Chapter 12

Issues of power and disclosure for women with chronic illness in their places of work

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Introduction

The impact of a disclosed chronic illness has the potential to influence the power women with chronic illness are able access in the workplace. The disclosure decisions of women with chronic illness in their places of work are influenced by a number of factors, these include: the stigma associated with their diagnosis, available flexibilities, and the individual's power within their workplace. Access to labour market power improves the workforce outcomes of individuals with disability and chronic illness (Werth 2012). The topic of power as it relates to women with chronic illness is largely unexplored in the literature. This chapter contends that without disclosure women with chronic illness cannot access specific accommodations. The impacts of disclosure have previously been explored by Werth (2010, 2014).

Literature: power

Power and the disclosure decision are two factors which influence the outcomes of women with chronic illness. Disclosure theory is drawn from the literature on social groups who have potentially socially stigmatising characteristics, which include sexual identities (DeJordy, 2008) and mixed racial backgrounds (Clair et al., 2005). An important aspect of the experiences of women with chronic illness in the workplace is the power that they are

able to hold or exercise. Researchers who examine chronic illness in the workplace tend to focus on the disadvantaging effects of chronic illness (Pinder, 1996; Vickers, 2009) but not specifically on the role that power plays in their experiences. If individuals with chronic illness wielded some form of power it would be expected that they would experience fewer negative working outcomes.

The study of power has a long tradition in political sociology (Bachrach & Baratz, 1970; Dahl, 1961; Lukes, 1978). The literature in that field experienced a number of important developments from the 1950s through to the 1970s with the debates about "faces of power", which relate to whether and how power is exercised and is observable. The debate was advanced by Dahl who rejected a prevailing conception of power based on reputation. He indicated that greater rigour was required and proposed what he saw as a precise definition: "A has power over B to the extent that he can get B to do something that B would not otherwise do, (Dahl, 1957, pp. 202-3).

This came to be known as the first face of power. He argued that the pluralist system is comprised of competing interests. Within this framework, "power… can be observed in the outcome of decisions, where the overtly conflicting interests of employees and corporations are somehow resolved" (Peetz, 2006, p. 75). In the negotiation of agreements between workers and corporations, "if the workers got what they wanted, you would say that they had considerable power" (Peetz, 2006, p. 76). While workers with illness might not enter into negotiations in the same formalised manner, the outcomes of their requests for accommodations, where they are seen to compete in some way with the concept of good business, may be evidence of their power.

Bachrach and Baratz (1970), a few years later, identified what they claimed was a second face of power. They contended that: "the pluralists themselves have not grasped the whole truth" (1970, p. 4). The second face is thus where the interests of one side are

subverted because key issues of concern to them are absent from decision making processes. This aspect of power may also apply to those with chronic illness, in situations where the individual has chosen non-disclosure, due to a need for privacy. That is, a person with chronic illness may be unable to have their specific interest relating to their chronic illness considered if their illness has not been disclosed. In this circumstance, disclosure may provide the key to power. Where there is no disclosure there may be lower levels of power available to people with chronic illness through the "second face" effects. In addition, employers may display adverse social attitudes which discourage or prevent a full disclosure of work-related information pertaining to the illness. Workers with chronic illness may feel that they are unable to raise matters because of indications from management that they would not be sympathetic. Thus, while conflict is overt in the first face of power, it is covert in the second face.

In the 1970s, Lukes developed a third face of power. This is where power is exercised through ideologies or values that prevent people (with lower power) from recognising their true interests. This focuses on the role of ideology and attitudes. Lukes said that this third face of power "allows for consideration of the many ways in which potential issues are kept out of politics, whether through the operation of social forces and institutional practices or through individuals' decisions" (Lukes, 1978, p. 78). The third face is when conflict is latent (that is, present but not active) because the interests of the stronger prevail over the weaker (Peetz, 2006, p. 75). In analysing how power is exercised in relation to women with chronic illness at work, it is important to understand these different faces. In practice, this study mainly focuses on the first two faces. We may not be able to observe the third face, as that would only really be exercised if the development of ideology in the workplace was such that women with chronic illness saw no conflict of interest between themselves and managers or

co-workers. This is not an idea that is well developed in the literature or observed amongst our interviewees.

