still working full time. Second, several were younger than I had expected, and the youngest woman I interviewed had had fibromyalgia since she was a child. Third, participants talked about their fatigue as much or sometimes more than their pain. Before and after my comprehensive paper, I had thought of fibromyalgia as primarily a chronic-pain condition. Hearing participants’ experiences of fatigue broadened my conceptualization of fibromyalgia beyond pain. Later, when writing funding proposals and Chapters 4 and 5, I described fibromyalgia differently, moving away from describing it as chronic pain to a more multifaceted illness. The interviews also helped me move from thinking primarily about
illness to accomplishing work tasks when impaired with pain and fatigue. This helped move me from a focus on illness to a focus on work.

The next three chapters are manuscripts that have been published or submitted for publication. Chapter 3, a chapter of Working Bodies: Chronic Illness in the Canadian Workplace (2014) reports on the first study. Chapter 4, forthcoming in Disability and Rehabilitation, and Chapter 5, to be submitted to Social Science and Medicine, report on the second study.
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Chapter 3
Portrayals of Fibromyalgia and Paid Work: Too Sick to Work?

Fibromyalgia (FM), which can produce “invisible” symptoms such as widespread pain, sleep problems and confusion, is a chronic illness that affects 440,000 Canadians. Most of those with FM are women (80%), most of whom (65%) are between the ages of 40 and 64. Many people with FM leave the workforce, but almost half of Canadians with FM (44%) remain in paid employment (Statistics Canada, 2010).

Findings from quantitative research show that, for people with FM, personal health/illness beliefs are strongly associated with outcomes, including employment-related outcomes. For example, Van Ittersum et al. (2009) found that people with FM believed that the chronic condition would compromise their daily lives. Among women with FM, Kurtze et al. (2001) found that perception of physical capacity to work best predicted whether or not women were employed. We need to know more about why people with FM decide to leave or stay in paid employment, and this chapter is intended to contribute towards an understanding of factors that may be influencing the decision-making process.

I came to the research presented in this chapter through my own experiences of FM. After being diagnosed almost 20 years ago, I participated in a variety of FM rehabilitation programs and thoroughly enmeshed myself in the FM self-help movement. While participating in rehabilitation programs, I observed that other participants (all female) tended to use the same phrases to describe their experiences of FM, and that these phrases recurred in the self-help books of the time. One example was “When I wake up, I feel like I’ve been hit by a truck.” I began to suspect that this talk was part of a “FM culture” in which we all

seemed to be enmeshed. Indeed, five years after my own diagnosis, I decided to distance
myself from this FM culture. Slowly, over the course of the next decade, my FM-related
impairments receded. I realized that there was a need to investigate the ways in which
available information might influence perceptions and experiences of FM, and how this may
in turn influence employment outcomes.

FM is a contested illness in the sense that there is widespread skepticism about
whether it is a “real” illness. Researchers and physicians debate whether FM has a
psychogenic or bodily cause (Ghazan-Shahi et al., 2012; Wolfe, 2009). Regardless,
physicians tend to report insufficient knowledge about FM (Hayes et al., 2010). There is,
however, a wealth of information available on the Internet, and women often turn to the
Internet for information about chronic illness (Crooks, 2006). In this chapter, I present
findings from a critical discourse analysis (Fairclough, 2003; Lazar, 2005) of selected
material available on the Internet about engaging in paid work while living with FM. My
purpose is to highlight messages about working with FM that are aimed at those who have
the illness, in an attempt to trace where beliefs about working with FM are likely to come
from.

**FM in the Workplace: What the Evidence Shows**

As discussed in the introductory chapter of this book, there are numerous advantages
to remaining employed when living with chronic illness. Among people with FM,
employment appears to help them avoid significant deteriorations in health status over time
(Rakovski et al., 2012). With specific reference to women with FM, research shows that they
value their employment and see it as a fundamental part of their identity and enjoyment of
life (Henriksson et al., 2005; Löfgren et al., 2006). Work gives them a feeling of being a
useful member of society whose contribution is appreciated. Work also provides social relationships, daily routine, and economic independence (Liedberg & Henriksson 2002; Henriksson et al., 2005; Löfgren et al., 2006). Women with FM who remain in the workforce report spending less time managing pain or negative emotions, and having more satisfaction with their life situation than women who have left their jobs (Liedberg et al., 2004). Being appreciated by one’s supervisor and co-workers is also important for remaining at work (Henriksson et al., 2005).

There are numerous disadvantages associated with leaving employment for people with FM. People with FM who leave work lose their professional identities and feel isolated from others (Rakovski et al., 2012). Not having work as a distraction, women with the condition are likely to focus more on their health problems (Liedberg & Henriksson, 2002). It is not surprising, then, that leaving paid employment does not necessarily improve one’s health. In fact, this move can worsen health. In a longitudinal study of women with FM, Wigers (1996) found that collecting a full disability pension predicted negative health outcomes (pain, lack of energy, and lack of work capacity) among people who had similar levels of symptom intensity at the beginning of the study. Wigers concluded that granting lifelong disability pensions to people with FM may do them a disservice.

People with FM describe multiple ways in which they combine FM and paid work. Generally, their strategies fall into four categories. First, they may prioritize paid work over other activities (Crooks, 2007; Sim & Madden, 2008) and reduce their leisure activities to allow more time to rest before workdays (Liedberg & Henriksson, 2002). Second, they may use self-care strategies, including exercise, relaxation, avoiding unnecessary stress, and enjoying pleasures (Löfgren et al., 2006; Werner et al., 2003) to enable them to continue to
work. Third, they may negotiate adjustments to their work schedules, such as taking breaks, reducing work hours, starting later in the day, varying work hours from day to day (Henriksson et al., 2005), taking a day off without pay or using holiday pay, and working at home (Liedberg & Henriksson, 2002). They often move to flexible work hours, modify the type of work they do, and even change occupations (Rakovski et al., 2012). Fourth, they may adjust their work environments by, for example, getting adjustable chairs and tables (Liedberg & Henriksson 2002) or alternating work positions and tasks (Henriksson et al., 2005; Löfgren et al., 2006).

Negotiating changes at work requires support not only from supervisors and co-workers but also at higher levels of the organization (Liedberg & Henriksson, 2002). In addition, working for the same employer for a long time makes it easier to negotiate workplace accommodations (Henriksson et al., 2005). Nonetheless, as discussed in Chapter 1, negotiating such accommodations requires disclosing impairments, which not all employees may be willing to do. Even if people with FM disclose their often-invisible impairments, disclosure does not necessarily guarantee accommodation. They may face the same disbelief that they face when trying to convince doctors, family, and friends that they are chronically ill (Schaefer, 1995). In high-stress workplaces, women with FM may feel guilty asking colleagues for help or asking supervisors to adjust work tasks and hours, because they do not want to increase the workload of their colleagues (Liedberg & Henriksson, 2002).

Besides paid work, employed women with families typically do unpaid work in their homes, which may include childcare, housework, and elder care. When family members do not share domestic work, employed women with FM typically have neither time to recover
from paid work at home (Henriksson et al., 2005) nor enough energy left over from work for family and social life (Liedberg & Henriksson, 2002). Therefore, they are more likely than others to leave the labour force (Henriksson et al., 2005; Liedberg & Henriksson, 2002; Liedberg et al., 2004). When other family members share unpaid work, however, women with FM are more likely to remain employed.

The Study

To investigate popular messages to which people with FM are likely exposed, I turned to information available on the Internet. As Barker (2008) has noted, the Internet is a principal source of health information for people with FM. Barker (2005, 2008) has usefully analyzed the contribution of FM self-help organizations to illness identity and the medicalization of FM, but there is a lack of analysis regarding information from other sources.

Accordingly, in 2011, I downloaded information that those newly diagnosed with FM in the Ontario cities of Ottawa and Toronto were likely to encounter. I analyzed documents about FM posted on sites run by:

- FM-CFS Canada, a self-help organization;
- National ME/FM Action Network, a self-help organization;
- Canadian Pain Coalition, a self-help organization;
- Arthritis Society, a health-education organization;
- Canadian Women’s Health Network (CWHN), a health-education organization; and
- three hospital-based rehabilitation programs: Toronto Rehabilitation Institute’s FM Group (TRI-FM), the St. Joseph’s Health Care FM Program (SJHC-FM), and Ottawa Hospital’s Chronic Pain Management Group Treatment Program (OH-CPM).
The precise documents analyzed are listed at the end of this chapter. I used four criteria for analyzing the content of the collected texts: what I understood the materials to say about FM; what appeared to be assumptions underlying these statements; what appeared to be implications embedded within the statements about FM; and what I found to be missing from the information materials. I began data analysis with a reading of each text, looking for key messages and statements to illustrate the messages and any mention of paid work. I then grouped these messages under headings that expressed their commonalities, to create a list of six main messages. Next I grouped these main messages into two categories: messages about FM in general; and messages about FM and work. Within each of these two categories, I arranged the main messages in the general order in which they appeared across texts.

**Portrayals of FM**

In this section I discuss the six main messages distilled from the critical discourse analysis, each of which has implications for shaping how those with FM decide what to do about paid employment:

1. FM is a Debilitating Chronic Illness/Disease;
2. Symptom Self-Management;
3. Professional versus Experiential Knowledge;
4. Leaving Paid Employment;
5. The Responsible Employee; and
6. The Fortunate Employee.

**FM is a debilitating chronic illness/disease**

The information materials frame FM using medical language, discussing symptoms, causes, and the debilitating impact of symptoms. The description of widespread pain as FM’s
primary symptom follows the widely used diagnostic criteria for FM (Wolfe et al., 2010). A short list of other symptoms usually follows, again consistent with the diagnostic criteria. The following text, from the Toronto Rehabilitation Institute’s (TRI) FM Program, is typical of symptom descriptions: “FM is characterized by widespread pain, multiple tender points, fatigue, sleep disturbance, problems with concentration and memory, and often psychological distress” (TRI, 2011). Beyond listing the symptoms that are major diagnostic criteria for FM, some texts also include long lists of other symptoms. In this manner, FM is portrayed as a complex condition that affects individuals in heterogeneous ways.

FM is alternately portrayed on different websites as an illness, a disease, a disorder, a condition, or a syndrome. Sometimes more than one of these words is used in the same text. This ambivalence reflects controversy over FM’s status and even its very existence. FM self-help organizations respond by emphasizing that FM has a bodily cause and that people with FM are legitimately sick. The abnormal brain scans illustrating the cover of the Clinical Overview, posted on the National ME/FM Action Network’s website, represent FM as caused by brain abnormalities, while FM-CFS Canada consistently describes individuals with FM as patients. A “patient testimonial,” as the FM-CFS Canada website names stories posted by people with FM, illustrates this viewpoint: “There is no cure for FM and nor [sic] surgery that can be performed for this disease… I pray and hope that researchers will find a cure for this devastating and debilitating disease” (No longer be [sic] a Champion at my martial art class, FM-CFS Canada, 2011). Texts from the other information sources, however, describe people with FM using a variety of terms other than “patient,” such as “people living with FM.” In this way, they imply that FM is a chronic condition rather than a disease.
The texts go on to describe the impact of FM in terms of functional impairments. Some texts, such as one published on the TRI-FM Program website, portray the impact as severe. It says, for example, that FM is “A debilitating condition [that] interferes with every aspect of someone’s life” (TRI, 2011). Another example is an emotional “patient testimonial” on the FM-CFS Canada website, where Sherri Lynne tells readers that FM “absolutely ruined my life … I no longer have any quality or enjoyment of life … and no future at all” (FM-CFS Canada, 2011).

Other rehabilitation texts downplay the severity of FM’s impact, suggesting that, for example, it intermittently impairs physical endurance. The Arthritis Society’s FM factsheet offers hope that FM’s impact will diminish with time: “Over time most people with FM are able to find a balance that is acceptable and their disease improves considerably” (Arthritis Society, 2008). Regardless of whether the information materials portray FM’s impact as severe or moderate, they carry the potential of leading readers to question how FM impairments will affect their ability to do paid work.

**Symptom self-management**

The information materials tell individuals with FM that they can reduce the impact of symptoms through self-management strategies that incorporate the advice of health professionals. Under the philosophy of self-management, people with chronic illnesses are encouraged to actively participate in decision-making with health professionals and take responsibility for managing their illness (Lawn et al., 2011). In making individuals responsible, however, self-management ideology accounts neither for the unequal distribution of resources that people need to manage their chronic illnesses, such as the ability to pay for drugs and healthcare and access to adequate information (Mead et al.,
2010), nor for structural and cultural barriers to self-care that are beyond individual control (Lawn et al., 2011).

The rehabilitation and health education texts advise those with FM to accept the limitations that FM imposes on them. As the CWHN factsheet on FM tells readers, “Listen to what your body is telling you and adjust your life accordingly” (2007). Personal testimonials on the self-help website also reflect this adjustment advice. For example, Pat advises others with FM, “You have to accept that pain is part of your life and live ‘around’ it” (FM-CFS Canada, 2011).

Two rehabilitation programs tell participants that, by learning “lifestyle management strategies” (TRI, 2009, p. 2), such as “assertiveness, attitude change, reducing pain ‘body language’, etc.” (SJHC, 2010) they can “achieve greater control over their symptoms” (SJHC, 2010). Personal testimonials on the FM-CFS Canada website discuss specific self-management strategies. In this manner, individuals are led to believe that, through self-management, they can improve their quality of life.

Being held responsible for controlling their FM symptoms, readers may be led to believe that the time and effort that self-management requires may not be compatible with paid work. Because self-management advice focuses on individual change, options for changing social environments, such as workplaces, are not offered. This missing information may implicitly encourage people with FM to leave the workforce.

**Professional versus experiential knowledge**

It is noticeable that only one sponsoring organization, FM-CFS Canada, offers information to suggest that knowledge gained through lived experience with FM is just as valuable, if not more valuable, than professional knowledge. The primacy of medical
expertise is continually reinforced with statements such as that found in the CWHN FM factsheet: “It is very important to select a doctor who knows this syndrome … [a] rheumatologist, the acknowledged FM specialist” (CWHN, 2007). Similarly, the SJHC-FM rehabilitation program warns: “Participants are expected to attend … follow-up sessions … to review their progress” (SJHC, 2010). Meanwhile, there is no mention of participants evaluating the program’s effectiveness.

The CWHN factsheet does not recognize that others with FM can be a source of knowledge, but explains the supportive role of others with FM as follows: “Participation in a self-help group can help FM sufferers to feel less isolated, to share their experience with others … who can listen and provide support and encouragement” (CWHN, 2007). Only on the FM-CFS Canada website does the experiential knowledge of people with FM appear as equally valued with professional knowledge. Under its Patient Resources menu, the website lists support groups and provides space for people to share their experiences of FM in personal testimonials.

Personal testimonials offer readers with FM more than simply support, they also offer knowledge about how others have handled various employment-related situations. As such, they are an invaluable source of knowledge. Indeed, Werner et al. (2003) found that, for women with chronic musculoskeletal pain in a rehabilitation program, experiential knowledge, strengths, and “recovery competence” (p. 505) contributed to improving their quality of life. In addition, the women found the experiential knowledge of other program participants more concrete than advice from health professionals. With regard to paid work, there is every reason to suspect that those with FM could benefit from learning about the
experiences and advice of others with FM who have negotiated participation in the workforce.

**Leaving paid employment**

As explained at the beginning of this chapter, almost half of Canadians with FM are employed. Nevertheless, few of the information materials that I analyzed mention paid work at all. This omission may imply that paid work with FM is impossible and that it is better to apply for a disability pension. This is the route implicitly advocated by the FM-CFS Canada website. The appropriateness of applying for a disability pension is reinforced by poignant personal testimonies on the FM-CFS Canada (2011) website. One example is Rita’s story: “I tried to keep working, but I was too sick … severe chronic pain which became debilitating, and anxiety … I have not returned to work since.”

The other self-help national organization, the National ME/FM Action Network (NME/FMAN), also presents applying for a disability pension as the appropriate route. It offers advice regarding how to make a successful application, as well as links to lawyers who can represent those making claims for disability pensions (NME/FMAN, 2011, 2012). Such advice is offered because the process of obtaining a disability pension can be difficult. Episodic conditions such as FM do not fit eligibility criteria that require impairments to be constant and applicants to be permanently unable to work (Lightman et al., 2009; McKee et al., 2006). Nor do the criteria take into account disabling work environments (Crooks et al., 2008).

The NME/FMAN website contains a ”Clinical Overview” that discusses the concept of “workplace aggravators.” Workplace aggravators are described as work tasks that “may cause pain, as well as physical and cognitive fatigue” (Clinical Overview, 2005-2006). A list
of work tasks that may aggravate FM symptoms is provided and physicians are advised to use this list when supporting patients’ applications for disability pensions. Missing from the Clinical Overview are recommendations for changing work tasks to reduce symptom aggravation as well as alternatives to full-time work. For those with FM who read this text, the only two choices appear to be full-time work with all its aggravators, or applying for a disability pension.

In summary, few information materials mention work at all, and the self-help website encourages individuals with FM to apply for a disability pension. The fact that most of the information materials are silent about paid work, a central part of adult life, may lead those seeking information on FM to believe that the condition is incompatible with paid work.

**The responsible employee**

Even though most of the materials portray FM as incompatible with paid work, two of the sources suggest that remaining in the workforce is desirable. The Arthritis Society publishes a pamphlet about arthritis in the workplace (AS, 2010a) and the FM factsheet (2008) tells readers, “Over time most people with FM … remain in the workforce and lead satisfying, fulfilling lives.” Also, the SJHC-FM Program recognizes that “A return to work is a vital part of the overall rehabilitation process” (Nielson, 2010). Together, these sources offer a counter-discourse to the overall message in the other texts that most individuals with FM are too sick or impaired to work. Nevertheless, both sources advise readers to adopt strategies for self-managing FM symptoms at work, which places the onus on the individual with FM to take responsibility for remaining in the workforce.

Only one text, on the SJHC-FM Program’s website, discusses workplace accommodations so as to suggest that the employer ought to take some responsibility. This
text advises employers to “Make appropriate ergonomic adjustments…Allow the worker to pace his or her activities,” and, starting with work hours and a workload that the worker can manage, gradually increase them (Nielson, 2010). Although this advice encourages employers to accommodate employees with impairments, there is no mention that they are obliged to do so under human rights legislation. Nor does other SJHC material about FM contain information about employees’ rights.

The pamphlet *Arthritis in the Workplace* (AS, 2010a) offers a number of suggestions to help people with FM remain in paid employment. First, there are suggestions for changing the workplace, so that employees are advised to change the pace of their work, alter their work schedules, and seek help from co-workers. Although well meaning, these suggestions assume that employees have control over their work pace and tasks, a situation that may not apply to occupations such as factory work where assembly lines control the pace of production, or to workplaces where staffing cuts have intensified the workload of remaining staff, or to professionals in high-workload occupations such as nursing or social work (Henriksson et al., 2005). The suggestions also assume that employees have enough power to negotiate accommodations with their employers. This may not be the case for low-paid, non-unionized workers or those with short-term or part-time jobs.

Second, the pamphlet suggests that, “if possible … work from home occasionally or arrange a reduced work schedule…If you have access to flex-time at work (working different hours), use it if you find it helps.” Although these flexible working arrangements require employer approval, the pamphlet does not offer advice on how to negotiate accommodations. Nor does it advise employees about their right to accommodations under federal or provincial legislation. Instead, it assumes that employers will provide accommodations when employees
request them. This may or may not be the case, depending on the employer, the status and negotiating ability of the employee, and the level of employer support for the worker with FM.

Third, the pamphlet suggests that, “If you know you have an important event coming up at work, make sure you rest at home before.” Resting, however, may not be possible, especially for women, who are likely to be responsible for domestic work at home as well as childcare. Missing in the information materials is acknowledgment that women are inequitably responsible for domestic work. There is no advice to women on how to negotiate sharing household work with family members.

Fourth, the pamphlet suggests: “Try asking a co-worker for assistance.” Such requests may require disclosing invisible FM impairments. The consequences of disclosure may be positive; co-workers may indeed be supportive and willing to help. On the other hand, co-workers may resent taking on extra work to help a colleague with impairments. Indeed, the SJHC-FM Program acknowledges that asking co-workers for help could harm relationships with other employees (Nielson, 2010).

In summary, even when information materials portray work as desirable for those with FM, their overall emphasis suggests that it is up to individuals to make themselves fit for work by managing their symptoms. The suggestions offered for workplace accommodations mostly assume that individuals have control over their work tasks and enough power to negotiate flexible work schedules.

**The fortunate employee**

Stories about experiences with employment that are posted on the FM-CFS Canada website can be understood as offering cautionary tales to those contemplating their own
employment prospects. For example, Cheri’s story illustrates that people who cannot manage to keep their symptoms under control may not be able to maintain a job. As Cheri describes, “I was unable to hold a job, even part time. Between calling in sick and my physical limitations, it was just too frustrating for employers” (FM-CFS Canada, 2011). Here, Cheri seems unaware that employers are obligated to accommodate employees with FM impairments.

Even when employees with FM are aware of their right to accommodations, they are not always able to keep their jobs. In her testimonial, Theresa tells a discouraging story: “I worked for the federal government and I was honest with my supervisor about my illness and she was not impressed that I was losing so much time for appointments and tests. In 2002, I was ‘laid-off’…They are not supposed to discriminate but..........[sic] we all know they do. As well my old job gave me a bad reference as being unreliable and an abuser of sick time. I put in a claim with Human Rights and it was dismissed when my former employer said that I was let go because I was incompetent” (FM-CFS Canada, 2011).

The preponderance of stories such as these leads those who have employment to feel fortunate. Sophie, for example, suggests in her story that she is lucky to have a benevolent employer willing to accommodate her impairments. As Sophie tells readers, “I have [a] job that I work 37.5 hours a week, in a call centre that cares about their employees and listens to their complaints and rectifies it…And I lucked out…I have steady hours, (days even) and a great benefit package which even cover my medicine (ok so I don't qualify for short disability or long term disability) I'm not really any worst off Am I?” (FM-CFS Canada, 2011).
Altogether, the employment stories reinforce the message that the individual ought not expect employers to do anything to accommodate impairment-related needs (not even Sophie’s story suggests this) but the employee is herself responsible for maintaining employment. To the extent that she, like Sophie, is able to do so in a congenial workplace atmosphere, she ought to count herself lucky.

**Missing Messages**

In general, the information materials I reviewed portray FM as a debilitating chronic illness, but suggest that symptoms can be self-managed. Although the materials communicate that most people with FM are too sick or impaired to work, those who are able to do so are seen as responsible for managing their symptoms on the job, and those who get workplace accommodations are portrayed as fortunate to have benevolent employers.

There are, according to Statistics Canada (2010), 176,000 Canadians with FM who are employed. Collectively, they could no doubt offer a wealth of knowledge that would be useful for those with FM contemplating how to find or maintain employment. This experiential knowledge could be tapped through research and shared with others through rehabilitation programs and through self-help organizations and peer-support groups.

