The personal and the professional: betwixt and between the paid and unpaid responsibilities of working women with chronic illness

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Abstract

The labour market outcomes experienced by women with chronic illness are subject to a number of influences. These influences have been recently expanded to include the normative expectations of wellbeing as a prerequisite for productivity in their various social and working roles. Discussion of these factors is often situated within the bounds of the workplace. One area, external to the workplace, which needs greater attention is the role of family and friends as part of the support network for these women. The personal environment has the potential to allow women with chronic illness to excel in their work and careers, it may also result in less positive outcomes. This paper examines the workforce experiences of women with chronic illness and role that personal and professional influences play in their workplace outcomes.

Introduction

Women with chronic illness, which might include a variety of diseases such as diabetes, rheumatoid arthritis, lupus, mental illness or multiple sclerosis, may face difficulties with managing the expectations of others in any social interaction. The World Health Organisation (WHO) states that "disability [which includes health and health related states] is a complex phenomena that is both a problem at the level of the person's body, and a complex primarily social phenomena" (2002, p. 9). Society often holds the bearer of the disability or chronic illness responsible for their condition/impairment, however WHO also comments: "disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external" (2002, p. 9). Work and family relationships can be sources of disabling attitudes which influence the outcomes of women with chronic illness at home and at work.

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Individuals are willing to stigmatise individuals with chronic illness, even when a legitimate explanation is given regarding the extent of their disability (Werth 2013). Perhaps, we might generally expect that women with chronic illness would, could or should receive a greater degree of consideration from within their family or home life, however there is a small but growing body of research that suggests that this may not be the case (Thomeer et al. 2015). Various sources suggest that the divorce rate for women with chronic illness is higher than the divorce rate for men with chronic illness and that the divorce rate generally for individuals with chronic illness is higher than that of the general population (Karraker & Latham 2015)

This paper will explore the outcomes for women with chronic illness, paying particular attention to aspects of their personal and professional lives. The qualitative data gathered in this study examined the support that women with chronic illness experienced in their personal circumstances, generally this support is provided by immediate and extended family members and sometimes by friends. Supportive family and friends play an important role in the success of these women in the labour market. This paper will explore the literature relating to the various influences that working women with chronic illness need to manage, subsequently the methodology for this extended project will be outlined and discussion and conclusions will be put forward.

Women managing chronic illness: at work and at home

A variety of concepts have been explored in literature in relation to managing the way an individual with a chronic illness copes. These have come from the fields of gerontology (Thomeer et al. 2015); chronic illness (Bury 1982; Werth 2011); sociology of work and work roles (Bury 1982; Corbin & Strauss 1985; DeJordy 2008); and, cancer research (Yoo et al. 2010). Much of this research reflected on the personal performance required of individuals with differing forms of chronic illness to show capability despite their impairment in various social and work settings. Bury (1982) reflected on the biographical disruption created by chronic illness and the adaptations required of the bearer and those with whom they live and work. He also pointed out that "disruptions in biography are, at one and the same time, disruptions of social relationships and the ability to mobilise material resources" (Bury 1982, p.

180). Corbin and Strauss (1985) identified three concepts including illness work (self care), everyday work (occupational work or work done in the family environment) and biographical work – "necessitated by the continual or occasional reconstruction of his or her life [relating to illness]" (Corbin & Strauss 1985, p. 230) – undertaken by individuals with chronic illness. Illness trajectory was the concept used by Corbin and Strauss, to refer to "the course of an illness, the related work as well as the impact on both the workers and their relationships that then further affect the management of that course of illness" (1985, p. 225).

These early studies identified that individuals with chronic illness were required to undertake various types of "work", in order to achieve particular health and social outcomes. Subsequent research has identified other types of work that describe the means by which individuals with stigmatised identities might attempt to manage the way they appear to others. Goffman (1986) highlighted the role played by stigma in the effort to "pass" as normal, or where the stigma is obvious, or "cover" the degree to which an apparent disablement could cause social non-conformity. Other authors have pointed to behaviours which might include deliberate concealment (Myers 2004) or the misrepresentation of the self to project conformity (DeJordy 2008). Passing and covering may be deployed along with emotion work and aesthetic labour to project social conformity in social and work spaces.