Resource dependency theory (RDT), as put forward by Nienhüser (2008) is useful in developing a more complete understanding of power. Resource dependency theory reflected some of Max Weber's ideas of power, which argued that power rests on an individual's or a group's ability to achieve their ends no matter what opposition they face. RDT also draws on the thinking of Richard Emerson (1962) and Oliver Williamson (1975). Amongst other key proponents have been Jeffrey Pfeffer and Gerald Salancik (1978) as well as Mark Mizruchi (1982) and, more recently, Alejandra Salas-Porras (2012). There are several key ideas here, but the core notion is that whoever controls resources has power over those who need access to those resources (Nienhuser 2008). Two key aspects are:

– the greater the dependency of B upon A, the more power A has over B; and
– the dependence of B upon A is: (1) directly proportional to B's amount of motivational investments in goals mediated by A and (2) inversely proportional to the availability of those goals to B outside the A-B relation (Emerson, 1962; Nienhuser, 2008).

Thus, workers in strategic positions in an industry (e.g. those holding specialist technical skills or a central role in a production process) have more bargaining power if they take strike action than do low skilled workers, because the company is more dependent upon the former's resources. You will often hear of particular workers possessing, or not possessing, "labour market power". Those who possess labour market power have skills or knowledge that an organisation may need. Sometimes it might be "external" labour market power – their skills are in high demand from many employers but short supply. At other times their skills may be fairly generic but they have extensive "specific" knowledge – "corporate history" – that their employer values and is dependent upon, even if other employers may not feel the same way. Those workers can be said to possess "internal" labour

market power. Either way, whether they negotiate individually or bargain collectively, those with high labour market power will be in a better position to extract gains from their employer.

Resource dependency theory provides an additional perspective that may help explain how some women with chronic illness might exert higher levels of power than others in their workplace. Power accrues to entities that have resources of which others wish to make use. "A fundamental assumption of resource dependence theory (RDT) is that dependence on 'critical' and important resources influences the actions of organisations" (Nienhuser, 2008, p. 10). Thus, workers with skills or knowledge which are in short supply and high demand may be able to access the accommodations they need because of the dependence of the organisation on the resources that they possess (Peetz & Murray, 2013).

This "labour market power" is also referred to as "structural power" by some writers. It is the "power that results simply from the location of workers within the economic system" such as that from "tight labor markets" and is contrasted to the "associational power" that comes from workers combining to form trade unions (Wright, 2015). Associational power also takes advantage of the dependency or employers upon labour resources, by making those labour resources harder to access where the employer does not act in the interests of labour, and therefore is consistent with resource dependency theory. Associational power becomes critical for some workers who do not have access to structural or labour market power.

Literature: disclosure

An individual's "social identity is derived from the groups, statuses or categories that the individual is socially recognised as being a member of" (Clair et al., 2005, p. 80). Characteristics, which indicate belonging to particular groups, are clear indicators of membership. Where these indicators are invisible, people may have a choice about

disclosure. Literature on disclosure of invisible social identities derives from sexual identity research (Ragins, 2008).

As sexuality is not easily observed, disclosure of sexual orientation in the workplace depends on the value of passing to the individual. Research indicates that most workers limit the disclosure of their sexual identity in the workplace (Ragins, 2004, p. 52). Badgett acknowledges that while lesbian, gay and bisexual workers disclose for similar reasons, "the differences in economic and workplace contexts that gay workers find themselves in because of their race and gender may lead to different disclosure patterns" (Badgett, 1996, p. 43). The decision to disclose may also affect their occupational choice and be affected by their level of income (Escoffier, 1975; Schneider, 1986; Gates & Viggiani, 2014).

Individuals from multi-racial backgrounds may also have an option about disclosure (Leary, 1999). Decisions made by individuals with invisible social identities about whether to pass (hide a particular social identity) are made based on an understanding of the risks of disclosure. One of the factors which influences the disclosure decision is the degree of stigma associated with a particular social identity. Non-disclosure may represent "a form of self-protection" (Leary, 1999, p. 85) in situations where stigma is perceived to be a problem. The way that individuals with differing social identities approach disclosure varies. It depends on the social setting, the reactions of others and the stigma generally associated with that particular social identity.

Women, power and chronic illness

Women with chronic illness are disempowered through the absence of disclosure, which creates difficulties in terms of the second face of power. Some individuals might choose a strategy which includes disclosing or "coming out" of the closet of illness (Vickers, 2003). "Coming out with illness can be liberating – a move from the 'resistance identity' of defensiveness stemming from a devalued sense of self, to a 'project identity' where one

proactively constructs a new identity that redefines her position in society" (Myers, 2004, p. 268). The decision to "come out" is governed by a variety of factors including the nature of the disease, its symptoms, the expectations of illness held by the individual and their family and colleagues. These combine to establish the potential results of revealing their disease (Bury, 1991, Charmaz, 2010).

