'It's a terrible thing when your children are sick': Motherhood and home healthcare work

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ABSTRACT: This article draws upon research involving in-depth interviews with 60 mothers of young children about the home healthcare in which they engage when promoting their children's health and dealing with their illnesses, allergies or developmental problems. The study found that a series of often interconnected discourses were evident in the women's accounts. These included the discourses of health states as controllable, good health as an outcome of good management and the child's body as vulnerable. Other discourses were related to the concept of the 'good mother'. The interviewees also employed the discourses of home healthcare as emotionally distressing and as hard work and of children's illness as a mother's loss of control. As this suggests, such caring was often an intensely embodied and negative emotional experience for the mothers, particularly if they felt as if they had lost control over their children's bodies.

Keywords: motherhood, health, the 'good mother', children's illness, children's embodiment, home healthcare, caring, sociology

others in contemporary western societies **V** are expected to adhere to the principles of intensive parenting, spending a great deal of time and effort caring for their children, protecting them from harm and illness and promoting their health, development and wellbeing. They are called upon to position their children as more important than themselves, for children are now represented as precious and highly vulnerable to risk (Beck & Beck-Gernsheim, 1995; Christensen, 2000; Hays, 1996; Lee, Macvarish, & Bristow, 2010). Mothers have also increasingly been drawn into a network of health promotional and medical expert advice in relation to their caring practices for their children, to the point where they are often blamed for health or developmental problems in their children. As part of the idealised 'health-promoting subject' privileged in contemporary neoliberal discourses on citizenship (Lupton, 1995; Petersen & Lupton, 1996) mothers are encouraged to act as rational, entrepreneurial citizens in relation to their children and to actively seek out and act upon expert health advice in protecting and promoting their children's health (Bell, McNaughton, & Salmon, 2009; Coxhead & Rhodes, 2006; Maher, Fraser, & Wright, 2010; McNaughton, 2011). Concepts of the 'good mother' here interact with concepts of the 'good citizen'.

Promoting children's health and caring for them when they are ill are tasks which are an integral part of routine maternal labour which is often unacknowledged and yet is vitally important to children's health and wellbeing. Clarke (2006) uses the term 'home healthcare work' to refer to the unpaid labour that is undertaken at home to care for ill family members. As she notes, such care, which is overwhelmingly undertaken by women, is largely invisible, yet it is a fundamental part of healthcare in the community. This form of healthcare has also been largely neglected in sociological research. However some work has been published in relation to mothers caring for children with serious medical or developmental conditions or severe disabilities. This literature has demonstrated that emotional labour as well as physical caring is an integral aspect of caring for such children. Mothers must deal with and manage their own and their children's emotional distress. They often feel a great sense of responsibility to protect their child as much as possible from suffering and express the need to be in close proximity to their children to maintain surveillance over them and provide comfort. They also note the very close emotional bond they develop with their children as part of this carework and emotion work (Clarke, 2006; McKeever & Miller, 2004; Young, Dixon-Woods, Findlay, & Heney, 2002).

Little sociological research has been conducted on mothers' experiences of dealing with less serious illnesses or developmental conditions in children which are part of the mundane, everyday dimensions of maternal care. Some European and British studies have examined more generally the ways in which mothers conceptualise and recognise good health and signs of illness in their infants and young children (Backett-Milburn, 2000; Brownlie & Sheach-Leith, 2011; Cunningham-Burley, 1990; Irvine & Cunningham-Burley, 1991; Lauritzen, 1997; Murcott, 1993). These studies demonstrated the strong sense of responsibility mothers felt for promoting their children's health, their view of children as vulnerable to illness, the importance they placed upon encouraging their children to engage in behaviours deemed health promoting and the ways in which they identified the signs of illness in their children. None of these studies, however, focussed specifically on the interviewees' practices of care for their children when they are ill or how they felt when dealing with their children's illnesses. One study of Scottish mothers in paid work with school-aged children (Cunningham-Burley, Backett-Milburn, & Kemmer, 2006) focussed on the competing demands of home and work for these women. The researchers noted that these demands clashed when the women's children were ill. The women therefore tended to encourage their children to continue to attend school when suffering minor illnesses, thus reproducing moral values about soldiering on when one is ill and not 'giving in' to illness. It was also found that the mothers struggled with the notion of the 'good mother' as 'being there' for her children when they needed her in direct opposition to the demands of the 'good employee' who was reliably present at work.

