“She Hasn’t Been Very Well Lately…”: Working and Caring for Children with Chronic Illness – Questions of Workplace Disclosure

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ABSTRACT

This paper reports on one of the many dilemmas that was uncovered for working women who also cared for a child with a significant chronic illness (or disability). This qualitative, exploratory study involved two rounds of in-depth interviews, and a culminating group seminar, where women spoke of their experiences of juggling work and home while caring for a child with chronic illness. Here, I explore their concerns with disclosing their child’s illness at their place of work.

Keywords: Gender; Self-Disclosure; Employment; Qualitative Research; Chronic Illness

WORKING AND CARING FOR CHILDREN WITH CHRONIC ILLNESS

This paper addresses one issue that working mothers face when caring for children with chronic illness while also trying to hold down a full time job: that of the disclosure of their child’s condition.

For the purposes of this study, a "child" is defined as a male or female person aged between birth and 18 years of age. A chronic illness is a long term health problem or disability experienced by the child for at least 6 months; is a significant, ongoing condition requiring ongoing medical or professional intervention (via pharmacological or other treatment, visits to medical or other professional practitioners, or hospitalization) to treat acute episodes and/or ongoing problems (Vickers and Parris, 2005; Vickers, 2005a; Vickers, 2005b). The focus of this study was on the challenges presented to the carer who is also working full time, rather than the child's experiences with chronic illness.

Despite common beliefs to the contrary, children with chronic disease are a significant group of the population (Martin and Nisa, 1996: 1). Newacheck (1994; cited in Melnyk et al, 2001) reports that approximately 31% of children under the age of 18 years have one or more chronic illnesses. While it is acknowledged that illness and disability tends to be associated with the aging process, children are still at a significant risk of having a disability or long-term health condition due to accidents, environmental factors or through being born with a particular disorder (ABS, 2002: 5). Of particular

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2 For the purposes of this study, a "Chronic Illness" also includes disability. That is, any health problem or disability lasting longer than six months.
interest are conditions that occur more frequently in this age group, such as asthma, attention deficit disorder (ADD), intellectual and developmental disorders, and hearing or speech loss (ABS, 2002: 5). Of the 3.9 million children in Australia aged between 0 to 14 years in 1998, almost one in seven has a long-term health condition (594,600 or 15%), with boys (18%) more likely to be affected than girls (13%) (ABS, 1999). In this study, the children had conditions such as severe epilepsy resulting in multiple seizures, varying intellectual and physical disability, attention deficit disorder (ADD), lipoma, midline cleft to the face, hydrocephalus, Down's syndrome, leukemia, paraplegia, muscular dystrophy and autism.

This study provides an especially important contribution to current debates around the work-home conflict. Women continue to take primary responsibility for the care of children and for associated domestic work (Giordano, 1995: 5; Albelda and Tilly, 1998: 43). The traditional division of labor between men and women in the home has shown remarkable resilience, even alongside dramatic increases in women’s participation in the paid workforce (Baxter, 2000: 12). Women continue to juggle multiple responsibilities in various settings, including households, workplaces and communities (Gjerdingen et al., 2000: 3) and for finding or providing child care (Albelda and Tilly, 1998: 43). Women remain workers of two shifts: one for their employer and one in the home (Hochschild, 1989). One area of overlap between work and home is illustrated here.

**METHODOLOGY**

The research question for this study was: *What is life like for a full time worker who also cares for a child with a chronic illness?* For this exploratory, qualitative study, nine women were interviewed who were living the phenomenon under investigation. The numbers for this study were kept small on the basis that smaller numbers of respondents in qualitative studies allow for more penetrating insights. Purposive sampling was used to recruit participants. Respondents could have been either male or female although, of interest, all participants referred for participation were women. Respondents needed to currently be engaged in full time employment (or study), or have been during
the last 12 months. They also needed to be a parent of a child with a significant chronic illness, as defined above. Respondents were recruited via a modified chain referral technique. Success has been experienced elsewhere with this recruitment technique, especially given the small sample size and the sensitive nature of what was being investigated (see Watters and Biernacki, 1989; Vickers, 2001a). "Intermediaries" (such as colleagues, friends, and family) were contacted and asked if they would make contact with potentially eligible participants, who were then referred for participation. Being alert to opportunities for recruitment was an important factor during casual, professional and social discussions duration of the fieldwork. A three-stage qualitative study was undertaken:

**Stage 1:** In-depth Interviews from a *retrospective* perspective: What did you do? What happened? How did you feel?;

**Stage 2:** In-depth Interviews from a *prospective* perspective: If you had your time over, is there anything you might do differently? What would you change in the future? What *would* you do? Stage 2 interviews were also used to clarify Stage 1 data, and to also gather responses to fictional vignettes that had been developed based on data collected in Stage 1.