Interestingly, there is an historical link between self-management and the valuing of chronically ill people’s lived experience. Rogers et al. (2009) locate the roots of today’s self-management discourse in the self-help movements of the 1960s and 1970s, where chronically ill people’s experiential knowledge was valued as much as medical knowledge. However, self-management discourse has since been adopted by governments eager to restrain expenditures in healthcare systems that value professional knowledge over experiential knowledge. In addition, Lawn et al. (2011) point out that self-management may not equalize
the power imbalance between professionals and chronically ill people. As is evident in the information materials, other than those on the self-help website, professionals define self-management strategies based on their own expertise, not based on what they may learn from people with FM themselves.

Completely missing from the information materials is a discourse of human rights. The very few information materials that suggest people with FM seek workplace accommodations assume that employers will benevolently accommodate their employees’ FM, without mentioning that workers with impairments are legally entitled to accommodations. Nor do the materials offer any advice on how to negotiate accommodations with employers or, if employers are unwilling to provide them, how to lodge complaints. As McKee et al. (2006) highlight, discriminatory social attitudes can pose greater impediments to the employment of people with episodic conditions than their functional impairments. Human rights legislation addresses this discrimination. However, the legislation’s success rides on awareness of human rights by both employers and employees. Given that at least one rehabilitation program, the SJHC-FM Program, recognizes the centrality of work to FM rehabilitation (Nielson, 2010), Canadians with FM deserve to have all the information they need to successfully remain in, or return to, the workforce, including information about their right to accommodations and how to negotiate them.

**Conclusion**

The information materials I analyzed in this chapter portray FM as a chronic, debilitating illness or disease causing impairments that can, nonetheless, be somewhat controlled through self-management. Fewer than half of all Canadians with FM are in the workforce, and one reason for their relative absence could be because they are led by
portrayals of fibromyalgia to believe that most people with FM are too sick or impaired to work for pay. At the same time, the materials suggest that those who can work are responsible for making themselves fit for work, while those whose employers are willing to accommodate their impairments are fortunate. Only one website, sponsored by the self-help organization FM-CFS Canada, offers information to suggest that those with FM can learn anything useful from the experiences of others with FM.

Missing from all of the materials is information about how to negotiate accommodations with employers and about employees’ legal entitlement to workplace accommodations. Thus, individuals are not made aware of their right to ask for accommodations, and this too could be a reason for their relative lack of participation in paid labour.

Quantitative research on FM outcomes (Van Ittersum et al., 2009; Stuifbergen et al., 2006; Neilson & Jensen, 2004; Kurtze et al., 2001) has found a strong association between beliefs about the condition and outcomes, including employment. Wigers (1996) also found that, when those with FM leave the labour force to collect disability pensions, their outcomes worsen. In this chapter, I explored one of the potential sources of beliefs about FM, messages and discourses in Web-based information materials about the condition. Although there are many other potential sources of information about FM beyond the Internet, such as magazines, television, friends and family, and personal interactions with health professionals, the sources analyzed here are ones that those with FM are quite likely to come across in their search for authoritative information. The information does not, to say the least, encourage those with FM to remain in the workforce with an awareness of their right to do so.
Acknowledgments

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Group/fact_sheet09_Fibromyalgia_and_rehabilitation.pdf.aspx


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Chapter 4

Impromptu Everyday Disclosure Dances: How Women with Fibromyalgia Respond to Disclosure Risks at Work

Abstract

Purpose: Findings from a study examining how women with fibromyalgia remain employed are used to explicate a conceptualization that adds to literature on workplace disclosure of stigmatized illnesses and impairments: disclosure dances that employees improvise in response to workplace-relationships needs and disclosure risks.

Methods: Critical-discourse-analysis methodology framed the study. Data were collected through 26 semi-structured, individual interviews with participant triads or dyads comprising women with fibromyalgia, family members, and supervisors or co-workers. Interviews with managers who supervised disabled employees other than the women supplemented these data. Following coding, data were compared within and across triads/dyads through code-dimension summaries, narrative summaries, and relational diagrams.

Results: Women with fibromyalgia and other stigmatized illnesses improvised everyday disclosures when they needed to explain fluctuating work ability, when others needed reminding about invisible impairments, and when workplace relationships changed. These impromptu disclosures comprised three dimensions: exposing oneself to scrutiny by disclosing both illness and impairments, divulging stigmatized illness, and revealing invisible impairments selectively.

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4 This article was accepted with minor revisions by Disability and Rehabilitation in April 2015. It was resubmitted in August 2015.
Conclusion: Through impromptu disclosure dances, women tailored disclosure to changing immediate circumstances. While assumptions from psychological theories of risk underlie current conceptualizations of disclosure as planned in advance, this article examines disclosure through a different lens: social theories of everyday risk.

Introduction

For employees with invisible chronic illnesses, controlling disclosure is key to job retention (Fowler, 2011); yet, disclosure is fraught with problems. When the illnesses are stigmatized, disclosure is even more problematic. Although literature examines how employees plan and implement disclosure of chronic illnesses to employers, less is known about how disclosure plays out in day-to-day relationships with co-workers and supervisors. To enable more people with stigmatized, chronic illnesses to remain employed, a better understanding is needed of how these employees operationalize disclosure in their quotidian work lives. This article examines such disclosure from the point of view of employees with fibromyalgia, a contested chronic illness affecting primarily women, who experience varying degrees of pain, fatigue, memory problems, and other health issues (Statistics Canada, 2010). Nonetheless, a substantial portion of people with fibromyalgia remain in the workforce (Statistics Canada, 2010).

Even though disclosing illnesses or impairments may bring support and accommodations, many employees do not disclose (Beatty, 2012; Gignac & Cao, 2009; Munir, Leka & Griffiths, 2005), because doing so may change how workmates view them. With fibromyalgia, disclosure risks arise not only from the illness’ invisibility but from its contestation as a so-called real disease with a known biological cause (Moss & Teghtsoonian,
This contested label may stigmatize employees (Link & Phelan, 2001). Disclosure of any chronic illness, stigmatized or not, marks an employee as an unexpected worker (Stone, Crooks, & Owen, 2013) who does not fit employers’ expectations of healthy staff consistently able to fulfill their duties. Yet, to gain workplace accommodations, employees with chronic illnesses must at least disclose a need for accommodation, which marks them as an unexpected worker. Disclosing need, however, does not necessarily guarantee accommodation (Stone, Crooks, & Owen, 2014) and may instead bring discrimination (Lysaght & Krupa, 2014).

Literature on workplace disclosure of invisible illnesses generally conceptualizes it as planned with the intent of seeking accommodations (Henderson et al., 2013; Stone et al., 2013; von Schrader et al., 2014). Yet disclosure is much more complex. To broaden the understanding of workplace disclosure, the authors propose an additional conceptualization based on their research findings: everyday disclosures that employees improvise in workplace conversations and actions. In this concept, ‘everyday’ is not meant to imply that disclosures occur every single day; rather, that they occur within ordinary conversation (Kalekin-Fishman, 2013). Impromptu everyday disclosures are mainly unplanned responses to immediate needs and disclosure risks within workplace relationships and are improvised repeatedly as workplace relationships and circumstances change.

This article draws on a broader study examining how women with fibromyalgia remained employed. The focus of this article is a key finding of the broader study, impromptu everyday disclosures, and the article demonstrates how women, their family members and workmates approached disclosure in their quotidian work lives. In addition, everyday-risk theory is used to understand impromptu everyday disclosures. The article also
introduces two issues to the literature on disclosing stigmatized illnesses at work: being unfavorably compared to others with the same illness and being offered unwanted advice.

The next subsection outlines disclosure risks that women with fibromyalgia may face in their work lives, to which their impromptu everyday disclosures respond, as described in the Results section.

**Risks of disclosing stigmatized, chronic illnesses at work**

Medical debate continues over whether or not fibromyalgia is a legitimate disease (Wolfe, 2009), and many women with fibromyalgia report being marginalized in healthcare (Oldfield, 2013). Because medical legitimacy may determine social legitimacy, women with fibromyalgia may also be discredited (Charmaz, 1991) at work. As pain and fatigue are largely invisible, chronically ill employees can avoid disclosure, and many do (Gignac et al., 2012; Gignac & Cao, 2009; Munir et al., 2005). Increasingly, precarious work (Facey & Eakin, 2010; Tompa et al., 2006) adds to disclosure risks. Employees with chronic illnesses compete with abled-bodied colleagues to keep their jobs in shrinking labour markets (Stone et al., 2014). Disclosing anything that harms their competitiveness may be risky.

Research on workplace disclosure documents risks across multiple stigmatized conditions. Risks include disbelief, dismissal, stereotyping, damage to reputations and workplace relationships, discrimination, and job loss. First, supervisors and co-workers may not believe that a stigmatized illness is ‘real’ or that an invisible impairment is a legitimate disability. If illness is disbelieved or impairments not considered disabilities, co-workers may judge accommodations undeserved and resent them (Dunstan & MacEachen, 2014). With disbelief, workmates may downplay the condition’s seriousness (Toth & Dewa, 2014), assuming that the employee is lazy (Kristman, Shaw, & Williams-Whitt, 2014) or
malingering (Eakin, 2005). A second risk, dismissal, may follow disbelief. Workmates who
disbelieve the ‘realness’ of an employee’s illness may dismiss it as psychological
(Richardson, 2005) or imagined. Employees may then be called complainers,
hypochondriacs, or attention seekers (Vickers, 1997). These personal attacks, expressed
through anger or laughter, may distress ill employees (Cameron & Chouinard, 2014).

A third risk, stereotyping, may devalue employees (Church & Luciani, 2005) with
chronic illnesses in co-workers’ eyes, and damage employees’ reputations. Workmates may
assume these employees are less competent (Brohan et al., 2012), will be unreliable (Munir
et al., 2005), burden their colleagues (Lysaght & Krupa, 2014), and lower team productivity
(Vickers, 2012b). Supervisors may make decisions based on stereotypes (Crooks et al., 2014,
decreasing ill employees’ responsibilities and denying them promotions (Ellison et al., 2003).
Stereotypes may also fuel reputation-damaging gossip (Vickers, 2012a). Fourth, disclosing
illness may damage workplace relationships. Employees may receive unwanted pity, and
their behaviour may be interpreted as illness-related when it is not (Stone et al., 2013). They
may also be blamed for causing or exacerbating their illnesses (Vickers, 2012b).

Disbelief, dismissal, and stereotyping contribute to a fifth risk, discrimination: being
treated unfairly because of difference. Ill employees may be monitored more closely than
others (MacDonald-Wilson et al., 2011), targeted for unreasonable demands (Vickers,
2012a), and harassed (von Schrader et al., 2014). Such bullying strategies (Vickers, 2008)
may lead to severe stress that exacerbates their illnesses (Vickers, 2012b). They may then
quit their jobs on the recommendation of their doctors (Vickers, 2012a). Although illness
appears to be the reason for job loss, discrimination plays a key role (Vickers, 2008).
Damaged reputations and workplace relationships may also contribute to job loss. Finally,
employees may lose their jobs through layoff or contract non-renewal (Beatty, 2006; Lysaght & Krupa, 2014), again hiding discrimination.

The next subsection outlines how workplace disclosure of stigmatized illnesses is conceptualized in the literature reviewed for the article.

Conceptualizations of workplace disclosure

Literature on stigmatized illnesses conceives of workplace disclosure in the following ways: as a yes-or-no decision; a choice or non-choice; a process; and as partial, selective, strategically timed, or full.

In some research, disclosure is seen as a one-time, yes-or-no decision (Henderson et al., 2013; Jans, Kaye, & Jones, 2012) made after weighing pros and cons (Smith-Young, Solberg, & Gaudine, 2014). Although some research considers disclosure a choice because chronic illness is often invisible (MacDonald-Wilson et al., 2011), disclosure is also seen as a non-choice, because ability to choose is constrained by workplace rules and expectations (Church & Luciani, 2005). Two types of disclosure are not considered choices: forced and inadvertent (MacDonald-Wilson et al., 2011). Disclosure is forced, for example, when impairment becomes visible (Beatty, 2012) or inadvertent when, for example, employees accidently blurt out illness clues (Ellison et al., 2003).

In other research, disclosure is conceptualized as a looping process (Toth & Dewa, 2014), in which employees respond to changing contexts and opportunities to disclose (Irvine, 2011), re-evaluating risks and benefits with each opportunity (Toth & Dewa, 2014). Disclosure is also seen as selective (MacDonald-Wilson et al., 2011) (e.g., telling only certain people at work) and partial (Beatty & Kriby, 2006) (e.g., disclosing the least stigmatized of multiple conditions). Employees may use selective, partial disclosure to pass
as members of the dominant so-called normal group (Clair, Beatty, & MacLean, 2005) and thus avoid appearing different (Beatty, 2006). They may strategically time disclosure (MacDonald-Wilson et al., 2011), waiting until after they pass probation, feel secure with colleagues (Jans et al., 2012), or until their impairments affect their work (Brohan et al., 2012). Employees may fully disclose gradually over time if they see disability as central to their identity (MacDonald-Wilson, 2011) and want to educate workmates about their condition (Irvine, 2011).

In summary, the literature generally conceptualizes workplace disclosure of stigmatized illnesses as planned, with advance reflection. The next subsection describes the social theory of everyday risk, which will later be used to discuss the additional conceptualization of disclosure proposed in this article: impromptu everyday disclosures that are unplanned, without advance reflection.

**Everyday-risk theory**

One way of understanding current conceptualizations of workplace disclosure is through risk psychology, in which people decide what is risky based on expert advice (Tulloch & Lupton, 2003). This advice may come from, for example, websites about chronic illnesses. However, to understand impromptu everyday disclosure, which occurs within workplace relationships, a social theory is needed. Everyday-risk theory posits that people’s risk logics may not be reflexive but, instead, grounded in relationships (Lupton, 1999). Rather than a cognitive weighing of pros and cons calculated by experts, as risk psychology theorizes, in everyday-risk theory risks are shaped by social networks (Tulloch & Lupton, 2003; Wilkinson, 2010). As these networks change (Wilkinson, 2010), so do everyday risks (Tulloch & Lupton, 2003; for example, when workplace relationships change.
Everyday-risk theory helps explain why workplace disclosure of stigmatized illnesses is risky. As governments reduce social-support programs (e.g., unemployment insurance, welfare), risk becomes increasingly individualized (Wilkinson, 2010). Increasingly as well, health-promotion advertising portrays individuals as responsible for managing their own health (Oldfield, 2014). With jobs becoming less secure, individuals may now view employment in terms of everyday risk (Scott-Jones & Raisborough, 2007). All of these social contexts make disclosure risky, not only for ill employees but for the families their jobs support. Everyday-risk theory also explains why being seen as different is risky. Healthy people may perceive chronically ill people as threats to the certainty of their own health (Lupton, 2013) and, at work, as threats to team functioning (Vickers, 2012b). Being stigmatized as different can strip people of their moral rights, without which they are then targets for discrimination (Lupton, 2013), another disclosure risk.

The next section describes how the study on which this article draws was conducted. Findings from the study generated the concept impromptu everyday disclosures.

**Methods**

The broader study examined how women with fibromyalgia remained employed despite numerous challenges and took a qualitative approach, appropriate to under-researched phenomena. The study was framed by critical discourse analysis (CDA), which focuses on the logics and assumptions beneath participants’ talk, because a secondary aim of the study was to understand how discourse about fibromyalgia shapes decisions to stay in the workforce or leave it. Multiple perspectives on the women’s situations were elicited through interviews with participant triads or dyads comprising women with fibromyalgia, family members, and supervisors or co-workers. Having multiple perspectives on the situation of
each woman with fibromyalgia revealed contrasting viewpoints as well as similar ones, which helped the authors to discern discourses beneath participants’ accounts. Triad members were interviewed separately in 2013, for an average 1.5 hours, at a location each chose. The study received ethics approval from the university where the research was based (see Appendix 2).

Participants were recruited through listservs, newsletters, posters, and networking, and the 23 women who responded were screened by telephone for eligibility. Inclusion criteria were being over 18, medically diagnosed with fibromyalgia, and willing to recommend a family member and workmate for interviewing; speaking and understanding English; and living in the Toronto metropolitan area. Budget limits restricted in-person interviewing to the first author’s area of residence, and telephone interviews did not allow her to observe emotional body language or make eye contact to comfort participants when discussing sensitive topics. Nine potential participants lived elsewhere in Canada, and four did not meet other inclusion criteria. Of the 10 remaining women who met all inclusion criteria, one did not respond to the interview request. The other nine women were interviewed after giving informed consent (see Appendices E and F). During interviews, they were asked to recommend family members and workmates, who were then contacted and, if willing, interviewed. These efforts produced five triads and three dyads.

Twenty-six participants were interviewed: nine women with fibromyalgia, seven family members, six workmates, and four additional managers (see Table 1 for participant characteristics and pseudonyms). Full triads were not achieved in all cases, because, although recommending family members and workmates was an inclusion criterion, some were unwilling to be interviewed. A semi-structured interview guide was created and revised
several times to incorporate topics participants brought up in interviews. The guide’s aim was to generate rich data by encouraging participants to tell stories of their experiences. Intra-triad confidentiality, which had been promised in the study information sheets (see Appendix 5), precluded questions specific to stories told by other participants in the same triad. Two sets of field notes supplemented interview data: in one, the first author described the research context before, during and after the interview and, in the other, she summarized the interview immediately after it ended.
Table 1. Participants’ Characteristics and Their Relationships to Each Other

<table>
<thead>
<tr>
<th>Women with fibromyalgia</th>
<th>Breadwinner status</th>
<th>Family members</th>
<th>Workmates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emilya Freelance researcher, 27</td>
<td>Secondary</td>
<td>Sandy Best friend</td>
<td>N/A</td>
</tr>
<tr>
<td>Amy Teacher, 32</td>
<td>Sole</td>
<td>Samantha Cousin</td>
<td>Eileen Workplace friend</td>
</tr>
<tr>
<td>Pam Social worker, 41</td>
<td>Equal</td>
<td>Robert Husband</td>
<td>Susan Co-worker</td>
</tr>
<tr>
<td>Meg Daycare worker, 57</td>
<td>Sole</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Cindy Office manager, 61</td>
<td>Sole</td>
<td>Rachel Adult daughter</td>
<td>Peter Supervisor</td>
</tr>
<tr>
<td>Nicole Nurse, 50</td>
<td>Primary</td>
<td>Paul Husband</td>
<td>Ruth Supervisor</td>
</tr>
<tr>
<td>Gail Call-centre agent, 38</td>
<td>Equal</td>
<td>Barbara Mother</td>
<td>N/A</td>
</tr>
<tr>
<td>Pilar Psychoterapist, 69</td>
<td>Primary</td>
<td>Bruce Close friend</td>
<td>N/A</td>
</tr>
<tr>
<td>Milagros Housing coordinator, 54</td>
<td>Sole</td>
<td>N/A</td>
<td>Francesca George</td>
</tr>
</tbody>
</table>

Other managersa

<table>
<thead>
<tr>
<th>Relationship to employees with chronic illnesses</th>
<th>Employer size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isabel Supervises employees with chronic illnesses</td>
<td>Under 50 employees</td>
</tr>
<tr>
<td>Steve Manages short-term and long-term disability leave</td>
<td>Over 5000 employees</td>
</tr>
<tr>
<td>Elizabeth Manages workplace accommodations</td>
<td>Over 5000 employees</td>
</tr>
<tr>
<td>Helen Oversees health and safety of union members</td>
<td>N/A</td>
</tr>
</tbody>
</table>

N/A = not available. *All names are pseudonyms.

After the audio-recorded interviews were professionally transcribed verbatim, the first author listened to each recording while reading its transcript, to check accuracy (Poland, 1995) and re-immers was herself in the interviews (Braun & Clarke, 2006). She coded each transcript using NVivo10. The first two authors collaborated to develop a code list based on
the literature review for the broader study and the first three interviews. Examples of these initial codes were Disclosure, Hard Worker, and Work Relationships. As transcripts were coded, some initial codes were divided when they captured large amounts of data (e.g., Accommodations – Not including negotiating, Negotiating accommodations), and some new codes were added when topics recurred in the newly analysed data (e.g., Identity-personality, Others’ worries about woman with FM). After coding the transcripts, the first author compared data across triads/dyads by summarizing code dimensions from four perspectives (women with fibromyalgia, family members, workmates, and managers). Analytical memos (Sandelowski & Barroso, 2003) and reflective memos (Doucet, 2008) contributed to data interpretation. Alongside code summaries, narrative summaries (Mautner & Doucet, 1998) were used to compare entire interviews within triads/dyads.

Theoretical sampling was used to further explore early findings. For example, during early data analysis, it was found that mothers’ domestic work may increase their impairment and thereby decrease their work capacity. Mothers were then specifically recruited through a second advertisement on the listserv that had generated most of the responses to the initial call. Also, because several women had not disclosed to supervisors or felt they were unsupportive, they tended to recommend co-workers for interviews. Co-workers’ interests tended not to align with supervisors’. Therefore, to better understand supervisor perspectives without jeopardizing the women’s jobs, managers of disabled employees other than the women with fibromyalgia were recruited. These interviews provided additional data on supervisors’ perspectives.

The triad/dyad design revealed differing accounts of situations shared by triad members, as noted in other triadic research (Ribbens McCarthy, Holland, & Gillies, 2003).
For example, family members talked about workplace problems that women with fibromyalgia had not revealed. Sometimes, family members and women with fibromyalgia had very contrasting perspectives, also noted in other triad-design research (Noiseux et al., 2010).

Conceptualizing began early in the research, when the first two authors discussed the interview field notes. They continued conceptualizing while discussing the code summaries and diagrams of relationships between developing concepts (Clarke, 2005) that the first author produced, and as this article was written. The first author read related empirical and theoretical literature, using it to make sense of emerging findings. To try out developing concepts, she presented them at conferences, and discussed them with colleagues and while conversing with women who had stigmatized illnesses.

Several measures enhanced research quality. Procedural changes made during data analysis and interpretation were tracked in methodological memos, yielding an audit trail. The research involved three kinds of crystallization (Janesick, 2000; Richardson & Adams St. Pierre, 2008): multiple participant viewpoints on shared situations (Mays & Pope, 2000), multiple analytical methods (coding, code-dimension summaries, narrative summaries), and discussing data interpretations with others.

**Results**

Participants mentioned concerns that were identified in the disclosure risks reviewed earlier, particularly disbelief, stigma, being suspected of malingering and laziness, impairments not being taken seriously, co-workers resenting accommodations, being judged incapable of doing their jobs, and fear of losing them. Although some women with fibromyalgia reported planned disclosures, more often they recounted interactions at work
where they responded immediately to disclosure risks in everyday work situations. These interactions arose partly from fibromyalgia impairments that fluctuate day to day or even hour to hour (Vick & Lightman, 2010), multiplying the times women needed to ad-lib explanations, as did relationship changes (e.g., new supervisors or co-workers).

**Impromptu everyday disclosures**

This section describes three dimensions of the impromptu disclosures within participants’ accounts: exposing oneself to scrutiny by disclosing both illness and impairments, divulging illness, and revealing invisible impairments selectively without divulging illness. Participants combined one or more of these dimensions to suit different needs, at different times, within different relationships. (See Table 1 for triad/dyad participants’ pseudonyms and their relationships to each other.)

