This is the published version (version of record) of:


Available from Deakin Research Online:

http://hdl.handle.net/10536/DRO/DU:30006548

Reproduced with the specific permission of the copyright owner.

Copyright : ©2004, Early Childhood Australia
WORKING MOTHERS OF CHILDREN WITH CHRONIC ILLNESS: Narratives of working and caring

Margaret Vickers
Melissa Parris
Jeff Bailey
University of Western Sydney

This paper reports the initial findings of an exploratory, qualitative study of the life and work of people who are working full-time and also caring for a child with chronic illness. The demands of such a lifestyle are significant. Respondents - all women - often reported ‘doing-it-all’ while constantly being frustrated and challenged in their mothering role.

Children with chronic illness
Living with chronic conditions can be very difficult, both for the child involved and for his/her parents and siblings (Martin & Nisa, 1996). Shared here are the concerns of women who are working full-time and also caring for children with chronic health problems. In many instances, these women were either without partners or with partners who took little ultimate caring responsibility for the child. We know that women continue to do most of the work in the home, even if also in paid employment. Reported here are stories of women working the home and office ‘shifts’, but who also shoulder the primary responsibility for caring for a child with chronic illness.

We have defined a ‘child’ as a male or female person aged between birth and 18 years. For the purposes of this study, a chronic illness is considered to be a long-term health problem or disability experienced by the child for at least six months. This is a significant, ongoing condition, requiring ongoing medical or professional intervention (via pharmacological or other treatment, visits to medical or other professionals, or hospitalisation) to treat associated acute or chronic health problems. Because the focus of this study is on the challenges presented to the parent who is also working and caring, rather than on the child’s experiences with illness, the study is less concerned with the specifics of the child’s illness, disability, or condition than it is with the full-time working parents’ experiences. On that basis, we follow the lead of Lee (2001), whose study of older women carers was, similarly, concerned with the experience of the carer rather than the specifics of the illness or disability of the person being cared for. Specifically, she asked respondents: ‘Do you regularly provide care or assistance to any other person because of their long-term illness, disability or frailty?’ (Lee, 2001, p.395). This consideration of the issues and concerns faced by working parents who care for a child with a chronic illness is an important step forward to inform both educational and medical professionals in their support of these individuals.

Children with chronic illness are a significant group of the population (Martin & Nisa, 1996). Newacheck (1994) reports that approximately 31 per cent of children under 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 from accidents and environmental factors or through being born with a particular disorder (ABS, 2002, p.5). 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%). Examples of children’s chronic conditions include (but are not limited to): cerebral palsy, muscular dystrophy, asthma, cystic fibrosis, diabetes, hydrocephalus, cleft palate, burns, cancer, or other physical disability as a result of trauma or congenital anomalies (Burke, Kauffman, Harrison & Wiskin, 1999). Because of advances in scientific knowledge and technology the number of children with a chronic illness is increasing (Gibson, 1995, p.1201).
This means that, rather than facing acute, life threatening situations (although these may also occur), the central concern is the ongoing care of the illness (Melnyk, Feinstein, Modenhouwer & Small, 2001). In this study, the children were reported to have various intellectual and physical disabilities, in addition to severe epilepsy, leukaemia, Down’s syndrome, myotonic dystrophy, attention deficit/hyperactivity disorder, and autism.

**Methodology**

This exploratory, qualitative research sought to explore what life is like for a parent who works full-time and cares for a chronically ill child. The study comprised three phases, each involving a relatively small number of participants who had lived (or were living) the phenomenon under investigation. The numbers for the study were deliberately small, allowing for more penetrating insights. The first phase of this study entailed qualitative, in-depth, phenomenological interviews being conducted with nine participants to gather their narratives, and shared experiences and concerns, from a retrospective viewpoint. Respondents were asked a series of open-ended questions about their experiences caring for a child with chronic illness while working full-time. Seven of these respondents also participated in the second phase of the study where a second interview further explored, in a more prospective manner, issues raised in the first interview. This involved asking respondents to think about their experiences and the reported experiences of others, and to comment on what they might do in the future should such a situation arise. Finally, the third phase of the study is now scheduled, and is termed the ‘Culminating Group Experience’. We have invited respondents to participate in a group discussion of their experiences, drawing from and learning from one another and the researchers. The data presented here is drawn from phase one only.

Theoretical sampling was used to recruit participants (Glaser & Strauss, 1967), with its emphasis on respondents who meet the determined criteria for providing insights into the area of study (Stake, 2000). Respondents could be either male or female although, it should be noted, all nine respondents identified were women. Respondents were required to be in full-time employment, or have been in full-time employment during the past 12 months, and have full-time caring/parental responsibility (which may be shared with a live-in partner) for a child with chronic illness.

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 & Biernacki, 1989; Vickers, 2001a).