More recent research in the field, which covers differing forms of disability and chronic illness, has started to move towards the roles that aesthetic labour and emotion work play in the lives of those with chronic illness, particularly women, in their place of employment and at home. Yoo et al (2010) discussed the way that emotion work was deployed by women diagnosed with breast cancer when they undertook disclosure in different settings. They noted that "disclosure has emotional consequences such as strained relationships…" (2010, p. 206). Yoo et al also pointed out that:

> Emotional work between women and their families has often been overlooked in the midst of a healthcare crisis because emotional involvement is regularly assumed to be a gendered duty, automatically fulfilled as part of being a daughter, sister or mother (2010, p. 206).

In a similar type of circumstance, men with prostate cancer did not choose to do the emotion work of disclosing as this was left to their female partners to undertake (Yoo et al. 2010). Thomeer et al added:

> The provision of "natural" emotion work by women regardless of women's own health status, coupled with the relative lack of men's corresponding emotion work helps us better understand the mental, emotional and physical consequences of having a health-impaired spouse are more detrimental to the health and well-being of women compared with men (2015, p. 16).

Women who are employees with chronic illness have particular characteristics which differentiate them from other groups within organisations. These characteristics include the types of illnesses with which they have been diagnosed. Fairweather et al (2008) point out that 78% of those with autoimmune disease (ie rheumatoid arthritis, Crohn's disease or lupus) are women. Autoimmune diseases have no cure and are not influenced by lifestyle factors, however expectations in social and work settings are that women should be able to do "something" to improve their own health outcomes (Myers 2004). Therefore the responsibility or blame for the disease, and subsequent labour market outcomes, are often attributed to the individual (Vickers 2003). If, over time, they are unable to improve, then the responsibility is theirs to find an appropriate social role to fulfil. This might mean resignation from their job and exiting the labour market, however there are few ways to withdraw from expected family responsibilities.

It has been shown that roles within families influence personal outcomes for women with chronic illness. "Gender norms regarding the role changes that frequently accompany illness may yield gender differences in the relationship between illness and divorce," also noting that it is only the wife's illness that is associated with increased incidence of divorce (Karraker & Latham 2015, p. 423). Karraker and Latham go on to point out that:

> Given the gendered nature of caregiving [to others] and care receiving [from others toward the person with chronic illness] and caregiving's frequent stressful nature, it is plausible that situations in which ill wives are dependent on husbands for care are more stressful than when wives are caring for ill husbands (2015, p. 423).

Vickers states that "the dynamics of male domination continue in many ways and at different levels: at work [and] in the home…" (Vickers 2001, p. 63). Women with chronic illness are more likely to be subjected to patriarchal attitudes in multiple settings, which might include the role of the medical profession, managers, colleagues and family (Vickers 2001).

The World Health Organisation (2016) listed gender specific risk factors for common mental health disorders which include a number of issues which might influence women with chronic illness such as low income and the responsibility for the care of others. These are issues which have been shown to impact on the lives of women with chronic illness (Werth 2013). We also know that, "being female increases the likelihood of co-occurrence of physical, mental, or physical and mental long-term conditions" (Steadman et al. 2016, p. 5). The difficulties associated with chronic illness, are not just that the individual has no chance of becoming well, but that they are more likely to eventually be diagnosed with more than one disease. Caring roles and specific disease characteristics make it difficult to fit in with the concepts of an ideal worker which is "essentially a worker with the male characteristic of freedom from domestic responsibilities" (Whitehouse & Preston 2005, p. 271).

Methodology

The stories related by women with chronic illness and their experiences at work and home do not always have happy endings, but qualitative research which investigates these stories is important because of the otherwise invisibility of the participants within society. Groups, such as women with chronic illness, who are difficult to access because of the stigma associated with their condition (Vickers 1997) can be accessed using a snowball sampling technique (Atkinson & Flint 2001). This technique involves using known insiders, in this instance women with chronic illness, to refer participants from within the group that is not readily available to outsiders. Atkinson and Flint point out that, "this process is based on the assumption that a bond or link exists between the initial sample and the others in the same target population, allowing a series of referrals to be made within circles of acquaintances" (2001, p. 1). Participants were also sought through the newsletters of various chronic illness support groups and networks.