*Exposing oneself to scrutiny*

Some women with fibromyalgia exposed both their illness and impairments in everyday conversation to convince co-workers of fibromyalgia’s legitimacy, to remind others about invisible impairments, and to educate them about fibromyalgia’s impact. For the women in this study, exposing had both benefits and drawbacks. They described benefits ensuing when exposing the illness and impairments bolstered empathetic relationships. Drawbacks ensued when others unfavorably compared participants to people they knew with fibromyalgia and gave them unwanted advice, and when co-workers resented accommodations.

First, the benefits: exposing illnesses and impairments appeared to strengthen empathetic workplace relationships, ones in which workmates both had stigmatized illnesses (not necessarily fibromyalgia) or knew someone who did. Each person thus understood
chronic illness’ work impact and disclosure risks. In one triad, exposing enabled two participants in an empathetic relationship to support each other in confronting workplace discrimination. Susan imparted that, after her co-worker Pam returned from medical leave, two of their team members doubted Pam could now do her job and tried to take over an event she was organizing. Susan helped Pam remain as the organizer—at a cost of being personally attacked herself. Both Pam and Susan separately described how workplace stress worsened their illnesses. When Susan returned from her own medical leave, she was given a job that threatened her health. She was accommodated by being transferred to a job that co-workers wanted. She said that they launched a union grievance, and the director was also angry about her transfer. Susan decided to fight to keep the job, because she needed the good income and generous benefits.

Some participants exposed themselves to scrutiny to convince others that their illness was legitimate and their impairments serious. Although participants highlighted the importance of being believed, even supportive family members and co-workers recounted difficulty believing invisible illness. Cindy’s daughter Rachel explained that, being a scientific person, she disliked having to take Cindy’s fibromyalgia pain on faith because she saw no evidence of it. Given this invisibility problem, Cindy and other women with fibromyalgia used medical terms to describe their symptoms at length during their interviews. They seemed to believe that they needed to prove their illness and impairments to the interviewer. For example, Gail said that her pain was so severe she vomited in the morning because of it and that her arm muscles shook so much she would drop things. Milagros demonstrated the seriousness of her illness when describing why coming to work was important to her: ‘I think if I stay home this illness is going to kill me and take
everything away [Crying]…You can’t let it do it. [sniffs] I just fight it and get up and come to work.’

Gail provided another reason for exposing herself to scrutiny: to remind others of illness and impairments. She linked the need for reminders not only to fibromyalgia’s invisibility but to its fluctuations. As Gail explained in talking about her husband,

There needs to be constant reminders because they do, they see you push through and then they think you’re okay…because they don’t realize it’s episodic—it can come and go…I can be well enough that I can push and do things more than I normally can, but it sets me back into [a pain] episode.

It may have been that Gail’s husband was not good at reading the signs of her fluctuating illness. As Nicole’s husband Paul explained when asked what family members could do to help women with fibromyalgia remain employed:

If you know yourself they’re hurt, it must be the fibromyalgia kicking in even though Mom won’t say anything...Be respectful and try to understand, try and pick up some of the signs of when you—it’s obvious that they’re going through some difficulty, try and be helpful around the home, make their life a little easier.

However, even family members who were better at reading illness signs needed reminding, as Paul remarked about himself:

I’m a very touchy, feely kind of person. I like my hugs…Well, to Nicole that could be just sort of clench your teeth and jump through the roof, depending on how she’s feeling. Or it might be okay. And she’ll say, ‘For crying out loud, that hurt!’…And it’s like ‘Oh gosh, I’m sorry.’ I forget myself sometimes.
Exposing oneself to scrutiny also had drawbacks. Gail felt it important to educate others about fibromyalgia and its effects; however, educating others led to problems. Gail recounted that, when she told her supervisor about her fibromyalgia, he told her to discuss it with the workplace’s occupational health nurse, not with him. Gail felt he became more distant afterward and, by rejecting her disclosure, demonstrated lack of caring. Later in her interview, however, she noted that Ontario human rights legislation prohibits supervisors from asking about their employees’ illnesses. Her supervisor may have been protecting himself from being sanctioned for having this information. If so, Gail’s exposing created risk for her supervisor and appeared to damage their relationship, a disclosure risk.

Even in supportive work cultures, such as Milagros’, employees may feel that educating others about one’s illness and impairments is risky. Francesca, Milagros’ supervisor, told the interviewer that an employee with rheumatoid arthritis (RA) had disclosed his illness to co-workers but did not want to educate them about it, nor did he want Francesca to. Even though George, Milagros’ co-worker, suggested in his interview that employees with chronic illnesses should educate co-workers about their conditions, the man with RA did not want to expose himself to scrutiny. Francesca observed that co-workers did not understand his accommodation, arriving an hour later than other staff, and tattled to Francesca about what they assumed was lateness. Without the man’s permission to explain the accommodation, she could not tell co-workers that he left an hour after they did. By tattling on the employee, his co-workers revealed their workplace to be less supportive than both Francesca and George claimed.

Exposing oneself to scrutiny had another drawback. It opened participants to being compared to others with fibromyalgia and receiving unwanted advice. These two disclosure
risks are not mentioned in the literature reviewed earlier. Pam, for instance, expressed annoyance that workmates compared her to people they knew with fibromyalgia who seemed to be worse off, suggesting she was not as ill. In this way, her illness was not taken seriously, a disclosure risk. Exposing also opened participants to suggestions that they had aggravated their illnesses through unhealthy lifestyles. Gail reported being compared to others and given unwanted advice in talking about a previous supervisor, whose mother had supposedly cured her fibromyalgia through a vegan diet. The supervisor advised Gail to adopt it. Annoyed by this comparison and unwanted advice, Gail defended herself in her interview by exclaiming that she had neither time nor money for healthy eating.

Unwanted advice-giving also followed exposing within families. Three family members repeatedly told the interviewer what they believed the women with fibromyalgia in their families should do to relieve their pain. The family members all expressed annoyance that the women with fibromyalgia did not follow their advice. Interestingly, the family members seemed much more worried about their loved ones’ health than the women with fibromyalgia. Perhaps the women wanted to maintain control over their own lives, or they found family members’ worry unhelpful in dealing with their illnesses.

Exposing oneself to scrutiny can engender resentment of accommodations by co-workers, a disclosure risk amplified by gossip, another risk. Nicole and Ruth reported separately that co-workers gossiped about a woman with rheumatoid arthritis on their team. Both observed that co-workers did not believe she deserved her accommodation (working part-time), even though arm braces made her impairment visible.

Given the drawbacks of exposing oneself to scrutiny at work by fully disclosing illnesses and impairments, participants’ accounts evinced two other dimensions of
impromptu disclosures: selectively divulging illness, and selectively and partially revealing impairments.

*Selectively divulging illness*

In this dimension, participants told certain people in certain circumstances about their fibromyalgia, a label that could stigmatize them. Some divulged in the context of empathetic workplace relationships, where telling seemed less risky. When both people face disclosure risks, they may trust each other more than others. By divulging their illness, participants sought legitimacy and emotional support. Several women with fibromyalgia and family members remarked that empathetic workmates understood what having a chronic illness felt like. As Pam explained about Susan and another co-worker,

> I have one workmate who I actually think she has it, just the way she describes her pain and her tiredness…She gets it, she totally gets it and that’s really nice. She’s my best friend on my team, and it’s nice having someone there. There’s someone on [another team]…who gets it, doesn’t have it but she understands it. She has someone in her family who has it, so I can talk to her.

Participants divulged their illnesses during conversations. They noted several reasons for divulging: (1) pre-empting co-workers from resenting accommodations, (2) explaining inability to do tasks, (3) helping others, and (4) being honest. First, Gail tried to pre-empt co-worker resentment of her accommodation (not working shifts before 9:30 a.m.) and her frequent sick leave:

> Co-workers are always the first ones I tell. Because if my disease may affect them and I want them to understand that I’m not just faking. I’m not calling in sick to go hang out with some—you know what I mean.
Second, Pilar, whose current heart disease overshadowed her older fibromyalgia, told clients who noticed her difficulty climbing stairs about her heart condition. Third, she helped others by divulging her illness when colleagues related their own health problems:

[Interviewer: Have you told anyone at work?] Whenever it comes up. It comes up in the form of, I’m also struggling with something, and nobody’s perfect… and if you have something that is bothering you, you can either avoid it or you can live with it, accept it, and commit yourself to just going forward…Somebody didn’t feel well.

Fourth, Nicole felt she needed to be honest by telling her supervisor Ruth about her fibromyalgia, even though her union advised that managers cannot be trusted. Nicole’s stance contrasted with that of Susan, Pam’s co-worker. A union activist, Susan was adamant that managers have no right to employees’ health information. Although she did not divulge her post-traumatic stress disorder in conversation, it was inadvertently disclosed when she took medical leave. Susan observed that taking leave marked her as different in co-workers’ eyes and led to discrimination.

Some participants waited until they trusted a workmate before divulging their illness. For example, Ruth, who had depression, said she waited two years to tell her own supervisor, until she had observed her long enough to trust her. At this point, Ruth explained, the depression was affecting her work, so she felt she needed to let her supervisor know. It may have taken Ruth longer to divulge her own stigmatized illness than it took Nicole, because Ruth did not seem to have an empathetic relationship with her own supervisor.

In Milagros’ workplace, divulging was part of her organization’s culture, because it served clients with another stigmatized illness. The culture facilitated Milagros’ confiding in her co-worker George. He had known another employee with fibromyalgia before Milagros
divulged her illness, and so they had an empathetic relationship. The conversations that Milagros and George had when each workday began, where they talked about her fibromyalgia, resembled check-ins that began their organizations’ staff meetings. Staff shared their personal issues and how they might affect interactions at work. The culture of Milagros’ workplace appeared to encourage divulging illness, even though it may not have been entirely supportive, as demonstrated by the reluctance of the employee with RA to expose himself to scrutiny.

*Revealing impairments selectively and partially*

This dimension differs from divulging illness in that participants told workmates about their impairments without naming their illnesses. In addition, they revealed impairments to some people and not others, and revealed more details to some than to others. Finally, one participant’s body revealed her impairment against her will.

First, instead of naming their impairments as fibromyalgia symptoms, participants said they used commonplace names they felt people would understand. These names were also conditions with little stigma, unlikely to be disbelieved. For example, when Emily taught piano at a music school, she told its owners that she got cold easily and had frequent backaches. They replaced her piano bench with a chair and brought in a heater, without Emily having to ask. Similarly, Amy, a teacher, told her students she had a ‘really bad knee.’ This, she said, was easier for them to understand than ‘fibromyalgia.’ They willingly helped her by writing on the blackboard so she could teach sitting down. They rearranged desks and fetched textbooks and ice for her pain. Pam also called her impairments something other than fibromyalgia. She said that, when she could not help her volunteers lift heavy bags, she told them she had a ‘bad back.’ She felt they would understand this reason better than ‘using FM
as an excuse,’ as she said. By not naming the source of their impairments, these women avoided disbelief and stigma—both disclosure risks—while still obtaining informal accommodations.

Second, participants revealed impairments to some people at work but not others. Nicole, for instance, told her supervisor, with whom she had an empathetic relationship because of their shared experiences of chronic stigmatized illness, about her pain. However, she did not tell co-workers:

I don’t want people to think she’s making it up, she’s, malingering, she’s using it as an excuse…There are times I’ve talked to my manager about my pain—“It’s just really bad today.” But I wouldn’t say that to my whole team.

Other participants did not tell their supervisors. They may have felt doing so was riskier than telling co-workers, since supervisors may assume that impairments compromise job performance, a disclosure risk. Supervisors can make decisions that have serious consequences for ill employees; whereas, co-workers have less power. Amy may have been aware of this power difference. She conveyed that, although she told two friends in her school ‘everything,’ as Amy explained, she only told her immediate supervisor that she could not climb stairs. She described a conflict with the supervisor and did not want him spreading rumours about her. Not only did he have power over her, but she did not trust him. She tried to avoid the disclosure risks gossip and damaged reputation.

Finally, bodies can reveal impairments against employees’ will. Meg, for example, wanted to work in a new location opening up at her workplace. She explained that, if co-workers told her empathetic supervisor, who had a chronic illness herself, how much pain Meg was in, her supervisor would not allow her to work in the new location. Meg wanted to
control where she worked, even though it might be more painful. So she tried not to reveal her pain. However, her body did that on its own. Meg recounted:

So the kids when they’re on me at my daycare…they jump on me…so I’m screaming right…Oww!…Like the staff see me struggle to get up…I don’t talk about it a lot to the people at work because I don’t want them to think I’m not capable of doing my job…Not that I can’t do the job but getting up and down is difficult…So when I show them that, when they see me having difficulty getting up and down. I just don’t say anything. You just see them looking at you…as if oh, you look like you’re in pain because it does look like I’m in pain.

Meg felt that, by revealing her impairment, she risked being considered incapable of the job she wanted, and that her supervisor might make a decision on her behalf based on stereotyped assumptions about her work capacity. Both being considered incapable and supervisors making decisions based on stereotypes are disclosure risks.

The disclosure risk of job loss may have influenced to whom women with fibromyalgia divulged their stigmatized illness and how much they revealed. Nicole was a primary breadwinner, with a higher income than her husband, as was Amy, whose income exceeded that of her family member, Samantha. By both their accounts, only Amy paid into the mortgage. Three of the other women with fibromyalgia were sole breadwinners, two with adult children living at home who did not contribute to household expenses. Being primary or sole breadwinners, most of the women with fibromyalgia could ill afford to lose their jobs.

In summary, participants’ accounts evinced many instances of unplanned disclosure in response to immediate needs and disclosure risks within workplace relationships. These everyday disclosures were improvised when women needed to explain fluctuating work
ability, when others needed reminding about invisible impairments, and when workplace relationships changed. Impromptu everyday disclosures comprised three dimensions: exposing oneself to scrutiny by disclosing both illness and impairments, divulging illness, and revealing invisible impairments without divulging illness.

**Discussion**

An additional conceptualization of disclosing stigmatized chronic illnesses at work, impromptu everyday disclosures, is proposed in this article. Impromptu disclosures differ in two ways from disclosure as conceptualized in the literature reviewed earlier. First, instead of being planned in advance after reflectively assessing risk, they are improvised on the spot in response to needs within workplace relationships. Second, happening in the back-and-forth interaction of everyday workplace conversation, they are dances rather than declarations. This section uses everyday-risk theory to explain these dances and discusses the benefits of the study’s triad design as well as the study’s limitations and strengths.

Everyday risks are shaped by social relationships (Lupton, 1999), which in turn are shaped by hierarchies of power. These hierarchies magnify disclosure risks, which may explain why some participants divulged their stigmatized illnesses to co-workers but not supervisors. In addition, some participants divulged stigmatized illnesses only within empathetic relationships, with employees who also had stigmatized illnesses or knew someone who did. Trust within empathetic relationships may have lowered disclosure risks, because both people in the relationship faced them.

Risks are also shaped by prior experiences—one’s own (Lupton, 2013) and others’ (Ellison et al., 2003; MacDonald-Wilson et al., 2011; von Schrader et al., 2014). As an example of the former, Susan’s experience of co-worker hostility may have played a role in
her perspective on disclosure risks. As for the latter, when disabled employees hear co-workers’ derogatory comments about other disabled employees, this observation erodes their trust and makes disclosing to these co-workers risky (Toth & Dewa, 2014). Such was the case for Nicole and Ruth, who reported separately hearing derogatory gossip about their team member with rheumatoid arthritis. This observation may have been why Nicole did not reveal her impairments to co-workers.

People much unlike oneself may be considered threatening and then marginalized (Lupton, 2013). Conversely, when participants consider workmates to be much like themselves (e.g., in empathetic relationships), they may view them as unthreatening and may more often divulge their illnesses to such people in everyday conversation. If both employees are marginalized by co-workers, they may have discrimination experiences to share. These shared experiences may in turn strengthen their empathetic relationship and shape their perceptions of everyday risks (Lupton, 2013) and, in turn, their views of workmates. The stories Susan told of discrimination she and Pam experienced and her fight to keep her job despite co-worker hostility, contain examples of bullying strategies that push employees with hidden illnesses to quit their jobs due to unbearable stress (Vickers, 2008). Being able to share stories of discrimination within an empathetic relationship may have helped Pam and Susan not succumb to co-workers’ efforts to push them out of their jobs.

In this study, some participants exposed themselves to scrutiny by both divulging illness and revealing impairments. One reason given was educating workmates about fibromyalgia and its impact. Fibromyalgia self-help websites advise readers with fibromyalgia to educate others, as evinced by the introduction to fact sheets distributed by the National Fibromyalgia and Chronic Pain Association (2014). The introduction reads,
Here are some facts about fibromyalgia that most people who do not have this chronic-pain condition do not understand or know. This is an excellent way to raise awareness while educating the people you know best about your condition. Go here [hyperlink] to read and make copies of this information to share.

Gail mentioned belonging to online fibromyalgia support groups, possibly located on self-help websites. These groups belong to her social network, and such networks, according to everyday-risk theory, shape everyday risks (Tulloch & Lupton, 2003). It could be that Gail saw no risk in exposing herself to scrutiny, because her social network encouraged educating others, an exposing dance. However, Gail reported a drawback of this dance: her soured relationship with her supervisor. Self-help websites’ advice to educate others may not be helpful for workplace relationships in jurisdictions where human-rights legislation prohibits employers from inquiring about employees’ medical conditions. Nor does the websites’ advice account for workplace disclosure risks.

Because fibromyalgia is a contested illness (Moss & Teghtsoonian, 2008), women with the condition often feel they need to legitimate themselves. Gail described in her interview how fibromyalgia made her feel so dreadful in the morning she vomited. Pain psychologists categorize such descriptions as ‘catastrophizing’ (Sullivan, Tripp, & Santor, 2000). However, for women with fibromyalgia, these examples serve a purpose; they emphasize the seriousness of impairments that may be disbelieved and dismissed (Oldfield, 2013). Both are disclosure risks. People with invisible illnesses need to repeatedly remind others about their impairments, because they have good days and bad days (Charmaz, 1991). This was Gail’s rationale for regularly reminding her husband about her invisible pain. She
said he assumed that, because she was able to do housework on good days, she could do it every day. It appeared he was not good at reading the signs of pain on her bad days.

Job loss is a serious disclosure risk not only for employees but for families, particularly when employees are primary or sole breadwinners (Tulloch & Lupton, 2003), as were all but two of the women with fibromyalgia in the study. In today’s economy, with jobs no longer lifelong, job insecurity has become a risk borne by individuals and families, rather than a collective risk borne by governments (Scott-Jones & Raisborough, 2007). Job insecurity may explain why most of the women carefully controlled information about their illnesses at work.

Through everyday disclosure dances, women with fibromyalgia controlled information that could stigmatize them as different. Difference is central to thinking and acting about risk (Lupton, 2013), and not being seen as different may be key to impromptu disclosures. Through them, employees try to mitigate both interpersonal risks (e.g., discrediting) and economic risks (Lupton, 2013) (e.g., job loss) that are particularly acute in precarious-work environments where employees compete to keep their jobs (Vickers, 2008). The two risk types are connected: interpersonal risks become economic risks, when, for example, chronically ill employees are pushed out of their jobs (Vickers, 2008). With governments off-loading responsibility for economic well-being to individuals (Wilkinson, 2010), disclosing difference at work becomes increasingly risky without alternative social supports; for example, disability pensions above poverty level and affordable housing. One meaning of everyday risk is losing control over the future (Tulloch & Lupton, 2003). Women with fibromyalgia may have tried to control their futures by avoiding, or at least reducing, risk. While they could not control how their workmates responded to impromptu disclosures,
they could control whether they divulged stigma, how much impairment they revealed, and their exposure to scrutiny.

The study findings reinforce the importance of workplace relationships, particularly with co-workers (Dunstan & MacEachen, 2013), to the ability of employees with fibromyalgia and other stigmatized illnesses to remain employed. Even though workplace relationships may be as important to job retention as employees’ work capacity, the former receive far less attention in work-disability literature (Tjulin et al., 2011). More research about workplace relationships as experienced by women with stigmatized illnesses would help us better understand the influence of these relationships on disclosure risks.

**Conclusion**

Through impromptu everyday disclosure dances, women with fibromyalgia and other stigmatized illnesses improvised responses in everyday conversation to disclosure risks within their workplace relationships. The concept of impromptu disclosures broadens our understanding of stigmatized-illness disclosure in workplaces by considering how employees operationalize it in their day-to-day work lives. Literature reviewed for this article conceptualizes disclosure as decisions planned through cognitive reflection about risks. In contrast, impromptu everyday disclosures are dances rather than declarations. While assumptions from risk psychology underlie current conceptualizations of workplace disclosure, this article examined it through a different lens: social everyday-risk theory.

Viewing workplace disclosure as actions tailored to changing immediate circumstances complicates advice that rehabilitation professionals may give to clients. Accordingly, rehabilitation professionals may want to reconsider the common assumption that disclosure is unproblematic. Employer concerns for protecting employee privacy, in
accordance with human rights legislation, may impact how disclosures are received. In contrast, before recommending disclosure, professionals may first want to learn from clients about their workplace cultures and relationships as well as their perceptions of disclosure risk. Professionals may also want to take into account pressures that these clients may experience, such as the need to remain competitive, whether they are precariously employed, and increases in their workload due to budget and staff cuts. Using this information, professionals can then suggest a range of disclosure responses, depending on the relationship and risk.

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Chapter 55
“You want to show that you’re a valuable employee”: A Critical Discourse Analysis of Portrayals of Employed Women with Fibromyalgia

Abstract

Employees with fibromyalgia, a chronic illness primarily affecting women, rarely receive advice on how to stay at work. In addition, it is often assumed that they will leave the workforce; yet, many do not. As part of a larger study exploring how women with fibromyalgia remain employed, this article aimed to understand how employees with fibromyalgia, their family members, and workmates portray the women and how these portrayals may help women with fibromyalgia stay employed. Using critical discourse analysis, in 2013 we interviewed 22 participants in the Greater Toronto Area, Canada, comprising five triads and three dyads. This data-collection method elicited multiple perspectives on each woman’s situation, which allowed us to see similarities and differences among the accounts of related participants within the triads/dyads. To gather more data on supervisors’ perspectives, four additional managers who did not know the women were interviewed. Data within and across the triads/dyads were analyzed through coding, summaries of the code dimensions, narrative summaries of the triads/dyads, and mapping the relationships between developing concepts.

Participants reported societal assumptions that women with fibromyalgia are lazy, malingering and, when employed, less capable than healthy employees. To counter these assumptions, participants portrayed the women as normal, valuable employees who did not

5 This article will be submitted to Social Science and Medicine.
‘give in’ to their illness. In their portrayals, they drew on the largely unquestioned discourse of normalcy, the dominant discourse that the mind controls the body, and a narrative common in the media, overcoming disability. Participants’ admiring portrayals may have helped the women manage their identities in workplaces where employees competed to keep their jobs and where chronically ill employees were assumed to be less productive than healthy employees. The portrayals may have also bolstered the women’s confidence and motivation, helping them to meet the challenges of working when chronically ill.