**Stage 3:** Culminating Group Experience. This was a group meeting, where respondents were invited to comment on emerging themes and on their experiences as participants in this research (Vickers, 2005a; Vickers, 2005b; Vickers, 2006).

Readers should be aware that, in the limited space available here, I have utilized data from Stages 1 and 2 only, because the sub-theme of Disclosure at Work was developed from the first two Stages of the study only. This paper reports a single section of a much larger theme (Working and Caring (see Vickers, 2006, Chapter 7)). Still other themes of concern have been reported elsewhere (See Vickers, 2005a; 2005b; 2006; Vickers & Parris 2005). The specific sub-theme discussed here is entitled Disclosure at Work.

**DISCLOSURE AT WORK**

When a man [sic] discloses his experience to another, fully, spontaneously, and honestly, then the mystery that he was decreases enormously. When a man discloses himself to me, my
preconceptions about him are altered by the facts as they come forth -- unless, of course, I have a vested interest in continuing to believe untruths about him (Jourard, 1971: 5).

Research has shown that a person will permit themselves to be known when they believe their audience includes people with good intentions. Self disclosure shows an attitude of love and trust (Jourard, 1971: 5) – not always present in modern workplaces. Unfortunately, the disclosure of truth, the truth of one's being, is often penalised. Nowhere might this be more anticipated than in one's place of work. Self-disclosure requires courage, not just the courage to be the person one is, but also the courage to be known by others as one knows oneself to be (Jourard, 1971: 6-7). So, why would a child's illness be a possible source of non-disclosure? The question of disclosure is about:

To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and, in each case, to whom, how, when and where (Goffman, 1963: 57; Vickers, 1997; 2001a: 81).

Many studies have confirmed the profound psychological impact of illness on the affected individual (Vickers, 1997a; 1997b; 2001a). For example, Kaplan (1980: 3) reported the importance of self-feelings or self-attitudes in response to illness. Varying psychological responses to illness are reported: anxiety; denial; questioning; ambivalence; suspicion; hostility; regression; loneliness and rejection; depression and withdrawal (Lambert and Lambert, 1979: 5-15); self-doubt; self-loathing; elf-dislike; uncertainty; loss of self-esteem; and guilt (Donoghue and Siegel, 1992: 29-36). Similarities in these kinds of responses have also been observed for varying chronic disorders (for example, comparing genital herpes, MS, cerebrovascular accidents and epilepsy), including denial, fear, depression and anger (Parsonson, 1989: 213-214; Vickers, 1997a: 60). What has not been explored is the response of parents of children with chronic illness, especially as it relates to the parents’ work. How do they feel about their child’s condition and, in particular, telling other people about it?

Psychological responses to illness may vary depending on the individual personality, cultural milieu and the illness involved (Vickers, 1997a; 2001a). Individuals react to their own illness depending upon their perceptions of themselves, their body images and how they feel significant others view them and their
illness (Mead, 1955; Lambert and Lambert, 1979: 2). These same factors are likely to be relevant when considering the response to and disclosure of a serious chronic illness in one's child. The presence of disease may invoke a change in the personal identity of the bearer (Fabrega, 1981) and may also raise concerns for the parent as to how best to address this in their child. Concerns for working parents about their child may also relate to the perception that others may have -- especially at work -- as to their capacity to fulfil their work responsibilities, especially if it is perceived that their child’s condition might detract from their workplace performance. Social and managerialis pressures encourage non-disclosure of a child's chronic illness, especially in the work context. The question of organisations being unreasonable, hurtful and alienating places is not new (Fromm, 1942/1960; 1963/1994; Blauner, 1964; Marx, 1975/1994). The abusive workplace, one that demonstrates little humane concern for its workers, is alive and well (Powell, 1998; Vickers, 2004). The notion of “rabid managerialism” (Vickers, 1999; 2001a) also points to the difficulties that exist for marginalised individuals in “sick” workplaces. Modern workplaces are not conducive to the trust and sharing that self-disclosure entails.