The present study built upon this previous research by identifying how Australian mothers from various socioeconomic backgrounds conceptualised their young children's health, illness and embodiment, what actions they considered important in promoting and maintaining the optimal health and development of their children, how they went about putting this into practice, what risks they saw as potentially affecting their children's health and how

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they responded to illness in their children. The findings emerging from the women's discussions concerning the latter topic – how the mothers responded to their children's illness – are detailed in the present article (for discussion of other findings, see Lupton, 2008, 2011, 2012a).

The study

A total of 60 women living in Sydney with at least one child aged 5 years or younger were recruited for the study. The participants were recruited by a research assistant who was experienced in recruiting and qualitative interviewing for market research and other researchers. She used a variety of methods to recruit participants, including drawing on contacts made in previous studies, snowballing from these contacts, advertising in places such as libraries and child health clinics and randomly approaching women with young children in shopping areas and day care centres. The research assistant deliberately sought participants in different areas of Sydney to include participants with differing education levels and income. As a result, the 60 women were a heterogeneous group, with half from socioeconomically advantaged and the other half from disadvantaged suburbs (based on the Social Atlas of Sydney classification of suburbs by the Australian Bureau of Statistics). They ranged in age from 19-48 and had between 1-11 children. Eleven of the interviewees were from a non-English-speaking background (including Chinese, Middle Eastern and Latin American) but were fluent in English and required no interpreters to take part.

An interview schedule with open-ended questions was used that allowed the interviewees to explain their beliefs and opinions and recount experiences at length. Ethics approval for the research was granted by Charles Sturt University (where I was employed at the time of data collection). The research assistant conducted the interviews, which were audiotaped and transcribed, and the author undertook the analysis of the transcripts. The names of the interviewees and their children were not kept in any records and any names of family members they mentioned in the interviews were substituted with pseudonyms to ensure confidentiality.

The analysis of the interview transcripts took a critical discourse analysis approach, with a central focus upon identifying the broader sets of discourses which underpinned the women's explanations of their beliefs and experiences. This approach uses a Foucauldian approach in adopting a critical approach to discourse. It views language as both reflecting and perpetuating taken-for-granted assumptions which underpin power relations and social structures, and thus rests upon a social constructionist perspective on knowledge formation. Discourses are understood as structures of knowledge which are embedded in social, cultural and political settings, and used for certain purposes. Discourses compete with each other to gain dominance in providing meaning and position speakers in certain ways (Parker, 1999; van Dijk, 1994).

No computing software was used for analysis of the data collected for the present study. Instead, I carefully read and re-read each interview transcript and compared it with the others as emergent topics and discourses were identified, with supporting quotations listed under each heading. In this analysis, a 'topic' was viewed as the specific issue addressed by the interviewees in their accounts. A 'discourse' was determined to be a particular pattern of words used when discussing and giving meaning to topics. In the case of the data here analysed, the discourses that are identified in the interview transcripts give certain actions and ideas context and meaning. Whether consciously or otherwise, people draw on particular discourses emerging from their personal experiences and interactions with others and from popular media and expert sites to explain and justify their experiences, practices and ideas.

FINDINGS Mothers' home healthcare beliefs and practices

The interviewees all agreed that good health was of prime importance for their children. Good health in one's children was not viewed as a matter of luck, however, but regarded as the outcome of maternal caring work. As was noted by one of the mothers: I definitely believe that the power of the child's health is totally in control of the parents. Obviously you can't help genetic stuff that happens, but you can do your best during pregnancy to make it as healthy as possible, the birth as stress-free as possible. And then once the child is born, diet is really important.

