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Working Parents of Children with Chronic Illness/Disability: Narratives of Concern

Margaret H. Vickers, University of Western Sydney
Jeff G. Bailey, Children's Hospital Education and Research Institute (CHERI),
Melissa A. Parris, University of Western Sydney

Abstract

This paper reports some initial findings of an exploratory, qualitative study of the life and work of people who are, concurrently, parents of a child with chronic illness/disability and working full time. The respondents of this study happen to be all women. Two emerging themes of interest are explored here. The first is a revisit of traditional notions of the abusive workplace, which seems to be of special interest when considering the plight of these women. Secondly, the numerous work and home demands on the working mother, especially the working mother of a child with chronic illness or disability. It was unsurprising that these women reported extensive and multiple physical and emotional demands while trying to manage full time work with significant home and caring responsibilities. What is surprising is that these narratives of concern have not previously been explored, and should be.

Keywords: Chronic Illness; Disability; Phenomenology; Qualitative Research; Employment; Carers.

Caring for Children with Chronic Illness/Disability

Children with chronic disease and illness are a significant group of the population (Martin and Nisa, 1996: 1). Newacheck (1994) 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 usually 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). For example, of the 3.9 million children in Australia aged between 0 to 14 years in 1998, almost one in seven had a long-term health condition (594,600 or 15%), with boys more likely (18%) to be affected than girls (13%).

As a result of the advances in scientific knowledge and technology, the number of children with a chronic illness is increasing (Gibson, 1995: 1201). Examples of children's medical diagnoses may include (but not be limited to): cerebral palsy, muscular dystrophy, asthma; cystic fibrosis; diabetes; myelodyplasia; hydrocephalus; cleft palate; burns; cancer or other physical disability as a result of trauma or congenital anomalies (Burns et al, 1999). As with adults, children with chronic illness are not necessarily faced with acute, life threatening situations (although they may be). The central concern for us is the longer term "care" of the illness (Melnyk et al, 2001). 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/disability is a long-term health problem or disability experienced by the child for at least 6 months. The focus of this definition is on the challenges presented to the parent who is also working full time,
rather than a medicalised definition of the child's condition. This is not a study about the child's life with illness/disability but, rather, the experiences of the parent who works full time. The participants in this study reported caring for children with conditions such as severe epilepsy, varying levels of intellectual and physical disability, attention deficit disorder, and autism.

Methodology

The first phase of this research is currently underway and seeks to explore what life is like for a parent who works full time and cares for a chronically ill/disabled child. Qualitative, in-depth, phenomenological interviews are currently being conducted to gather the narratives of respondents participating in the study. These "first-round" interviews are exploring the experiences of respondents from a retrospective viewpoint. For this exploratory, qualitative study, a small number of respondents will participate (approximately 10) who have lived (or are living) the phenomenon under investigation. Theoretical sampling is being used to recruit participants. Respondents may either be male or female although, it should be noted, all ten respondents identified are women. Respondents must be in full time employment, or have been in full time employment during the last 12 months and have (or have had) full time caring/parental responsibility (which may be shared with a live-in partner) for a child with chronic illness/disability. Respondents were recruited via a word-of-mouth, snowball technique. Success has been experienced elsewhere with this recruitment technique, especially given the small sample size and the sensitive nature of what is being investigated (see Watters and Biernacki, 1989; Vickers, 1997; 2001). No-one referred has declined participation and, indeed, the take-up rate was so rapid, that interviews have had to be delayed.

Narratives of Concern

The Hostile Work Place?

One of the primary concerns with this study was to find out just how respondents experienced the crossover between work and home, especially when considering the likely weight of their caring responsibilities. The concept of the workplace as being hostile, abusive or "sick" is not new and is closely linked with managerialist and capitalist doctrines. We know that managers inconsiderate of other members of organisations, through ignorance or the chasing of efficiency objectives, may feel exempt from responsibility (Vickers, 1999: 72). Twining (1997) described such individuals as being 'terrifyingly normal' when feeling no guilt for their actions. The question of organisations being alienating and hurtful places is not new (See, for example, Fromm, 1942/1960; Blauner, 1964; La Bier, 1984; Braverman, 1994; Powell, 1998). We were concerned that respondents may have experienced

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5 There are two other planned stages to this research. The next "round" will also include interviews with respondents to explore issues raised in the first round, but from a more prospective approach, that is, asking respondents to think about their experiences and the reported experiences of others, and to comment on what they might do in the future. Finally, the third round will involve what we have termed the "Culminating Group Experience", and will involve inviting respondents to participate in a group discussion of their experiences, where respondents draw from and learn from one another and the researchers.
unreasonable work situations, further straining their capacity to survive their multiple responsibilities.