The paradox that Jourard (1971: 6) observed regarding the disclosure of anything perceived negatively by others, is the Western expectation of disclosure and, yet, the truth of penalty upon doing so: Impossible concepts of how people ought to be make them so ashamed of their true being [or their child's true being] that they feel obliged to seem different, if for no other reason than to protect their jobs. The penalty that Journard is referring to is enacted stigma (Scambler, 1984: 215) (or discrimination) (Vickers, 1997b; 2001a). Enacted stigma has two perspectives: the socially determined and the personally accepted. Stigma is not just the outcome of other people's devaluations of differentness. For stigma to exist, individuals possessing such differentness must also accept this devaluation (Jacoby, 1994: 269; Vickers, 1997b; 2001a). Several respondents demonstrated concern about disclosing their child's condition where they worked (Sally, Polly, Sandra, Wendy). This may have been out of concern for themselves and their careers, for the sake of their child, or both. I asked Wendy for some clarification about who she wasn’t telling about her daughter’s diagnosis of muscular dystrophy, and why:

**Researcher:** So, you’re not going to tell any of your colleagues about her diagnosis?
Wendy: No.

Researcher: Can you tell me exactly why?

Wendy: I’ve told only one, who’s a very close friend colleague; who’s a colleague who’s become like a friend. And why? [sigh, then pause] I don’t think it serves to have a label … Part of it is coming from Samantha not wanting to label herself, so it’s partly respecting that … Secondly, because it’s not an obvious situation, so it’s something that doesn’t necessarily need to be named. And thirdly, I guess there’s something about protecting my own privacy. A warning from you, an experience myself of saying something and it being repeated, and not wanting to have to explain because the disease isn’t understood, it’s not in the community as well. All of that (Wendy, Interview 2: 3-4).

The marginalised nature of those with an invisible illness often raises the challenging question of illness disclosure, especially in the employment context (Vickers, 1997b: 240; 2001a: 81). Self disclosure of illness or any other potentially stigmatising trait (Jourard, 1971: 6) is a major and complex decision. In this example, not only is the child with the stigmatising illness making her choice of disclosure for her own complex reasons, so is her parent. This is further complicated when one brings to bear employment related factors and perceptions. The information game (Goffman, 1969: 7) and the choice of information control (Goffman, 1963: 113; 1969: 123) still also rests with parents. Even if their child has a chronic illness or disability that is visible, because the child is not usually present in the workplace, the parent still has a choice regarding disclosure. For example, Sandra (Interview 1) reported that her son, Evan, was very sensitive about having ADD and she was careful to respect that. But she also reported not wanting others to know of some of Evan’s more notable temper outbursts that have been associated with anger management as a result of ADD. She did not, for instance, want to let anyone know about an incident where Evan became very angry -- out of control -- and threatened members of his family with a knife.

It is entirely possible, that in our capitalist and alienating workplaces, that information regarding a child’s significant chronic condition, might be regarded by a career-oriented parent as stigmatising (Vickers,
Current research into bullying in the nursing workforce (Hutchinson et al, 2004; 2005) tells me that Sally’s non-disclosing choices may have been linked to her concerns about what colleagues might think, especially as one working in a bullying environment. Sally had this to say about disclosing her child’s illness. She does not routinely tell people at her work about her intellectually disabled daughter:

Sally: I’m probably a bit naughty sometimes, because I’ve probably use it as a –, not as a shock thing, that’s really mean. But I guess people, society in general, devalues people with a disability and, as health professionals, we are members of society. And, tragically, I think it’s reflected in the work that we do as nurses. So sometimes I’ll find myself in situations where they’ll be having a really derogatory conversation around, you know … “Did you see that …[disabled] kid out in bed eight?” And I just cringe. So I might say things like, “That’s probably somebody’s daughter. It could be my daughter, you don’t know that.” “Oh yes, Sally, right.” [being sarcastic]. “Well actually, I have a daughter with a disability.”

Researcher: Good for you. What happens then?

Sally: “Ohhhh --.” People aren’t freaked out about it, but I sort of use it to put people back in their box. “Be warned. You just never know who around you has a child with a disability.” Generally people -, I don’t feel that they go, “Ugh” [indicating dislike or disgust]. I think it gives them another perspective of who I am and where I’m coming from. Perhaps it gives them a better insight into what I’m all about. (Sally, Interview 1: 9).

Sally is electing to share what Jourard (1971) describes as her “mystery”. When Sally chooses to disclose her daughter’s disability, she is revealing a great deal about herself that may influence the way others treat her at work. She may prefer not to do this in a hostile work environment. Wendy also spoke of her difficulties talking to people about her daughter's illness. She is demonstrating Goffman’s (1963) concerns with information control, feeling unsure what to say, to whom, when, where and how:
Wendy: … And I must have mentioned it [her daughter's illness] to Fred, that my daughter was not well. Anyhow, one time talking to Fred, and he said, “Oh, I’m terribly sorry to hear about your daughter.” And it was like it hit me out of nowhere, because I wasn’t expecting it. And when I thought about it afterwards, I must have said something to Fred at some stage. But it hit me out of nowhere - … And what I did, I cut him right off and I totally ignored it, and I went straight on with the business of the day. And I was absolutely stunned at what I’d done…

Researcher: You were surprised at your own response? Do you think it was because you didn’t want to go into that emotional realm with him?

