Stigma, stress and emotional labour: experiences of women with chronic illness at workⁱ

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Abstract

Women who work after being diagnosed with a chronic illness often find it difficult to fit in with the expectations of workplaces and for this reason often choose not to disclose their illness to their colleagues. The employment experiences of these women reveal that they negotiate the negative attitudes of their workplaces and employ strategies such as enlisting support and evaluating the risks of disclosure. They display a higher than usual amount of emotional labour in order to continue working specifically in relation to their severity or variability of illness, their avoidance of stigma and expected management and peer support. These variables form part of the model of disclosure and will be used to examine the factors which influence the decision to disclose their illness in their place of work.

Introduction

The twentieth century has seen a substantial increase in the participation of women in the Australian workforce and gradually their rights as valued workers have been recognised (Palmer, Shanahan & Shanahan 1999). Characteristics of women in the workplace have reflected their disadvantage in the labour market (Peetz 2007). The progression of women's pay and conditions has been advanced, through gender pay equity decisions, anti-discrimination and equal employment legislation in Australia. These have assisted in improving the rights of women in the workplace. This regulation of employment has exposed other groups who continue to be marginalised at work due to characteristics beyond their control. One of these groups is women who have a chronic illness. Women have been shown to experience greater barriers to labour force participation than men (Peetz 2007) and while we know that both men and women tend to encounter disadvantage in the workplace, their experiences are quite distinct (Werth 2010a). It is because of these differences that this paper will focus on the stories of women with chronic illness.

Women who work while suffering from a chronic illness often find it difficult to fit in with expectations of workplaces (Vickers 2001a). They may feel as though they are misunderstood by employers and they are often subject to the controls of workplaces which tend not to offer support to allow for their illness (Roessler, Turner, Robertson & Rumrill 2005). They may feel that it is necessary to produce an outward appearance of capability at a level which will, not only cover their illness, but will also prove that they are valuable employees. Decisions made by women who are balancing treatment regimes and labour market decisions are becoming increasingly important in a society where the participation of women in the workforce is increasing.

The topic of women, work and chronic illness has been shown to be a vexed one which requires more research in order to be better understood. The research questions on which this

^{*} The author gratefully acknowledges the invaluable assistance of David Peetz and Kaye Broadbent in the development of this paper.

paper is based are: amongst female workers with chronic illness, what are the key workplace factors associated with the illness that shape the decision to disclose? And, how do these factors influence the performance of emotional labour by female workers with chronic illness?

This paper will argue that women with chronic illness will put considerable effort into managing emotions in order to keep working using the model of disclosure. It will examine the variables of 'severity or variability of illness', 'stigma associated with illness' and 'expected management and peer support', as they each specifically relate to the performance of emotional labour by women with chronic illness in their workplace. Qualitative data and existing literature will be used to examine these variables. Data is drawn from the interviews of twelve women who have been working after a diagnosis of chronic illness, and will explore their reasons for disclosure, the perception of the risks associated with disclosure and their experiences of, support, stigma, display of emotional labour and illness at work. Existing literature which focuses on the working circumstances, including the emotional labour, of those with chronic illness has emerged largely from the fields of education (Jung 2002) and sociology (Bury 1991). While there is a growing body of research centred on specific aspects of work and illness in the management field (Vickers 2001a; 2001b; 2009; 2010), there is a need for further research in a society where there are increasing numbers of individuals working with chronic illness (Dwyer 2004; Chronic Illness Alliance 2009) and exerting considerable amounts of emotional labour to improve their labour force outcomes.