Most research on fibromyalgia investigates medical causes and treatments. A small literature explores illness experience among women with fibromyalgia, and an even smaller literature focuses on an important part of the daily lives of a substantial proportion of these women, employment. Our findings contribute to this neglected research area by expanding on the strategies identified in the few other studies of fibromyalgia and work and doing so using a new approach to the topic: critical discourse analysis. We also contribute two new perspectives to the study of fibromyalgia and work, those of family members and workmates. These perspectives expand the scope of research on fibromyalgia and work beyond women with fibromyalgia alone to other stakeholders who contribute to these women’s ability to remain employed.

**Keywords:** critical discourse analysis, Canada, chronic illness, employment, fibromyalgia, identity management, normalcy discourse, overcoming-disability narrative

**Introduction**

Fibromyalgia is a contested chronic illness affecting primarily women (Statistics Canada, 2010), who experience varying degrees of pain, fatigue, memory problems, and other health issues (Wolfe et al., 2010). Although many employees with fibromyalgia leave
the workforce, a substantial proportion stay. In Canada, for example, the proportion is 44% (Statistics Canada, 2010). Fibromyalgia affects 4.2% of women worldwide with widespread pain, fatigue, disordered sleep, and other problems (Queiroz, 2013). Few studies focus on employees with fibromyalgia, and those that do describe why women remain employed and their strategies for staying at work. Fibromyalgia-information materials rarely contain advice on how to remain employed. In addition, fibromyalgia self-help materials often assume that fibromyalgia is so debilitating it is incompatible with employment (Oldfield, 2014). A term common in these materials, ‘fibromyalgia patient’, posits patient-hood as a primary identity for people with fibromyalgia (Barker, 2002). To a large extent, this identity counteracts the belief of many physicians that fibromyalgia is not a physical illness (Harth, 2013; Hayes et al., 2010) and conveys that people with fibromyalgia need medical care, which they are often denied because of fibromyalgia stereotypes (Oldfield, 2013; Parlor & Halapy, 2014). However, this primary identity reinforces the assumption in self-help materials that fibromyalgia is incompatible with employment.

Retaining employees with fibromyalgia in the workforce benefits individuals and governments. For women with fibromyalgia, employment provides social relationships, daily routine, and economic independence (Henriksson et al., 2005; Löfgren et al., 2006). They express more satisfaction with their lives than women who have left the workforce (Liedberg, Hesselstrand et al., 2004). As income earners, they contribute revenue from income taxes and reduce expenditures on disability pensions. Reducing the rate at which women with fibromyalgia leave employment is an important goal, and greater understanding is needed of how they can remain employed. Our study contributes to this emerging understanding by describing how women with fibromyalgia, their family members, and workmates interacted
with dominant discourses to counter assumptions that women with fibromyalgia should not work. They also countered assumptions that supervisors and colleagues may hold that women with fibromyalgia are lazy and, when employed, less productive than healthy employees. Instead, participants\(^6\) portrayed the women with fibromyalgia as ‘not giving in’ to their illness, as normal, and as valuable employees. These depictions may have helped the women remain employed in job markets that are increasingly precarious because of cutbacks, work reorganization, and a shift from loyalty to employees to valuing employee productivity (Seing, MacEachen, Stahl, & Ekberg, 2014).

Drawing on a larger study of how women with fibromyalgia remain employed,\(^7\) this article aims to answer the following questions:

1. How did participants interact with dominant discourses to portray the women with fibromyalgia who remained employed?
2. How might these portrayals have helped the women with fibromyalgia to stay employed?

In focusing on fibromyalgia and employment, we do not intend to question the legitimacy of claims women with fibromyalgia make for disability pensions. The women in our study had employment situations that helped them to remain employed. We understand that many others who leave the workforce do not.

**Remaining employed with fibromyalgia**

The few studies of employment and fibromyalgia that currently exist describe multiple reasons why women with fibromyalgia remained employed. These studies suggest that first and foremost, they found their work meaningful through the satisfaction and

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\(^6\) Women themselves, family members, and workmates.

\(^7\) Oldfield (2015).
recognition it provided. Working helped them feel ‘normal’ and that they were contributing
to society (deVries et al., 2011; Palstam et al., 2013). Not only was work meaningful, it was
therapeutic. By providing daily structure and socializing, work distracted them from pain
(deVries et al., 2011; Palstam et al., 2013). Not surprisingly, women stayed at work because
they needed the income (deVries et al., 2011; Palstam et al., 2013). Furthermore, their work
environments were enabling. The working conditions were flexible, giving employees
control over work hours, work pace, and work location. In addition, employees’ work tasks
suited their health, in that they were not strenuous or ergonomic aids were available (deVries
et al., 2011). Lastly, they received support at work from colleagues and managers and outside
work from health care professionals, family, and friends (Palstam et al., 2013). Together,
these individual, work, and social conditions helped women with fibromyalgia remain
employed.

The limited literature on fibromyalgia and work also describes women’s strategies for
remaining employed. To begin, participants prioritized paid work over other activities and
reduced their leisure activities to allow more time for resting (Crooks, 2007; Liedberg &
Henriksson, 2002; Sim & Madden, 2008; Sallinen et al., 2010). In addition to resting, they
avoided stress and used exercise and relaxation to keep up their energy (Löfgren, Ekholm et
al., 2006; Werner, Sissel Steihaug et al., 2003). At work, women prioritized tasks so that they
could work at their own pace (Bossema et al., 2012; Sallinen et al., 2010). They also
requested accommodations to create more enabling working conditions, such as more breaks,
reduced or varied work hours, fewer physical demands, and working at home (Henriksson,
Liedberg et al., 2005; Liedberg & Henriksson, 2002; Sallinen et al., 2010). In addition to
these formal accommodations, women used their vacation leave, took days off without pay or
even changed occupations (Rakovski, Zettel-Watson, & Rutledge, 2012). Augmenting the strategies women with fibromyalgia reported, participants in Bossema et al.’s (2012) study identified desirable working conditions for employees with fibromyalgia: jobs that preserve energy for home and leisure, reasonable workloads, clear agreements with management, development opportunities, and help from colleagues. Many of the strategies that women with fibromyalgia used to remain employed involved manipulating time to fit their impairments.

There are several problems with the few studies on fibromyalgia employment. First, they recruited participants from clinical settings or support groups. Employed women who seek help from clinicians or support groups are more impaired by fibromyalgia (Rusu et al., 2015). Second, the studies omit the perspectives of key players who shape women’s employment possibilities: their family members and workmates. Third, they do not take account of precarious employment, insecure jobs without benefits that often employ disabled people (Wilton, 2006). Fourth, many of the studies are from countries where disabled employees can work part-time and receive partial disability pensions. It may therefore be easier for study participants to remain employed than for disabled North Americans. For instance, Canadians must generally prove they are totally incapable of working to receive pensions (McKee, Popiel, & Boyce, 2006). Finally, studies on employment with fibromyalgia identify employment facilitators and barriers and coping strategies. A broader, more social approach is needed, one that examines how women with fibromyalgia and others around them manage the women’s identities to help the women remain employed.

In our study, we addressed these problems by recruiting participants from the general community (see Appendix 3). We incorporated three additional groups of participants in
addition to employed women with fibromyalgia: family members, workmates, and managers.

Instead of identifying facilitators, barriers, and coping strategies, we focused on participants’ interaction with dominant discourses in managing the women’s identities to help them remain employed. Altogether, these constitute a new approach to the study of fibromyalgia and work. We now explain the theoretical foundation of our study.

**Discourses and narratives**

Language both reflects and constructs social processes, thereby directing thinking (Hodges, 2008). It does so through the work of discourses, webs of taken-for-granted assumptions that enable certain ways of thinking and exclude others (Phelan et al., 2014). Discourses are assembled, in turn, to create narratives: stories about the social world. Next we introduce two discourses and a narrative that bubbled under study participants’ talk.

Normalcy discourse has great disciplinary power (Gutting, 2005). Conformity to normalcy is ensured through fear of being labelled as different (Link & Phelan, 2001). As Warner (1999) says, “Nearly everyone, it seems, wants to be normal. And who can blame them, if the alternative is being abnormal, or deviant, or not being one of the rest of us?” (p. 53). At work, being labelled as different may lead to discrimination (Vickers, 2012). When people with invisible differences, such as chronic illnesses, perceive that they may be considered outsiders, they try to manage their identities (Watson, 2008). They do this in various ways; for example, by passing as normal and through selective concealment and disclosure strategies (Schneider & Conrad, 1983). People also present themselves favorably to distinguish themselves from discredited others (Litt, 2000). In most workplaces, employees are assumed to be able to complete their tasks without interference from their bodies (Beatty, 2012). These are ‘expected workers’ who demonstrate normalcy through
compulsory able-bodiedness (McRuer, 2002; Stone, Crooks, & Owen, 2013). Given the disciplinary power of normalcy discourse, presenting oneself as normal may be a matter of survival for ‘unexpected workers’ such as those with chronic illnesses (Bell, 2007; Stone et al., 2013).

The narrative ‘overcoming-disability,’ a common disability depiction in media stories, draws on normalcy discourse (Hardin & Hardin, 2004). These stories begin with the tragic onset of illness and loss of abilities. Next comes a long struggle to overcome this loss, inspiring admiration for the hero’s courage and perseverance. At the end of the story, the hero conquers disability and returns to ‘normalcy’ (Titchkosky, 2007). The overcoming-disability narrative implies that individuals’ strength of character alone leads to victory, without accounting for other factors such as home and workplace environments and social policies (deVolder, 2013; Silva & Howe, 2012). By individualizing disability in this way, the overcoming-disability narrative draws on the discourse of the mind controlling the body, a widespread Western notion that individuals’ minds control their bodies through will (Morris, 1991; Oliver, 1996).

**Methods**

We sought the perspectives of a diverse group of women with fibromyalgia in the general community. Inclusion criteria were being over 18, medically diagnosed with fibromyalgia, willing to recommend a family member and workmate for interviewing, and speaking and understanding English. In 2013, we recruited broadly through women’s health listservs (the most successful route), posters at community centres and grocery stores, and the first author’s networks. To allow in-person interviewing, the first author recruited within the Greater Toronto Area, where she lived. Of the 23 women who responded, 9 lived outside this
area, and 4 did not meet other inclusion criteria. Of the 10 women who met the inclusion criteria, one did not respond to the interview request. Thus interviews were conducted with nine women.

During interviews, the women were asked to recommend family members and workmates, who were then contacted and, if willing, interviewed using semi-structured guides (one for each participant group) (see Appendix 6). For the women, topics derived from larger study’s literature review included fibromyalgia’s effect on her job, disclosure, workplace accommodations, fibromyalgia’s effect on home responsibilities, and advice for other employed women with fibromyalgia. For family members, topics included allocation of responsibilities at home, what changes had been made because of fibromyalgia, and advice for other families of employed women with fibromyalgia. Workmates were asked about the workplace as a whole, not the woman with fibromyalgia. Topics included the effect of chronic illness on employees’ work and workplace relationships, what accommodations were offered, and advice for employees with chronic illnesses, co-workers, and supervisors.

Recruiting produced five triads (woman with fibromyalgia, family member, workmate) and three dyads (woman with fibromyalgia, family member or workmate), comprising nine women with fibromyalgia, seven family members, three co-workers, and three supervisors. Full triads were not achieved in all cases, because some of the recommended family members and workmates were unwilling to be interviewed. To gather more data on supervisors’ perspectives, four additional managers who did not know the women were interviewed. The study received ethics approval from a university research ethics board (see Appendix 2), and each participant gave informed consent. The consent form specified that participants would not be told what others in their triads/dyads had said (see
Appendix 5). To further protect anonymity, relationships among participants are not revealed in this article, nor are pseudonyms used. Instead, participants are identified by their roles.

During telephone screening to determine eligibility of the women with fibromyalgia who responded (see Appendix 4), the first author answered their questions about the study. They had been sent the study-information form (see Appendix 5), as were family members and workmates when they were later contacted. The 26 interviews, conducted by the first author, took place in locations participants chose. Each triad member was interviewed separately in 2013, for an average 1.5 hours. Field notes helped the first and second authors recall the interview contexts during data analysis and interpretation. The triadic data-collection procedure (Bourbonnais, 2009; Noiseux & Ricard, 2008) elicited multiple perspectives on the women’s situations, which allowed us to see similarities and differences among the accounts of triad members. Sometimes the contrasts were striking; for example, when family members presented the home or work situations of women with fibromyalgia very differently than the women did. These contrasts allowed us to compare discourses and narratives within triad/dyad members’ accounts.

We used critical discourse analysis (CDA) methodology to examine discourses and narratives within participants’ accounts so that we could discern their roles in participants’ portrayals of employed women with fibromyalgia. CDA is rooted in social constructivism, a philosophy that sees the human world as made through social processes (Marshall, 1998). From this perspective, the negative meanings of differences such as disability and impairment are socially constructed, not biologically derived. Constructivism also considers people’s use of language not as facts but as depictions of themselves and others. CDA is the
macro-analysis of texts (e.g., interviews) to understand the underlying discourses and narratives within the texts (Hodges, 2008).

All interviews were audio-recorded and professionally transcribed verbatim. The first author then listened to each recording while reading its transcript, to check transcribing accuracy and reimmerse herself in the interviews. Concept generation (Becker, 1998) began early in the research, while the first and second authors discussed the field notes. They collaboratively developed a code list, which the first author expanded as she coded each transcript, using NVivo10. Examples of these initial codes were Disclosure, Hard Worker, and Work Relationships. As transcripts were coded, some initial codes were divided when they captured large amounts of data (e.g., Accommodations – Not including negotiating, Negotiating accommodations), and some new codes were added when topics recurred in the newly analysed data (e.g., Identity-personality, Others’ worries about woman with FM). The final code list contained a mixture of deductive and inductive codes. The deductive codes came from the study’s literature review in the thesis proposal and the interview guide. The inductive codes were new topics that emerged from the data.

After coding the transcripts, the first author compared data across triads/dyads by summarizing code dimensions from the three perspectives and for the supplementary interviews. Analytic and reflective memos augmented data interpretation. Alongside code-dimension summaries, narrative summaries were used to compare entire interviews within triads/dyads, and relational diagrams to map relationships between emerging concepts (for an example, see Appendix 7) (Clarke, 2005). To develop the concepts, the first author discussed them with the other authors and also presented them at conferences.
Several measures enhanced analytic rigour. Decisions made during data analysis and interpretation were tracked in methodological memos, yielding an audit trail. The research involved three kinds of crystallization\(^8\) (Richardson, 1994): multiple participant viewpoints on shared situations, multiple analytical methods, and discussing data interpretations with others.

**Reflection**

The first author had fibromyalgia in the past, which influenced her choice of research topic and gave her insider status in the research (Foster, 2009). However, the authors decided that the substantial improvement in the first author’s health might make women with fibromyalgia feel defensive. Therefore, they decided that she would not disclose her past fibromyalgia unless participants asked about it, which occurred twice. In both cases, she replied that she had indeed had fibromyalgia but was more interested in the participant’s experience; nonetheless, she would describe her experience at the interview’s end. In one interview where she offered reassurance that impairments may diminish with time, the woman with fibromyalgia did not seem reassured. In another, the first author highlighted commonalities in their fibromyalgia experiences and enhanced rapport. To facilitate reflection on the influence of her insider status (Banister, 1999), the first author was interviewed by a colleague twice during the larger project.

**Participant profile**

Each triad/dyad centred on a woman with fibromyalgia. The women’s median age was 50 (range 27-69). Table 2 gives demographic information for the women with fibromyalgia, information about their employment, and the roles of other triad/dyad

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\(^8\) An alternative to the metaphor of survey-engineering triangulation, which aims to find a single, true point. The crystal metaphor recognizes multiple interpretive possibilities, depending on the angle from which the crystal (or phenomenon) is viewed.
members. We chose not to use pseudonyms in telling individual’ stories, because they had been promised intra-triad/dyad confidentiality in the informed-consent form.
Table 2. Profile of Women with Fibromyalgia

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Bread-winner status</th>
<th>Employer size(^a)</th>
<th>Sector</th>
<th>Job type</th>
<th>Highest education completed</th>
<th>Family member interviewed</th>
<th>Workmate interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher</td>
<td>Secondary</td>
<td>Small, large</td>
<td>NGO, public</td>
<td>Multiple contracts</td>
<td>Masters</td>
<td>Best friend</td>
<td>N/A(^c)</td>
</tr>
<tr>
<td>Teacher</td>
<td>Sole</td>
<td>Large</td>
<td>Public</td>
<td>Standard(^b)</td>
<td>Bachelors</td>
<td>Cousin</td>
<td>Co-worker</td>
</tr>
<tr>
<td>Social worker</td>
<td>Equal</td>
<td>Medium</td>
<td>NGO</td>
<td>Standard</td>
<td>Masters</td>
<td>Husband</td>
<td>Co-worker</td>
</tr>
<tr>
<td>Daycare worker</td>
<td>Sole</td>
<td>Small</td>
<td>NGO</td>
<td>Standard</td>
<td>DK</td>
<td>N/A(^d)</td>
<td>N/A(^d)</td>
</tr>
<tr>
<td>Office manager</td>
<td>Sole</td>
<td>Small</td>
<td>Private</td>
<td>Permanent,</td>
<td>High school</td>
<td>Daughter</td>
<td>Supervisor</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4 days/wk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>Primary</td>
<td>Large</td>
<td>Public</td>
<td>Standard</td>
<td>Bachelors</td>
<td>Husband</td>
<td>Supervisor</td>
</tr>
<tr>
<td>Call-centre agent</td>
<td>Equal</td>
<td>Large</td>
<td>Public (private in past)</td>
<td>Permanent, 5 hrs/day, 5 days/wk</td>
<td>College</td>
<td>Mother</td>
<td>N/A</td>
</tr>
<tr>
<td>Psychotherapist</td>
<td>Primary</td>
<td>Large</td>
<td>Public</td>
<td>Contract (16 hr/wk) + Self-employed (13 hrs/wk)</td>
<td>Masters</td>
<td>Close friend</td>
<td>N/A</td>
</tr>
<tr>
<td>Housing worker</td>
<td>Sole</td>
<td>Small</td>
<td>NGO</td>
<td>Standard</td>
<td>DK</td>
<td>N/A(^e)</td>
<td>Supervisor, co-worker</td>
</tr>
</tbody>
</table>

NGO = nongovernmental organization. N/A = not available for interviewing. DK = Don’t know. \(^a\) Large > 500 employees, medium = 50-500, small < 50. \(^b\) Full-time, permanent. \(^c\) Woman had not disclosed at work. \(^d\) During interview, woman requested that these triad members not be interviewed. \(^e\) Family member not available
Findings

Participants’ accounts reiterated societal assumptions they reported: that fibromyalgia and its impairments are not real, that women with fibromyalgia are lazy malingerers, and that chronically ill employees are unproductive and unreliable. All three groups of participants countered these assumptions by portraying the employed women in three ways: first, as “not giving in” to fibromyalgia; second, as being normal; and third, as being valuable employees. Although we explain these aspects of their portrayals separately for ease of understanding, in interviews they intertwined.

“Not giving in” to fibromyalgia

Women with fibromyalgia, family members, and workmates presented the women as “not giving in” to fibromyalgia. Their presentation entailed rejecting the identities ‘fibromyalgia-patient’ and ‘being-on-disability’ and highlighting the personal attributes ‘pushing through pain and fatigue,’ ‘strong will,’ ‘positive attitude,’ and ‘noncomplainer.’ These identities and attributes are discussed below.

A first way that women with fibromyalgia depicted themselves as not giving in was remaining employed and thereby rejecting ‘fibromyalgia patient’ as a primary identity. They contrasted themselves with other women who had “given in” (their words) and left employment. One woman with fibromyalgia said she learned in childhood how others got through troubled times and then applied that learning to her own pain. In their depictions of women not giving in, family members used metaphors, such as “soldiering on” and “shouldering pain and carrying on.”.

A second way that women depicted themselves as not giving in was by rejecting the label ‘being-on-disability’. Although some explained that they could not afford to leave work
(being sole or primary breadwinners), they and some family members viewed going on disability as ‘giving in.’ In contrast, giving in involved, as several participants put it, “staying home and doing nothing”, being bored, not having a reason to leave home, and losing charge of one’s life. Not all the women with fibromyalgia rejected the label ‘being-on-disability’ however. One woman said she planned to apply for a disability pension when her children finished university, when she could then relocate to a town where living on a disability pension was affordable. Another woman stayed at work against the wishes of her family member, who explained that, after diagnosis with a life-threatening illness, he had taken medical retirement. He felt she should do the same.

A third aspect of the depiction of women as not giving in countered the assumption that women with fibromyalgia are lazy. Women talked about “pushing through” (their words) pain and fatigue to fulfill their family and work responsibilities. However, pushing through sometimes had negative consequences. As one woman with fibromyalgia remarked,

If I have…something I need to do, I’ll just do whatever I have to do to get it done, no matter how much pain I’m experiencing or how tired I am. But then of course my family pays for that when I get home and there’s nothing left because I’ve been pushing myself all day at work.

Some family members expressed concern about pushing through. As one observed,

I would say she…doesn’t live the life of someone that has fibromyalgia, like I think she pushes herself and then gets sick a lot…I think mentally she has the capacity to do all those things, but physically she gets worn down.
A fourth way that participants portrayed women as not giving in was by attributing their ability to ‘push through’ and ‘not give in’ to their ‘strong will’. As a family member noted,

If you have a very calm and passive demeanour, fibromyalgia will eat you alive. I don’t think that type of personality can handle it very well, because that type of personality gives in to things. I think if you have a strong personality and you are strong-willed, it does not have to rule your life.

Characterizing women with fibromyalgia as having ‘strong will’ countered the assumption that, as one family member put it, people with fibromyalgia lack willpower.

A fifth aspect of their presentations of women with fibromyalgia was ‘positive attitude,’ which one woman felt was key to not giving in. Another woman demonstrated positive thinking by comparing herself to someone with a worse fate:

There’s lots of worse things I could have than fibromyalgia. Like I could have cancer, I could have a terminal illness. As illnesses go this is harder to function but it’s not going to kill me.

Considering herself better off than those with terminal illnesses may have helped this woman not ‘give in’ to fibromyalgia.

A last way that family members and workmates characterized the women with fibromyalgia as not giving in was by describing them as “not complainers” (their words). As with other aspects of not giving in, this description countered assumptions often mentioned in interviews: that fibromyalgia is not a real illness and women with fibromyalgia are lazy malingerers. The latter belief may have explained why the women did not talk about having fibromyalgia, particularly at work where talking about illness or impairments may have been
risky. Women themselves gave another rationale for ‘not complaining’: exceeding limits on others’ tolerance of illness talk. One described how annoyed she had been with her mother, who also had fibromyalgia:

So I tend to not talk about my pain and try to live with it…partly because I don’t want people to be like I was with my mother, [when she said] ‘I’m so tired’ [and I’d say] ‘Will you just shut up about your pain, I’ve had enough.’

Another woman’s story reflected a similar limit on workplace tolerance:

We’ve been hearing these stories about somebody’s foot, their knee, their back, their, you know, whatever for a long time. So people are tired of all this.

Not complaining may have also been a way of appearing normal, the second aspect of portrayals of employed women with fibromyalgia.