The researcher was an insider in this population and thus had privileged status within this group and some access to the population. Merton stated, with regard to insider research, that "you have to be one in order to understand one" (1972, p. 15). Positioning myself as an insider resulted in developing trust and credibility with participants that would otherwise not have been possible.

Thorne and Paterson refer to the dynamic between the researcher and insiders (participants) "It seems evident that both researchers and insiders operate within a socially constructed reality that is dynamic and difficult to appreciate until the passage of time allows social and historical analysis" (1998, p. 174). The role of an insider researcher more readily allows access to the socially constructed reality which may differ considerably for a researcher who is not an insider. The passage of time provides a particular view of the way society is constructed and perceived by both insiders and outsiders. These views may vary so considerably that it influences, "what gets studied, what research questions are posed, and what methods are used…" (Thorne & Paterson 1998, p. 174). Insider research may be the only way to research some groups where being an outsider equates to a lack of access to effective data. Merton points out that "only through continued socialisation in the life of a group can one become fully aware of its symbolisms and socially shared realities" (Merton 1972, p. 15).

In 2009-2010, the first round of in-depth semi-structured interviews was undertaken with 24 women who had been diagnosed with a chronic illness and who were currently or previously in paid employment. The project had the broad objective of developing a better understanding of the experiences of women with chronic illness in the workplace, these included: issues of disclosure, stigma, performance of emotion work and other forms of presentational emotion management, managerial attitudes, and power and disclosure (see Werth 2015; Werth et al. 2018). Through the process of theming the data we discovered an unexpected theme relating to the personal outcomes of working with a chronic illness. This paper draws on both the first (2009-10) and the second rounds of interviews (2016-17) wherever this theme emerged. For some participants this allowed a longitudinal view of their outcomes, whereas for other participants they were able to reflect on specific events in their life

from a particular point in time (ie at the time of the interview). This paper draws on five participants from one or both rounds of interviews as illustrative of the themes.

The ages of participants ranged from 29 years to 63 years, and they worked in a variety of professional and non-professional roles. Pay ranged from less than $10 000 to over $100 000 per year. In 2016-17, as many participants as possible are being followed up with a subsequent interview that is structured similarly to the initial interview. Data from the interviews carried out so far has been analysed thematically and data relating to the "domestic influences" experienced by these women is presented in this paper.

Domestic influences on work outcomes

Women with chronic illness engage in different ways with colleagues, friends and family in order to present, as far as they are able, as a "well" person. This involves three layers of management, which are identified as negotiating the self, managing the self and managing the perceptions of others. These layers of management are particularly useful for examining the way women with chronic illness manage caring responsibilities and paid work in such a way that they have the best chance of remaining employed, although this outcome is not assured. Yoo noted that women are "trained to care and to be concerned about the feelings of others over and above their own feelings and concerns" (2010, p. 213). Women with chronic illness are particularly disadvantaged by this tendency to prioritise the needs of family above their own. We see in the data that they try to find ways to manage personal situations to minimise disadvantage.

Negotiating self

Negotiating self involves how women with illness see themselves. The perception of self as one who is "sick but fit or fit but sick" (Pinder 1996), provides a complex view of one's own disease, its impact on the individual and the environments in which it needs to be managed. An understanding of the individual's belief in self is also important in developing strategies for negotiating the self.

Professional women were more likely to display the ability to adapt their careers to allow for the difficulties of their disease. Lucy and Cheryl were also able to change the direction of their careers after their diagnosis, with family support to do so. Interestingly, the support of extended family is important here and assisted these women to undertake the adaptations that they needed to change the direction of their careers.

Lucy was a brand manager for a national company when diagnosed with Crohn's disease, but after experiencing disadvantage in her workplace she decided to study in order to work as a lawyer in her mother's law firm. She had the support of her extended family which enabled her to do this. Lucy navigated the difficulties of the diagnosis by leveraging her family's support to find work that allowed her to balance her work and her illness, this work has also enabled her to work from home to care for her young children.

Cheryl who was previously a nurse, undertook additional study in order to change her career because of her diagnosis with arthritis. She studied and achieved a position as a manager, which would ultimately enable her to transfer to be closer to family in another city. The support of family was important for her and facilitated her change of career and also would provide support with possible future difficulties related to working and her disease.

