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Towards Ending the Silence: Working Women as Carers of Children with Chronic Illness/Disability[^1]

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Towards Ending the Silence: Working Women as Carers of Children with Chronic Illness/Disability

Abstract
This research presents stories from Australian women who work and care for a child with a significant chronic illness or disability. The paper considers the theory of Silencing the Self (Jack, 1991) in relation to the reported experiences and behaviours of these women. We report three themes of Caring and Working: "Otherness", "Doing it All" - but "Wanting to Live a Normal Life". As in Jack's study, these women engaged in silencing of the self. However, we also observed other people contributing to their silence and, unlike the respondents in Jack's study, many of these women fought the silence and did not accept that their unhappy situations should continue. They sought a life where silencing may not have been necessary.

Keywords
Women, Self, Chronic Illness/Disability, Work, Caregiving.

Caring for a Child with Chronic Illness/Disability: A Silent but Significant Problem
The aim of this manuscript is to highlight the difficulties for full time working women who also care for a child with a significant chronic illness/disability. The problem of providing primary care in our communities, for the elderly, the disabled, and for children, is increasingly being recognised as a growing problem. Here, the focus is on women who have to juggle their caring responsibilities for a child with a chronic illness/disability with full time work - not an easy thing. Reported are three themes of caring and working that emerged from a recent qualitative study in Australia. Jack's (1991) theory of Silencing the Self is used to explore these women's experiences of managing the working and caring mix.

Much research has been undertaken into the time bind experienced by working women and men as they deal with the dual responsibilities of home and work (Hochschild, 1997; Roxburgh, 2002). One key area of this research has been a consideration of the multiple roles of women - at home and at work - and the demands of each role in terms of time, energy and commitment (Kinnunen and Mauno, 1998). Notions of the work-family conflict encapsulate the strain that can develop as one struggles to balance the demands of work and family (Greenhaus and Beutell,

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2 We note that, for this study, the term "working women" is used to include women in full-time paid employment or its equivalent, whether self-employed, undertaking multiple part-time/casual roles, full time study, or in the full time permanent paid labour force. That said, we recognise that much of women's work is not paid, a point especially evident in this paper.
1985). For many women, high levels of conflict and increased time pressures are experienced as they deal with substantial family responsibilities alongside significant workloads (Cinamon and Rich, 2002). Of particular relevance for this study is the primary role women still undertake with respect to caregiving for children (Robinson and Godbey, 1999; Mattingly and Bianchi, 2003). Not only does this role entail the physical demands of care, but the "mental work" — worrying, and seeking advice and information — that is involved in raising children (Renzetti and Curran, 1999: 166). This paper expands the discussion on the time pressures of working mothers by considering the additional burdens involved in caring for a child with a chronic illness/disability. The second shift (Hochschild, 1989) worked by the women in this study includes the additional demands of caring for children with special needs. In Australia, this is no small problem.

As a result of the advances in scientific knowledge and technology, the number of children with a chronic illness is increasing (Gibson, 1995: 1201). 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 with adults, children with chronic illness are not necessarily faced with acute, life threatening situations (although they may be). The central concern is the longer term care of the illness (Melnyk, Feinstein, Moldenhauer and Small, 2001). In this study, the children had conditions such as severe epilepsy, intellectual and physical disability, attention deficit and hyperactivity disorder (ADHD), Down's syndrome, leukaemia and autism.

While there have been numerous studies about caring for a child with disability or chronic illness (Gibson, 1995; Martin and Nisa, 1996; Melnyk et al., 2001) and, especially, the impact this may have on parents, relationships, families and siblings (Clements, Copeland and Loftus, 1990; Quittner, DiGirolamo, Michel and Eigen, 1992; Sawyer and Spurrer, 1996; Murray, 1998; O'Brien, 2001), as well as the difficulties of employment in terms of the work-family challenge (Wolcott, 1993; Lewis and Lewis, 1996; Eagle, Miles and Icenogle, 1997; Edwards and Rothbard, 1999; Clark, 2000; Russell and Bowman, 2000; Clark, 2001), there are few studies
focused on the lives of women who work full time while also having to care for their child with chronic illness/disability. Those studies that exist tend to focus on time away from the child because of work (see Bianchi, 2000), the need for carers to miss work to care for a sick child (Van den Heuval, 1993; Erickson, Nichols and Ritter, 2000), the coping strategies of mothers (van Eyk, 1992), including difficulties experienced with day care centres (Crowley, 1990), and whether Australian workplaces are family friendly (Kilmartin, 1996). None of these studies focused on these women's holistic experience of working and caring, and the meaning it held for them, and none considered these experiences in relation to Jack's (1991) theory of silencing the self. We focused on women in this study simply because they were the ones referred to us. No men were referred or volunteered to participate.