**Being “normal”**

Women with fibromyalgia countered assumptions that chronically ill employees are less capable than healthy employees by depicting themselves as “normal.” They described employment as key to normalcy, explaining that it enabled them to maintain their lifestyles, took their minds off illness and problems at home, and got them out of the house. In describing her future, one young woman equated normalcy with living (in her words) “a meaningful, productive life”: a job that contributed to the economy, a husband, and future children. Yet, another woman who was already living this life juggled a “crappy job” (as she put it) with a busy home including three young children and responsibility for most of her family’s housework. She also described enduring high levels of stress and pain. Although remaining employed was important to her, her unpaid work at home made that difficult.
For women with fibromyalgia, portraying themselves as normal may have also been a strategy for avoiding workplace discrimination. Understandably, several women with fibromyalgia told only trusted fellow employees about their illness or gave their impairments labels other than fibromyalgia, using descriptions such as “back problems” or “bad knees.” One woman told no-one, saying that she did not want pity. Another woman did not seek formal accommodations because she had observed how co-workers gossiped about a colleague with chronic illness, believing that she did not deserve her accommodation. Other participants (both women and family members) used benefits available to all employees (e.g., sick leave and time-in-lieu of overtime pay) to self-accommodate their needs. They may have felt that requesting accommodations would confirm others’ assumptions that chronically ill employees are less capable than healthy employees. Family members and workmates also countered this assumption by characterizing the women with fibromyalgia as valuable employees.

**Being a valuable employee**

Many women with fibromyalgia and their family members and workmates emphasized how good the women were at their jobs. One supervisor enthused:

> We had hired other [staff] and realized you can have an able-bodied [employee] whose work ethic is way worse or, if they’re 10 years out of school, their skills aren’t anywhere near…[woman with fibromyalgia] can spell, she can add, she’s a self-learner, she’s motivated, she can think. She can do all these things. Those are in somewhat rare supply.
In most cases women described their jobs as bringing them happiness, often via workplace relationships. This revealed another rationale for remaining employed. As one woman declared,

Teaching is my passion. I love what I do. I love those connections that I make.

[Interviewer: What motivates you to keep going at work?] It really is the kids.

A second woman observed,

The love I have for the children makes me feel good about who I am…my boss, she’s very supportive…the parents are wonderful…and there’s nothing like little ones for me…it actually makes me feel alive.

Likely aware that employers value productivity, participants described the women with fibromyalgia as hard workers. A workmate conveyed the importance of employees proving their productivity, regardless of their health status. She relayed a colleague’s account of a workplace event:

Managerial staff…[were] talking about all the cost factors and all of the workload increases and...cutbacks...This supervisor turned around and said, ‘Well I know how to control my workers and get them to get their work done. You just put enough pressure on them and they all scatter like cockroaches.’…So therefore…people are feeling…unsupported by each other, all of a sudden you get worried about yourself in the workplace and so then you are becoming super-achievers in the workplace, attempting to make yourself outshine others.

The participant also pointed out that employees with chronic illnesses competed with healthy employees in this work-overload environment. A woman with fibromyalgia, also aware of
the need to compete with healthy employees, said she did not want future employers assuming she was less productive:

   I’m a very hard worker and I’m very productive…I might not do [the job] in the same way they would do it, but that doesn’t mean I’m not going to get it done…bad health does not equal bad outcomes and bad work.

This woman’s family member described her similarly:

   She’s the hardest working person that I know, like absolutely, and she just doesn’t stop.

   Although family members and workmates described the women with fibromyalgia as hard workers, some felt they worked too hard. For example, a supervisor who admired her employee’s strong work ethic worried that it might hurt her health. The supervisor noted that that the woman had a number of health problems and…she works 150 per cent... [she’s] the kind of person you have to push to say take care of yourself…she’s got such a strong work ethic…if anything she worries me sometimes.

In summary, participants countered dominant societal assumptions they reported that women with fibromyalgia are lazy and malingerers, and that chronically ill employees are less capable than ‘normal’ ones by portraying the women with fibromyalgia as not giving in to their illness, being normal, and being valuable employees.

**Discussion**

In increasingly precarious work environments (Seing et al., 2014), employees compete with each other to keep their jobs. Employees with chronic illnesses may be disadvantaged in this competition, not only because of illness-related impairments, but by
stereotypes that coworkers and supervisors may hold about chronically ill employees; for example, that they cannot handle challenging work, threaten team productivity, or will soon leave the workforce (Beatty, 2012; Vickers, 2012). Through their portrayals of women with fibromyalgia, participants countered these stereotypes. This section answers the two questions posed in the introduction.

**Participants’ portrayals of employed women with fibromyalgia**

In their depictions, participants interacted with two dominant discourses, normalcy and mind-controlling-body, and with a narrative that draws on these two discourses, overcoming disability. Their depictions in turn helped manage the women’s identities as valuable employees.

Given the power of normalcy discourse (Gutting, 2005), it is not surprising that participants characterized the women with fibromyalgia as normal. As our participants with fibromyalgia did, employees with other illnesses have equated employment with normalcy (Saunders & Nedelac, 2013). Other studies have also found that people who face discrimination distance themselves from those who already experience it (Eakin, 2005; Low, 1996). Distancing oneself from people labelled disabled (Garland-Thomson, 1997) by rejecting the label ‘being-on-disability’ may be an identity-management strategy that emphasizes normalcy. So may not accentuating difference by not complaining, another one of our findings. Given the risks of disclosing difference at work (Oldfield, MacEachen, Kirsh, & MacNeill, forthcoming), drawing on normalcy discourse to manage identity may have been a way for the women with fibromyalgia to keep their jobs in competitive workplaces and a way for family members to support them in doing so.
Participants drew on the overcoming-disability narrative in depicting women as ‘not giving in’ to fibromyalgia, crediting their positive attitude and strong will for keeping them from giving in. In rejecting the ‘fibromyalgia-patient’ and ‘being-on-disability’ identities, the women themselves drew on the overcoming-disability narrative, portraying themselves as having overcome their challenges enough to remain employed. Family members and workmates admired the women with fibromyalgia who did not complain, again drawing on the conceptualization of overcoming disability as a matter of individual fortitude. Depictions of women pushing through pain and fatigue to meet their work and home responsibilities drew on the related mind-controlling-body discourse. Women’s own descriptions of their positive attitudes also drew on this discourse.

Portraying the women with fibromyalgia as ‘valuable employees’ was a sensible identity-management strategy. It enabled women and their family members to deflect stereotypes about chronically ill employees and thereby may have safeguarded the women’s employment. With health being a form of human capital, any health issue that reduces productivity is problematic (Vickers, 2001). In other studies, disabled employees have also described themselves as hard workers, who feel they have to work harder than non-disabled colleagues to prove their value (Hansen & Philo, 2007; Mak, Chaidaroon, Fan, & Thalib, 2014; Saunders & Nedelac, 2013). Doing so may mean taking work home, working longer and on weekends to keep up, thereby damaging their health (Hansen & Philo, 2007; Vickers, 2001). Being valued by employers increases the likelihood of being accommodated (Seing et al., 2014), which may further enable women to remain employed.
How might participants’ portrayals of women with fibromyalgia have helped them stay employed?

Notwithstanding the women’s need for income—most were sole or primary household breadwinners—they had other reasons to remain employed. These reasons have been noted in other research. For example, one study of employees with terminal illnesses found intrinsic motivation for work a stronger predictor of remaining employed than extrinsic motivation (i.e., pay) (Westaby, Versenyi, & Hausmann, 2005). Women with fibromyalgia in our study generally described their work as meaningful and as providing a contribution to society, a sense of normality, daily structure, and socializing, as is the case in other studies (deVries et al., 2011; Palstam et al., 2013).

Admiring depictions by supportive family members and workmates may have given the women with fibromyalgia confidence and motivation, the latter a sustainer of employment for women with fibromyalgia (de Vries et al., 2011). Women and family members described the women as loving their jobs, being good at them, and deriving happiness from workplace relationships. These conditions may also sustain employment. Similarly, admiring depictions of women as not ‘giving in’ to fibromyalgia and as normal may have bolstered their pride and helped them feel successful in meeting the challenges of working while chronically ill.

Overcoming disability, controlling the body with the mind, normalcy, and the valuable-employee identity all place responsibility for meeting these challenges on disabled employees, rather than on employers or the wider society. But at what cost? Other studies have found that women with fibromyalgia stayed at work when ill (Sallinen et al., 2010), a phenomenon called ‘presenteeism’ (Munir, Yarker, & Haslam, 2008). Employees use this
strategy to avoid being disciplined under strict attendance-management policies. However, staying at work when ill can worsen employees’ health, ultimately leading to longer-term absence (Munir et al., 2008). In our study, some women with fibromyalgia described the toll of pushing through pain and fatigue: loss of family time and pain flare-ups that required taking sick leave. In addition, some family members and a workmate expressed concern that women’s hard work exacerbated their illnesses. Yet, the women with fibromyalgia in the same triads said they enjoyed their work and were proud of their productivity. Nonetheless, working hard and pushing through pain and fatigue contrast with the characteristics of suitable work identified by women with fibromyalgia (Bossema et al., 2012). This contrast points to a question for further research: How can employees with chronic illnesses maintain employment in competitive workplaces without the deleterious consequences of presenteeism?

**Triad-dyad data-collection design**

Our triad/dyad data-collection design had several advantages and disadvantages (Oldfield, MacEachen, Kirsh, & MacNeill, forthcoming). First, having multiple perspectives on each woman’s work situation helped us better locate participants’ accounts in the contexts of their home and work lives. Second, the triad/dyad design revealed contrasting perspectives that would not have been visible had we interviewed only the women with fibromyalgia. Some of these contrasts may have stemmed from participants’ differing social locations in shared situations. For example, family members could perhaps afford to criticize the women’s employers, whereas the women could not. The contrasts revealed through the triad/dyad design proved to be fruitful in critical discourse analysis, allowing us to compare discourses, narratives, and identities within triads/dyads and better understand contrasting
perspectives and the impact of differing interview contexts. Third, our design produced two ethical challenges that impacted the interviews and re-presentation of the data. Because participants had been assured of confidentiality and anonymity in the informed-consent form, the interviewer had to frame questions based on previous interviews within triad/dyads very generally, without revealing what others in the triads/dyads had said. Also, in writing this article, we eschewed pseudonyms in telling individuals’ stories, because doing so may reveal their identities to others in their triads/dyads. Despite these challenges, the triad/dyad design enhanced the study’s analysis and rigour.

**Conclusion**

Employed women with fibromyalgia rarely receive advice on how to stay at work, and it is often assumed that they will leave the workforce. In an effort to help these women retain their jobs, we explored how women with fibromyalgia remain employed. In our study, employed women with fibromyalgia, their family members, and workmates portrayed the women as normal, valuable employees who did not ‘give in’ to their illness. In doing so, they drew on the largely unquestioned discourse of normalcy, the dominant discourse that the mind controls the body, and a narrative common in the media, overcoming disability. Family members’ and workmates’ admiring portrayals may have helped the women manage their identities in workplaces where employees competed to keep their jobs and where chronically ill employees were assumed to be less productive than healthy employees. The portrayals may have also bolstered the women’s confidence and motivation, helping them to meet the challenges of working when chronically ill.

The medical literature on fibromyalgia causes and treatments is very large. For example, a search of the Cochrane Reviews database in July 2015 on the keyword
‘fibromyalgia’ yielded 22 systematic reviews. A small literature explores illness experience among women with fibromyalgia, and an even smaller literature focuses on an important part of daily life, employment. Our findings contribute to this neglected research area by expanding on the strategies identified in the few other studies of fibromyalgia and work. In addition, we approached the topic in a new way: critical discourse analysis of participants’ engagement with societal discourses and narratives, and how they used them to counter assumptions that may prevent other women with fibromyalgia from staying in the workforce. Our findings also contribute two new perspectives to the study of fibromyalgia and work, those of family members and workmates. These perspectives expand the scope of research on fibromyalgia and employment beyond women with fibromyalgia alone to other stakeholders who contribute to their remaining employed.

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Declaration of interest

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Chapter 6
Synthesis and Conclusion

The preceding two chapters presented how employed women with fibromyalgia improvised disclosure dances to respond to everyday disclosure risks in workplace relationships as well as how they and their family members portrayed the women as normal, valuable employees who had not given in to their fibromyalgia. Both of these identity-management strategies helped prevent their employment from being threatened by the socially driven stigma process (Link & Phelan, 2001). In the first section of this chapter, I integrate the findings of Chapters 3 to 5, engage with existing literature, and use the concepts of the stigma process and identity management, introduced in Chapter 2, to understand the integrated findings. At the end of the first section, I answer the main research question: How do employed women with fibromyalgia stay at work? Then I present implications of the thesis findings for work disability literature, research using the triad/dyad data-collection method, workplace practice, internal and state workplace policy, and rehabilitation practice. Next I cover the strengths and limitations of the thesis and suggest areas for future research and knowledge translation. The chapter ends with the thesis’ contributions and concluding remarks.

Remaining employed with invisible chronic illnesses such as fibromyalgia can be difficult. In the increasingly precarious world of work, with its lower job security and employee protection and higher competitiveness than in the past (Krupa, Kirsh, Cockburn, & Gewurtz, 2009), employees are expected to be healthy and able to meet the demands of their jobs consistently. Employees with chronic illnesses that fluctuate unpredictably do not fit
such expectations (Vick & Lightman, 2010). Yet, aside from periods of poor health, they may be fully capable employees. Current disability policies generally require applicants to be permanently incapable of working (McKee, Popiel, & Boyce, 2006), creating a dilemma for employees with chronic illness: leave the workforce or struggle to work full-time. In addition, invisible illnesses, particularly fibromyalgia, lack medical and thus social legitimacy (Moss & Teghtsoonian, 2008), which brings a risk of damaged workplace relationships and potential workplace discrimination for people with this illness. Their home lives may also impact their ability to remain employed, in conjunction with their impairments. Yet, despite varying degrees of pain, fatigue, and other health issues, 44% of Canadians with fibromyalgia remain in the workforce (Statistics Canada, 2010). How do they do it?

This thesis aimed to understand how, given the challenges of remaining employed, women with fibromyalgia stay at work. It examined the roles played by women, their family members and workmates and what discourses underlie the perspectives of these groups. Guided by critical discourse analysis methodology, I sought the perspectives of women with fibromyalgia, their family members and workmates on how the women remained employed. Although the employed women at the centre of this study all had one invisible, stigmatized illness in common, fibromyalgia, they had others as well. In comparing the concepts developed in the thesis to studies on employees with invisible, stigmatized conditions later in this chapter, I show that the concepts are consistent beyond employees with fibromyalgia.

**Key Findings of Chapters 3 to 5**

Chapter 3 presents findings from an analysis of selected material available on the Internet about fibromyalgia. These were information resources that women newly diagnosed
with fibromyalgia in Ottawa and Toronto were likely to encounter. Information materials came from patient-advocacy organizations, health-education organizations, and rehabilitation programs. The materials that I analyzed portrayed fibromyalgia as a chronic, debilitating illness whose impairments can be somewhat controlled through self-management. Very rarely mentioned was staying at work, evincing an underlying assumption that fibromyalgia is incompatible with employment. The patient-advocacy materials I analyzed focused instead on how to apply for disability pensions, reinforcing the message that fibromyalgia is incompatible with employment. The very few materials that mentioned employment suggested that those who can work are responsible for making themselves fit for employment. This suggestion views disability as an entirely individual problem, in contrast to the modified social model of disability that informed this thesis. That model argues that people are disabled by their bodies and by society. The very few information materials analyzed in Chapter 3 that covered work conveyed that employees with fibromyalgia whose employers are willing to accommodate their impairments are fortunate. The idea of disabled employees’ human rights to accommodation is missing. While slightly broader than conceptualizing employees’ disability as an individual responsibility, this message locates the solution to staying at work in the realm of relationships between individual employees and their employers, rather than in the realm of society at large.

Chapter 4 presents a new conceptualization of workplace disclosure of invisible illnesses and impairments: disclosure dances that employees improvise in response to workplace-relationships needs and disclosure risks. I found that, despite prevailing advice about full disclosure being the best approach (Munir et al., 2005), women with fibromyalgia and other contested illnesses improvised everyday disclosures when they needed to explain
fluctuating work ability, when others needed reminding about invisible impairments, and when workplace relationships changed. These impromptu disclosures comprised three dimensions: *exposing* oneself to scrutiny by disclosing both illness and impairments, *divulging* stigmatized illness, and *revealing* invisible impairments selectively. Impromptu disclosure dances differ in two ways from disclosure of invisible illnesses and impairments as currently conceptualized in the literature. First, instead of being planned in advance after reflectively assessing risk, they are improvised on the spot in response to needs within workplace relationships. Second, happening in the back-and-forth interaction of everyday workplace conversation, they are dances rather than declarations.

Chapter 5 aimed to understand how participants (employed women with fibromyalgia, family members, and workmates) portrayed the women and how their portrayals might have helped the women with fibromyalgia to stay employed. I found that participants frequently reported societal disbelief that women with this illness are legitimately ill as well as consequent assumptions that they are lazy or malingering. These assumptions carry over into workplaces, where supervisors and colleagues may also assume that employees with chronic illnesses are less productive than healthy employees. In the increasingly precarious world of work where, as described by some participants, employees compete with each other to keep their jobs, such assumptions can harm employees. To counter these assumptions, participants portrayed the women as normal, valuable employees who did not ‘give in’ to their illness but, instead, overcame their impairments. In their portrayals, participants drew on the largely unquestioned discourse of normalcy, the dominant discourse that the mind controls the body, and a narrative common in the media, overcoming disability. Participants’ admiring portrayals helped the women manage their
identities at work to remain competitive and avoid discrimination. The portrayals also bolstered the women’s confidence and motivation, helping them to meet the challenges of working when chronically ill.

**Synthesis of Chapters 3 to 5**

This section synthesizes the findings of the three manuscripts, compares them with existing literature, and uses the concepts of the stigma process and identity management (introduced in Chapter 2) to understand the findings. The section is organized according to six themes in the thesis findings: Rejecting fibromyalgia-patient identity and going on disability, Managing identity at work by controlling disclosure, Challenging the necessity of social support at work and at home for remaining employed, Portrayals as responses to moral judgement, Comparing oneself to others, and Portrayals of value to employers. At the end of the section, I answer the primary research question, How did women with fibromyalgia in the study remain employed?

To begin, in Chapter 3 I discerned six messages in fibromyalgia information materials, whose names are Fibromyalgia is a debilitating chronic illness/disease, Symptom self-management, Professional versus experiential knowledge, Leaving paid employment, the Responsible employee, and the Fortunate employee. Most of these messages were reflected in participants’ accounts, and in the rest of this section, I discuss how these messages intertwine with the findings in Chapters 4 and 5.

**Rejecting fibromyalgia-patient identity and going on disability**

Participants’ portrayals of the women with fibromyalgia contrasted with the first message that fibromyalgia is a debilitating chronic illness. Instead of focusing on the debilitating effects of fibromyalgia, as is the case in patient testimonials on patient-advocacy-
organization websites, participants emphasized that the women with fibromyalgia had not given in to the illness and, instead, had overcome their impairments. The first message also contributes to the fibromyalgia-patient identity, with its focus on impairments rather than abilities. By staying at work, women in this study implicitly rejected this identity. Their accounts (and those of family members and workmates) focused more on how good they were at their jobs and how much they “loved” them (in their words).

Fibromyalgia-patient-advocacy-organization websites use the term ‘fibromyalgia patient’ as moral language (Parsons et al., 2008) to convey that fibromyalgia has a medically legitimate (bodily) cause and that people with fibromyalgia are truly ill. This is an attempt to prevent the label ‘fibromyalgia’ being linked to negative stereotypes by a powerful group, physicians. There is research evidence that this does, indeed, happen (Album & Westin, 2008; Hayes et al., 2010). Once the label is linked to negative stereotypes by a powerful group, this lowers the status of labelled people, and discrimination can occur (Link & Phelan, 2001). In my study, participants were trying to prevent loss of status. It risks damaging workplace relationships, one of the disclosure risks explained in Chapter 4. Participants were also trying to prevent the fourth component of the stigma process, discrimination. At work, this could range from gossip to bullying (both of which participants reported) to job loss, which one participant faced.

The fibromyalgia information materials I analyzed portray fibromyalgia as a chronic condition akin to a disability. In Chapter 5, I discussed how women with fibromyalgia distanced themselves from women who had ‘gone on disability’ (left the labour force) and thus ‘given in to fibromyalgia’, as participants phrased it. Rejecting the identities of ‘fibromyalgia patient’ and ‘going on disability’ not only helped women with fibromyalgia
stay at work but it disassociated them from disabled people, a group that has already been negatively labelled, separated as an out-group (Alvesson et al., 2008), and lost status.

Women with fibromyalgia who pushed through pain and fatigue and then ‘paid for it,’ in their words, appeared to reject the self-management advice in the analyzed information materials to ‘listen to your body’ and ‘adjust your life accordingly.’ The term ‘pay for it’ might indicate that those who used the term were aware that they were not following self-management advice to carefully pace their activities. In another study (Stone & Owen, 2014), academics with multiple sclerosis reported that they needed to rest before and after teaching, because they had little control over its timing, unlike other work tasks that they could pace. While it is possible for some employees with chronic illnesses (e.g., those with a lot of control over their work, secure jobs, or low workloads) to pace their work activities and incorporate rest into their workdays, it is difficult for women to find the time at work, or at home if they have pressing family responsibilities. In addition, demonstrating value to employers by working hard and being productive also reduces opportunities to rest at work or pace activities. In sum, the work and home environments of women in this study who described ‘pushing through’ appeared to impede their ability to follow self-management advice about listening to their bodies. In addition, enacting this advice could have pushed them to leave the workforce, which they regarded as “giving in to FM.”

Changing working conditions to better manage symptoms at work (e.g., changing the pace of work, altering work schedules, and seeking help from co-workers), as advised by information materials, would have been difficult for women in the study, because doing so would have required disclosure of their impairments or need for formal accommodations. In giving this advice, information materials assume that disclosure is unproblematic for
employees with invisible illness, which it is not, as explained in Chapter 4. Seeking help from co-workers is risky in workplaces where co-workers have resented accommodations for employees with invisible (and even visible) conditions, such as situations participants described. Nonetheless, some women in the study were able to adopt the advice to seek help from colleagues without marking themselves as different and thereby entering the stigma process (Link & Phelan, 2001). They revealed their impairments selectively by naming their source as common problems and received help from colleagues. These common problems were signs of less stigmatized attributes (Goffman, 1963). Hansen (2008) found that her participants, employed women with chronic illnesses, did something similar: they revealed less negatively stereotyped impairments while concealing more negatively stereotyped ones. Toth and Dewa’s (2014) participants, employees with mental disorders, adopted a similar tactic. Dyck (1999) also found that her participants, employed women with multiple sclerosis (MS), gave coworkers reasons for impairments that were less negatively stereotyped than MS; for example, a back problem or a twisted ankle. This selective revealing of impairments, as demonstrated in Amy, Susan, and Pam’s stories (Chapter 4) and in other studies harks back to Link and Phelan’s (2001) stigma process. People with impairments in my study and others are aware that their illnesses have already been linked to negative stereotypes, and they try to stop the stigma process from progressing further, to separation, status loss, and discrimination.