However, what was initially surprising was that respondents did not complain about their workplaces being unsupportive. Certainly, I (Vickers) found this contrary to previous work with adults who worked with chronic illness and disability (Vickers, 2001). Evalyn reported:

**Evalyn:** ... And so, and, my managers here, Peter and Ruby, they are just really wonderful and they've been very accommodating and they've -, they've looked, have been extremely supportive about me, you know, working at home and that sort of thing. I mean, I'll give you an example ... I used to work for, at Chase Manhattan. I mean he used to complain when I went and, you know, took time off to see my gynaecologist when I was pregnant. You know, and I just said "I can't help it! I've got to go. It's every month I have to go, every month or every six weeks I have to go. There's nothing I can do." And he, you know, he would, you know, he would let me go but it was just, you know, coming to work you just felt, you know, you have to go through the whole thing again.

**MV:** Have there been any negative situations pertaining to Kevin?

**Evalyn:** No, no. No. There really hasn't been. I've been extremely fortunate. You know, but I have to say he's never been that sick while I've worked here.

**MV:** What about earlier, at the previous jobs?

**Evalyn:** [pause] No. Well, you know, I was, when he was the sickest I was at Arab Bank and they were very good. I mean they were very good to me. They never said, you know, they never looked at me when I, you know, didn't come to work because I was, you know, looking [after him]. (Evalyn, #1: 30-33).

Interestingly, Evalyn remarked on her good fortune and her view that support currently enjoyed was related to her employment in the public sector, where she believed family-friendly workplaces and flexible workplace practices were routine, while pointing to less favourable experiences in the private sector. An earlier workplace where Evalyn also felt supported was a non-profit organisation whose task was to provide people with disabilities services in the community. Cate similarly reported a positive work environment in a disability support center. With this employer she reported working for a great boss, who also had a disabled daughter, a member of the board of directors with a child with autism (Cate, #1: 25), even a customer offering money to assist her with child care when she was desperate:

**JB:** So the environment is actually supportive, because of the nature of the services you provide?

**Cate:** Yes, totally. For me it is. And I've talked to other parents where it's not. They have to quit jobs and stuff because the job won't tolerate it.

**JB:** Have there been any very positive situations you can recall regarding your colleagues and William? Anything that stands as "that was a really cool thing that happened"?
Cate: Yes, definitely. Including a man who's a consumer of services here offering family support - money - to me to pay for childcare ... So it was like "Cool". (Cate, #1: 26-27).

However, concurrently, Cate also reported that her son was denied access to the work-provided daycare facility (Cate, #1: 28) on the basis that he would have taken too much care. She also related negative changes in relationships with co-workers (previously friends) after her child stopped developing in the same ways as theirs. They no longer chatted with her or spent time with her or asked her about her child.

Dolly (#1) and Sandra (#1) both reported being in positions of "being the boss", with Sandra as the Managing Director and Dolly the HR Director of her former employer. Both are now working in their own businesses, to which they both attribute the great deal of the flexibility they need. Sandra (#1: 1) reported taking her son everywhere with her during the first two years of his life: to work, to meetings with clients, everywhere. She described "having him on her hip" and a "baby gurgling in the background" at all times when she was at work in the early years of her business. Dolly attributed her support in a large corporation partly to the organization, but partly to her central and senior role in policy development:

Dolly: Extraordinarily supportive, absolutely. Yeah, very family-friendly. Well, you know, the irony here is that I was the HR director, so I wrote the family policies, I wrote the maternity leave policies, so I took advantage of it. You know, I wrote the tele-commuting policy. So I had other people that I worked with, obviously senior colleagues and that, but they were all extraordinarily -, "Just do whatever you need to do" (Dolly, #1: 26).