In the interviewees' accounts, mothers were positioned as playing a vital role in preserving and protecting their children's health. As one mother argued: 'I think that is a mother's job, or part of a mother's job, to manage her children's health'. It was commented by all the interviewees that as part of their job as mothers they needed to maintain constant vigilance in terms of monitoring their children, observing them for signs and symptoms of illness or developmental problems and ensuring that they followed lifestyle behaviours to promote good health and optimal development. They observed and monitored such features as their children's appearance, the colour in their face, their energy levels, their weight, dietary intake, sleep and exercise patterns, their bowel habits and their general demeanour to make judgements about how healthy or otherwise their children were. Mothers of infants and very young children, in particular, represented their children's bodies as vulnerable to infection, as more permeable and open to invading 'dirt and germs' than older children or adults because their immune systems were viewed as underdeveloped. They therefore attempted to prevent their children from being exposed to people who had an infectious illness (see Lupton, 2008, 2011, 2012a for further details on these aspects of the interview data).

The women were also well aware that they were charged with the primary responsibility for ensuring that they observed when their children were ill and took steps to deal with the illness. They noted that it was largely their job – rather than their partners' – to monitor and medicate children with chronic conditions. Mothers were therefore discursively positioned as knowing their children better than anyone else and also as being far more vigilant than anyone else, including their children's father, at ensuring that illness or chronic conditions were monitored and treated appropriately. According to the mother of an asthmatic child:

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[Asthma] is something we have to continually monitor. That's the reason we got him into swimming, because it supposed to be good for his asthma – and making sure he's on a preventative medication. As Mum I've got to make sure because Dad doesn't always remember that [the medication is] taken religiously, that he gets the check-ups that he requires.

The interviewees were therefore drawing on the discourses of good health as controllable, good health as the outcome of good management and mothers as responsible for promoting and managing their children's health. These discourses were combined with that relating to the need for surveillance of children's bodies. The discourse of the importance of knowing one's child and her or his bodily signs of health and illness was part of these explanations.

Some women commented that they had experienced difficulties in finding what they saw as appropriate medical help for children when there was a difficult-to-diagnose illness or developmental problem, or when a condition did not seem to be responding to the treatment prescribed by health professionals. The mothers knew that something was wrong, as they felt that they knew their child very well, but had difficulty persuading the doctors they consulted of this. A discourse suggesting that mothers should be persistent in seeking health for their children, even in the face of resistance from medical experts, emerged in these accounts. The interviewees spoke about conducting their own research, seeking out advice on the internet and from other media and from people with children with similar problems, and repeatedly seeking further medical advice even when they were initially told that nothing was wrong with their children.

One woman, for example, had a son who had eventually been diagnosed at the age of 5 with Asperger's Syndrome and Social Anxiety Disorder. Although this interviewee had realised from a very early stage in her son's life that 'something was not quite right', as she put it, it took years of seeking out her own information and of visiting numerous healthcare professionals insisting that they examine her child before she received a diagnosis. Another woman spoke about her infant son suffering gastroenteritis and finding it difficult to get a diagnosis and treatment from the doctors she consulted. She commented that as a mother, she knew instinctively that something was wrong and that treatment was required:

You've just got to – you know your children and you just have to go with your gut. If your gut tells you there is something seriously wrong, even though a doctor is saying that there is nothing wrong, I think you really have to go with that. You've got to run with it because you're not going to feel better unless you do.

Here a somewhat different practice is required of women as part of the expectations incorporated into the discourse of maternal responsibility for children's health. They must be able to determine at the subconscious or visceral level if something is wrong with their children ('you have to go with your gut'). Mother's knowledge and surveillance of their children, therefore, may involve not only rationally observing signs and symptoms of illness or developmental problems, but relying upon an instinctive response to their children's demeanour or behaviour to alert them that there is something wrong with the child. As this implies, it is the mother's unique relationship with her child which underpins her special knowledge of her child's body: Only she is able to respond instinctively to her child's needs.

The challenges of home healthcare

As noted in the Introduction, caring for a very ill child or a child with major disabilities is fraught with emotion and requires emotional labour on the part of the mother to manage her own and her children's negative emotions. The interviews showed that dealing with their children's illness or developmental problems, even when they are relatively minor, is also often a very emotional experience for women. When the interviewees talked about their children being ill or suffering a developmental problem they often recounted their feelings of frustration, sadness and guilt. Watching their children suffer from illness often caused the women to feel very distressed and anxious. As one interviewee commented:

It's a terrible thing when your children are sick. It's very hard when they're looking at you saying 'Help me'

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when they're vomiting. It's quite an emotional time as a mother I think ... You feel sad for them; you just want to help them.