**An Exploratory Study: An Emergent Research Design**

The research question for this exploratory study was: “What is life like for a full time worker who is concurrently the primary carer for a chronically ill/disabled child?” Because the focus of this study was on the challenges presented to the parent who is also working and caring, rather than the child's experiences with illness, the study was less concerned with the specifics of the child's illness, disability or condition, than it was with the full-time working parents' experiences (Vickers, Parris and Bailey, 2004). Lee's (2001) study of older women carers also shared our concerns with the experience of the carer, rather than the specifics of the illness or disability of the person being cared for.

From a philosophical standpoint, Heideggerian phenomenology and naturalistic inquiry were combined as methodological choices because they are each aligned with the need to explore and uncover life experiences. The value and acceptance of the existence of multiple identities and multiple lives is noted, especially in phenomenological research (see Vickers, 2001). Heideggerian phenomenology is anti-reductionist and holistic (Oiler, 1982; Omery, 1983; Benner, 1985; Wilkes, 1991) and allows for a composite of realities (Oiler, 1982: 179).
Naturalistic inquiry, similarly, recognizes the need for a window of meaning on the lives where multiple realities can be revealed through thick description (Green, 2002: 14). Indeed, the postpositivist paradigm proposes a reality where all aspects are interrelated. Individual perspectives give rise to multiple realities (Harris, Trezise and Winser, 2002). Many of the tenets of Heideggerian phenomenology and naturalistic inquiry overlap and include the use of: the human being as instrument; tacit knowledge; qualitative methods; purposive sampling; inductive data analysis; the case report; thick description; idiographic interpretation; and trustworthiness (Lincoln and Guba, 1985; Green, 2002).

Like Mason's (2001: 311-312) naturalistic inquiry study, this project included several stages and modes of data gathering, which all contributed to a richer understanding. The stages included:

**Stage 1 - In-depth Interviews – Retrospective.** Interviews encouraged in-depth discussion, sharing of experiences, and retrospective reflections (eg What did you do? What happened?).

**Stage 2 - In-depth Interviews - Prospective: Responses to Vignettes.** The second stage interviews had three purposes: To clarify any uncertainties from Stage 1; to ask respondents to reflect on their experiences from a prospective perspective (eg. What would you do in the future); and, to seek responses to vignettes developed using case material from Stage 1.

**Stage 3 - Culminating Group Experience.** This final stage enabled the researchers to check that the interpretations made were representative of respondents' experiences.

Nine women participated in Stage 1; six participated in Stage 2; and two participated in Stage 3, the culminating group experience. Pseudonyms were used to protect the anonymity of participants, and anyone named in interviews. All interviews were transcribed verbatim and, particularly in the first phase, were very long. Of interest, several respondents indicated that no-one had ever asked them about their experiences prior to this experience; any concern had always been directed to their child.
Towards Ending the Silence: Themes of Caring and Working

The theory of Silencing the Self (Jack, 1991) lent itself well to the interpretation of these stories. This theory argues that women are affected by social learning within the context of their personal and professional relationships. Women learn not to express what they need and feel, openly and directly (DeMarco, Lynch and Board, 2002: 90). There were numerous parallels in this study with Jack's findings, for example, the problematic role of gender norms (Jack, 1991: 14), a loss of voice, especially in partner relationships (Jack, 1991: 30), and the perceived need to silence the self. However, we also found distinctions. First, the women in this study did not show feelings of self-doubt or worthlessness, as the women in Jack's study did (see Jack, 1991: 32). On the contrary, they were impressive and capable people who managed particularly difficult circumstances extremely well. It appeared that the silencing came from other people, especially at work, and that these women were rallying against the silence they experienced, especially as this related to their career. The stories shared here explore themes of "otherness", "doing it all" and "wanting to live a normal life".

"Otherness"

Respondents frequently reported feeling different - other - from those around them; that others did not really understand their lives. Jack (1991: 39) argues that feelings of disconnection come from feeling unsupported and alienated, from themselves and others, through a loss of voice. Voice is an indicator of self, and speaking one's feelings and thoughts is part of creating, maintaining and recreating one's authentic self (Jack, 1991: 32). Evalyn described feeling different from other people and families, as well as sharing her experience of being apart from other people at her workplace. She reported that her colleagues, even when being compassionate, sympathetic or supportive, still didn't really understand:

Evalyn: [pause] -- I do feel different. -- People are very -. 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 guess, you know, they don't
have the same perspective on life as say someone with a high support needs child has. Like, my child is nine years old now but, you know, for another parent with another nine year old child, they probably think, "I've got another nine years where my child will live at home, stay at home." But I, I don't know what the future is for my child, what will happen to him and I'm very --, and that's something that really worries me about, you know, what will happen to Kevin. I obviously can't care for him forever ... I mean so there will be a time when I can't care for Kevin and he may, he will most probably live longer than I will. So, you know, I'm always worried about the time that, you know, when I can't look after him. 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).