**Managing identity at work by controlling disclosure**

As described in Chapter 5, participants managed the identity of the women with fibromyalgia through their portrayals of the women as normal, valuable employees who had not given in to fibromyalgia. These portrayals responded to societal assumptions that
participants reported, about people with fibromyalgia and employees with chronic illnesses. Impromptu everyday disclosure dances are also a form of workplace identity management, in response to everyday stresses in workplace relationships (Alvesson et al., 2008) as well as the disclosure risks reviewed in Chapter 4. These risks are magnified by the job insecurity of precarious work: part-time, temporary, contract, and non-unionized (Lewchuck et al., 2014). Some of the women with fibromyalgia in my study were in precarious jobs, and others worked in organizations that had experienced budget cuts and ensuing job losses. Six of the nine women were primary or sole breadwinners, expanding the economic risk of potential job loss to their families. Through identity-management actions, such as portraying themselves as valuable employees, the women reflected the power of employers to decide whether or not they would remain employed.

Although a few of the women exposed themselves to scrutiny (one of the impromptu everyday disclosure dances) by both divulging their illnesses and revealing their impairments, most did not. More often, participants eschewed disabled identities, as Parsons et al. (2008) noted about their participants, employees with cancer. Women in my study more often divulged their illnesses in empathetic relationships with colleagues who were equally at risk of separation and loss of status (Link & Phelan, 2001) and thus unlikely to gossip, and they revealed their impairments selectively. Both of these impromptu disclosures helped the women enhance their work identities as normal people who had overcome disabling challenges and thereby keep themselves out of the stigma process that could threaten their employment.

Avoiding separation (being considered a ‘them’), another component of Link and Phelan’s stigma process, was a rationale for managing women’s identities at work to avoid
marking them as different. By avoiding separation, the women remained part of the in-group (Alvesson et al., 2008), in other words, valuable employees on their work teams.

Studies of work disability describe how employees other than those with chronic illnesses managed their identities to protect their jobs and did not seek services they were entitled to, because doing so would have required disclosing disability. Lipscomb, Schoenfisch, & Cameron. (2015), for example, found that carpenters injured at work did not report their injuries and thus access time off to recover and workplace accommodations upon returning to work. They feared being labelled high risk employees, losing their jobs, and not being hired elsewhere. In job markets where workers can be easily replaced, they can have low value for their employers (Seing et al., 2014). Disclosing disability can reduce their competitiveness, putting them at risk of being laid off or not hired by another employer. Instead of reporting work injury, carpenters in the Lipscomb et al. (2015) study felt pressured to use their personal health insurance to access rehabilitation, a form of self-accommodation.

In another study, employees with musculoskeletal disorders could avoid disclosing their impairments because they had flexibility in their jobs, control over their work, and private health insurance coverage for treatments (Smith-Young, Solberg, & Gaudine, 2014). Similarly, Reichert, Augurszky, and Tauchmann (2015) found that employees managed their identities to avoid disclosing health problems to employers and thus damaging their competitiveness in situations of self-perceived job insecurity. As Smith-Young et al. note, their participants’ circumstances enabled them to “self-manage” their impairments at work (2014, pp. 227-228), echoing the message in fibromyalgia-information materials that employees should manage their symptoms at work. In their conclusion, the authors reinforce self-management discourse by recommending that employees with chronic illnesses be
taught self-management strategies so that they can successfully continue working. This use of self-management discourse draws on the medical model of disability, placing responsibility for remaining employed onto disabled employees, rather than taking a more social approach to disability. These similarities between my findings and those of other studies suggest that identity management through controlled disclosure is an issue for employees well beyond those with fibromyalgia.

**Challenging the necessity of social support at work and at home for remaining employed**

The thesis findings demonstrate the importance of empathetic workplace relationships to staying at work with fibromyalgia by providing safe spaces to divulge illness and reveal impairments and thereby gain mutual support in dealing with the challenges or employment with chronic illness. In this way, the study adds to a growing literature on the role played by coworkers in disabled employees staying at work. Interestingly, not all the women had empathetic relationships at home; indeed, there was evidence of intra-family conflict in some of the triads. Although social support at work and at home have been found to help women with fibromyalgia remain employed (Palstam et al., 2013; Schoofs, Bambina, Ronning, Bielak, & Woehl, 2004), this study shows that support at home and at work is not essential for remaining at work. In contrast, in some of the triads in this study, participants portrayed the supervisors or coworkers of the women with fibromyalgia as unsupportive or even toxic. Instead of portraying women as fortunate employees with benevolent bosses, one of the messages discerned in Chapter 3, some family members and coworkers cast supervisors or higher level managers as challenges to overcome in remaining employed. In other triads, women appeared to seek refuge from difficult home situations in their work. Brodwin (1992)
tells the story of a woman with chronic pain who escaped her emotionally painful home life by immersing herself in helping others at work. This was also the situation for two of the three women in my study who had conflict at home. Both said they loved their jobs. Not only did not having empathetic relationships at home not impede these women from staying in the workplace, the contrast between their emotionally fulfilling work lives and their emotionally difficult home lives encouraged them to stay in their jobs.

The thesis findings contribute to the literature on fibromyalgia and employment by challenging the notion that supportive workplace and home relationships keep employees with fibromyalgia at work. Although these supports are enabling, this study shows that they are not essential.

**Portrayals as responses to moral judgement**

The narrative of overcoming disability that underlay participants’ portrayals is akin to what deVolder (2013) calls “compulsory heroism.” This, she explains, is the pressure to produce ‘good-news’ overcoming stories in mainstream media as antidotes to bad news. Hardin and Hardin (2004) describe a type of media-generated heroism particular to people with impairments, the ‘supercrip’ hero. This representation of a person who, through individual strength, overcomes obstacles to live a ‘normal’ life contrasts with the other predominant media representation of people with impairments: as tragic figures or ‘helpless victims’ (p. 6). The ‘supercrip’ representation sets up an impossible expectation of disabled people: that all should be able to overcome the challenges of their impairments. ‘Compulsory heroism’ and the ‘supercrip,’ like the overcoming-disability narrative, draw on normalcy discourse. Heroism is the only attractive media-generated social role, not only to people with impairments but to anyone facing adversity. It divides those who return to normal from those
who do not. For employees with impairments, returning to work is an indicator of returning to normal by overcoming disability (Saunders & Nedelec (2014). For deVolder and Hardin and Hardin, individual heroism obscures ableist social contexts. In this study, portrayals of the women as strong willed and ‘pushing through’ also ignored circumstances in their social environments that helped them overcome their impairments. Similarly, Orgad (2009), in a genealogy of survivor discourse, argues that, in matters of health and illness, ‘survivor’ is the only acceptable public identity, with ‘patient’ and ‘victim’ derided as survivor’s binary opposites. Both of these socially preferred identities, hero and survivor, help explain why participants portrayed the women with fibromyalgia as not ‘giving in’ to their illness (i.e., not victims or patients).

Heroism, survivorship, overcoming disability, and not giving in are all portrayals of moral agency in the face of adversity. Other authors have noted how their participants portray themselves as moral agents. Parsons et al. (2008), for example, note that their participants, employees on leave to recover from cancer, portrayed themselves as hard at work on recovery, rather than as passive victims of their illness. In this study, participants’ portrayals also displayed moral agency (e.g., overcoming disability) rather than victimhood (e.g., giving in to fibromyalgia). Robinson, Kennedy, and Harmon (2013) also noted how their participants with chronic pain portrayed themselves as moral agents, saying that they did not complain about their pain. In this study, participants did the same, describing several women with fibromyalgia as noncomplainers. For Robinson et al., this portrayal of moral agency was a response to assumptions that people with chronic pain are exaggerating it and thereby malingering. This is the same type of moral judgment participants reported in my study, and to which I interpreted their portrayals as responding. The similar findings in these
three studies suggest that portraying moral agency is a key response to explicit or implicit moral judgement inside and outside of workplaces.

**Comparing oneself favorably to others**

The women with fibromyalgia also managed their identities by comparing themselves favorably to others with fibromyalgia who had ‘gone on disability’ and ‘given in’ to their illness. Other researchers have found similar strategies among participants with chronic pain. Richardson (2005) described how their participants compared themselves favorably to others with pain, portraying themselves as stoic and others as not having high pain tolerance. Similarly, Werner et al. (2004) observed that their participants distinguished themselves from other women with chronic pain by stating that they were not complainers. They saw complaining as an indicator of falling into the stereotype of weak, whining women, in contrast to their self-portrayals as strong women who did not complain. Like participants in this study, they tried to prevent being negatively stereotyped and then moving forward in the stigma process. Werner et al. interpreted these portrayals as performances in response to skepticism and distrust the women reported; in other words, moral judgment like the presumptions of laziness and malingering reported by participants in my study. Eakin (2005) names this judgement the “discourse of abuse.” She reports how injured workers “perform integrity” (p. 166) to counter the discourse of abuse and to distance themselves from other injured workers, who they portray as “milking the system” (p. 166). Performing integrity was a rationale for the portrayals by participants in my study of the women with fibromyalgia as not having ‘given in’ to their illness. The similarity of findings in these three studies with my own suggests that contrasting oneself favorably with others in one’s group who are
discredited and distancing oneself from them as identity-management actions in response to moral judgment are common across invisible conditions.

Eakin (2005) observes that the discourse of abuse is reproduced by institutions such as compensation boards and employers. Yet, the discourse of abuse targets not only employees with invisible impairments, but all employees in some workplaces. In my study, this discourse underlay the punitive sick-leave policies described by several participants. Under these policies, employees were paid less the more sick leave they took or were required to attend educational sessions on health self-management if they exceeded a sick-leave threshold. All employees who took sick leave were suspected of “milking the system” (Eakin, 2005, p. 166). Several participants opined that punitive sick-leave policies were unfair to employees with chronic illnesses, who were not malingering. This was a case of structural, not individual, discrimination (Link & Phelan, 2001).

Comparison to others and advice-giving was integral to several triads/dyads in this study in which family members told me what they thought the woman with fibromyalgia should do and then expressed annoyance that the women did not take their advice. There appeared to be a tension over control within some these triads/dyads. My study showed how the women’s identity management efforts were part of a strategy for maintaining control over how they were morally judged (by family members or workmates). The strategy was thus a way of fending off unwanted advice giving, at which women with fibromyalgia expressed annoyance.

**Portrayals of value to employers**

For the women with fibromyalgia, contrasting themselves with others also enhanced their value to employers. Participants’ portrayals of the women as having not only not given
in to fibromyalgia, but pushed through pain and fatigue via their strong will, positive attitude, and noncomplaining showed that, if they were able to push through personal challenges to stay employed, such personal strength would also help them work hard for employers. Other researchers have noted that how much an employer values an employee affects how far employers will go in accommodating any impairments (Seing et al., 2014). This value differentiation among employees who need accommodations showed up in my interview with Nicole’s supervisor Ruth. In extolling Nicole as someone who “works 150%,” Ruth showed how much she valued Nicole. This high valuation partially explained why the supervisor willingly informally accommodated Nicole. Not only that, but she said she wished Nicole would take time off. In contrast, Ruth expressed disappointment in another employee who she had allowed to work part-time because she had a chronic illness different than Nicole’s. Ruth related her disappointment in the other employee, after it turned out that she started a consulting business on the side while working part-time, instead of giving all her available energy to her primary employer. Ruth’s disappointment may have coloured her future willingness to accommodate employees less valuable to her work team than Nicole.

Awareness of the need to demonstrate high value to employers informed participants’ portrayals of the women with fibromyalgia. Employees with other chronic illnesses have portrayed themselves as hard workers. In Prodinger et al.’s (2014) study, women with rheumatoid arthritis portrayed themselves as working extra hard to prove their productivity in the face of assumptions that employees with chronic illnesses are less productive than healthy employees. This was the same assumption to which participants in this study responded in their portrayals of women with fibromyalgia as hard-working, productive employees. Hansen (2008) found a slightly different rationale that her participants, employed
women with chronic illnesses, gave for working hard: to justify their presence in the workplace.

In this synthesis, I compared my findings to other studies and showed that, in many cases, similar processes occur across employment with invisible chronic conditions other than fibromyalgia. This indicates that the thesis findings are transferrable outside the group examined this study, women with fibromyalgia, their family members, and workmates. I end the synthesis by answering the study’s primary research question.

**How did women with fibromyalgia in the study remain employed?**

This study shows how rejecting the identities of ‘fibromyalgia patient’ and ‘going on disability’ helped the women with fibromyalgia remain employed. At work, the women managed their identities by carefully controlling disclosure of their differences through impromptu everyday disclosure dances and, in some cases, by self-accommodations, through which they avoided disclosing a need for formal accommodations. Empathetic relationships with workmates who also had chronic illnesses gave the women safe spaces to divulge their invisible illnesses and reveal their impairments, and employees were able to support and sometimes defend each other.

In general, the women took responsibility for managing their impairments at work, in accordance with advice in fibromyalgia-information materials. They and their family members and workmates helped to manage their workplace identities by portraying the women as normal, valuable employees who had not given in to their fibromyalgia. These identity-management strategies helped prevent moral judgement and the women’s entry into the stigma process, and thus helped the women stay at work. The admiring portrayals also
boosted the women’s confidence and pride, helping them to meet the challenges of working with fibromyalgia.

On the other hand, there were negative influences that appeared to keep the women employed. Since they were portrayed as not having given in to fibromyalgia, had rejected the identity ‘being on disability,’ and took pride in their strong will, leaving the workforce would have been an indicator of defeat. They also expressed that going on disability meant poverty. In addition, although most of the women had support from empathetic relationships at work, several did not have such relationships at home and, indeed, faced conflicts there. Not only did the lack of empathetic relationships at home not impede these women from remaining employed, the contrast between their emotionally fulfilling work lives and their emotionally difficult home lives appeared to encouraged them to stay in their jobs.

**Implications of Thesis**

**For work-disability literature**

Work-disability literature tends to assume that disclosing impairments (or at least the need for accommodations) and formally requesting accommodations is the best course of action for employees with impairments (Munir et al., 2005). However, in Chapter 3, I found that people with fibromyalgia are advised by information materials to self-manage their symptoms, suggesting that they take responsibility for making themselves fit for work. This advice works at cross-purposes with encouragement to request formal accommodations. If employees with fibromyalgia and other invisible illnesses embrace the self-management philosophy, then these employees may not disclose their need for formal accommodations and request them. Instead, as evinced in this thesis, they may self-accommodate or negotiate informal accommodations with their managers.
Embedded in work-disability literature is the assumption that, if employees with impairments seek accommodations, they will receive them. This is not necessarily the case. (Stone, Crooks et al., 2014) cite Statistics Canada data showing that 35% of disabled Canadian workers do not receive the accommodations they request. In small workplaces, where accommodations are requested directly from supervisors and disclosure is therefore not confidential, nonapproval of accommodation requests may negatively affect workplace relationships. Aside from disclosure risks, some participants in this study said they noticed how others with chronic illnesses were resented by coworkers after they received accommodations. Such observations made them wary of seeking accommodations.

Chapter 4 gave an example of the difficulties faced by a supervisor in justifying accommodations made for an employee whose impairments she needed to keep confidential. Participants in other triads/dyads reported observing co-worker resentment of accommodations, which coworkers can construe as preferential treatment (Krupa et al., 2009) if they do not know why the accommodations were made. A tension was evident between avoidance of co-worker resentment, which in turns affects accommodated employees (Dunstan & MacEachen, 2013; MacEachen, Clarke, Franche, & Irvin, 2006) and the need of employees with impairments for confidentiality. In addition to this tension, several participants in this study recounted conflicts between employees’ human rights to accommodation and union seniority rights. This conflict can be magnified by co-workers not knowing the reasons for accommodations because of confidentiality requirements, and thus grieving accommodations as unfair, as described in Chapter 4.
For research using the triad/dyad data-collection method

The study raised some methodological issues that have implications for future research collecting data from triads and dyads. In this study, recruiting triads was more difficult than recruiting only women with fibromyalgia. Although I received an enthusiastic response to my recruitment notices from employed women with fibromyalgia who were eager to talk, recruiting much less eager family members and workmates was time-consuming. I depended on the women with fibromyalgia to recruit other triad participants. In cases where their recruitment efforts failed, I was left with dyads, not triads. Although being willing to recommend others to interview was an inclusion criterion for the study, some of the women changed their minds after being interviewed. In addition, simply because the woman was willing to recommend others in order to join the study did not mean that the others would agree. In some cases, both the women and I asked family members or workmates to join the study without success. Ethical issues encountered with the triad/dyad data-collection method are discussed in the section ‘Strengths and Limitations of the Thesis.’ The methodological and ethical issues pertaining to the triad/dyad data-collection method contribute to future research using this method.

For workplace practice

Employers tend to prefer that employees fully disclose (Church, Frazee, Panitch, Luciani, & Bowman, 2008; Henderson et al., 2013) and ask for accommodations. Yet many employees with invisible illnesses do not disclose, as evinced in this thesis and other studies (e.g., Gignac & Cao, 2009; Munir et al., 2008; Stone et al., 2013). Requesting accommodations implicitly requires identifying oneself as disabled; whereas, many employees with invisible conditions do not adopt this identity (Crooks et al., 2008; Parsons et
In addition, seeking accommodations and then ensuring that they are maintained can be stressful, energy-consuming work, and it also takes time away from job responsibilities (Hansen, 2008). This work of trying to obtain and then retain workplace accommodations for chronic illnesses has been documented by Chouinard (2010) and by Cameron and Chouinard (2014). Research has also shown that employees with chronic conditions feel that the stress of seeking accommodations exacerbates their symptoms and saps their energy (Stone et al., 2013). People with fibromyalgia have limited energy, and stress also aggravates their symptoms. Therefore, some women with the condition in this study understandably avoided the onerous work of accommodation-seeking, especially after observing resentment among coworkers of employees who received accommodations.

For these reasons, employers who want their employees with invisible impairments to identify themselves and seek accommodations will need to provide organizational structures and resources to reduce the energy required and the ensuing stress for employees with chronic illnesses. Employers will also need to ensure that, not only are accommodations implemented as planned but that they remain appropriate to the employee’s needs, which change with time.

Although human rights legislation, employment-equity legislation, and requirements for workplace accommodations (the last at least in Ontario) have been the main Canadian policy vehicles for improving participation of people with impairments in the labour force, they have fallen short of their goal (Baldwin & Marcus, 2011; Jongbloed, 2009). Given the

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9 This is an issue for federally regulated Canadian employers (e.g., banks, telecommunications and transportation companies) who must report the proportion of their employees in employment-equity groups to the federal government. If employees with invisible impairments do not disclose them, these employees are not countable. With the gradual implementation of the Accessibility Standard for Employment under the Accessibility for Ontarians with Disabilities Act, all Ontario employers will eventually be required to report the proportion of their workforces with impairments to the provincial government.
importance of workplace social relations to job retention for employees with invisible impairments, as demonstrated in this study, legislating accommodation is not enough. Accounts of participants in this thesis contained stories of co-workers gossiping about employees with chronic illnesses and resenting their accommodations. Nicole and Ruth both told me that members of their work team resented the accommodation a coworker received for her rheumatoid arthritis, linking her with the stereotype ‘maligner’ through gossip. Nicole said she did not tell her coworkers about her fibromyalgia, not wanting to be linked to the same stereotype (Link & Phelan, 2001). Yet, one type of workplace relationship, empathetic relationships, seemed, for women with fibromyalgia and their workmates with other chronic illnesses, to mitigate gossip and co-worker resentment. Fostering empathy, not only tolerance, among employees who do not share differences might improve working conditions for employees with chronic illnesses.

The issues of fibromyalgia’s social illegitimacy and the moral judgement that ensued for women with the illness resound throughout information about fibromyalgia, and they rippled through the study participants’ accounts. Gaining legitimacy is central for people with fibromyalgia inside and outside of work. In this thesis, managing workplace identities to sustain legitimacy was one of the means women with fibromyalgia used to stay at work. Another, more social, approach could relieve this burden. Workplace strategies could be developed to prevent or at least mitigate moral judgement of employees with invisible illnesses and halt the stigma process. Such strategies could prevent employees from being pushed out of their jobs by toxic social environments, such as those described by Susan in Chapter 4.
As this thesis and other research shows, disclosure entails risks for employees with invisible conditions, many of whom do not identify as disabled and self-accommodate instead (Prodinger, Shaw, Rudman, & Stamm, 2014; Stone et al., 2013; Stone & Owen, 2014). Yet, under current accommodation policies, requesting accommodations hinges on disclosing a need for them, a process that marks an employee as different, pushing them into the stigma process, and as less valuable than healthy colleagues. With an increasingly aging workforce, there may be an increasing proportion of employees who are reticent to jeopardize their employment by disclosing their need for accommodations or adopting a disabled identity. Parsons et al. (2008) call for alternatives to accommodation that do not require employees to take on this identity. The findings of this study contribute to that call.

**For workplace and state policy**

An issue that came up repeatedly in participants’ accounts was tension between union collective agreements and accommodations. For example, Susan relayed that, when she was transferred to another job in her workplace, colleagues who wanted the job complained to their union that the job had not been posted and they were thus unable to apply for it. Sokolaridis, Ammendolia, and Cassidy (2010) found, in their study of employees with low-back pain, that union policies erected barriers to accommodating employees. Union members were unable to transfer to jobs that were covered by other unions, or to non-unionized jobs. These workplace policy barriers created combative relationships between unions and supervisors, who were ready to accommodate the employees and previously had good relationships with them. As my study and Sokolaridis et al.’s (2010) show, unions, employers and employees with impairments need to work together to resolve the tension between union
members’ rights as defined in their collective agreements and the rights of fellow members with impairments to accommodations.

All but one of the women with fibromyalgia in my study said they would prefer to work part-time but could not afford to do so. One woman planned to apply for disability-income-support benefits when she could lower her expenses by moving to a country where she could live cheaply. As explained in Chapter 1, Canadian government disability-income-support programs generally require that applicants prove total inability to work. This, however, is often not case for employees with chronic illnesses, whose impairments fluctuate (Vick & Lightman, 2010). Although some changes to disability-income-support have allowed recipients to try returning to work, there are barriers to doing so, such as losing prescription-drug coverage.

There are limited possibilities in Canada for combining disability and employment income. Cameron and Chouinard (2014) report that a university employer agreed to accommodate Chouinard’s chronic illness by paying half her salary and having the other half paid by the disability insurer. Stone et al. (2013) mention the possibility of a Canadian academic with multiple sclerosis being accommodated with an 80% workload while on full salary. However, these permanent part-time disability payments are available only to employees of organizations that can afford the extra premiums to include this option in their private insurance plans. In Scandinavia, permanent part-time disability payments are available from governments. Sick-listed employees can receive 25, 50 or 75% disability pensions, depending on their work ability as assessed by the Swedish social insurance agency (Palstam et al., 2013; Seing et al., 2014). A similar system in Canada could expand
permanent part-time disability coverage to more Canadian employees with chronic illnesses and other episodic conditions, enabling them to stay in the workforce at least part time.