Another woman talked about her experiences with her fourth child, who was born with a very large head that required x-rays and continuing monitoring to determine whether there was a problem with his brain development. She described the stress and worry that this issue caused her:

You want the best for your kids and you'd just be devastated if there was something wrong that you couldn't fix for them. It's not like you could put a Band Aid on it and make it better if it was something that was a major, either developmental problem or something that required some sort of surgery. All those things run around your head.

Severe illness in children, requiring hospitalisation, was described as an extremely frightening experience for their mothers, who, as noted above, are acutely aware of the physical vulnerability of infants or small children. One mother described her daughter's experience of hospitalisation in the following way:

She had a viral infection that caused her to come out in a severe allergy. Everywhere was puffy, her eyes, her mouth, everything and she ended up in hospital again for that. That was quite frightening actually, just knowing how serious it could be, that she might not be able to breathe. You know that they're so little and you don't have much control, and you're thinking 'Why is it happening to them, they're so little?'

When children are constantly ill, the appropriateness or efficacy of their mothers' practices may be called into question. For example, an interviewee observed that the chronic ill health of her children made her question her mothering abilities and sometimes made her feel as if she could not cope:

I feel, sometimes I question how good I am as a mum. If I was better at it maybe they wouldn't get sick, but I think I'm doing everything I possibly can ... I feel sometimes, especially with Jasmine being born and sick as well, sometimes I want to – not walk out the door and leave it all, but I just want to have a break.

Not having a diagnosis or appropriate treatment for one's child is again fraught with emotion, causing worry, frustration and a nagging feeling that 'something is wrong'. As one of the women quoted above noted, women do not 'feel better' about their concerns unless they find some answers. Finding these answers allows them to reassert control over what was seemingly becoming an unmanageable and chaotic situation. Children's illness represents a loss of control for women over their children's bodies, and they feel powerless as a result. As the above quotations note, 'you just want to help them': but sometimes mothers cannot 'fix it for them' despite their best efforts, because 'you don't have much control'.

In attempting to explain the ramifications of a mother's loss of control over her child's health, the discourse that mothers suffer distress when their children are very ill was employed. This discourse interrelates with the discourse of children's vulnerability ('they're so little') and in tension with the discourse of maternal responsibility, as this responsibility cannot be fulfilled when a child's illness cannot be prevented or readily managed by their mother. So too, the discourses which claim that health states are controllable and that good health is an outcome of good management are in direct contradiction to the loss of control that children's illness may signify for mothers. In a sociocultural context in which mothers are positioned as responsible for their children's health status, such a loss of control may represent a major challenge to their sense of self as a 'good mother'.

Several of the interviewees observed that the tasks associated with caring for children when they are ill, as well as being emotionally challenging, can also be very physically tiring and hard work. As a mother of three commented:

I find when one of them gets sick they all tend to get sick. One instance, they had this vomiting/diarrhoea bug, all three of them got it and that was a real drain on me. I had to actually go out and buy new sheets and things because I had everything soaking. They were up all through the night, all of them, vomiting and whatever, so that was a real challenge.

Another mother with three children, all with food allergies and asthma, pointed out that dealing with chronically ill children makes parenting more challenging and demanding. She noted that monitoring and managing such conditions requires constant attention and vigilance, the kind of attention that mothers are able to give but which other people may not be able to.

The discourses of caring for ill children as hard work and again, of illness in one's child as emotionally distressing, were articulated in these accounts. So too the discourse of control was central in the women's comments. Women's control over the conditions of their lives and their sense of autonomy are disrupted by children's illness: their usual routines and sleep patterns are thrown into disarray, they must engage in extra household labour such as changing and washing soiled bed sheets as well as seeking medical advice and ensuring that their children take their medication. Those women with children with chronic conditions may be reluctant to relinquish control to others for fear of what might go wrong.