The support of family in both of these cases was instrumental in their success in changing their careers despite their illness. Both Lucy and Cheryl appeared to derive self-belief from knowing that they could perform in high level professional roles with the support of their extended families. Support from family also allowed these women to explore opportunities to find work that fitted the needs of their illness, however outcomes are not always positive. There is an assumption that "disability is everywhere constituted the same way," (Pinder 1996, p. 150) but the following sections will examine the circumstances of capable women who have experienced a variety of outcomes while attempting to navigate the difficulty that exists between those with chronic illness and a non-disabled society (Pinder 1996).

Managing self

Managing self is the next layer of management that women with chronic illness are required to navigate in order to preserve their outcomes in the workplace. Managing self is a way that women with chronic illness can project an image of capability in multiple spheres of life. They might adopt strategies relating to working hours, medical and self-care, as well as managing personal priorities.

Heather, who suffered from rheumatoid arthritis, worked as a high level senior public servant, she had a number of outside influences that affected her perceptions of what it meant to be sick and the importance of coping in each aspect of her life. Heather's sister was diagnosed with a chronic illness and Heather felt that it was important to support her through the process of learning to deal with her diagnosis. Heather commented that, "Of course part of the problem, for both us, is that we're both pretty independent women. We feel pretty miserable about things [due to illness] but we sure as hell don't want people helping us all the time either." Heather also pointed out that she worried about being a "burden" for her husband because of her health, but while she had this concern she was also supporting her sister so that "she [didn't] feel like she's isolated or 'in this' by herself." Heather valued her independence. Her outcomes within her workplace indicated that she was extremely capable. She admitted to working because:

> I wanted the challenge not because I wanted to be anybody. Not because I wanted to be the Prime Minister of Australia or anything like that, it was always about the challenge for me. And so I guess for me now, I don't feel like my body wants to keep doing it. And so it's that real conflict between what your mind or your heart might want to do and what your body wants to do.

Through the various roles undertaken by women with chronic illness, normative role expectations are brought into question and implicated in the wider social expectations of caring and family responsibilities, while also caring for themselves (Pinder 1996).

Managing perceptions of others

The final layer of management relates to the way women with chronic illness manage the perceptions of others. Yoo et al noted that "telling others about illness takes emotional resources and opens one up to vulnerability, scrutiny and possible

rejection" (2010, p. 206). It's because of these risks that women with chronic illness undertake some form of presentational emotional management (Bolton & Boyd 2003) also known as emotion work (Hochschild 1983). Presentational emotional management can be defined as a way of presenting oneself to others to produce particular outcomes. Chronic illness creates a disruption in life generally, but also in social situations, these relationships influence a woman's ability to mobilise resources (Bury 1982).

Society generally expects that resources should be provided to individuals with chronic illness through the medical system, and that people should take time away from social responsibilities, seek appropriate medical assistance and return to their responsibilities when they are well (Parsons 1970). Bury points out that:

> Important though the place of medicine is in facilitating and constraining the adaptation of individuals (and those with whom they live and work) to the presence of chronic illness, this is clearly not the only, or necessarily the most important, issue (1982, p. 180).

Medicine has also been noted as forming part of an ambiguous relationship between individual with chronic illness and their workplace (Pinder 1996). Medical support for women with chronic illness rarely covers the "limits of tolerance" they will face within their families and within their workplace (Bury 1982). Bury also notes the "disruption of reciprocity, the problems in legitimating changed behaviour and the overall effects of stigma associated with chronic illness, all affect the individual's ability to mobilise resources to advantage" (1982, p. 180). More recently the research of Thomeer et al (2015) and Karraker and Latham (2015) has shown the detrimental impact that these problems create within the personal lives of women with chronic illness.

Heather, despite admitting to moments of doubt about her future at work, also made this comment: "I'm pretty assertive and if I've heard people [at work] have had something to say about it [how she manages work and illness], I usually just go and confront them. That, of course, makes me a bit scary." So while at work she was in control and coped with her managerial role, privately she had to come to terms with her sister's illness and also her father's degenerating illness, which required that her mother care for him until his passing. The experiences within her family relating to

health, influenced her own approach to her ability to continue working in the longer term.