Heideggerian Phenomenology (Heidegger, 1927/1962) was selected as a methodological perspective concerned with underscoring the importance and value of the informant’s reality, and the need for the researcher to share that reality with others (Swanson-Kauffman, 1986; Vickers, 2001a). Heideggerian phenomenology has only one legitimate source – the informants who have lived the ‘reality’ under investigation. In particular, there is concern with understanding everyday practices, experiences and meaning (Benner, 1985; Vickers, 2001a). Reported here are the initial results from the first phase of the study – the in-depth, qualitative interviews concerned with gathering narrative on participants’ experiences. These interviews were fully transcribed and thematic analysis was undertaken. Themes and understanding emerged as both commonalities and differences in these experiences were uncovered. Although the emphasis of thematic analysis was on a common meaning, there was also an interest in the situations and conditions that gave rise to distinctions as they served to enhance understanding (Benner, 1994). Two of the themes to have emerged are presented here: ‘Mothers doing it all – again’ and ‘Mothers frustrated and challenged’.

**Narratives of working and caring**

**Mothers doing it all – again**

In most parts of the Western world, care for chronically ill children remains the responsibility of female relatives, mainly mothers (Martin & Nisa, 1996; Burke et al., 1999). Indeed, a common view is that the mother has the primary responsibility while others merely ‘help’ 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 and, indeed, all home duties.

Unsurprisingly, respondents often reported being the first point of call if assistance with their child was required (Sandra, Leah & Evalyn). Mothers, even working mothers, are usually the ones to take the child to the required medical and professional appointments,
and stay with the child during hospitalizations (Gibson, 1995, p.1205). Dolly, Otic, Evalyn and Cate all reported lengthy stays in hospital with their children. Of the nine participants, four were single mothers and five were currently in partner relationships. However, it was evident that even when a partner was present, this was not always a satisfactorily supportive relationship. In this exploratory study, the partner's role and contribution varied, but was mostly less than the mother's. We note, however, that the small size of the study does not allow for generalisations to be made and we recognise that not all fathers are non-contributing partners.

Dolly reported the constant strain of being the sole carer for her child, having just separated from her husband. For Dolly, even without a crisis, getting up to go to work each day was a strain because of her routinely interrupted night's sleep, an experience colleagues and friends would rarely understand. She commented on her daughter's regular night seizures and wakefulness:

**Dolly:** Maggie wakes nearly every night, and calls out and squeals and starts off with something small... and then progresses to something much larger. So by about half an hour of this I'm hanging off the ceiling of the bedroom, and I give up and I open the gate and she comes in and cuddles up to me and goes straight back to sleep. So we get about another sort of hour-and-a-half before we have to get up. But, yes, every night it's usually—, yes. It's very rare that she actually sleeps through (Dolly, #1, p.4).

As fathers tend not to have the same investment in caring responsibilities for the child, their confidence and expertise in relation to the chronic illness tends not to be developed over time, and certainly not commensurately with the mother's (Gibson, 1995, p.1205). The mothers remained, for the most part, as the 'sweepers' in the family, needing to be ever-attentive to the wellbeing of their family (Bianchi, 2000). Dolly confirms the imbalance in caring responsibilities reflected in many of the stories:

**Dolly:** 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.'... I don't expect two or three sets of pyjamas to come back filthy'. 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, p.36).

Note that Dolly is still asking her ex-partner to 'help' her with caring tasks - in this case, to wash some of their daughter's clothes. If he does this, it will still be regarded as assistance to her in her responsibilities. Of greater concern though, was Cate's story. Not only was support for Cate in all home duties apparently lacking from her partner, Cate felt unable to leave her disabled child with the father for any length of time. She shared one particularly worrying incident where both very young children were left at home alone:

**Cate:** I don't know. We never talk about it. I never sat down and said, 'I don't trust you'. I just kind of manufacture our schedule so that it [the father being left as sole carer] 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... 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... 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 40 minutes later he shows up — with alcohol. You know, he's got alcohol. He was already 'alcoholised' up. He was already 'shit-faced'. And I'm like, 'Not only are you here with the kids drunk--', and this is what he would do. 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 do this. And if you're going to flip out, you've got to call me. That's the way it is' (Cate, #1, p.21).

Although the level of involvement in parenting differs among fathers, clearly, the weight of responsibility these women bear in balancing the competing demands of the child's caring regimes, working, and personal and family responsibilities is challenging and exhausting (Melniky et al., 2001).

**Mothers frustrated and challenged**

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 & Nisa, 1996). Unfortunately, the nature of chronic illness is that there may be no cure, no sure way to ensure the preservation of the child's life nor their social acceptability and intellectual and social development. This sets up the mother in a state of constant challenge and, also, the possibility of her constant failure (Martin & Nisa, 1996). Dolly reports her fears about her ability to cope alone with her daughter:

**Dolly:** I'm wondering whether I'm going to cope with all this as well... In some ways I think, 'Is this going to have a significant impact on me?' And, 'Am I really up for it?', as well. And I don't know. My husband seems to be—, well, it's not fair to say he's a much better dad than I am. He's great at play. If I'm with normal children, I can spend hours reading to them, [Dolly's voice cracks with emotion again], puzzles and all that. I don't—, [tears in voice]...I find it hard to connect with Margaret sometimes because she's often in her own little world. So, whilst her and I, you know, we have cuddles and we have kisses and we have little chasings and things like that, there's only so much I can do of that with her. Whereas Steven seems to have an endless amount of energy to do that. And patience to do that. I just don't...My biggest worry is that he's been great at the moment, and taking Maggie three weekends out of four and all this sort of stuff. There's a part of me that thinks, 'Would she be better off full-time with him than with me? Is he better equipped, because he's with a partner, to look after her than I am?' Because she does need—, you do need to have two people to help you. It is hard work looking after a child like that, and somebody needs to have down-time. Like, I mean, usually of a night when she would wake, it would be, 'It's your turn'.