**For rehabilitation practice**

Since the Web is by far the most frequently accessed source of information on fibromyalgia, according to a cross-Canada survey (Daraz et al., 2011a,b), rehabilitation professionals will likely encounter clients with the illness who have accepted the narrative in patient-advocacy-organization websites that fibromyalgia is incompatible with employment, as revealed in Chapter 3. It is likely that clients will have read little on the Web about how to stay at work, or the stories of people who do. Missing from fibromyalgia materials is information about how to negotiate accommodations with employers and about employees’ human rights. Instead, they offer self-management advice that promotes individual change. Options for changing social environments such as workplaces are not available to women with fibromyalgia struggling to stay at work. The above-described missing information implicitly encourages them to leave the workforce.

To help their clients remain employed, rehabilitation professionals will need to find the missing information. As a future knowledge-translation project, I hope to compile Web-based information on staying at work with fibromyalgia. This project will be based on one in which I am currently involved, which is building a website on returning to work after cancer treatment. Information on how to negotiate accommodations and employees’ human rights will be a key part of the website. The target audiences for this project are cancer survivors, health care providers (including rehabilitation professionals), and employers.

As argued in Chapter 5, fibromyalgia-patient-organizations advocate ‘educating’ others about fibromyalgia and its impairments; yet, this advice is ill-suited to workplaces
because of disclosure risks. Based on my finding that women with fibromyalgia carefully manage their identities through impromptu everyday disclosure dances and do not always seek accommodations, rehabilitation professionals should reconsider any assumptions they or clients have that disclosure is unproblematic and that requesting formal accommodations is the best strategy for all employees with impairments. In contrast, a more useful strategy would involve rehabilitation professionals talking to clients with fibromyalgia about their workplace concerns, learning about individual clients’ workplace relationships, and helping clients assess their disclosure risks. Rehabilitation professionals should also take into account work pressures that these clients experience, such as the need to remain competitive, whether they are precariously employed, and increases in their workload due to budget and staff cuts. Before recommending that clients seek accommodations, professionals should assess safety for disclosure in clients’ individual workplaces and the likelihood of accommodation requests being granted.

Finally, rehabilitation professionals should question the concept of ‘catastrophizing ’ in the pain psychology that underlies pain-management programs. As I argued in Chapter 4 and in Oldfield (2013), women with fibromyalgia often feel they need to legitimize their impairments. One way they do this is by emphasizing their impairments’ seriousness in ways that others may dismiss as exaggeration. If rehabilitation professionals consider women’s reasons for portraying their experience of fibromyalgia in this way, they can enhance the professional-client relationship by validating the experiences of women with fibromyalgia.

**Strengths and Limitations of the Thesis**

The major strength of this study is its ability to understand the situation of employed women with fibromyalgia not only through the women’s experiences but through the
experiences of their family members and workmates. Without multiple perspectives on the work lives of the women with fibromyalgia, I would not have been able to see the contradictions among accounts and the conflicts among people in relationships. Having multiple perspectives illuminated how people in relationships view issues they share very differently. Had I interviewed only women with fibromyalgia, I would not have been able to learn others’ viewpoints on having a family member or employee with chronic illness. Instead, I would have heard one viewpoint, the women’s, or possibly sanitized versions of dyad members’ perspectives—versions they were willing to say out loud in front of each other in which they may have toned down their conflicts or toned up their agreement. Being interviewed separately allowed family members to express their worries about the women with fibromyalgia; whereas, they might not have done so in front of the women, and vice versa. Without these sometimes contrasting perspectives, I would not have had as broad a picture of staying in the workforce with fibromyalgia.

Having multiple, contrasting perspectives on shared issues expanded the scope of the critical discourse analysis by allowing me to compare discourses and narratives across triads/dyads and notice the impact of differing interview contexts on participants’ accounts about shared situations. Although having multiple perspectives on the women’s work and home situations produced richer data than interviewing only the women would have, this complex data were more difficult to analyze. In addition, the triad/dyad data-collection method complicated the recruitment of participants and placed some strictures on how the data could be re-presented in research reports, due to the need to maintain data confidentiality within triads/dyads.
The ethical challenge of maintaining confidentiality between triad/dyad members affected not only what I could ask in interviews but the writing of Chapters 4 and 5, which will be published in scholarly journals. Interviewing people who knew each other required that I keep their accounts not only anonymous from readers of research reports and any others whom I discussed the data, but confidential from other members of the triads. This I promised in the study information sheets (see Appendix 5). If I had been able to ask family members and workmates, after I had first interviewed the women with fibromyalgia, to comment on issues the women raised in their interviews, doing so would have enhanced the critical discourse analysis and made it possible to directly compare perspectives on certain situations across all interviews in each triad. However, having promised in the information sheets that I would not share with other triad members what each member said, I did not follow up on issues raised. I did, however, add new topics to the interview guide when participants raised them. Thus, the ethical practice of promising confidentiality and anonymity to participants in some ways limited the types of data produced in the interviews.

Participants were recruited in the Greater Toronto Area and, therefore, the experiences of women, families, and workmates in small towns and rural areas may differ from the findings. For example, job opportunities and worker mobility are more limited than in or near large cities, and in-person social networks are smaller. However, the concepts developed in this thesis are transferrable beyond employees with fibromyalgia. As shown above in comparisons between the thesis findings and other research, employees with other invisible stigmatized conditions, such as multiple sclerosis, chronic pain and work injuries, have developed strategies similar to ones used by my participants to manage their identities at work.
Greater attention to gender issues would have enhanced the research. I chose to use critical disability theory to guide the thesis, rather than feminist theory, because the former was more fruitful for answering the research question: How do women with fibromyalgia remain employed? However, I have developed a research proposal to examine how the responsibility of women with breast cancer for unpaid family work interacts with their impairments to affect their ability to remain employed. This project will be guided by feminist theory.

Finally, the thesis offers a one-time snapshot of the lives of women with fibromyalgia, their family members and workmates. Although the women with fibromyalgia were employed at the time of the study, whether they remained in the workforce is unknown.

**Areas for Further Research and Knowledge Translation**

The thesis findings suggest the following avenues for further research and knowledge translation. First, it is often assumed that women with fibromyalgia leave the workforce because of their impairments (e.g., Daraz, 2011a, b; Rusu et al., 2015). Yet, stories that participants told me about themselves and others with fibromyalgia, as well as Theresa’s patient testimonial quoted in Chapter 3 and the risks of discrimination described in Chapter 4, reveal that women are also pushed out of their jobs by unreasonable employer expectations, not receiving requested accommodations, and toxic workplace relationships. Vickers (2008, 2009, 2012) argues that women with multiple sclerosis are pushed out the workforce not by their impairments but more so by discrimination, harassment, and bullying in the workplace. Similar cases of harassment and bullying leading employees with other invisible conditions to leave their jobs have been reported by other researchers (Dyck, 1999; Foster & Wass, 2012; Kosny et al., 2013; Petrie, 2013). Refusal of accommodation requests
and consequent worsening of chronic illness is another reason that employees leave the workforce (Stone et al., 2013). Other research has reported that employees with chronic illnesses are pushed out of their jobs through transfer to another job without the employee’s involvement in the decision or through involuntary medical retirement (Seing et al., 2014; Vickers, 2008). The latter was a reason a family member in my study gave for leaving his job shortly before he would have received a company pension. All of these push-out actions need to be investigated, to find out why, beyond illness and impairments, women with fibromyalgia leave the workforce. It is important to expand research in this direction to identify structural reasons for leaving the workforce that might be addressable through policy or social change.

Second, this thesis looked beyond employed women with fibromyalgia to explore what roles family members and workmates played in the women’s remaining employed. Literature on fibromyalgia as an illness experience emphasizes the importance of social support for women with the condition (Schoofs et al., 2004). In my study, I did find that some family members supported women with fibromyalgia emotionally as well as instrumentally. Yet, intra-family conflicts were also evident and, in other triads/dyads the women bore major responsibility for household and family-care tasks at home; yet, they remained at work. As described in the ‘Strengths and Limitations’ section above, I have developed a research proposal with my postdoctoral supervisor, Christine Maheu of McGill University’s Ingram School of Nursing, and an advisory committee to look more closely at how the unpaid family work of women with breast cancer interacts with impairments from their illness and its treatment and their paid work.
Third, in Chapter 4 I reviewed literature on the discrimination risks employees with invisible illnesses such as mental health conditions face if their conditions are disclosed. I argued that women with fibromyalgia create impromptu disclosure dances to mitigate these everyday risks. One of the women, who exposed herself to scrutiny by divulging her illness and revealing her impairments to her supervisor, described how their relationship changed for the worse afterward. Research on work injuries discussed in this chapter demonstrates both employees’ fear of repercussions for reporting injuries, particularly in precarious work environments, and the damage to workplace relationships and employees’ hire-ability after reporting. It would be fruitful to investigate the consequences of a parallel action by employees with invisible chronic illnesses: disclosure of difference and accommodation seeking. If employees with fibromyalgia or other invisible conditions do decide to seek formal accommodations, how does disclosing their status as unexpected workers who do not fit employers’ expectations of healthy staff consistently able to fulfill their duties (Stone et al., 2013) affect their workplace relationships, prospects for promotion, and job retention?

Finally, there is need for knowledge translation of the thesis findings. As concluded in Chapter 3, fibromyalgia information materials contain very little about work and thus may lead readers to believe that employment is incompatible with the illness. Employed women with fibromyalgia need advice on how to remain employed and need to know that it is possible to do so. As explained in Chapter 3, there is a wealth of experiential knowledge among the 176,000 Canadians with fibromyalgia who are in the labour force (Statistics Canada, 2010). This experiential knowledge could be tapped through research and shared with others through rehabilitation programs and through self-help organizations and peer-support groups. A first step in addressing this information and support gap might be to create
a website specifically about staying at work with fibromyalgia. Such a website could bring together existing resources that I did not find in the first study (Chapter 3) and could translate knowledge from this thesis under the guidance of an advisory committee. This is the knowledge-translation project described in the section ‘For rehabilitation practice,’ above. The website could also contain stories of women with fibromyalgia who have remained employed and how they did it. An online forum for employed women with fibromyalgia could be created, where women who have remained employed could support each other not only emotionally (in empathetic relationships) but in strategizing how to prevent and confront discrimination at work.

**Contributions of the Thesis**

Research that examines narratives in fibromyalgia information is rare (Barker, 2002, 2005). My key finding that fibromyalgia-information materials very rarely address employment awakens rehabilitation scientists to the need to compile and create information that helps clients with fibromyalgia remain employed, while going beyond the current individual approach, self-management of chronic illness.

The second study, reported in Chapters 4 and 5, pushes the fields of rehabilitation science and work disability beyond another individual approach, work capacity. Rehabilitation literature tends to view individual impairments as the reason why employees with fibromyalgia leave work. This view aligns with a biomedical focus on remedying functional restrictions (Annandale, 1998). Both approaches conceptualize disability as an individual attribute, not a societal issue. In line with the modified social model of disability that guided this thesis, scholarship needs to move beyond individual work capacity (Hansen,
2008). The thesis contributes to this change of direction by looking beyond levels of impairment for reasons why women with fibromyalgia stay at work.

A few studies in the work disability field have included supervisors and co-workers of disabled employees. This thesis broadened the research scope beyond the workplace into the home domain, which affects the work ability of all employees, particularly those with family responsibilities.

The first of two concepts developed in this thesis, impromptu everyday disclosure dances, expands the literature on workplace disclosure from its current conceptualization of disclosure as a declaration planned in advance, to dances improvised on the spot that respond to tensions and needs within everyday workplace conversation. The thesis also examines disclosure through a different lens, social theories of everyday risk. It introduces two reasons for not disclosing stigmatized illnesses at work: being unfavorably compared to others with the same illness and being offered unwanted advice.

The second concept, management of women’s identities through portrayals (by the women themselves, family members, and workmates) moves the limited literature on fibromyalgia and employment beyond facilitators and enablers of remaining employed to participants’ linguistic representations. Whereas prior studies generally took the accounts of participants at face value, this thesis took a different approach, critical discourse analysis. As far as I know, no one has explored the discourses and narratives underlying people’s thinking about both fibromyalgia and employment. Nor have researchers looked at how women and others around them manage the women’s identities to help the women remain employed. The second concept also brings into the literature on fibromyalgia and employment the issue of precarious work. Nonetheless, a critical approach has been taken by scholars studying
employment with other health conditions (e.g., Eakin, Dunstan, Hansen, MacEachen, and Parsons). This thesis both draws on and complements their research. Finally, interviewing not only women with fibromyalgia but their family members and workmates broadened the research scope to key stakeholders in the women’s lives.

**Concluding Remarks**

In this thesis, social relationships, from empathetic to conflicted, figured prominently in the identity-management actions that helped women with fibromyalgia stay at work: controlled disclosure of illness and impairments through impromptu everyday disclosure dances and portrayals of the women as normal, valuable employees who had not given in to their fibromyalgia. Through these identity-management actions, the women, their family members, and workmates tried to stop the stigma process. The thesis findings highlight the importance of workplace social relations to job retention for employees with invisible impairments. In essence, staying at work with fibromyalgia is as much a social achievement as a biomedical one.
References


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https://tspace.library.utoronto.ca/bitstream/1807/35223/1/12.1.Oldfield.pdf


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Appendices

Appendix 1: Presentations and Publications from the Thesis Research

PEER-REVIEWED PUBLICATIONS


Forthcoming manuscripts


Manuscripts submitted

Oldfield, M., MacEachen, E., MacNeill, M., & Kirsh, B. “You want to show that you’re a valuable employee”: A critical discourse analysis of portrayals of employed women with fibromyalgia by the women themselves, their family members and workmates. Submitted to *Social Science and Medicine.*

PEER-REVIEWED PRESENTATIONS


Oldfield, M. A. & MacEachen, E. (2014, May 24-26) Welcoming Workplaces for All: Various Forms of Leave as a New Way to Retain Employees with Chronic Illnesses through Universal Accommodation. Canadian Industrial Relations Association Conference, St. Catherines, ON.


OTHER PRESENTATIONS


Oldfield, M. A. (2014, Nov. 25). Everyday disclosure dances: One way that women with fibromyalgia remain employed. Invited presentation to Ontario Cluster meeting, Centre for Research in Work Disability Policy, Toronto.


Oldfield, M. A. (2014, May 14). Staying in the workforce with fibromyalgia, an invisible chronic illness [poster]. Rehabilitation Research Showcase, Faculty of Medicine, University of Toronto.

Oldfield, M. A. (2011, May 11). *You’re too sick to work: Messages about fibromyalgia and paid work in information materials* [poster]. Rehabilitation Research Day, Faculty of Medicine, University of Toronto.


**OTHER PUBLICATIONS**


Appendix 2: Research Ethics Board Approvals

PROTOCOL REFERENCE # 28819

May 3, 2013

Dr. Ellen MacEachen
DALLA LANA SCHOOL OF PUBLIC HEALTH
FACULTY OF MEDICINE

Ms. Margaret Oldfield
DALLA LANA SCHOOL OF PUBLIC HEALTH
FACULTY OF MEDICINE

Dear Dr. MacEachen and Ms. Margaret Oldfield,

Re: Your research protocol entitled, "Staying in the workforce with episodic chronic pain: Women with fibromyalgia"

ETHICS APPROVAL

Original Approval Date: May 3, 2013
Expiry Date: May 2, 2014
Continuing Review Level: 1

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol under the REB’s delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Judith Friedland, Ph.D.
REB Chair

Daniel Oyewu
REB Manager

OFFICE OF RESEARCH ETHICS
McMurtrie Building, 12 Queen's Park Crescent West, 2nd Floor, Toronto, ON M5G 1X8 Canada
Tel: +1 416 946-2773 • Fax: +1 416 946-5763 • ethics.review@utoronto.ca • https://www.research.utoronto.ca/research-administer/research-ethics
PROTOCOL REFERENCE # 26819

July 24, 2013

Dr. Ellen MacEachen  Ms. Margaret Oldfield
DALLA LANA SCHOOL OF PUBLIC HEALTH DALLA LANA SCHOOL OF PUBLIC HEALTH
FACULTY OF MEDICINE FACULTY OF MEDICINE

Dear Dr. MacEachen and Ms. Margaret Oldfield,

Re: Your research protocol entitled, "Staying in the workforce with episodic chronic pain: Women with fibromyalgia"

We are writing to advise you that a member of the Health Sciences Research Ethics Board (REB) has granted approval to an amendment (Received July 4, 2013) to the above-referenced research protocol under the REB’s delegated review process.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Best wishes for the successful completion of your research.

Yours sincerely,

Elizabeth Peter, Ph.D.
REB Chair

Daniel Gyeku
REB Manager
Dear Dr. MacEachen and Ms. Margaret Oldfield,

Re: Your research protocol entitled, "Staying in the workforce with episodic chronic pain: Women with fibromyalgia"

We are writing to advise you that a member of the Health Sciences Research Ethics Board (REB) has granted approval to an amendment (Received October 18, 2013) to the above-referenced research protocol under the REB’s delegated review process.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signatures]

Elizabeth Peter, Ph.D.             Daniel Gyewu
REB Chair                           REB Manager
PROTOCOL REFERENCE # 28819

April 21, 2014

Dr. Ellen MacEachen
DALLA LANA SCHOOL OF PUBLIC HEALTH
FACULTY OF MEDICINE

Ms. Margaret Oldfield
DALLA LANA SCHOOL OF PUBLIC HEALTH
FACULTY OF MEDICINE

Dear Dr. MacEachen and Ms. Margaret Oldfield,

Re: Your research protocol entitled, “Staying in the workforce with episodic chronic pain: Women with fibromyalgia”

ETHICS APPROVAL

| Original Approval Date: May 3, 2013 |
| Expiry Date: May 2, 2015 |
| Continuing Review Level: 1 |
| Renewal: Data Analysis Only |

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signature]

[Signature]
April 23, 2015

Dr. Ellen MacEachen  Ms. Margaret Oldfield
PUBLIC HEALTH SCIENCES (DLSPH) PUBLIC HEALTH SCIENCES (DLSPH)
DALLA LANA SCHOOL OF PUBLIC HEALTH DALLA LANA SCHOOL OF PUBLIC HEALTH

Dear Dr. MacEachen and Ms. Margaret Oldfield,

Re: Your research protocol entitled, "Staying in the workforce with episodic chronic pain: Women with fibromyalgia"

ETHICS APPROVAL

Original Approval Date: May 3, 2013
Expiry Date: May 2, 2016
Continuing Review Level: 1
Renewal: Data Analysis Only

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signature]

[Signature]
Appendix 3: Recruiting Materials

Advertisement Seeking Participants

Are you a woman with fibromyalgia—and employed?

Would you like to share your experiences, so that others can learn from them? People like government policymakers, health professionals, and other women with FM. Then please join us in the study ‘Staying in the Workforce with Fibromyalgia’. The study is being conducted by Margaret Oldfield, a PhD student at the University of Toronto. She is interviewing women who have been medically diagnosed with FM, as well as people who can make a difference in whether they stay at work: an adult family member and someone in her workplace.

If you’d like to join the study, or simply want more information about it, please email the researcher at margaret.oldfield@mail.utoronto.ca or phone her at 416-975-5199. If you don’t have FM yourself but know a woman who might want to join the study, please forward this message to her. Thank you.

Script for Telephone Calls Seeking Employer Representatives

First contact at organization: Good [morning or afternoon]. My name is Margaret Oldfield, and I am a PhD student at the University of Toronto. I would like to speak to someone in your organization who is knowledgeable about how employees with disabilities in your organization are accommodated [prompt: human resources department, disability manager, other knowledgeable staff member].

After reaching the appropriate staff member: Good [morning or afternoon]. My name is Margaret Oldfield, and I am a PhD student at the University of Toronto. I am studying how women with long-lasting health issues stay employed. Key to keeping these women employed are the policies and processes of employers. Would you be the most appropriate person to speak to about how employees with disabilities in your organization are
accommodated? [If no] Could you refer me to the appropriate person? [If yes] Would you be willing to talk to me for half an hour?
Appendix 4: Telephone Screening Questionnaire

Name: __________________________ Date: __________________________

Contact: __________________________

1. Do you have fibromyalgia?
2. Did a doctor diagnose it?
3. Are you currently employed?

If the woman answers no to any of Questions 1-4, say:

Thank you for your interest. Our study has only been approved for women who have been diagnosed with FM by a doctor and are currently employed. Would you like to receive a summary of the study results when they are available? [If yes, obtain email or mailing address.]

4. How did you hear about the study?

5. Can you tell me what kind of work you do?
   *Probes: occupation, education level, part-time, full-time*

6. Have you told anyone at work that you have FM?

7. Would you be comfortable connecting me with someone in your workplace?

8. Can you tell me what kind of place you work in?
   *Probes: employment relationship (standard or precarious work, self-employment), size of employer, public/private/not-for-profit sector,

9. Can you tell me a bit about your living situation?
   *Probes: live alone, housemate, partner, children living at home or not*

10. Would you be comfortable connecting me with a family member?

11. Could you tell me how long you’ve been in Canada?

12. Do you mind if I ask you your age?
Appendix 5: Information Sheets/Informed Consent Forms

Graduate Dept. of Rehabilitation Science letterhead

**Staying in the Workforce with Fibromyalgia**

**Information Sheet for Women with Fibromyalgia**

Thank you for your interest in our study. This sheet explains who is doing the study and why. It also explains what we will ask you to do if you join the study, and the risks and benefits of joining.

**Who is doing this study?**

The researcher is Margaret Oldfield. She is a PhD student at the University of Toronto. The research is her thesis, which Dr. Ellen MacEachen is supervising.

**Why are they doing the study?**

It can be hard for women with long-lasting health conditions to stay at work. We want to understand how women with fibromyalgia stay at work by learning from them. We also want to learn from other people in the lives of women with fibromyalgia. These are their family members, work supervisors, and co-workers. We hope that the research findings will help to make staying in the workforce easier for women with fibromyalgia. We will tell key groups, such as women with fibromyalgia, family members, employers, and government policy makers, about the study findings.

**Who is participating in the study?**

We are interviewing women with a medical diagnosis of fibromyalgia who agree to connect us to two adult family members. We will also ask women who have disclosed their chronic health issues at work to connect us to two people in their workplace. We are asking for two people from each group in case one of them does not want to join the study. We will interview you first. Then we will ask you to identify two family members (such as partners, siblings, cousins, or parents) who we might interview. If you disclosed your health issues at work, we will ask you to identify two people at work (such as co-workers or supervisors) who might also talk with us. The researcher will ask you to approach one of these family members and one of these people at work to tell them about the study. She will then contact them to invite them to participate in an interview. If either the family member or person at work does not want to join the study, the researcher will contact the other people you recommend.
What will the researcher ask me to do if I join the study?

The researcher will invite you to an interview, which is just like having a conversation, at a time and place convenient for you. We will talk for up to one hour, and we will audio-record the conversation with your permission. You will not need to prepare. The researcher will ask you general questions about what it is like to work while having fibromyalgia. She will also ask you what changes could be made to help women with fibromyalgia stay at work. If you wish, we will send you a summary of the study’s findings.

What are the risks and benefits of joining the study?