What demands further exploration is whether these women have, consciously or unconsciously, gravitated to work contexts that enabled them greater support, such as working in an organization sensitive to the needs of people with disabilities, or working in one's own business, or whether it was just coincidence.

Surviving Work-work, Mothering-work, and Caring-work

In most parts of the Western world, care for chronically ill children remains the responsibility of female relatives, mainly mothers (Martin and Nisa, 1996: 3; Burke et al, 1999). Indeed, a common view is that the mother has the primary responsibilities and others merely "help" her with "her job" (Burke et al, 1999). Despite the fact that the statistical norm is for women to work outside the home, cultural beliefs continue to preserve the unequal division of labour in parental care. It is interesting to consider the importance and responsibility attached to mothering, especially when it is mothering of a child with a chronic illness or disability, and when that mother also has to work full time. Three major imperatives dominate the work of mothering: to preserve their children's lives, to foster the child's development, and to ensure that the child is socially acceptable (Martin and Nisa, 1996: 3). Unfortunately, the nature of chronic illness and disability is that there may be no cure, no sure way to ensure the preservation of the child's life, let alone their social acceptability and intellectual and social development. This sets up the mother in a state of constant challenge and, also, the possibility of constant failure (Martin and Nisa, 1996: 3). The child's failure to achieve
normal milestones is also a likely source of maternal distress (Martin and Nisa, 1996). This was reported by Evalyn, who considered this to be the worst thing that had happened to her, relating to her son's disability:

Evalyn: [very long pause] The worst thing, well to me, the worst thing that happened was that he was actually, when he was 14 months old and he went to see the Pediatrician, and the Pediatrician said that he was developing normally. And he was just, "He's doing really well." And then, the seizures started to increase in frequency and you could see a regression. And then you know that, and then he had suffered brain damage. And so you knew that the path he was taking, which was this way [Evalyn indicates with her hand] a steep slope upwards] going upwards, has actually flattened out a lot [Evalyn indicates a much flatter slope with her hand] and [pause], so the worst thing is, I guess giving up the idea of what he was going to be when he grew up. And then realizing that that's not going to happen. He's actually going to have this sort of a life. And that is really the worst thing. (Evalyn, #1: 52).

Problems can also arise in maintaining family normality. Siblings may react at turning points or stressful events for either the sibling, the child with the chronic condition, or the family (Burke et al, 1999). Further, the exhaustion of the primary caregiver is related to managing the care of the child. For working mothers trying to keep themselves and the rest of their family healthy, this can be a considerable challenge. Sandra reported her daughter, the sister of her son with Attention Deficit Disorder, being hugely resentful of the son, even that she hated him, and had said so many times (Sandra, #1: 4). On the other hand, Evalyn reports her son, the brother of her intellectually disabled child, being very caring and protective towards his brother. However, she also reports her concern with not "spoiling" him, of not over compensating for time she may not be able to share with him because of the needs of the child with the disability:

Evalyn: Yes, I have an older child, Mathew. He's now twelve. So he was three and a half years older than Kevin. And he's, he's a lovely lovely child. He, you know, he's gone through everything with us and we call him "the parent" because [Evalyn laughs] because he feels responsible for Kevin. And it's just, he's never --, you know, he's never been one to get angry or, you know, jealous. The fact that Kevin has just so much of our immediate attention and he has more needs, and more immediate needs than Mathew, than you know, himself. So, Mathew's been a really wonderful child. And I think being a sibling of a child with a disability, he, it's really made him a better person. He's certainly a lot more considerate and a lot more, just a lot, he's more giving than other, I think, other children. And he's very mature for his age. And he knows what, he knows what to do, you know, in an emergency, because he's been through so many of them with Kevin. He's a really wonderful, he's a really wonderful child. (Evalyn, #1: 13)

Unfortunately and unsurprisingly, the burden of caring responsibilities for a sick child continue to fall on the mother, which is a primary source of frustration. Because fathers tend not to have the same investment in caring responsibilities, their confidence and expertise in
relation to the chronic illness/disability is not developed over time commensurately with the mother's (Gibson, 1995: 1205). Dolly’s comments depict her sense of "doing it all":