While Evalyn speaks of her colleagues being very compassionate, in the same breath she tells us that they just don't understand her experiences with Kevin. One aspect of silencing the self involves women learning that the way to meet the needs of others is to deny the importance of their own needs and feelings, which subsequently inhibits their self-expression (Jack, 1991; DeMarco, Lynch and Board, 2002: 89). When Evalyn describes her colleagues as compassionate, while concurrently acknowledging that they don't understand her needs and feelings, she is diminishing and devaluing her self and her need to feel understood. In contrast, Cate's sense of "otherness" was not through her own self-silencing. Cate's colleagues magnified her sense of otherness, by contributing to and ensuring her silence. Cate shared the changes in her relationships with her colleagues as the news emerged that her new baby had autism. Cate initially told us how she used to relate with her colleagues - before the diagnosis of her son's illness:

**Cate:** What happened was when you're at work and you're pregnant, it's a big deal. People know; you are obviously -. They can see it. And it's, "Wow, a kid's going to be born". And then when they're born, everyone's asking you about the kid and what they
are doing. And you develop relationships with other people who have kids of the same age. So then come the comparisons and the milestones that they reach when they’re doing that. And a couple of people here have kids of the same age, and what happened was I would be, "No. He didn’t talk yet". "Well, my daughter says 'shoe' now." And I would say, "Well, mine doesn’t say anything. And all he does is go like this [indicates the child's movements] all day" (Cate, #1: 7).

At this stage, Cate is talking about her son's unusual behaviour and slower-than-usual development. However, once her son was diagnosed with autism, things changed for Cate at work. Her colleagues no longer asked about her child, and gave her no opportunity to discuss him, or how she felt. She admitted changes in her relationships at work:

**Researcher:** Do you feel different or misunderstood by colleagues or excluded or alienated in any way because of William?

**Cate:** Just from the ones that I was friendlier with about the kids. Just those guys. They’re really nice to me every day. They’re never mean to me, ever. But we just kind of don’t talk like we used to. And it’s kind of like, "Oh well. Now Cate’s one of them. She’s not one of us anymore." But that’s, you know, that’s OK [voice slightly dropped]. (Cate, #1: 12; our emphasis).

The drop in Cate’s voice suggests that, from her point of view, her colleagues’ behaviour is not OK and that she may be feeling hurt and rejected. She highlights her experience of "us" and "them". Cate is also exhibiting another of the characteristic behaviours of women who silence themselves: she has inhibited her self-expression and action to avoid conflict and the possible loss of the relationship (DeMarco, Lynch and Board, 2002: 90). She has not discussed her feelings with her colleagues. However, Cate still claims: "They're really nice to be every day. They're never mean to me, ever" - even though they are silencing her concerns about her child by not enabling her to discuss them. They may be discomforted by Cate's child's disability and may
be alleviating their discomfort by silencing themselves - and Cate - as a result. As Jack's (1991) study indicates, Cate may well have been silencing her self to avoid giving colleagues a reason to reject her (Jack, 1991: 138). However, unlike Jack's study, others contribute to Cate's silence.

"Doing it All"

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, Kauffman, Harrison and Wiskin, 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. The mother, even if she works outside the home, is usually the one to take the child to the required medical and professional appointments, and stays with the child during hospitalisations (Gibson, 1995: 1205). This has certainly been the case in the stories reported here. All respondents reported, in some form or another, of being expected to "do it all", especially regarding responsibility for the child. Even when supportive relationships were evident (and, often, they were not), these women reported that they were ultimately responsible for the child's welfare and development, and for all decisions and actions surrounding that. For example, Dolly reported the lack of pragmatic, physical assistance from her ex-husband, which contrived to give her even more to do:

**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, 'cause 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, 'cause 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).