A partial model of disclosure including emotional labour

Emotional labour is defined as the labour that 'requires one to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others' (Hochschild 1983, p. 7). It could be argued that an employee would consider a 'proper state of mind' in their supervisor, as one where they are valued and worth consideration of their specific circumstances of illness. To this end, women with chronic illness perform emotional labour in order to cover their symptoms so that they may be considered 'normal' in the workplace. These women might also display emotional labour amongst their colleagues and subordinates as they may be under unspoken pressure to 'act in a fashion deemed appropriate by management to ensure they are not targeted as outsiders' (Townsend 2008, p. 180). It is this pressure which causes women with chronic illness to navigate the self-control and management of circumstances, which allow them to successfully negotiate the expectations of others in their workplace (Jocoy 2003). However, the internal feelings of these individuals are often very different to those they display in order to conform with social expectations, this surface acting can result in feelings of inauthenticity. Non-disclosure of an illness in the workplace requires the performance of constant emotional labour to maintain an appearance of capability and normality. Alternatively, disclosure may result in a lesser amount of tension between outward appearances and inward attitudes.

Management might expect a certain level of emotional labour and require that employees 'fit in' with the culture at work (Townsend 2008). Women who are working to maintain their appearance of capability may find that the emotional labour becomes a major part of who they are at work. This results in ongoing differences between their outward emotions and their private realities (Noon & Blyton 2002). These differences may be the result of stress and fear of stigma associated with having an illness. Women with chronic illness might also try to circumvent negative attitudes by being hard workers. Obtaining support from management and peers may be a goal for workers when they are working towards meeting the emotional labour requirements of the workplace.

Personal reactions to working with an illness can also include tiredness (Vickers 2003) which may be associated with the illness itself, the additional emotional labour carried out or the extra work undertaken to gain management and peer support. Vickers (2003) comments that this tiredness exists in its own right and nothing can relieve it. The types of advice that women with illness often receive at work about taking better care of themselves, while well meaning, can result in that person feeling misunderstood, under greater pressure to hide their symptoms, leave them feeling stigmatised or influence their decision to disclose (Myers 2004). The stress of hiding their illness, of presenting their 'happy face' in order to be fully accepted at work or of juggling their work and personal lives, can have a detrimental impact on their illness (Vickers 2010). The causes of each of these types of stress and stigma may vary, however they are interrelated and they each play a role in the workplace disclosure decisions and the degree to which they need to undertake emotional labour.

Disclosure

Disclosure at work is a decision taken by women with illness who are mindful that once the decision is made it cannot be taken back. Negative attitudes of colleagues can compound misunderstandings of the individual and of their illness, thus there are risks associated with disclosure. The model of disclosure (Werth 2010b) depicts the decision making process and assessment of some of the risks an individual considers before disclosing information about their illness in the workplace (figure 1). A number of variables influence the perceptions of the individual on the risks (of disclosure or non-disclosure) associated with disclosure. These variables include: severity or variability of illness (Vickers 2010), stigma associated with illness (Millen & Walker 2001), and expected management and peer support (Vickers 2010). Individuals may have personal preferences for disclosure, influenced by their need for privacy or openness, and therefore in the same circumstances two individuals may make different disclosure decisions.

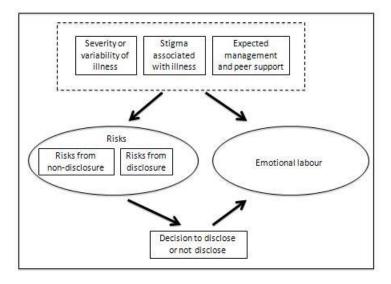


Figure 1: A partial model of disclosure and emotional labour

Source: Werth, S. 2010b, 'Chronic illness, women and work: a model of disclosure', *The Australian Sociological Association Conference 2010*, pp. 1-12, Sydney.

The three variables examined in this paper include: 'severity or variability of illness', 'stigma associated with illness' and 'expected management and peer support' and their influence on the employment of emotional labour in the workplace by women with chronic illness and subsequent impact on the disclosure decision making process. The decision to disclose carries

with it risks which may result in limited career opportunities, stigmatisation of the individual as professionally incapable or as a 'problem' worker, or even as someone who would prefer to feign illness (Vickers 1997). Because of these risks some will not reveal their illness until the severity of symptoms requires that they have no choice (Myers 2004). Others will choose to reveal their illness in order to gain support and the flexibilities they need to continue working (Vickers 2010). Emotional labour becomes a very real part of the working lives of individuals with chronic illness. The business of keeping up appearances is important for the preservation of professional credibility in the face of powerful norms which indicate that those with illness have a 'spoiled identity' and are not considered 'normal' (Millen & Walker 2001). These workers may perform emotional labour to avoid telling others about their illness or if they have already disclosed their illness, they may employ emotional labour to maintain their credibility (Vickers 1997).