‘OK’. He'd be up. Or, 'I've got an early meeting'. 'OK, I'll get up'.

**MV:** And it's all you.

**Dolly:** And it's all me! That's right. And even when he's got her on the weekend... he can still partner with the girlfriend... He can say, 'Can you just go and see to her?' or 'Can you just change her nappy this time? I'll get it next time'. Whereas it's all me now. And I worry about my ability to actually long-term sustain that (Dolly, #1, p.28).

Uncertainty and fear about the future is a constant worry for parents of children who are chronically ill (Melniky et al., 2001). For the sole parent trying to hold down a full-time job, think about their child's future, and care for them day to day, or during a period of exacerbation or crisis, the strain is immense. The child's failure to achieve normal milestones is a likely source of maternal distress (Martin & Nisa, 1996), a concern confirmed by Evalyn. Evalyn described the 'worst thing' for her as the recognition of the decline in her child's current and future capacities, after he became so sick:

**Evalyn:** 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 paediatrician and the paediatrician 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 realising 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, p.27).

Respondents also commented on the reactions of siblings, at turning points or stressful events for either the sibling, the child with the chronic condition, or the family (Burke et al., 1999). Sandra revealed her concerns in this area, remarking that her daughter, Katrina, the sister of her son with attention deficit disorder, was hugely resentful of Edward. Katrina regularly told Edward that she 'hated' him (Sandra, #1, p.4). On the other hand, Evalyn's son, Mathew, the brother of her intellectually disabled child Kevin, was very caring and protective towards his brother. However, Evalyn
recognised her guilt and need to compensate one child for time she may not be able to share with him because of the more constant and immediate needs of the other:

**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'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 [pause], 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. So, Mathew's been a really wonderful child... He's a really wonderful child and it's really hard to be a parent of two, so totally opposite kids... It's really hard because you tend to compensate by giving your child that, you know, because you're feeling all this guilt, it's in your mind constantly, by giving him everything that he wants because, Kevin [pause]...  

**MV:** Takes so much of your time?  

**Evalyn:** Yes, and he doesn't want anything. Kevin doesn't want, you know, Nintendo or Playstation or anything like that, because he doesn't. It doesn't mean anything to him. He's just as happy playing in my plastics cupboard. But Mathew's, you know, right up with, you know, the Internet and right up with what's happening. And like any normal child wants everything and we tend to give him everything because we don't give Kevin anything, and he doesn't want anything. But we try very hard not to spoil them. Yes (Evalyn, #1, p.7).

**Conclusion: Working and caring**  
The role of mothers as primary carers of children remains despite the shift of many women to the full-time workforce. These stories reflect a familiar theme: women juggling full-time work against competing and conflicting demands at home (See for further discussion, Vickers, 2001b). However, the stories presented here are of grave concern.

These women reported 'doing it all' as they bear the additional burdens of caring for their child with chronic illness. Alongside the demands of full-time employment, these women are often the first point of call for their child's needs, whether at home, at school, or with medical requirements such as doctors visits and hospitalization. Furthermore, they may often shoulder the main responsibility for both the daily physical and emotional care of their chronically ill child. For childhood educators relating with these women, an understanding of these competing, and often overwhelming, demands is essential in establishing rapport and working together for optimal benefits for their children.

The women in this study also spoke of the frustrations and challenges in endeavouring to foster their child’s development, while at the same time having responsibility for the healthy functioning of their entire family. These demands often create a sense of uncertainty and fear about the future. Again, in working with these women and their families, recognition of these stresses and fears is paramount when determining ongoing strategies.

These exploratory stories flag a very serious problem in our communities, homes, and workplaces. On the strength of the findings presented in this paper, and other emergent themes, we would recommend a larger, more generalisable study of the concerns experienced by these respondents. If women are expected to shoulder the burden for all this, then it is inevitable that their children and families will suffer, especially those in greatest need – their children with chronic illness.

**Acknowledgements**  
Financial support for this study is gratefully acknowledged from the Children’s Hospital Education and Research Institute (CHERI), Trauma Research International Pty Ltd, and the University of Western Sydney.

**References**  
Australian Bureau of Statistics (2002). Health: Disability and long term health conditions (ABS Catalogue No. 1301.0), Canberra: ABS.  

Interview Transcripts:
- Cate, Interview #1, 15 April 2003.
- Dolly, Interview #1, 7 April 2003.
- Evalyn, Interview #1, 2 May 2003.
- Leah, Interview #1, 10 June 2003.
- Otis, Interview #1, 12 May 2003.
- Sandra, Interview #1, 4 April 2003.