Children's chronic illness or behavioural problems may also cause women to experience feelings of difference and result in social isolation. For example one mother talked about the sense of feeling different she experienced because of her infant's health and behavioural problems, and how this had led to her feeling isolated from other mothers. This woman, too, had limited her social interactions and her movements outside the home because of the difficulties she experienced in dealing with her infant's problems:

Yes it was hard. No-one else's baby threw up, no-one else's baby cried all the time ... Like, if I did take Lachlan out, he would cry and vomit the whole three hours. We might be at a mothers group or something and I couldn't sit down, I couldn't have a cup of tea and I couldn't talk to anyone. It actually got to the point with Lachlan that as he got a little bit older I stopped going places with him, it became that difficult.

In these accounts, the women drew on the discourse of children's vulnerability to provide explanation for choices they made about going into public space. Children's illness, therefore, can cause continuing limitations upon some mothers who feel obliged to avoid some places and spaces and the people within them, either because of their concern about potential contamination or their sense of difference or inability to participate socially. They may also call into question women's sense of themselves as 'good mothers' and make them feel self-conscious in public because of feeling different and conspicuous because of this difference.

The discourses of maternal responsibility for children's health, health as controllable, good health as an outcome of good management, the need for constant maternal surveillance and knowing one's child's body were articulated across the socioeconomic groups. All the mothers agreed that these aspects of promoting and maintaining their children's health were integral to their role as mothers and tended to employ a similar range of discourses when talking about this. As I have noted elsewhere, however, mothers from working-class backgrounds were more likely to discuss their concerns about the safety of the physical environment in which they and their children lived, and about the 'bad influence' of the people who traversed these spaces (Lupton, 2012a). Another difference which emerged between middle-class and workingclass women that is relevant to the discussion here was evidence that some of the latter may not have had access to resources or the educational background to seek out information or challenge medical professionals. They therefore faced greater obstacles when attempting to achieve a diagnosis or adequate help.

One example is a young woman from a working-class area with two children who had become a mother in her teenage years and as a result was unable to complete her secondary education. She felt as if she was not respected by the health professionals with whom she had had dealings because of her youth and lack of education. This mother worried that her 5-yearold son had developmental delays and possible autism, but could not find a doctor to take her concerns seriously. She therefore felt disempowered, unable to do anything to help her child: 'nothing I try works. I've done everything the paediatrician told me to do and I've tried things and nothing works'. Her experiences of encounters with medical staff had left her feeling that she was not conforming to their expectations of 'good motherhood', albeit often through lack of knowledge, which reduced her

confidence further. This mother was unable to re-establish control over her child's body despite her best efforts.

DISCUSSION

The research reported here revealed a number of discourses underpinning women's accounts of their children's health and illness. These included the discourses of maternal responsibility for protecting and promoting children's health and for caring for them when they are ill, the discourse of 'knowing' their children, their bodies and their illnesses better than anyone else, the discourse of maternal instinct as alerting women that something may be wrong with their children, that which contends that mothers should persist in seeking help for their child and the discourse of surveillance of children's bodies as part of the practices of maternal responsibility. These discourses all relate to concepts of the 'good mother': the mother who puts her child's needs ahead of her own; knows her child more intimately than anyone else; and is concerned to protect and promote her child's health and wellbeing (Hays, 1996; Lupton, 2000).

Several discourses related to health and embodiment were also drawn upon by the interviewees. The discourse of children's bodies as particularly vulnerable to illness, especially those of infants and very young children, dominated the interviewees' accounts and supported their beliefs that children's bodies required constant monitoring and surveillance. Other discourses contended that good health is an outcome of good management and is subject to individual control. These discourses, in concert with that of maternal responsibility for children's health, support the concept of the entrepreneurial selfresponsible and self-managing subject discussed in the Introduction. They are central to contemporary understandings of personal responsibility for health status and the moral meanings that are often attributed to people who are viewed as inviting illness by not properly taking up expert medical or health promotion imperatives (Lupton, 1995, 2012b).