We see Dolly silencing herself through self-sacrificing; that is, caring for others before attending to her own needs (Jack, 1991; DeMarco, Lynch and Board, 2002: 90). However, unlike Jack's (1991) study, Dolly did not feel that her needs should come last, nor that a situation where she continued to put the needs of others ahead of her own was a positive or acceptable one. Whatever her thoughts, if the father ultimately decides to wash Maggie's clothes, it will still be to "help" Dolly (Vickers, Parris and Bailey, 2004). The self-sacrificing characteristic of silencing behaviour emerged frequently in these women's stories, with respondents continually demonstrating that they were (and were expected by others to be) the ones who continually took responsibility for their child's needs.

Sadly, Cate also described a situation where her husband actually added to her burden, creating a hindrance to her caring work. Cate reported doing the shopping - with her autistic son present, and her husband absent - because it was easier for her than being mocked by her husband, arguing with him, upsetting her routine with her son, and transforming a mundane task into a nightmare. We note that Cate did the shopping, caring, cooking and other home duties, around her three paying jobs, presumably because it was "her job". However, we emphasise that at no time did Cate suggest that it should be this way, that caring about her needs is selfish, or that ignoring her needs is morally right (Jack, 1991: 155).
Sandra also exhibited her divided self in her reported experience of having to "do it all": bring in the money, manage the household, and keep the family together emotionally. She said that it was always she who got the calls from her son's school if there was a problem. It was she who went to School information evenings, and it was she who organized any doctor's visits and counseling that was required. However, Sandra struggled against the pressure to silence herself. She reported feeling very resentful, believing that her having to "do it all" added immeasurably to the strain of an already difficult situation (Sandra, #1: 9). She also admitted that she was unhappy that her partner, Robert, was not able to provide more emotional support when it was needed (Sandra, #1: 9).

Sandra refused to silence herself in other ways too. For many women, the rules constructed by the social group are not necessarily congruent with what she values (DeMarco, Lynch and Board, 2002: 90), but she will follow them anyway. However, in Sandra's case, she did her best to work around them. She did not "self-sacrifice" herself (DeMarco, Lynch and Board, 2002: 90) or her career by giving up work to look after her very sick baby. Instead, Sandra broke traditional social conventions by bringing her child to the office to care for him - although it is acknowledged that it was still she who had to do this. Sandra (#1: 1) reported taking her son, Edward, everywhere; "having him on her hip" and having a "baby gurgling in the background" during meetings.

"Wanting to Live a Normal Life"

The challenge of normalisation for families of children with chronic conditions has been considered previously (eg. May, 1997; Horner, 1998; Deatrick, Knafl and Murphy-Moore, 1999; Knafl and Deatrick, 2002), specifically, that others have concluded that, over time, family members come to view both the child and their life as normal (Knafl and Deatrick, 2002). The respondents sought to live normal lives - to live like others do - as far as they could. However, their stories suggested that they did not feel that their lives were like other
people's lives. Relief and delight were evident when instances arose which suggested they were. For example, Sally was pleased to see other people experiencing the same problems that she did - even when their child didn't have a disability. This enabled her to feel like her life was the same as everyone else; that her household was "normal". Sally thought it was "really nice" when others reported the mayhem in their lives:

Sally: But then I go to other people's places and I think it's so refreshing that it's just not my place [where things are crazy]. It's not just me! People are saying the same things and yelling at their kids too, so that's nice. People say, "We're not normally like this". And I'm going, "No, please, don't stop! It's really nice. Keep going." (Sally, #1: 40)

The desire for a normal life extended to the rest of respondents' families. We know that maintaining the health and wellbeing of their families is a primary concern for mothers (Martin and Nisa, 1996: 3). For some, this may include the ability for the family to operate as a family. Evalyn shared her pleasure, even pride, in having her family do some things together, as a "normal" family would - even if this required more effort and even if, sometimes, it was not always possible:

Evalyn: I find it very difficult when Kevin got invited to a birthday, like a, his cousin's birthday party. And you see all these kids doing things and my child is sitting somewhere else, and not participating and not eating like the other kids, not enjoying the entertainment like the other kids. That's when it really hits home and that was very, that's very difficult. But as a family we tend to cope pretty well. We don't, we can't go to movies as a family because Kevin just can't sit through a movie [laughs]. We --, when we got out, sometimes we have to take Kevin in a stroller because he can't walk, he doesn't walk very far so we have to, we're constantly juggling things. But we've tried not to let that stop us. We go, we have gone overseas, the four of us. And we do go on
holidays where we have to catch a plane. Kevin now knows what a plane is and he loves going on a plane. We don’t, we try not to let his disability stop us from doing things. You know, I turn 40 in five weeks time and we’ve got, we’re going to the sunshine coast, all four of us. Like, we’re all going to go. And we’re all going by plane and, you know. So we manage. Yes (Evalyn, #1: 24).