Undertaking a strategy of disclosure may be seen as an action which organises management and peer support and which increases the probability of a positive outcome (Bury 1991), it also has the potential to require a greater amount of emotional labour. For this reason 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). Disclosure decisions can be made voluntarily and with the aim of achieving positive outcomes, despite the risks.

Women with chronic illness may be concerned about the degree to which they are able to access 'accommodations' at work to assist them in the balance of illness and work (Jung 2002). Managers may prefer to demand that individuals take sick leave and not return to work until they are well, which creates difficulty for individuals with chronic illness who cannot be sure when they will improve (Myers 2004). Discussions between those with illness and their employers have potential for building a more compassionate response to the circumstances of their staff, however experience has shown that this type of understanding from employers is not to be expected (Vickers 2009). Disadvantage may be experienced by workers through the judgements of others which:

include assessments of the [chronically ill] individual's 'deservingness' of accommodation and implications of the visible symptoms of the disease, predictions of whether or not chronically ill women will be capable of full employment in the future, and appraisals of their suitability for their chosen professions (Jung 2002, p. 193).

Opinions or beliefs of others can sometimes be used to pass these judgements. Add to these circumstances, other factors such as stress, stigma, tiredness associated with illness and the lengths to which these women will go to keep their jobs while achieving some support at work; the result is a working life which is dependent on their ability to perform sustained amounts of emotional labour.

Methodology

This research focuses on the working lives of twelve women, whose positions include administrative assistants, nurses and managers with varying levels of responsibility. Participants were enlisted using a snowballing technique (Atkinson & Flint 2001), initial contact was made through publications and networks of chronic illness support groups throughout Australia (Somers & Gibson 1993). Snowballing was employed because of its

ability to find participants who are part of a largely invisible population which is difficult to access. Each of the women interviewed has been diagnosed with chronic illnesses such as, varying forms of arthritis, mental illness and epilepsy. They are in paid employment and undertake part-time or full-time work. Interviews took about one hour, they were recorded, transcribed and themed using NVivo8. Identifying features have been removed from the data to preserve the anonymity of participants.

Our research has been undertaken to expand existing understanding of what it means to work with a chronic illness (Vickers 1997). The study has been limited to women because of their specific labour market disadvantage associated with being a female in the labour force. The themes emerging from this research include issues of disclosure (Goffman 1976) and attitudes of supervisors and peers (Myers 2004), fear of stigma (Vickers 2001a), tiredness (Vickers 2003) and the extra effort they perceive is needed to obtain support at work.

Limitations of this study centre on the difficulty in accessing women from working class populations despite some strategic efforts to snowball into low socio-economic status areas in Victoria and regional Queensland only two administrative assistants were included in this stage of the study. Snowballing was extremely successful in finding participants from a variety of professions from throughout Australia (Brisbane, Sydney, Perth and Toowoomba).

Stigma

Stigma is defined as a complex concept that 'encompasses individual experience, the interaction between non-marginalised and marginalised groups' (Stuber, Meyer & Link 2008, p. 351). In order to cope with stigma in the workplace, women require a boldness not often exhibited in negotiations with their employers (Olekans 2005). The responses of employers to the disclosure of illness by an employee, shape the meaning of stigma for that worker within the culture of that workplace (Garcia & Crocker 2008). Social rules which define situations when the application of stigma is acceptable are framed around the expectations of individuals in the workplace (Stuber *et al.* 2008). The amount of emotional labour required will depend on the stigma that they experience or fear they will experience if they disclose. An employee's revelation of illness to an employer can freeze the resources that were available to them while they were regarded as a 'useful' worker (Bury 1988; Myers 2004).