When women have children, they are then expected to manage their children's health as

part of their status as responsible maternal citizen. Just as pregnancy has become 'remoralised' as an 'ethical practice' (Weir, 1996, p. 373), the caring work of motherhood is now viewed as part of a moral and ethical project of the self (Lupton, 2012c). It is clear that the women in the study had voluntarily taken up this ethical subject position as the person primarily responsible for their children's health. This subject position involved attempting to exert control in various ways: in their continual monitoring and regulating of their children's bodies; managing children's exposure to germs outside the home; dealing with their illness in public spaces; ensuring medication is taken; finding appropriate medical treatment for children; and generally confronting the anarchic nature of illness in children. A child who is often ill, therefore, may be viewed as a sign of failing to meet these expectations. 'Allowing' one's children to become unhealthy or hurt (beyond the usual bumps and grazes, coughs and colds of childhood), or failing to recognise and deal with the signs of illness, allergies or developmental delays may be viewed as a failure of 'good mothering'. Children's bodies, however, are unruly and excessive, open to infection, not always compliant with their mothers' attempts to control and regulate them. They may become ill despite their mothers' best attempts to keep them well.

It is in relation to this perceived lack of control that women employ the discourses of health carework as sometimes emotionally distressing and as sheer hard work. As the interviewees' responses suggested, caring for children is not simply about the children's embodiment, but may often also be an intense embodied experience for mothers themselves. It may involve disrupted sleep and resultant tiredness and social isolation as well as the strong negative emotional feelings that may be part of experiencing worry about an ill child or a child who has a developmental problem or allergies. In a sociocultural context in which control over the vagaries of life and risk is a privileged value and an integral expectation of the self-managed, entrepreneurial citizen, mothers' loss of control over their children's health is often experienced by them as confronting, frustrating,

stressful and distressing. They may feel helpless, anxious and fearful in the face of acute or continuing health problems in their children. The 'gut instinct' to which many of the women referred is also an embodied emotional response which signals to mothers that something is wrong with their children.

The 'invisible mental labour' (Walzer, 1996) required of mothers expects them to continually anticipate children's needs and worry about them when they are ill. As the research reported here suggests, this mental labour may also involve dealing with the negative emotions mothers may experience under the weight of the expectations of intensive parenting. The sociological literature has largely been silent on the topic of the emotional dimensions of caring as part of motherhood, particularly among mothers of children who have passed the age of infancy. The ambivalent feelings that ordinary mothers may harbour for their children, including, on occasion, anger, hatred and frustration as well as deep love (Beck & Beck-Gernsheim, 1995), is rarely acknowledged in the expert literature or in popular forums, and has yet to be fully explored in sociological research. The reflexive, entrepreneurial subject as described in the literature on neoliberalism is often disembodied and lacking in emotion (Lupton, 2012c). While there is some research noting the emotional ambivalence many mothers experience when dealing with the demands of tiny infants (see, for example, Lupton, 2000; Sevon, 2007) little research has uncovered how mothers feel about the demands of caring work once their children have become older.

While the sheer physical and emotional intensity of the early months of motherhood may wane, the present findings suggest that well past this stage the maternal experience may be redolent with strongly felt emotional states as part of the interconnected and extremely close relationship which most mothers have with their young children. The findings of the present study suggest that although these feelings may change in intensity as children grow older, they may still be experienced by mothers when their children are ill. I referred in the Introduction to previous research with mothers who had children with cancer or severe disabilities, and the intense emotional relationship that such women tended to develop with their children. So too in the present study mothers talked about the strong emotional connection they had with their children that caused them to feel helpless and distressed when their children were ill.

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To conclude, a dialectic of connectedness and alienation was evident in the ways in which the women in the present study both articulated their strong sense of emotional connection with their children and their negative feelings about being charged with the responsibility for dealing with their children's health and development. They shared the feelings of distress that their children felt when ill, but also struggled to deal with the burden that such an intense emotional connection and the sheer hard caring work or social isolation involved with dealing with ill children or those with allergies or developmental conditions may pose. It is evident that despite the figure of the self-reflexive, disciplined, information-seeking, rational-thinking mother that is valorised in both lay and expert discourses on the 'responsible maternal citizen', in this caring relationship, conscious judgement and reflexivity are not the sole modes of response to the small bodies for whom mothers care. Responses may be preflective, operating at an embodied visceral ('gut instinct') level of emotional response that may be hard for women to articulate or describe but which they see as an integral dimension of caring for, and caring about, their children.

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