Wendy: I think so, I think so.

Researcher: Too much going on, and you didn’t want to talk about it?

Wendy: Yes. And in fact - , you asked me why didn’t I want to tell people, that’s right. [Pause] … I think because I want to - , the most important thing for me in managing all this is Samantha’s self-efficacy … She said, “I’d like to be able to forget all about it and get on with my life.” … “I don’t want to be a hero and I don’t want to be a victim; I want to get on with having a normal life.” She sees herself – irrespective of the illness – as a pretty normal, average person. And so I think I didn’t want her constructed – by other’s goodwill or not goodwill – as anything other than that. But I’m still finding it quite difficult to come to terms with how I’m going to do that in the practicality. I saw someone this morning and they said - - they haven’t seen Samantha for six months – “How’s Samantha?” And I think, “How am I going to answer that?” And really what I want to say is, “She hasn’t been very well lately”, but then I don’t want to say why. So I haven’t found a place around that for myself. (Wendy, Interview 1: 27-28).

The difficulties surrounding self-disclosure are significant. We have known for some time that stigmatizing conditions, such as disability or illness, may present problems for people in a work context (Vickers, 2001a). However, here the choice is even more complex. First, these women, often, needed and wanted to acknowledge and respect their child’s choice of non-disclosure, especially if
they perceived disclosure might entail pigeonholing their child in manner that might be negative for them, now or in the future. Second, they needed to give thought to their own situation. Whether they made their choices of disclosure consciously or unconsciously, some of the issues that might have been manifest (whether acknowledged or not) might have included: whether they believed their child’s disability stigmatized themselves in any way; whether others’ knowledge of their child’s disability might have disadvantaged them, especially at work; whether they trusted those around them sufficiently to share such intimate information, especially in a work context; and, whether they cared what those around them thought. Few with what they believe to be stigmatizing conditions will willingly disclose their existence (Jourard, 1971; Vickers, 1997b; 2001a). However, there are exceptions. Below is a fictional vignette that was developed to evoke potential concerns and discomfort that the respondents might have been felt, especially in relation to the disclosure of their child’s illness in a workplace context. The vignette was designed to draw attention to the possibility that their child’s illness might be perceived as a "career-block" for these women:

Vignette 5

At your work there is a big annual, staff bar-b-que coming up. All the families and children are invited. Everyone is going to be there, even senior management. You are coming up for promotion very soon, and have been encouraged strongly by senior staff recently, and publicly praised for your recent achievements.

Do senior management know about your child? Will you take your child to the bar-b-que?

Not all respondents were concerned about disclosing their child's illness, even at their place of work. Evalyn reported being completely open about her child's illness, even at work. Evalyn had this to say about taking her child, with an intellectual disability, along to the function:

Evalyn: Now that’s interesting, that’s very, very interesting. [Long pause] Firstly, senior management know about my child. In my current situation, senior management do know about my child. Now, my child is a very –, I’d have to know what kind of
environment that its [the bar-b-que's] going to be. If it’s around a big pool where there’s no
fencing or anything, then there’s no way I’d take my child because it would be a totally
stressful situation for me. I’d be constantly worried about my child jumping into the pool.
So, that kind of thing, I wouldn’t. But if it was out in a big park somewhere, and if my
husband was going -- if I had adequate support -- I’d take my whole family, because, you
know, that’s my family. And I happen to think my children are very attractive [laughs]! And
even if Kevin was slightly different looking or something, that’s life nowadays. I mean,
Kevin goes to a regular school, with a high support unit attached to it. So, he’s quite used to
-, he’s no different. I mean, even if he was different, he’s no different, if you know what I
mean. (Evalyn, Interview2: 13; emphasis added)

CONCLUSION

Research into the lives and experiences of women who concurrently care for a child with a significant
chronic illness, and also work, continues. Their experience tends to be one where they feel that, in
working and caring, they are “doing it all” and “disconnected” from those around them (Vickers,
Parris and Bailey, 2004; Vickers and Parris, 2005). They also experience a great deal of grief along
the way (Vickers, 2005b) and not a lot of support (Vickers, 2005a). Here, I have raised the
problematic question of the disclosure of their child’s illness. There may be several motivations for
these women not disclosing their child’s illness: Not wanting to “label” their child unnecessarily; not
wanting to share an aspect of their own lives they consider private; not knowing what to say.
However, not all women were discomforted by the question of disclosing their child’s illness. More
needs to be learned about the experiences of these women as they juggle work and home while caring
for their child.

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