Heather's attitude towards illness and coping was influenced by her family's experiences of illness and caring as well as her own desire for satisfying work. She had negotiated for the conditions at work that she needed while she also managed the needs of her extended family. At the time, Heather felt that she might not continue to work because of the conflict that she felt between what was important to her and what her illness allowed her to do. It appeared that she may have been seriously considering, at some time in the future, cutting short her career to improve the management of her illness and to avoid being a burden to her husband. After the initial interview Heather did leave her job, not because of her illness, but because her husband's job required that they move overseas. Heather's experiences also appear to have given her confidence in undertaking presentational emotional management within her workplace to preserve her appearance as a capable manager, but also in her personal life when providing support to other family members.

Rhonda suffered from arthritis and her experience as a small business owner with a husband and teenage children was quite different. Rhonda's personal life influenced her ability to continue working because, not only did she have her own business to manage, but she also played a role in her husband's business. She said that her illness significantly changed the way her family managed at home.

> My husband, I think he kind of had a mid-life crisis at the same time [as my diagnosis] because he would try and bully the kids into doing the chores and he would stand over them like a sergeant major and I think they really resented that. They didn't mind helping but they thought he should help too. [Sometimes] I'd say I don't feel like cooking dinner tonight and he'd say, "It doesn't matter I had something while I was down town." And I'm thinking, "What about me?" [He] just shut down. Or, if I said, "I can't hang out the washing", he'd say, "That's ok, just do it tomorrow." In the end, I just used the dryer.

She went on to say that her diagnosis and the subsequent changes in her life had a significant impact on her husband. "He didn't know how to cope at all. And we're separated now as a result of this I think." Rhonda's illness resulted in the loss of her

source of income and possibly her marriage. Because of the lack of support she experienced at home, Rhonda was unable to continue attempting to work. Rhonda's situation was different to other participants in this study because she was self-employed. She had full responsibility for her income and would appear to have a high level of control of her work context. However, her illness, the size of her enterprise and its reliance on her personal skills meant that her only source of support was her family. Rhonda reported that her children were helpful but were in their late teens and in the process of leaving home for work and university. So the support role fell to her husband who was unable to provide her with the assistance she needed. Rhonda was unable to undertake the presentational emotional management needed in her caring and work roles, she also struggled with the lack of reciprocity within her home relationships and she felt there were problems with legitimating her behaviour which was caused by her arthritis. Rhonda was physically incapacitated and could not undertake some household tasks for lengthy periods of time, but her husband seemed to have placed a limit on the support available for her, as if she had a short term illness. He would allow her time away from the responsibilities he perceived to be part of her role, but he then expected that she would be able to provide assistance again in the short term. Rhonda reported "I was so tired and exhausted, I just lay on the bed for 18 months I didn't do anything. It wasn't a good time."

After losing her business because of illness and separating from her husband, Rhonda decided to study for a change of career. She moved to be closer to her brother's family in order to have the support needed to undertake a university course. After the changes in her life, she started on the first layer of management – negotiating self – in order have a life and career that she enjoyed and could manage with arthritis.

Melanie worked in a public service role and experienced the unhelpful attitudes of her family to her illness. These influenced the way she managed her work and juggled the sometimes competing responsibilities of family and work. Melanie said, "Getting your head around putting yourself first is quite a difficult thing, especially when you're a mother and you have to be available for the children and my husband and that sort of thing." She explained, "My husband's highly strung, so if I'm having a

bad day sometimes he's not understanding." This affected her work as she needed to decrease her working hours by one day per week in order to better manage her health. She said, "This position originally was five days, and I've already cut it back to four, and we've got kids in private schools and that sort of thing. My husband wasn't very impressed that I was going to cut it back a day, so I can't cut back any further," although she indicated that would be her preference. Melanie's husband required reciprocity in terms of meeting costs of their children's schooling and may have prevented her from achieving exactly the work related outcomes that would best suit her illness. Even though Melanie had a good working environment that enabled her to cope quite well with her illness at work, it was her lack of family support that proved to be the most negative influence on her outcomes at work. It was not that her home influences prevented her from attaining particular levels in her professional life, but that they kept her from working the hours which helped her to best manage her illness.