Maree found, after some time of having her work recorded and reported (particularly any mistakes she made) that she lost all belief in her ability to work in her field.

Maree: It was the way they were going about it, they were slowly eroding my own confidence and slowly building a case behind my back so that it was all me, [as if] it were all my fault. I was downright ready to quit my job, they had me convinced.

Maree's illness was exacerbated by stress and because she had very visible and debilitating but short term symptoms, she attempted show her ability to work hard and fit in with culture of the organisation, employing emotional labour to do so. Despite this, she was so stigmatised that she believed she was being pressured to resign from her job.

Maree: Another supervisor felt I was being discriminated against, on the grounds of my illness.

Maree also described what went on as a 'witch hunt'. Ultimately, she did resign from that job and worked in the same role with another employer, who was supportive despite knowing about her illness. In this role Maree still reported working hard to manage her symptoms in order to be valued in her new position. Subsequently, with a decreased amount of stress, Maree's illness abated.

The type of support Maree experienced in her second position isn't always available, in fact some women choose to hide their illness for as long as possible for fear of the reactions of others. Donna felt so much embarrassment about the symptoms of her disease that she hid her diagnosis even from those closest to her at the time she was originally diagnosed. The strategies she developed to minimise her embarrassment required the performance of emotional labour. These enabled her to continue studying without disclosing her illness to anyone.

Donna: Probably when I was younger I didn't tell anyone really. When I first started working and certainly when I first got it when I was 18, even some of my family members didn't know. I was very embarrassed. I would never talk to anyone about it. And I remember in uni lectures, I'd pretend to have a coughing fit because I needed to leave because I felt sick.

Rhonda finds that when she uses her walking stick she is questioned if she's ok by people around her, it seems to lend validity to her disability.

Rhonda: Quite a few times in the last little while, since I've had to use my walking stick and then as soon as I stop taking it, people say 'So you're fine now'. I could be hobbling up the stairs on my own without a stick and people wouldn't have said anything, or perhaps they forget I have arthritis. As soon as I bring the stick they go, 'Oh, what have you done?' 'Have you hurt yourself, what's wrong?'

Ironically, Rhonda would prefer to manage without her walking stick wherever possible, because she feels it's an acknowledgement of her reluctance to be labelled as an ill person. She employs a significant amount of emotional labour, particularly when she goes out without her walking stick so that she can appear 'normal'. There is another issue that arises for women in the workplace, and that is one of achieving validity through the use of aids which assist with their symptoms. Rhonda also needs splints for her hands at times and felt that while she was working in retail, that the people she came in contact with would presume that she was 'better now' when she stopped using the splints even her though her condition is chronic. The comments of others no matter how well intentioned, can be stigmatising and while the use of aids may assist in providing validity in the eyes of others, also take away the individual's choice about disclosing.

Severity or variability of illness

The support of supervisors and colleagues has the ability to worsen or mitigate the stress felt by women with chronic illness. Jane has an unsupportive supervisor who would prefer she 'went away' until her health improved when he would be happy for her to return to work. This places Jane in a difficult position. She needs to exert emotional labour to keep her boss happy in order to try to prevent being disadvantaged by being forced to take sick leave unnecessarily.

Stress can attract a lot of negative attention, and staff who take stress leave may find that they are stigmatised because of a perceived lack of ability to manage at work. Despite being unwell and feeling significant amounts of stress due to work or their illness, these women utilise emotional labour to preserve their outward appearance of professional ability in order to reassure colleagues of their willingness to be part of the team. The added stress that fear of stigma contributes to the pressures on women with illness is considerable, such that it influences their employment and career decisions as well as their decisions to disclose.

The exhaustion that some of the women associate with working is an issue which impacts on their lives generally. Building a reputation of capability despite feeling tired (as a general

symptom associated with chronic illness (Vickers 2003) or experiencing symptoms directly related to their illness, is important for women who prefer not to disclose their illness. A number commented that because they work they need to spend time on the weekend recovering. Jane reports feelings of exhaustion and some desperation to catch up with her work.