The way that individuals choose to present themselves and manage information about their illness in their workplace will influence their disclosure decision. Charmaz points out that, "understanding chronically ill and disabled people's present and preferred identities and the context of their work are prerequisites for understanding the form, content and logic of disclosing illness and disability in their respective workplaces" (2010, p. 16). Decisions about disclosure also need to take into consideration whether the workers require accommodations (Charmaz, 2010). Any accommodations or flexibilities that are made available to an individual with chronic illness will increase the power they have due to second face effects.

Methodology

This research was undertaken using qualitative research methods. Twenty-four semi-structured interviews of employed women with chronic illness were carried out. Participants were employed in a range of positions with a variety of pay levels. These including nurses, teachers, a lawyer, an engineer, a town planner, a senior public servant, a home help assistant, and retail assistants. They varied in age from 28 years of age to over 60 years of age and were from various cities and regional areas throughout Australia. Illnesses included various forms of arthritis, cancer, inflammatory bowel disease, depression, and lupus.

Participants were found using a snowballing technique. People with chronic illness might prefer non-disclosure, for this reason it can be difficult to access this group as they form a hidden population. The research was advertised with various chronic illness support groups including Kidney Health Australia and the Crohn's and Colitis Association.

Participants were also sought via the Liquor, Hospitality and Miscellaneous Workers' Union (LHMU) now called United Voice, as an avenue for specifically accessing workers in industries which employ predominantly casualised and lower paid workers. The snowball chain of contacts worked well for those in professional positions, more deliberate attempts to access those with lower incomes were required.

The stories of these women are presented as narratives. Chronic illness influences each part of an individual's life. Using a narrative approach provides a greater understanding of these influences and the connections between each of them. "Narratives are constellations of relationships (connected parts) embedded in time and space, constituted by causal emplotment" (Somers, 1994, p. 616). The use of narrative gives information which is more accurate as it is framed within its context. Issues of illness, power and disclosure form interconnected parts of each participant's story. The opportunity to understand relevant themes from events and the relationships between events is enabled through the use of narratives. However, for the sake of brevity in the section on unions only the salient points of each narrative are examined.

Disclosure and power

Disclosure decisions can be made voluntarily and with the aim of achieving positive identity outcomes. Disclosure of an illness may vary with the goals of each individual and the social environment in each organisation. The power that workers have when they disclose influences their outcomes at work. Resource dependency theory helps explain the influence of labour market power on the outcomes of these workers. Here we see chronically ill women seeking to influence their outcomes by considering the positive and negative effects of disclosure on identity, which show the faces of power at work.

The power exhibited by participants reflected the first or second faces of power and influences explained by resource dependency theory. The first face of power was evident in

the experiences of the women who had disclosed, amongst whom resource dependency theory helped to explain how the power of those with skills and knowledge were of value to the employer. The second face of power was evident where disclosure had not occurred and this negatively influenced the power of that individual, by keeping the interests off the agenda for decision making.

High levels of external or internal labour market power help to mitigate the difficulties associated with working with illness. Pinder highlights some of these difficulties of managing the way individuals with disability (including chronic illness) appear at work:

> What disabled people are faced with at work is the task of establishing trust or repairing trouble, which in turn highlights the differential ability of individuals to persuade employers to "run with" ambiguity and disturbance, and of organisations' [ability] smoothly to dispose of it: one of the classic tensions of contemporary life (1995, p. 607).

The greater the amount of labour market power resulted in better management of working circumstances by participants. Improved labour market power also improved their balance of work, illness and the impact on their identity.

Emily

Non-disclosure appears, from the data, to be quite rare. Emily was the only participant who had decided not to disclose. Emily was a highly qualified engineer with Crohn's disease. Emily was concerned about the way she appeared to her colleagues and was reluctant to disclose, she was also unwilling to reveal the impact that her illness had on her life. Her efforts to pass, in order to fit in with the dominant social paradigm within her office were considerable. Pinder states that: "unruly bodies which fail to do their owner's bidding may release powerful messages that affect the presentation of ourselves" (1995, p. 610). Those with chronic illness are aware of this and undertake to manage the way they present

themselves in various social spheres. “Increasingly, organisations put pressure on workers to maintain a positive “face” to the public and others in the workforce” (Schaubroeck & Jones, 2000, p. 182). Choosing to disclose is a decision which is influenced by the attitudes of colleagues and supervisors. Organisations create social expectations which affect the disclosure decisions and ultimately the ability to preserve their identity as a capable worker with illness.