These mothers, frequently frustrated in the normal quests of mothering, have another challenge - enabling and encouraging their child to live a "normal" life. Charlene confirmed the importance in her mind of her child being raised to be like other children. She recounted, for example, of how she took her paraplegic son hiking; if they came across a log on the path, Charlene and her friend simply lifted his wheelchair over the log and on they would go (Charlene, #1: 13-14). Achieving a normal life for her son, for Charlene, was the nicest thing that has happened to her:

**Researcher:** What would you say to them was the nicest thing that ever happened to you, or the best thing that ever happened to you in all those years?

**Charlene:** I’d say, "Just do your best to raise your child to be normal. Try not to treat him -." With Jamie, it was, "You have chores, and you have to wash dishes. You can’t put them away in the cupboard because you can’t physically reach into the cupboard, but that doesn’t mean you can’t wash them." You know, "You can take your clothes and put them away. Just because you can’t do other things or you can’t reach here or you can’t do that; you do what you can do." And I tried very hard to raise my kids so that they were accepting, that they did things that way (Charlene, #1: 10).

It appears that, for Charlene, her attempts to normalise the life of her son were very successful. Jamie obviously thought of himself as just like everyone else, as the following delightful anecdote indicates. Jamie, Charlene’s sone, is a wheelchair user:
Charlene: He was probably five. It was Halloween; they dress in costumes. I had purchased for him a Spiderman costume, because Spiderman was his favourite. And it was a cape, and he wore it later after that as a raincoat. And he put the hood on and put the cape on, and we went next door to go trick-or-treating. The lady opened the door, and she said, "Hi, Jamie!". And he looked at me and he said, "Mum, how did she know it was me?" And I told him, "Because your blonde hair is showing underneath your hat" [Laughter] (Charlene, #1: 15).

Charlene has not been silencing herself or her child and this may be related to her success in achieving as normal a life as possible. Jamie appears to be a happy and well-adjusted child, comfortable with his disability (even unaware of it), enabling others to be comfortable too. Charlene has demonstrated that her quest to live as normal a life has possible has been most fruitful.

Towards Ending the Silence: What Have We Learned?

It became apparent during the research that many respondents were sharing many of their feelings, thoughts and experiences of working and caring for the very first time. As we return to the theory of women silencing the self (Jack, 1991; DeMarco, Lynch and Board, 2002), we see many parallels in this study with those conducted earlier. The women in this study did engaged in silencing of the self. However, we also saw divergence from Jack's (1991) theory, perhaps in part because Jack's study dealt only with women who were clinically depressed. The women in this study did not slip into self-doubt when they lost their voice. They may have "bitten their tongues" sometimes, but they certainly did not force themselves to stop thinking or stop sharing their views, nor did they evaluate themselves as worthless. They seemed far from being intent on thinking it was morally right that their needs be ignored and seemed quite prepared to say so.
There was also evidence of others participating in the silencing process: colleagues no longer talking about that which is uncomfortable; partners not taking responsibility in their caring responsibilities; and others not asking about these mother's experiences at all. These women were struggling to end the silence, to find ways around it, and to live like other people. For these women, so well versed in juggling the competing demands of work and home, their confidence and capacity to cope with the extreme demands placed upon them points to a resilience that is at once remarkable and terrifying; it highlights the continuing and unabated expectations that women should still "do it all", despite how much there might be to do. For those concerned with gender studies and work, this may be somewhat disheartening.

Although each mothers' experience of caring for a chronically ill or disabled child was unique, there were remarkably consistent patterns (Gibson, 1995: 1202). Frustration has been found to be a central and powerful issue permeating stories from mothers of children with chronic illness (Gibson, 1995) - frustration with their experience of "otherness" and "doing it all" - as well as the expectation that they continue all that they do in silence. These frustrations and struggles mirror the stories of many women, as they deal with the competing responsibilities of work and home. However, the additional demands that the women in this study have to cope with requires acknowledgement and address, with attention being recommended to the development of workplace policies that continue to enable flexible working arrangements, especially as required by people who care for children with chronic illness or disability. However, of equal importance (perhaps more) is the need for recognition by partners, fellow workers, friends and family, of what these women are required to continually do - and to sacrifice - and how this recognition might be met with the provision of meaningful support. Such initiatives will contribute to ending the silence for these women, and enhancing their well-being. Finally, and notably, as the stories shared here reveal, along with frustration and silence came stories of pleasure and pride. It was apparent that,
sometimes, these women's striving for a normal life for themselves, their families and their child resulted in many aspects of a normal life being achieved.

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