Jane: You have broken sleep, your sleep patterns are up the creek. I've been getting up at 2 and 3 am and starting work for the day, because I'm so far behind. I've got to try and catch up. But then you're tired.

Jane reports that the work she is expected to complete is in excess of what others on her level of position in her organisation are expected to complete and there is a feeling of resignation about her circumstances because while she knows she isn't being treated fairly, she doesn't feel well enough to have it addressed through formal channels. Tiredness is a recurring theme from the interviews. Women with illness report that they fit their work and associated emotional labour around the management of their illness so that they have a choice about disclosure. Louise reports that while she is working part-time at the moment, she has applied for a full-time job and admits she doesn't know how she will manage if she is successful in gaining the position.

Louise: I still get nothing else done but sleeping and working during the week and by the end of the week, it's a case of I should be doing this and doing that. If I don't watch the amount of sleep I could sit there at the computer and what should only take me 5 minutes might take me half an hour or longer.

Heather works as a senior executive in a large organisation and her comments echo similar concerns about tiredness.

Heather: It's the fatigue that affects me. The physical [aspects], no problems. But the fatigue is what hits me. Some days I get to about 2 o'clock in the afternoon, and you hit that brick wall. You're almost at that point where you can barely get yourself home you're that exhausted. That's probably what I struggle with the most. And my job is such that it's stressful, I'm 2IC of a large department, so there's a lot of people relying on me I suppose. If I get to that stage some days where 2 o'clock comes around and I hit that brick wall, it's a bit of an effort. But physically there are no issues for me at work, physically.

Heather's workplace knows about her illness and while her supervisor is supportive, her colleagues are less understanding. Having already disclosed, Heather applies emotional labour to maintain an appearance of capability and uses strategies such as taking a short break to go outside and take some deep breaths, before going back to her desk.

Lisa is temporarily working full-time and she says:

Lisa: I'm really struggling at the moment, but I've only got another 2 weeks of full-time work. My weekends are just written off – sleeping. I usually work Monday to Thursday and I sleep on Friday and then I can have an actual weekend.

Working part-time gives Lisa the ability to balance her work and life while managing the tiredness that she experiences from working full-time. Lisa utilises large amounts of emotional labour to maintain her professional image, moreso while she's experiencing the additional pressure of working full-time.

It is apparent that continuing employment is so important to these women that they are prepared to sacrifice many aspects of working life which others take for granted, just so they can keep working. Fear of stigma and stress are themes which recurred in a number of interviews. Individuals with chronic illness are susceptible to tiredness. Each of these women have fostered careers, most in professional fields, but much of the stress that they relate is about how others might react to an outward display symptoms and the emotional labour they exert to stay within the bounds of acceptable outward appearances in the workplace.

Expected management and peer support

The data show that while women report that some concessions are made for their illness, it seems at times their success relates to their seniority, and the amount of control they have over their own work. After analysis, the data show that some of these women work over and above what is required of them in order to secure support from their supervisors and each makes use of aspects of emotional labour to do so. Interestingly, each of these women have disclosed their illness in their workplace. We would expect that for women to access support from colleagues and supervisors that disclosure to some extent is necessary, this is evident from the reports from these women. While the women in the following discussion have disclosed, this does not mean that they talk about their illness often, and possibly not at all. The disclosure is most often to the boss and sometimes to a few close colleagues.

Sally was talking about her symptoms among a group of colleagues who she trusted and found that she was criticised for sharing information about her illness.

Sally: I was complaining that I was feeling ill at work a lot. I wasn't looking for sympathy or anything like that, I generally felt ill and I thought they were my friends and [one colleague] said in front of other people, 'You know, she can't stop complaining'. I haven't indicated anything about my illness to that person ever again. There's only certain people I'll tell about my condition.