Discussion and conclusions

The Disability Movement advocates for the use of the 'social model' for providing a means for understanding disability and chronic illness. Oliver and Barnes state that, 'while impairment may impose personal restrictions, disability is created by hostile cultural, social and environmental barriers'(Oliver & Barnes 2010, p. 552). The attitudes of others may form part of the external barriers which influence disability or chronic illness. Over time these attitudes have developed around the personal characteristics and behaviours that are believed to constitute 'normal' in work or social roles. The health and wellbeing movement has provided another form of 'normal' which is unattainable by those who have a chronic illness. These programmes, for example the Global Wellness Institute, might characterise ill health as costly and which causes employees to become 'unmotivated, disengaged and unproductive' (Global Wellness Institute 2016, p. i), while conversely promoting health as bringing 'energy, focus and motivation' to the workplace (Global Wellness Institute 2016, p. i). Other research has suggested that wellness programs are able to improve organisational success (Hillier, Fewell, Cann & Shephard 2005) and enhance morale (Ngeno 2014). The health and wellbeing movement has reintroduced, to workplaces and into broader social thinking, the perception that

chronic illness is a 'negative label, rather than a political description of socially constructed barriers' (Foster 2017, p. 8). This shows a marked lack of understanding of the effects of long-term impairments that have no cure. Foster pointed out that

> A model is needed that is capable of challenging a range of value judgements based on normative definitions of health, ability, appearance and behaviour (among other things), and which is concerned with the empirical reality of workers' qualitative experiences' (2017, p. 9).

Social definitions of "normal" and the resulting expectations of women with chronic illness, have traditionally moved from society into the workplace (see Parsons 1970), however the development of negative perceptions relating to wellbeing in the workplace have the potential to negatively influence the social expectations of women with chronic illness in other spheres of life. Fostering an inclusive culture which welcomes difference would be important to overcoming normative definitions of wellbeing.

The characteristics of women at work include various elements of disadvantage. Vickers extended this discussion to include the difficulties of working with a chronic illness:

> For these women, all the problems reported elsewhere concerning discrimination, glass-ceilings, "invisible" barriers, sexism and stereotyping still exist. However, in addition to this, they live with the workplace marginalization and stigmatisation associated with unseen chronic illness (2001, pp. 62-3).

Judgments made regarding their "resilience" can now be added to this list of the disadvantages. "Resilience techniques [as part of wellbeing programs] normalise the idea that everyone could potentially 'cope' and be 'improved' if only they were willing to learn them" (Foster 2017, p. 7). The difficulty with a wellbeing approach is that it focuses on improving health outcomes or wellness in order to reach particular organisational or role related objectives and that additional normative expectations may be placed on individuals. These are individuals who are very often able to function in a capable manner, but need to undertake tasks in a different way due to their chronic illness.

The application of social stigmas to those who appear to be different in their social roles, readily occurs to those with chronic illness. Women who undertake paid work and caring roles are at risk of marginalisation both at work and at home and these women might feel obliged to make presentational choices in order to manage expectations in these spheres. Outside judgments about what constitutes an "ideal" worker, or "ideal" mother or wife, encourage women to manage the difficulties of their illness in different ways in order be able to present in ways that "project conformity" with social expectations (DeJordy 2008).

If we move outside the sphere of wellbeing initiatives, we could suggest that a working definition of wellbeing for women with chronic illness would include understanding and accommodations in social and work environments. Flexible hours and location of work would also contribute to their wellbeing as a person with chronic illness, but the context would need to avoid "adapting work from an able-bodied ideal, so that variations to a job are viewed as inferior or concessions to an 'ideal' norm" (Foster 2017, p. 8).

Women with chronic illness in their personal and work environments are "doing it all." They negotiate self through building their self-perception and self-belief; they manage self by assessing priorities, navigating medical and self-care and choosing work and social commitments carefully; and, they manage the perception of others through the use of presentational emotional management. Each of these strategies are specifically applied and may have different outcomes, however through the application of these actions each of these women have displayed agency and resilience in attempting to influence their own personal and labour market outcomes. These are women who are the "glue holding everyone together" despite, at times, being desperately ill themselves. The way these women manage their wellbeing is through wielding what little power they have over their circumstances to manage various personal and professional factors.

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