

Chronic illness and women: a model of disclosure at work

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Abstract

The paper examines the factors which form part of the decision process, undertaken by women with chronic illness, when considering the disclosure of information about their chronic illness in their workplace. A model is presented based on the individual's assessment of, the risks of disclosure, risks of non-disclosure and the influence of personal preferences for privacy or openness, which form the basis for decisions regarding disclosure. A number of factors are assessed by women when considering disclosure and these can be broadly grouped into: expected management and peer support, stigma associated with illness, severity or variability of illness, individual labour market power, institutionalised contingent flexibilities, institutionalised non-contingent flexibilities and outside influences such as caring responsibilities. The various aspects of this model and the relationship of each of these factors to the disclosure decision, will be assessed on the basis of the preliminary data drawn from a study on the workforce outcomes of women with chronic illness. The use of the model to interpret the qualitative data shows that disclosure decisions are influenced by a broad number of factors. Each of these factors need to be considered during in the process of evaluating the risk of disclosure or non-disclosure of a chronic illness in the work environment.

Keywords: Chronic illness, Employment, Women, Disclosure, Disadvantage

Introduction

The decision to disclose a chronic illness at work is one that is difficult and is influenced by a number of different factors. Women with chronic illness choose to undertake strategies of disclosure or non-disclosure to minimise their risk of being treated differently in their place

of employment. Chronic illness is defined as an on-going illness which unlikely to have an end point. This paper will put forward a model of disclosure which is based on the assessment of, the risks of disclosure, risks of non-disclosure and the influence of personal preferences for privacy or openness, which form the basis for decisions regarding workplace disclosure. It will also examine qualitative data and literature on: expected management and peer support, stigma associated with illness, severity or variability of illness, individual labour market power, institutionalised contingent flexibilities, institutionalised non-contingent flexibilities and outside influences such as caring responsibilities.

A Model of Workplace Disclosure

Existing research on the working lives of women with chronic illness has highlighted the disadvantage that these women experience on various fronts. The key to gaining support in the workplace lies in the decision to disclose or not to disclose their illness to others at work (Vickers 2010). This disclosure may be undertaken with the best of intentions, perhaps to arrange the flexibility needed to manage symptoms of illness at work (Bury 1991). Disclosure might become necessary when symptoms become obvious or treatment options require lengthy or frequent absences from work (Myers 2004). Vickers reports that illness disclosure has the potential to 'do much harm: to identities, confidence, relationships, careers, financial futures, and to choices' (2010: 10). This damage is something that most workers try to avoid, as they attempt to comply with social expectations (Goffman 1976), the influence of these expectations on the behaviours they adopt as a 'sick' person is far reaching. These women are aware that disclosure cannot be taken lightly and has the potential for undesirable consequences (Myers & Grasmick 1990).

The pressure to comply with social expectations causes individuals with illness to fear decisions made by others at work on their behalf. These decisions can impact on working life and career in detrimental ways. Management and colleagues may employ "practices of scrutiny, evaluation and judgment" (Jung 2002: 194) which encourage workers to adopt a policy of non-disclosure at work in order to avoid their professional capability being questioned because of personal illness. However, "if they choose not to identify as disabled... chronically ill women contribute to their own social invisibility" (Jung 2002: 196), this brings with it issues associated with strategies of concealing illness which exacerbate stress and highlight the lack of voice these individuals experience (Vickers 1997; 2001b).

Individual assessment of the risks of disclosure, risks of non-disclosure and the influence of personal preferences for privacy or openness, combine to form the basis for decisions regarding disclosure. A more detailed examination of the literature and qualitative data show that the factors which impact on the decisions of individuals to disclose can be grouped into: expected management and peer support (Vickers 2010), stigma associated with illness (Goffman 1976), severity or variability of illness (Myers 2004), individual labour market power (Peetz 2007), institutionalised contingent flexibilities, institutionalised non-contingent flexibilities, outside influences such as caring responsibilities (Werth 2007). These factors then lead to a potentially greater or lesser risk associated with the disclosure of illness in the workplace, individual preferences also play a role in the decision to disclose (Werth 2007).

Figure 1 shows the interactions between these variables.