Sally is very aware that the image she projects, as a professional in a large organisation, is important to her ongoing employment (as she has witnessed the dismissal of a colleague on the basis of their illness). She has carefully utilised emotional labour to hide her symptoms with all but a few close colleagues. She found out the hard way that they weren't all as understanding as she had been previously led to believe. The opinions of others have an impact on the support that is available for colleagues who have illness. Jane noticed a difference between the support available from colleagues who she is friends with and those who she just works with. However, when she disclosed her illness to her boss he lacked compassion about her circumstances.

Jane: I said to my boss, 'What you need to understand is, while I might have an illness I believe that it's a disability and you need to think of it in that way because it is never going to go away. I've had it 9 years now, it's unlikely that it's going to go away'. And I said to him, 'You know, I'm struggling with the workload, and it is placing me under very difficult circumstances'. And he just looked at me, he eyeballed me and said, 'But the way the workload is allocated is fair'.

Gaining supervisor support isn't easy, even if the employee has worked there for a long time and has had a record of excellence and innovation throughout their career as Jane does. Jane works many additional hours to maintain the standard of work which she is accustomed to producing. She also employs emotional labour to show she is still capable of the excellent work that she is known for throughout the organisation to prove that she shouldn't be judged according to her symptoms of illness

Seniority does appear to involve greater support (particularly from supervisors) for these participants, however it is possible it is a function of increased power and control over their

own work. They also utilise emotional labour to not only promote their professional ability, but their ability to manage a section, a department or an organisation, no matter how ill they might feel. Heather reports that she does have some flexibility but she also has the 'right' to work extraordinarily hard.

Heather: I'd easily be pulling about a 9.5 hour day most days of the week. I think I'm pretty lucky. I guess I'm also at that level in the organisation where I've got a great deal more flexibility anyway.

Heather works long hours in spite of her illness, she projects the image of a high energy executive which is completely at odds with her personal reality of an unpredictable and debilitating illness. The emotional labour she feels is required is directly related to her responsibility within the organisation. The long hours she works during peak periods (sometimes until 2am in the morning) are managed by going home at lunch time to have a short sleep so that she can keep up with the expectations that others have of her role at work.

Heather's illness was diagnosed while she was working in her current organisation and so she had no choice about disclosure. This means that she is subject to the negative reactions of others from time to time, in spite of her very professional persona which she goes to some lengths to preserve.

Heather: I think at one point, I heard through the grapevine that some staff had some issues with the fact that I might appear to have a greater level of flexibility in terms of my working hours than others. I've certainly had staff, when I had needed to go home on one occasion, and I'd asked one of my admin support people to reschedule some meetings, one of my colleagues gave me a bit of lip about 'pick yourself up and dust yourself off and get on with it' and that sort of stuff. But it's usually limited to that. Not too many people would say anything directly to my face. It's usually that I've heard about it through other means.

Working hard to achieve particular career related outcomes is important to Heather, despite the fact that sometimes she needs to deal with negative reactions from her peers.

Heather: I think that with my diagnosis not being until later in my career, you've worked really hard to get where you are. So the last thing, for me when I first got crook, the most devastating thing was that all of this hard work that I'd done to get where I was, it felt like it was slipping through my fingers and so you work twice as hard to make sure that, that damn well doesn't happen. I've worked too damned hard to let this [illness] get in the way.

Achieving support for these women is dependent on them disclosing their illness. However, for each of these, their disclosure decisions were taken out of their hands through obvious symptoms except for Jane, whose supervisor found out without her consent. This may put pressure on individuals to perform increasing amounts of work and to be very careful about their degree of disclosure and preserving their 'useful' appearance at work. Maintaining their credibility at work is an on-going and emotional labour intensive process particularly after disclosure. These comments highlight the risks that women with chronic illness take when they disclose – voluntarily or not.

Emotional labour

Expectations of supervisors and peers play a significant role in the degree to which women with illness feel it necessary to employ emotional labour in the workplace amongst their colleagues.

Rhonda: They say 'You look so well today,' and I go, 'This is my outside face. I've come out today, I've put on a scarf, I've put my lippy on'. But they don't get it.