Emily kept to herself and focused on managing her illness, keeping the amount of sick leave for which she applied to a minimum. When she required time off for procedures, she obtained a medical certificate and provided only a minimum of required information to her supervisor. There were indications that Emily’s boss might have been supportive had she chosen to disclose, however her preference was to preserve her privacy. The fact that she worked in an all-male office was a factor in her decision not to disclose, particularly because her disease was one that carried stigma (Charmaz, 2010). Neither the symptoms nor procedures were easy to discuss in her work environment, causing Emily to consider her disclosure decision carefully. She appeared to be fortunate to have such an understanding boss. Not all supervisors are so willing to give sick days regularly without requiring additional information from the employee.

Emily’s non-disclosure brings with it the effects of the second face of power (Bachrach & Baratz, 1970), where she was unable to have her interests relating to her Crohn’s disease considered in her workplace because of her non-disclosure. This results in lower levels of power available to Emily because of these “second face” effects. Emily’s non-disclosure meant that she was unable to use her labour market power to achieve better working outcomes as they related to her illness. This is because disclosure in addition to labour market power has potential to facilitate understanding and support from supervisors.

Samantha

An illness may have immediate implications for colleagues and involve the safety of the employee, these factors may facilitate early pro-active disclosure. Samantha had particularly severe and difficult to control diabetes. Upon her appointment to a new position, Samantha elected to disclose her diabetes so colleagues could be prepared should she collapse (have a "hypo") at work. She said that she would not disclose at an interview, but once she had the job she took a proactive approach and said, "I have this condition and this is how we handle it." Very few employers had expressed any concern about this, but Samantha reported that they often did not fully appreciate the difficulties associated with diabetes. Once they realised how difficult her illness was, the response of her employers changed. She felt her illness had limited her employment prospects due to the attitudes of employers. In other casual positions she found that her rostered hours were reduced until eventually she was forced to seek work elsewhere. Samantha worked in a variety of casual positions, often in the hospitality industry, where she could find work easily. She had low levels of labour market power, because of her employment on casual contracts and because her labour was easily replaced. Consistent with resource dependency theory, we can see that the lack of labour market power held by Samantha contributed to her inability to access the understanding she needed. Where organisations prioritise employees of "value", those with lower levels of power are likely to experience less favourable outcomes.

Debbie

Debbie's time working in a large organisation involved a number of casual contracts and also a permanent part-time position. She developed a network of understanding people to whom she could talk about her illness, and also had the support and understanding of one of her bosses. She had learned how to discuss a potentially stigmatising illness without feeling embarrassed. Debbie had extensive experience in the organisation which gave her some

power and enhanced her identity to offset any potentially stigmatising or negative effects of disclosure. She was able to continue working on contracts with hours that suited her. In contrast to Samantha, Debbie had improved workforce outcomes because of her power.

Maree

Maree suffered from epilepsy when employed in a graduate nursing position. While in this role, she experienced considerable disadvantage because of the stigma associated with her illness, which resulted in a loss of a professionally credible identity in her workplace. Maree subsequently moved onto a different position with a different employer where she received understanding for her health conditions (epilepsy and later, arthritis). The positive employer and colleague attitudes to her epilepsy resulted in improved work outcomes for her in this workplace when compared with her former employer.

The combination of her external and internal labour market power, as a more experienced and senior nurse, and a less stigmatising illness (arthritis), resulted in positive workforce outcomes for Maree. Peetz stated that, "You can see who has power by seeing whose interests prevail" (2006, p. 75).

Donna

Donna suffered from ulcerative colitis and later developed bowel cancer. She worked as a teacher at a technical college, and was employed on an on-going casual basis, this assisted her with the management of her illness. Her diagnosis with cancer resulted in surgery to have her large intestine removed. Donna's colleagues had taken on additional workload to assist with her absence. She had made an effort to reduce the load on her colleagues, who were prepared to grant her extensive understanding and assistance. Donna reported that, "They were really great, really, really great." After her surgery, Donna returned to work and was still pleased to be employed there some two and a half years later.

Donna's disclosure enabled her to access understanding and flexibilities in her workplace. In this way she exhibited power, through the second face of power, in her workplace. She possessed the skills required by her employer and was willing to accept insecure work. These resources provided by Donna to her employer also contributed to her power in the workplace.