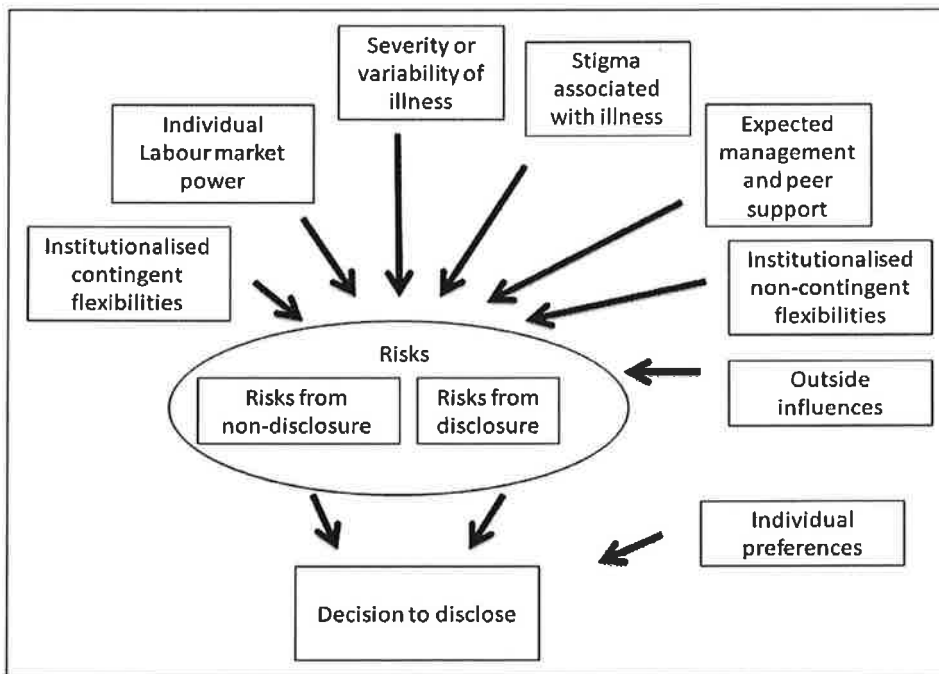


Figure 1: Model of disclosure

The literature on disadvantage in the workplace caused by chronic illness, has been developed over several decades, in fields such as sociology, management and, gender and work. A model based on the literature and the lived experience of women who work with the circumstances of chronic illness has the potential to provide a greater level of detail about the risks associated with the decision to disclose. This model covers actions, attitudes and

perceptions which occur in the workplace on both the side of the workplace and the side of employee. Sociology literature focuses on society and sickness, not specifically on the place of employment, this model seeks to integrate factors at the economic, institutional, workplace and personal levels.

It seems probable to assume that for most people the default preference would not be to disclose for reasons of privacy (otherwise we would observe that everyone would disclose, research shows that disclosure is often a fraught decision (Jung 2002). What we do know is that women make a conscious choice regarding specific aspects of disclosure. It is important to acknowledge that at the margin, two people in equivalent circumstances may make different disclosure decisions because of different personal preferences. Psychological aspects of the decision making process form an interesting part of disclosure decisions however, discussion of this is beyond the scope of this paper.

Methodology

This preliminary research examines the working circumstances of six women, five of whom hold professional positions and one is a paraprofessional. The workplaces of these women vary in size and function. Four participants work in large organisations, which are either government or semi-government organisations, one works in a small family business and another works in a medium sized enterprise. The focus of this research is on the relationships with immediate supervisors and colleagues as well as the institutionalised flexibilities as they exist in policy and in practice. This project is part of broader project focussing on the influence of the industrial relations legal environment on women with chronic illness, this paper concentrates its attention on a central aspect of that issue, which is workplace disclosure. Participants were recruited using a snowballing technique (Atkinson & Flint 2001), making contact with potential interviewees through the newsletters of chronic illness support groups and presentations at support group events. These women each have a chronic illness and are in paid employment, on a part-time or full-time basis. Participants were interviewed either face-to-face or by phone, the interviews were recorded, transcribed and the data was coded using NVivo8. The information used in this paper has been de-identified to preserve the anonymity of participants.