Despite colleagues knowing about her illness, Marilyn doesn't feel that it has any place in her working life. She takes on extensive emotional labour to preserve her image as a manager to the point where she projects 'normality' and never acknowledges her illness while she's at work.

Interviewer: Does anyone at work know about your illness?

Marilyn: Yes.

Interviewer: Are they understanding about it?

Marilyn: I don't talk about it. It's not a subject I bring up, when I'm at work, I'm at work.

Marilyn is determined to keep up her appearance of capability and doesn't admit to requiring assistance at work, if she needs flexibility she, as the manager, is able to make the arrangements. While her staff know about her illness, it's a topic that is off-limits, she doesn't talk about it at work because she considers that it isn't anyone else's business. She maintains a professional outward appearance, one that doesn't show the tiredness or other symptoms that she may be experiencing. She also reports that she rarely takes sick leave, this is part of the emotional labour that she employs to undertake her role at work. Marilyn disclosed her illness to the Board of her organisation in order to gain their support. The emotional labour Marilyn exerts is important to her to preserve her professional reputation and to meet the expectations of those who work for her as well as the Board.

Louise also is working on a policy of limited disclosure. She is in the unusual position of going back to work in her old workplace in a lower level position after some years away from work because of her illness. She believes that she will have some understanding there.

Louise: They're aware that, when I had to finally resign [from the former position] that my illness was the major problem, but I didn't really say too much

She also understands how important it is to look well at work, otherwise colleagues will comment.

Louise: Because people who know you, know, and I think for me probably my eyes are the biggest giveaway and I don't always wear makeup and stuff, but if I go in there without much makeup on, they'd go [aghast face]. I go, 'you should see me without makeup on, I'm very pale.' So, I guess the fact that I've been managing it quite well is good.

Emotional labour is a key strategy for avoiding stigma for women with illness in their places of work. Looking professional and acting in ways that make colleagues comfortable are a means of preserving their reputation. The pressure that this places on these women is considerable and they seem willing to accept managing their emotional labour as a necessary part of continuing to work.

Conclusions

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. The risks which influence disclosure decisions include a range of factors, as shown in the disclosure model. Severity or variability of illness, stigma associated with

illness and expected management and peer support all play noteworthy parts in the decision to disclose symptoms or circumstances of illness in the workplace. Emotional labour plays an important role in understanding what goes on in the working lives of women with chronic illness. It adds to work role from the standpoint of preserving the capable image of the individual who prefers not to disclose their illness, by employing emotional labour women can potentially avoid stigma associated with being ill, with the symptoms of their disease or the disease itself.

Disclosure or non-disclosure decisions can result in different forms of emotional labour being exerted. Disclosure of an illness in a place work will result in that individual needing to act at times to hide their symptoms in order to assure colleagues and management that they are capable. There is the potential for a greater amount of understanding or flexibility after disclosure. Non-disclosure requires constant attention to appearances, any symptom or difficulty that hints at something out of the ordinary, may suggest to colleagues that there is something amiss. The result could be an unexpected revelation of an illness which may not be desirable, depending on the attitudes of others in the workplace. The main aim of employing emotional labour is to preserve the professional appearance and reputation of the individual with illness and ultimately maintain or improve the labour force outcomes available.

Stress, stigma, tiredness and emotional labour are common themes in the working lives of women with chronic illness. The commitment that these women display by continuing to work despite their illness and the stress it can create, points to their desire to contribute to the labour force. However, the negative aspects of workforce participation are obviously more difficult to manage for this group of women than they are for women without illness.

Acting to be accepted as a 'normal' person is a strategy commonly employed by women with chronic illness. The risks associated with the decision to disclose are carefully considered. They combat tiredness, stress and stigma, they negotiate the unpredictable attitudes of workmates and supervisors and they take on a persona which might reflect more of the culture around them than it does of themselves. The role of women with chronic illness is complicated.

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¹ This paper has been peer reviewed by two anonymous referees