You may worry that people can trace confidential information back to you. We understand this concern. We have arranged the study so that joining it will not harm you. We will carefully protect your identity and will not share what you say with anyone outside of the research group. These people are Margaret Oldfield, Dr. Ellen MacEachen, and the person who transcribes the interviews. All of the information collected during the study will be confidential. We will replace your name with a made-up name. We will use this name if we quote anything from your interview in reports on the study. We will also omit or change any details that might identify you.

Joining this study is voluntary. This means that you may decide not to join, and you will not have to answer any questions if you do not want to. You can stop the interview or ask that we not use your interview after it is over. This you can do by contacting the researcher or her supervisor. Their contact information is at the bottom of this page. If you do not want to have your interview used in the study, you will need to contact us within a week after the interview. If you decide not to join, do not want to answer some of the questions, stop the interview, or withdraw, there will be no negative consequences.

While many people find that talking about their lives gives them insights, some may find that talking brings up uncomfortable feelings. If this happens, the researcher will stop the interview until you are ready to continue. If you feel that you need emotional support that you do not currently have access to, she will offer you a list of counselling services.

We will not tell anyone in the study what anyone said in their interviews. We will also not tell any participant in the study who else was interviewed. We will ask the family members and the people at work who you identify to not reveal to anyone that you joined this study.

People often find discussing their experiences to be helpful. While you may not benefit directly from the study, other women with fibromyalgia, their employers and family members may benefit. The research will help people understand what women with fibromyalgia need to stay at work and identify gaps in services or policies.
**What if I have questions or concerns?**

You may contact Margaret Oldfield at margaret.oldfield@mail.utoronto.ca or 416-975-5199. You may also contact Dr. Ellen MacEachen at emaceachen@iwh.on.ca or 416-927-2027, extension 2136. If you have any questions about your rights as a research participant, you may contact the University of Toronto’s Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

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**Staying in the Workforce with Fibromyalgia**

**Consent Form**

Thank you for agreeing to join this study about how women with fibromyalgia stay at work. This consent form asks you to agree in writing to the interview.

**Declaration of Consent**

I understand that researcher Margaret Oldfield has asked me to participate in the study ‘Staying in the Workforce with Fibromyalgia.’ I have read the information sheet and have had a chance to ask questions. I give my consent to participate in an interview for the study.

I agree to **not** reveal to anyone the identities of other people in the study.

____________________________________  ________________________________________
Participant Name (please PRINT)        Participant Signature    Date

I wish to receive a summary of the study’s findings.

Email address: ________________________________
Thank you for your interest in the study. This sheet explains who is doing the study and why. It also explains what we will ask you to do if you join the study, and the risks and benefits of joining.

Who is doing this study?

The researcher is Margaret Oldfield. She is a PhD student at the University of Toronto. The research is her thesis, which Dr. Ellen MacEachen is supervising.

Why are they doing the study?

It can be hard for women with long-lasting health conditions to stay at work. We want to understand how women with fibromyalgia stay at work by learning from them. We also want to learn from other people in the lives of women with fibromyalgia. These are their family members, work supervisors, and co-workers. We hope that the research findings will help to make staying in the workforce easier for women with fibromyalgia. We will tell key groups, such as women with fibromyalgia, family members, employers, and government policy makers, about the study findings.

Who is participating in the study?

We are interviewing women with a medical diagnosis of fibromyalgia who agree to connect us to two adult family members. We will also ask women who have disclosed their fibromyalgia at work to connect us to two people in their workplace. We ask for two people in each group in case one does not want to join the study. At the end of the interview with your family member who has fibromyalgia, we asked her to identify two adults in her family who we might interview. Then we asked her to approach you about joining the study.

What will the researcher ask me to do if I join the study?

The researcher will invite you to an interview, which is just like having a conversation, at a time and place convenient for you. We will talk for up to one hour, and we will audio-record the conversation with your permission. You will not need to prepare. The researcher will ask you general questions about whether having a family member with fibromyalgia who is in the workforce has affected your household. She will also ask you what advice you would
give to other families of employed women with fibromyalgia. If you wish, we will send you a summary of the study’s findings.

**What are the risks and benefits of joining the study?**

You may worry that people can trace confidential information back to you. We understand this concern. We have arranged the study so that joining it will not harm you. We will carefully protect your identity and will not share what you say with anyone outside of the research group. These people are Margaret Oldfield, Dr. Ellen MacEachen, and the person who transcribes the interviews. All of the information collected during the study will be confidential. We will replace your name with a made-up name. We will use this name if we quote anything from your interview in reports on the study. We will also omit or change any details that might identify you.

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While many people find that talking about their experiences gives them new insights, some people may find that talking brings up uncomfortable feelings. If this happens, the researcher will stop the interview until you are ready to continue. If you feel that you need emotional support that you do not currently have access to, she will offer you a list of counselling services.

We will not tell anyone in the study what anyone said in their interviews. We will also not tell any participant in the study who else was interviewed. We will ask the woman with fibromyalgia who recommended you for an interview to not reveal to anyone that you joined this study.

People often find discussing their experiences to be helpful. While you may not benefit directly from the study, other women with fibromyalgia, their employers and family members may benefit. The research will help people understand what women with fibromyalgia need to stay at work and identify gaps in services or policies.

**What if I have questions or concerns?**

You may contact Margaret Oldfield at margaret.oldfield@mail.utoronto.ca or 416-975-5199. You may also contact Dr. Ellen MacEachen at emaceachen@iwh.on.ca or 416-927-2027, extension 2136. If you have any questions about your rights as a research participant, you
may contact the University of Toronto’s Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

**Staying in the Workforce with Fibromyalgia**

**Consent Form**

Thank you for agreeing to participate in this research project about how women with fibromyalgia stay at work. This consent form asks you to agree in writing to the interview.

**Declaration of Consent**

I understand that researcher Margaret Oldfield has asked me to participate in an interview for the study ‘Staying in the Workforce with Fibromyalgia.’ I have read the information sheet and have had a chance to ask questions. I give my consent to participate in an interview for the study.

I agree to *not* reveal to anyone the identities of other people in the study.

_________________________________________  ________________________________________
Participant Name                        Participant Signature
_________________________________________  ________________________________________
Date                                  (please PRINT)  Date

I wish to receive a summary of the study’s results

Email address: ____________________________________________________
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It can be hard for women with long-lasting health issues to stay at work. We want to understand how women with such issues stay at work by learning from the women. We also want to learn from other people in their lives. These are their family members, work supervisors, and co-workers. We hope that the research findings will help to make staying in the workforce easier for women with chronic health issues. We will tell key groups, such as women with chronic health issues, family members, employers, and government policy makers, about the study findings.

**Who is participating in the study?**

We are interviewing women with chronic health issues who agree to connect us to an adult family member. We will also ask women who have disclosed their health issues at work to connect us to someone in their workplace. At the end of the interview with your employee or co-worker, we asked her to identify two people at her workplace who might also talk with us. We asked for two people in case one does not wish to talk with us. Then we asked her to approach you about joining the study.

**What will the researcher ask me to do if I join the study?**

The researcher will invite you to an interview, which is just like having a conversation, at a time and place convenient for you. We will talk for up to one hour, and we will audio-record the conversation with your permission. You will not need to prepare. The researcher will ask you general questions about whether chronic health issues affect an employee’s work and their relationships at work. She will ask about any advice you might have for employees with chronic health issues, as well as their supervisors and co-workers. The researcher will also ask you whether your organization has any publicly available documents that tell supervisors
how to accommodate employees with disabilities. If you wish, we will send you a summary of the study’s findings.

**What are the risks and benefits of participating in the study?**

You may worry that people can trace confidential information back to you. We understand this concern. We have arranged the study so that joining it will not harm you. We will carefully protect your identity and will not share what you say with anyone outside of the research group. These people are Margaret Oldfield, Dr. Ellen MacEachen, and the person who transcribes the interviews. All of the information collected during the study will be confidential. We will replace your name with a made-up name. We will use this name if we quote anything from your interview in reports on the study. We will also omit or change any details that might identify you.

Joining this study is voluntary. This means that you may decide not to join, and you will not have to answer any questions if you do not want to. You can stop the interview or ask that we not use your interview after it is over. This you can do by contacting the researcher or her supervisor. Their contact information is at the bottom of this page. If you do not want to have your interview used in the study, you will need to contact us within a week after the interview. If you decide not to join, do not want to answer some of the questions, stop the interview, or withdraw, there will be no negative consequences.

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We will not tell anyone in the study what anyone said in their interviews. We will also not tell any participant in the study who else was interviewed. We will ask the woman who recommended you for an interview to not reveal to anyone that you joined this study.

People often find discussing their experiences to be helpful. While you may not benefit directly from the study, other women with chronic health issues, their employers and family members may benefit. The research will help people understand what women with chronic health issues need to stay at work and identify gaps in services or policies.

**What if I have questions or concerns?**

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may contact the University of Toronto’s Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Staying in the Workforce with Chronic Health Issues

Consent Form

Thank you for agreeing to join this study about how women with chronic health issues stay at work. This consent form asks you to agree in writing to the interview.

Declaration of Consent

I understand that researcher Margaret Oldfield has asked me to participate in an interview for the study ‘Staying in the Workforce with Chronic Health Issues.’ I have read the information sheet and have had a chance to ask questions. I give my consent to participate in an interview for the study.

I agree to not reveal to anyone the identities of other people in the study.

______________________________________________________________
Participant Name (please PRINT) Participant Signature Date

I wish to receive a summary of the study’s results

Email address: _____________________________________________________
Staying in the Workforce with Chronic Health Issues

Information Sheet for Employer Representatives

Thank you for your interest in our study. This sheet explains who is doing the study and why. It also explains what we will ask you to do if you join the study, and the risks and benefits of joining.

Who is doing this study?

The researcher is Margaret Oldfield. She is a PhD student at the University of Toronto. The research is her thesis, which Dr. Ellen MacEachen is supervising.

Why are they doing the study?

It can be hard for women with long-lasting health issues to stay at work. We want to understand how women with such issues stay at work by learning from the women. We also want to learn from other people in their lives. These are their family members and employers. We hope that the research findings will help to make staying in the workforce easier for women with chronic health issues. We will tell key groups, such as women with chronic health issues, family members, employers, unions, and government policy makers, about the study findings.

Who is participating in the study?

We are interviewing women with chronic health issues and, with their permission, an adult family member and, if the woman has disclosed her health issues at work, someone in her workplace. To supplement these interviews, we are also talking to staff in organizations that are not the employers of the women with chronic health issues who joined the study.

What will the researcher ask me to do if I join the study?

The researcher will invite you to an interview, which is just like having a conversation, at a time and place convenient for you. We will talk for up to a half hour, and we will audio-record the conversation with your permission. You will not need to prepare. The researcher will ask you general questions about whether chronic health issues affect an employee’s work and their relationships at work, and whether your organization has offered any supports to employees with chronic health issues. She will ask about any advice you might have for employees with chronic health issues, as well as their supervisors and co-workers, unions and governments.
The researcher will also ask you whether your organization has any publicly available documents concerning the accommodation of employees with disabilities. If you wish, we will send you a summary of the study’s findings.

**What are the risks and benefits of participating in the study?**

You may worry that people can trace confidential information back to you. We understand this concern. We have arranged the study so that joining it will not harm you. We will carefully protect your identity and will not share what you say with anyone outside of the research group. These people are Margaret Oldfield, Dr. Ellen MacEachen, and the person who transcribes the interviews. All of the information collected during the study will be confidential. We will replace your name with a made-up name. We will use this name if we quote anything from your interview in reports on the study. We will also omit or change any details that might identify you.

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We will not tell anyone in the study what anyone said in their interviews. We will also not tell any participant in the study who else was interviewed.

People often find discussing their experiences to be helpful. While you may not benefit directly from the study, other employers may benefit, as well as women with chronic health issues and their family members. The research will help people understand what women with chronic health issues need to stay at work and identify gaps in services or policies.

**What if I have questions or concerns?**

You may contact Margaret Oldfield at margaret.oldfield@mail.utoronto.ca or 416-975-5199. You may also contact Dr. Ellen MacEachen at emaceachen@iwh.on.ca or 416-927-2027, extension 2136. If you have any questions about your rights as a research participant, you
may contact the University of Toronto’s Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Staying in the Workforce with Chronic Health Issues

Consent Form

Thank you for agreeing to join this study about how women with chronic health issues stay at work. This consent form asks you to agree in writing to the interview.

Declaration of Consent

I understand that researcher Margaret Oldfield has asked me to participate in an interview for the study ‘Staying in the Workforce with Chronic Health Issues.’ I have read the information sheet and have had a chance to ask questions. I give my consent to participate in an interview for the study

__________________________________________
Participant Name (please PRINT)  ________________________________
Participant Signature  Date

I wish to receive a summary of the study’s results

Email address: __________________________________________________

## Initial Guide for Interviews of Women with Fibromyalgia

<table>
<thead>
<tr>
<th>Topic</th>
<th>Sample questions, probes, and procedures</th>
</tr>
</thead>
</table>
| Warm-up/opening               | Thank you for participating  
Review information letter/consent form with participant. Answer questions. Make any changes participant requests. Sign consent form. Leave information letter with participant  
Use information women gives in phone/email screening to establish rapport (also nodding, active listening, no judgment, eye contact)  
Can you tell me what led you to take part in this study?                                                          |
| Overview of FM experience     | Can you tell me what fibromyalgia is like for you?  
Has it changed over time? How?                                                                                     |
| Nature of paid work           | Can you tell me about the jobs you’ve had since you first felt FM symptoms?  
Can you tell me about your current job?  
*Probes:* employment relationship (standard/precarious), job quality, control over work, benefits and drawbacks of work, motivation to work |
| Impairments at work           | Can you tell me whether FM affects your current job? How?  
Has FM affected your previous jobs? How?  
What helps/helped?  
Have you ever considered leaving a job because of FM? Can you tell me about that?                                 |
| Disability leave              | Can you tell me whether you have ever considered applying for disability leave? What happened?  
*Probes:* workers’ compensation, disability benefits                                                              |
| Social support for FM | Can you tell me who helps you to stay at work?  
*Probes:* emotional support, workplace parties, family members, friends, health care professionals, support groups, others |
<table>
<thead>
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<tbody>
<tr>
<td>Rehabilitation</td>
<td>Can you tell me about any programs you’ve attended to help with the FM? What advice did they provide about working? What advice did they <em>not</em> provide about working?</td>
</tr>
</tbody>
</table>
| Disclosure Invisibility | Can you tell me whether you’ve told anyone at your current or past work that you have FM? Can you tell me about that?  
*Probes:* who, why them  
Can you tell me what happened after you told them?  
*Probes:* believed or not, malingering, stigma, impact on reputation, etc. |
| Workplace social relations | In your current job, who has made a difference to your staying at work with FM?  
*Probes:* how? co-workers, supervisor, human resources manager, others |
| Accommodations       | Can you tell me what changes you’ve made to your current or past jobs because of FM? Can you tell me what led to these changes?  
What changes have your current or past employers made to your job because of FM? Can you tell me what led to these changes? |
| Negotiating accommodations | Can you tell me how these changes came about?

*Probes:* who involved, time it took, what offered, what resulted

How have the changes worked out?

*Probes:* communication, formal/informal agreement, impact on others in work team |
<table>
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<tbody>
<tr>
<td>Transition to home environment</td>
<td>Now I’d like to talk about whether FM affects your life outside of work.</td>
</tr>
</tbody>
</table>
| Effect of FM impairments outside work environment | Does combining FM with working affect your life outside of work?

*Probes:* How? domestic work, leisure, relationships with family members; trade-offs between work, family, leisure |
| Household/Family | Sometimes women find that their situation at home affects their ability to work. So related to that, I have some questions about your [family/living situation].

Can you tell me about your [family/living situation]?

*Probes:* live with someone or alone, partner, kids at home and their ages, other family members who live with woman |
| Responsibilities for domestic work | Can you tell me a little about housework arrangements in your home? For instance, who does the housework, taking care of the children, taking care of elderly parents?

*Probes:* planning of domestic work |
| Recommendations re. work | What would make staying at work with FM easier for you? |
### Initial Guide for Interviews of Family Members

<table>
<thead>
<tr>
<th>Topic</th>
<th>Sample questions, probes, and procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warm-up/opening</td>
<td>Thank you for participating</td>
</tr>
<tr>
<td></td>
<td>Review information letter/consent form with participant. Answer questions. Make any changes participant requests. Sign consent form. Leave information letter with participant</td>
</tr>
<tr>
<td></td>
<td>Use information family member gives in phone/email contact to establish rapport (also nodding, active listening, no judgment, eye contact)</td>
</tr>
<tr>
<td></td>
<td>Can you tell me about yourself?</td>
</tr>
<tr>
<td></td>
<td><em>Probes</em>: What do for a living?</td>
</tr>
</tbody>
</table>
| Overview of FM experience | Can you tell me what it’s been like for you to live with someone who has fibromyalgia and a job?  
*Probes: change over time, adjustment, instrumentally, emotionally* |
| Household/Family | Can you tell me about your household?  
*Probes: partner, kids at home and their ages, other family members* |
| Effects of FM on family | Have things changed for your family because of fibromyalgia?  
Can you talk about how things have changed?  
*Probes: roles, relationship quality, employment, sharing tasks, leisure, socializing, practical support, emotional support, own job, belief in woman’s pain, listening, need for guidance on how to support family member with FM* |
| Responsibilities for domestic work | Many people find that their family responsibilities affect their work. So I’d like to know a bit about your family’s arrangements.  
Can you tell me a little about housework arrangements in your home? For instance, who does the housework, taking care of the children, taking care of elderly parents?  
*Probe: Who plans domestic work?*  
How has fibromyalgia affected the sharing of these tasks? |
| Accommodations | Can you tell me whether you or other family members have made any changes to the way you do things at home because of fibromyalgia?  
*Probes: physical changes, time and task organization* |
<p>| Recommendations re. FM | What would make it easier for women with FM to stay in the workforce? |</p>
<table>
<thead>
<tr>
<th>Advice for other families of women with FM</th>
<th>What advice would you give to other families of women with FM who are in the workforce?</th>
</tr>
</thead>
</table>
| Cool-down/wrap-up | Is there anything else that you would like to tell me about having a family member with FM who is in the workforce?  
Thank you for participating  
Value of family member’s participation to study |

### Amended Guide for Interviews of Workplace Parties

<table>
<thead>
<tr>
<th>Topic</th>
<th>Sample questions, probes, and procedures</th>
</tr>
</thead>
</table>
| Warm-up/opening | Thank you for participating  
Review information letter/consent form with participant. Answer questions. Make any changes participant requests. Sign consent form. Leave information letter with participant  
Use information party gives in phone/email contact to establish rapport (also nodding, active listening, no judgment, eye contact)  
Can you tell me what kind of interaction you have with [woman with chronic health issue]? |
| Overview of experience with chronic health issue | Can you tell me what it is like for [supervisors/co-workers] to work with an [employee/colleague] who has a chronic health issue?  
_Probes:_ instrumentally, emotionally, adjustment, change over time |
| Impairments at work | In your view, does the chronic health issue seem to affect the work of a person with ?  
In turn, does this affect your work?  
_Probe for both questions:_ How? |
| Workplace social | In general, when someone has a chronic health issue, does it affect their |
| relations | relationships at work? How? Examples?  
<table>
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<tbody>
<tr>
<td></td>
<td><em>Probes:</em> relationship quality, social support, need for help; relationships with managers, supervisors, co-workers, HR personnel, unions, others</td>
</tr>
</tbody>
</table>
| Accommodations | Do you know if, at your workplace, any supports have been offered to people with chronic health issues? Examples?  
|           | Do you know if any changes have been made to the jobs of people in your workplace because of a chronic health issue? Examples?  
|           | *Probe for 2 questions:* Can you tell me about that? What happened? |
| Negotiating accommodations | In relation to these supports, do you know anything about the process of how these changes or accommodations come about? Examples?  
|           | *Probes:* What was involved, time it took, what offered, what resulted  
|           | How has it worked out?  
|           | *Probes:* communication, formal/informal agreement, impact on others in work team |
| Recommendations re. work | In your view, what kinds of changes in the workplace would make it easier for a person with a chronic health issue to stay at work? |
| Advice for others | What advice would you give to [co-workers/supervisors] of people with chronic health issues to help them stay in the workforce? |
| Cool-down/wrap-up | Is there anything else about staying at work with a chronic health issue that you would like to tell me about?  
|           | Does your organization have a policy on accommodating employees with impairments?  
|           | *Probe:* Could I get a copy? Contact person for more info?  
<p>|           | Thank you for participating |</p>
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<thead>
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<th>Topic</th>
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<tr>
<td><strong>Warm-up/opening</strong></td>
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<td>Review information letter/consent form with participant. Answer questions. Make any changes participant requests. Sign consent form. Leave information letter with participant</td>
</tr>
<tr>
<td></td>
<td>Use information party gives in phone/email contact to establish rapport (also nodding, active listening, no judgment, eye contact)</td>
</tr>
<tr>
<td><strong>Overview of experience with chronic health issues</strong></td>
<td>Have you had any experience advising or supervising an employee with a chronic health issue?</td>
</tr>
<tr>
<td></td>
<td>Can you tell me about it?</td>
</tr>
<tr>
<td><strong>Impairments at work</strong></td>
<td>In your view, when an employee has a chronic health issue, does it affect their work?</td>
</tr>
<tr>
<td></td>
<td><em>Probe:</em> How? Examples?</td>
</tr>
<tr>
<td><strong>Workplace social relations</strong></td>
<td>In general, when an employee has a chronic health issue, does it affect their relationships at work? How? Examples?</td>
</tr>
<tr>
<td></td>
<td><em>Probes:</em> relationship quality, social support, need for help; relationships with managers, supervisors, co-workers, HR personnel, unions, others</td>
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<tr>
<td><strong>Accommodations</strong></td>
<td>Do you know if, at your workplace, any supports have been offered to people with chronic health issues? Examples?</td>
</tr>
<tr>
<td></td>
<td>Do you know if any changes have been made to the jobs of people in your organization because of a chronic health issue? Examples?</td>
</tr>
<tr>
<td></td>
<td><em>Probe for 2 questions:</em> Can you tell me about that? What happened?</td>
</tr>
</tbody>
</table>
| Negotiating accommodations | In relation to these supports, how did these changes or accommodations come about? Examples?

*Probes:* What was involved, time it took, what offered, what resulted

How has it worked out?

*Probes:* communication, formal/informal agreement, impact on productivity and others on work team |
| Recommendations re. work | In your view, what kinds of changes in your organization would make it easier for a person with a chronic health issue to stay at work? |
| Advice for others | To help employees with chronic health issues stay in your organization, what advice would you give to:

- Employees with chronic health conditions
- Their supervisors/managers and co-workers
- [If workplace unionized] Unions
- Governments |
| Cool-down/wrap-up | Is there anything else about staying at work with a chronic health issue that you would like to tell me about?

Does your organization have a policy on accommodating employees with impairments?

*Probe:* Could I get a copy? Contact person for more info?

Thank you for participating

Value of workplace party’s participation to study |
Appendix 7: Identity-Management Relational Diagram

Adapted from Clarke (2005).