The purpose of this research is to investigate workplace factors which disadvantage women in their place of employment. Issues of disclosure and professional capability (Goffman

1976) and the attitudes of organisations, bosses and colleagues (Jung 2002; Vickers 2001a; 2003) are recurring themes in the stories of the women interviewed in this study. The research has been limited to women because their circumstances of labour force disadvantage are well established in the literature (Baird 2009; Peetz 2007), add to this the complexity of chronic illness which has been shown to effect women and men differently and the outcome is that women experience additional disadvantage (Werth 2010).

Expected management and peer support

Attitudes of organisations, bosses and colleagues can be among the sources of greatest concern for women with chronic illness. The decision to share information about their illness is often avoided for fear of finding themselves in a position of disadvantage (Vickers 1997), as they could then experience various types of, subtle and more obvious, marginalisation in the workplace (Goffman 1976). There are others who choose to disclose their illness in order to obtain support at work and have more positive experiences (Vickers 1997). Comments from participants support the various viewpoints of disclosure from the literature.

Sally related the circumstances surrounding the resignation of a friend from work who also suffers from a chronic illness. Her friend, after an exacerbation of her illness was told that she had to resign or she would be fired, so she resigned. Sally is quite distressed about this, she is fearful of what it means for her, as she is still an employee in the same organisation. Sally's fear of being treated similarly, of being forced to leave the security of her job or of not being considered competent is very clear in her comment:

I think that it's probably best not to tell the bosses too much information.

Conversely, Debbie has experienced a supportive work environment from the first casual position she held with her current employer, despite the fact that she suffered a relapse of her illness within a short time of starting work.

I did [feel supported] although I wasn't really explaining why I was ill. If my boss had an illness of their own I felt that I could relate to them a bit better. Fortunately the boss I had at the time had a similar disease and so it turned out that we were seeing the same specialist! And so that was sort of easier, I think because I did, I had fewer issues in case I had to talk [to my boss] about something related to my illness.

Donna related her experience of changing employment in order to work in an environment which best accommodated her illness. Her current job has a supportive supervisor and

colleagues.

At this work I definitely talk about it, because obviously.... I mean they knew about it before I got sick and then obviously once [my disease progressed]. My boss at the moment has been extremely supportive.

Such support is not always available, in fact some women choose to hide their illness for as long as possible for fear of the reactions of others. Jane reveals that she has disclosed her illness to others at work and has received mixed reactions.

Colleagues who I would call friends are supportive... yes; colleagues who are colleagues... to a lesser degree.

The disadvantage women feel at work, by choosing to disclose their illness and then being subjected to ridicule and discrimination, compounds the circumstances of their illness.

Stigma

Stigmatisation, fear of being discredited or the potential to be regarded as a malingerer are reported in the literature as key issues which influence the disclosure decisions of women in the workplace. The stigma of having a disease, particularly if it is a disease which involves parts of the body which are not the subject of polite conversation, creates difficulty when this is disclosed at work (Myers 2004). Revealing anything about an illness which makes individuals stand out has the potential for discrediting the sufferer as one who is not able to undertake work and who should stay at home in order to recover (Goffman 1976; Parsons 1970). Perceptions persist in the workplace that those who are sick may only be exhibiting symptoms or accessing available flexibilities because they are pretending to be ill, and they may be labelled malingerers (Hirth et al. 2003).

Sally reports that she struggled with the response of one colleague to her illness. The attitudes this colleague displayed were not only openly derogatory, but they placed Sally in a situation where she was put under suspicion of pretending she was ill.

One particular employee, when I was very sick one time, she just said I was being a hypochondriac.

Recalling the events that led to her boss accidentally finding out about her illness, Jane reports that he said that she was expected to take leave in order to 'get well', which isn't necessarily possible for those with an ongoing illness.

[My boss finding out] was not a bad thing I guess, but then he called me into

the office and he said... if you're sick take sick leave and get better.

Fear of stigma is a motivating factor in the decision of women not to disclose their illness at work. The attitudes which create this fear derive from out-of-date opinions about those who are different from what is considered to be the norm, and are perpetuated by management who attempt to recruit normal, so-called capable people to create an effective and efficient workplace.