**Dolly:** So it was this constant guilt thing. Or Steven would make, sort of, "Well, you’ve had half a day off today". And this was the deal. What he doesn’t understand is, yes, he takes Margaret three weekends out of four. But who organises all Maggie’s medication, organises all her doctor’s appointments? Who takes her to all her blood tests? Who irons all her clothes? Who washes all her clothes? Who changes all her bed? Who organises all the nappies? This all just happens. Who buys all her clothes? Who finds time to go and buy her clothes and get her shoes fitted? And this all happens around Steven, and he doesn’t get it. Who does all the grocery shopping? You know, the food’s just there, the clothes are there. She goes with a perfect little bag, like an overnight bag, with all the medication, all the stuff. And I’m really filthy with him, because it all comes back dirty. And I said to him, you know, "You can wash". You know, "It would be really good. You’ve got her from Friday night to Sunday night. You can wash a couple of -", you know, "I don’t expect two or three sets of pyjamas to come back filthy". You know, because Maggie’s a bit of a grub. You know, "It wouldn’t hurt you to do a wash and all that sort of thing." So hopefully he will do that. (Dolly, #1: 90)

Dolly has had to ask her ex-partner to do these things. Even if he does do them in future, it will be to help her, rather than take responsibility. However, of more concern, was Cate’s story, where not only was support for her in home duties lacking, she felt unable to leave her disabled child with his own father for any length of time. She shared one particularly worrying incident where both her very young children were left at home alone:

**Cate:** … I never sat down and said, "I don’t trust you." I just kind of manufacture our schedule so that it doesn’t occur. But the closest I ever came was, "If you feel like you’re going to flip out, you’ve got to call me. That’s the rule." This came about after something that happened that made me really mad … And what happened was, I told him that –. It was a day when the kids were home because it was Christmas Eve. The kids were home, no day care. I had to work but I was going to come home early. I said, "I’m coming home early. You’ve got to watch the kids, but don’t worry because I’ll be home early." And so I went home, and it was about two in the afternoon, and his car was not there. And I went inside and guess who’s there? The two kids – alone. I had my brother with me, because he was with me here, and the two kids were alone. And I was, "What is going on?" They were just sitting in the living room, but you can’t leave a two-year old and a four-year old home alone. So I started to hit the roof within myself, and then about forty minutes later he shows up – with alcohol. You know, he’s got alcohol. He was already alcoholed up. He was already "shit-faced" … He would go through days here and there where he would do that at home with William, when William was the only one, and then he would do it with the other one. And I basically said, "This is the way it is. You will not do this. And that’s the way it is. You will not to do this. And if you’re going to flip out, you’ve got to call me. That’s the way it is." (Cate, #1: 64).
Clearly, the question of needing partner support is magnified by the weight of responsibility that these women bear. Balancing the competing demands of caring regimes, working and personal and family responsibilities are known to be challenging and exhausting (Melnyck et al, 2001). It is worse for a woman who has to work full time as well.

Working and Caring: Being "Different"; Feeling Alone

These stories depict life experiences that seriously impinge on these women’s working lives. These women all described tremendous demands on their time, energy and resilience. All reported, unsurprisingly, feeling different, disconnected or apart from those they worked with. Evalyn shares:

Evalyn: [pause] I do feel different. [pause] People are very [pause], I guess on the whole people are, are, are pretty compassionate. They are very compassionate but I just don’t think they really understand, you know, my life ... And I don’t think anyone, people don’t. I mean, I guess they have an idea but they don’t really understand unless they’ve lived it or are living it. [nervous laugh from Evalyn]. (Evalyn, #1:33).

Those who find themselves in this situation, working full time and caring for a child with chronic illness or disability, do feel alone, different, and disconnected from those around them. They deserve to have their lives better understood. From a philanthropic perspective alone, there is value in improving the work lives of these parents: to make their work lives better and to make the lives of their children better too. Readers oriented towards managerialist concerns, will also appreciate the view that supporting staff at work, helping them feel less isolated and marginalized, can lead to a more productive work environment.

References Available On Request.