Unions

Another form of power—associational power—is available to workers through union membership. Unions are able to support the workers who have insufficient power to represent themselves regarding concerns with their treatment at work. This is turn is able to assist with the preservation of professional identity of women with chronic illness in their workplace. Participants were more likely to be union members if they were in traditionally union dominated fields (such as nursing and teaching). Eleven women in the study were union members, eight of those were either in nursing or teaching professions. This discussion focuses on the themes associated with power and union membership. This section focuses on specific events and actions from the narratives of participants.

Joy

Joy, a cleaner in a shopping centre, was a union member. Centre Management encouraged her to join because they had previously had difficulty with her employers, who were subcontractors within the Centre. Joy had diabetes and her supervisor was reluctant to allow her a short break in the middle of her shift to eat. This was important to maintain stable blood sugar levels because of the physical type of work she did as a cleaner. Joy resolved the situation by simply taking a break without approval. It is not clear how much additional power her union membership added to her ability to manage the situation, but it is possible that it contributed to an improved outcome for Joy. In this situation Joy's power was accessed

through disclosure and union membership. Disclosure also allowed Joy some power due to the seriousness of her disease and the importance of the flexibility.

Sally

Sally had witnessed the poor treatment of a colleague with mental illness by their employer and she joined the union as a result of this. She said, "The whole reason I joined the union was because I'm a bit worried about them [the employer] using my condition against me one day… it's peace of mind." Sally had ulcerative colitis and only disclosed to colleagues whom she felt able to trust. Sally explained that she had a dilemma regarding what was an appropriate amount of information to tell her supervisor, she felt that, "It was probably best not to tell the bosses too much information." The dilemma of disclosure is that the outcomes are often unknown. So while it would appear that disclosure did not add power to Sally in her situation at work, she joined the union which could provide her with the additional power she needed to handle any difficult circumstances which might arise with her supervisor, thus enabling her to preserve her identity as a capable worker.

Melissa

Melissa's disclosure of her heart condition was necessary in order to preserve her health, but after her disclosure she found at times there was little support or understanding available to her. Melissa's symptoms had worsened to the point where she needed to reduce her hours of work, but to do this she was required by her employer to bring a medical certificate to work each week to allow her to have one day off. Her employer placed further hurdles in her way, requesting verification of her illness from doctors nominated by her employer, they also specified that she undergo a series of tests which had already been carried out by her own specialists. After waiting to have these procedures, continuing to work and managing her supervisor's seeming unreasonable requests, she also needed to manage her deteriorating health. Understanding from supervisors regarding chronic illness and the

culture of the organisation, influence the way disclosure is received by a workplace both positively and negatively. Melissa eventually went to the union for assistance. She said, "Once they got involved it was solved very quickly." Melissa's disclosure was important for her to receive the flexibilities she needed to manage her work, but the power she needed to gain access to these and preserve her identity as a capable professional came from her union membership.

Conclusion

This chapter situates the working circumstances of women with illness in relation to power. Much of the existing literature refers to the disadvantage created by chronic illness without linking it to power. Now we can think of three ways in which the concept of power may be relevant to the issue of disclosure for workers with chronic illness.

First, disclosure influences whether issues are discussed and determined, or kept hidden and off the agenda for decision-making. If disclosure does not occur, then the worker with chronic illness suffers from the second face of power: matters of concern to her are permanently off the agenda for decision-making. If she discloses, then at the very least the matter must be decided, and the first face of power is at work.

Second, if matters are up for decision, then chronically ill workers with the greatest labour market power—upon whose resources their employer is most dependent—will be those who are most likely to be able to have their accommodations met. For many workers who lack this labour market power, the expectation that they will not do well discourages them from disclosing in the first place, and exacerbates their position of low power.

Finally, some workers' use of trade unions shows their willingness to make use of the associational power that unionism brings—that is, the power from combining the interests of workers. This is only available, of course, to those who belong to a union and who

disclose—and whose union is capable of acting in their interests. The existence of potential associational power may also be a factor in encouraging some people to disclose.

Disclosure provides the key to accessing power for women with chronic illness and the preservation of their identity as a capable worker. Where the individual has not disclosed they are significantly disadvantaged due to the way the second face of power weakens their position. Their interests, relating to their chronic illness, are prevented from being advanced. The difference between the first and second faces of power combined with resource dependency theory, including the availability of structural or associational power for some of those with chronic illness, help us understand disclosure outcomes. The cases here illustrate the importance of having the skills and knowledge, or access to other sources of power such as union membership, in order for these women to obtain the accommodations that they need for their illness.

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