Severity and variability of illness

Illnesses which have severe or variable symptoms may result in employers having difficulty understanding the disease, or why individuals may want to continue working when they have such a disease (Vickers 1997; 2010). Chronic illness is problematic as individuals may have unpredictable illness trajectories which can be hard to describe credibly to supervisors and colleagues, and which make it difficult to ask for accommodations which may be needed at various points in time (Myers 2004).

Jane has found herself in challenging circumstances at work, not because of her illness, but it is the symptoms of illness and an unsympathetic supervisor which make it difficult for her to improve her work environment.

For me when my disease is active, the stress comes out, the time where you didn't have this illness you would have more self confidence and courage and strength to stand up and fight at the time you need to fight, you don't have that because you've probably moved into a period where you are, tired-er, more teary, you don't feel you can present yourself, you don't feel you can fight and so that then means that it compounds.

The disadvantage Jane has experienced has been highlighted by the fact that she has reduced her working hours in order allow for her symptoms, however her supervisor has not reduced the amount of work that she is allocated. The changeability of some forms of chronic illness make keeping the appearance of capability at work, difficult. For some women reassuring their colleagues that they are indeed capable, is so important that they will resist revealing their illness.

Individual labour market power

Research shows that the ability of women to effectively negotiate favourable outcomes in

their workplace is influenced by factors such as the employer's ability to access alternative workers (Peetz 2007). When the labour of women is easily replaced, the result is the reduced individual power of these women in the workplace, they are more likely to experience disadvantage. Lucy comments that, in the job she held when she was diagnosed, she was disadvantaged because of the diagnosis.

Within months of getting the diagnosis, and in that time I had taken quite a lot of sick leave, there was a new job being offered in the group and the other girl was going to get it. And that was a manager's job and basically, I mean, there were no interviews, there was nothing, there was no reason for that girl to get it over me except for that I took a lot of sick leave and they were obviously concerned about my ability to continue with the work.

Other participants reported instances, where, because of the vulnerability they experience due to their illness they have been disadvantaged at work. The previous example of the circumstances faced by Jane, also shows this type of disadvantage. If women feel that their livelihood is at risk if they disclose their illness, then the power they have in the labour market becomes a significant factor in their disclosure decision.

Institutionalised contingent and non-contingent flexibilities

Institutionalised contingent flexibilities are those that are available specifically for people who have disabilities or chronic illness, they include Anti-discrimination laws which prevent discrimination against workers who have chronic illness, also Occupational Health and Safety legislation which prevents workplaces from contributing to the worsening of an illness of an employee. These protections are available to workers with chronic illness, there are instances in this research where it would seem that unhelpful responses from employers could perhaps be construed as breaching legislation (however, such discussion is not within the scope of this paper).

Institutionalised non-contingent flexibilities are those which are available for all employees but can be used by women with chronic illness to help to balance their circumstances of illness with their working responsibilities. Jane comments:

And how I find balance is that I try and work from home more than here I use the flexibility in working hours to my better advantage than I used to. So that's given me breathing space.

Debbie juggles her part-time permanent contract and part-time casual contracts to allow her the flexibility she needs to balance circumstances of her illness, her work and her family responsibilities. Other participants report that they simply take 'sick leave' when they need some flexibility to cope with their symptoms of illness.

If women feel that there is flexibility and protection available to them, this will influence their disclosure decision. However, perceptions of the effectiveness of the protections or what lengths they will need to go to ensure that their employer complies with legislation may increase the likelihood that they will not disclose.

Outside influences

Other influences play a role in the disclosure decisions of women who work with illness. The roles they hold outside the work place, their caring responsibilities, the perceptions that friends and family hold about how the individual should respond to their illness situation, are some of the possible influences these women cope with.

Caring roles add a dimension to the working life of women with chronic illness which appear to compound the disadvantage they experience. However, Donna reports that she has been able to negotiate the flexibility she needs to care for her chronically ill son. She does comment that she does a lot of extra work inferring that she deserves the flexibility because of the organisational citizenship she displays.

...with my son, if he needs to go to hospital, he's the priority. And my boss is really good about that, I just ring and say 'look I've got to take Billy to hospital tomorrow', she says 'fine, that's no worries'. I do a lot of extra stuff for the... like, I do a lot of extra hours free really.

Lucy has found a certain amount of balance with her illness, her children, her role in the home and her work. She reports that she misses out on doing the work she enjoys because the balance becomes too precarious and her health suffers.

I have tried to do more hours and I find, not so much that they [the kids] miss out but that my health deteriorates, because I get stressed trying to fit in managing the house, taking caring of them and doing work.

Caring responsibilities and other life roles have the potential to complicate an already complex work situation and place greater pressure on women who are faced with a difficult

disclosure decision.

Conclusions

Women with chronic illness may have a difficult task deciding whether or not to disclose their illness at work. The issues which they need to consider in the assessment of the risks of disclosure or non-disclosure include: expected management and peer support, stigma associated with illness, severity or variability of illness, individual labour market power, institutionalised contingent flexibilities, institutionalised non-contingent flexibilities, outside influences such as caring responsibilities and ultimately personal preference for privacy or openness.

The illness and symptoms might be difficult to deal with, but add to that the attitudes and potential misunderstanding by colleagues and the fear of disclosure becomes so significant that it featured in most of the interviews. These circumstances are also supported in the literature. The decision to disclose or not, is one that has not been taken lightly by these women, and the data reveals that there have been both positive and negative outcomes in relation to their disclosure decisions.

The stigmatising nature of chronic illness may cause these individuals to find it difficult to find acceptance in a workplace culture which is based on the functionality of its workers. The expectations of management tend to reinforce this view, any variations in the symptoms of illness which are not predictable, place the worker in a more precarious position. The lack of understanding of the nature of chronic illness has the potential to put future employment at risk particularly if there is a ready supply of replacement labour available. The working lives of women with chronic illness should not be limited by the perceptions others have of their disease.

References

- Atkinson, R. and R. Flint (2001) 'Accessing hidden and hard-to-reach populations: snowball research strategies', *Social Research Update* 33.
- Baird, M. (2009) 'Women's work - current issues and future agendas', *Australian Bulletin of Labour* 35: 608-610.

- Bury, M. (1991) 'The sociology of chronic illness: a review of research and prospects', *Sociology of Health and Illness* 13: 451-468.
- Goffman, E. (1976) *Stigma: notes on the management of spoiled identity*. Harmondsworth: Penguin.
- Hirth, R. A., M. E. Chernew, M. N. Turenne, M. V. Pauly, S. M. Orzol, and P. J. Held (2003). 'Chronic illness, treatment choice and workforce participation', *International Journal of Health Care Finance and Economics* 3: 167-181.
- Jung, K. E. (2002) 'Chronic illness and educational equity: the politics of visibility', *NWSA Journal* 14: 178-200.
- Myers, K. R. (2004) 'Coming Out: Considering the Closet of Illness', *Journal of Medical Humanities* 25: 255-270.
- Myers, S. T. and H. G. Grasmick (1990) 'The social rights and responsibilities of pregnant women: an application of Parsons' sick role model', *The Journal of Applied Behavioural Science* 26: 157-172.
- Parsons, T. (1970) *The social system*. London: Routledge.
- Petz, D. (2007) 'Collateral damage: women and the WorkChoices battlefield', *Hecate* 33: 61-80.
- Vickers, M. (1997) 'Life at work with 'invisible' chronic illness (ICI): the 'unseen', unspoken, unrecognised dilemma of disclosure', *Journal of Workplace Learning* 9: 240-252.
- Vickers, M. (2001a) 'Unseen chronic illness and work: authentic stories from "women in-between"', *Women in Management Review* 16: 62-74.
- Vickers, M. (2001b) *Work and Unseen Chronic Illness: Silent Voices*. London: Routledge.
- Vickers, M. (2003) 'Expectations of consistency in organizational life: stories of inconsistency from people with unseen chronic illness', *Employee Responsibilities and Rights Journal* 15: 85-98.
- Vickers, M. (2010) 'Exploring illness disclosure for workers with Multiple Sclerosis', 24th Conference of the Association of Industrial Relations Academics in Australia and New Zealand (pp. 1-11). Sydney.
- Werth, S. (2007) 'Image management for women with invisible chronic illness in the various aspects of life', International Women's Conference. Toowoomba: USQ Women's Network.
- Werth, S. (2010) 'Women, work and chronic illness', 24th Conference of the Association of Industrial Relations Academics in Australia and New Zealand (pp. 1-9). Sydney.