

Being concerned: Caregiving for Taiwanese mothers of a child with cerebral palsy

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Abstract

Aims: This article explores the Chinese social context and provides insight into Taiwanese mothers' challenging experiences when a disabled child is born into their families.

Background: International research indicates that barriers to maternal care-giving for a disabled child revolve around challenging relationships. Giving birth to a disabled child creates a huge challenge for mothers in Chinese society.

Design: Data was collected using in-depth interviews and journaling methods. A hermeneutic phenomenological approach, informed by the philosophical world views of Heidegger and Gadamer, provided theoretical guidance in revealing and interpreting mothers' experiences.

Method: Interviews were carried out with a purposeful sample of 15 mothers who were primary care-givers for a child aged between 0-18 years diagnosed with cerebral palsy and used Mandarin or Taiwanese as their primary language.

Results: Shared meanings revealed four modes of 'being-concerned': (1) experiencing burden as a sole primary care-giver; (2) managing the challenges by balancing demands; (3) being marginalised by others; and (4) encountering limited or no professional support.

Conclusions: Taiwanese mothers face the strain of managing barriers to care-giving in contexts where their children are not supported or acknowledged as being important contributors to family and Chinese society at large. This study highlights how the family can

be important to care-giving mothers in traditional Chinese family life. Poor support and dynamics will emerge when family members regard disability as a loss of face or a stigma.

Relevance to clinical practice: By learning from Taiwanese mothers who accommodate barriers to care-giving on a daily basis, nurses can seize the impetus to explore ways of reconceptualising nursing practice with families and people with disabilities. The aim is to explore ways which will ultimately align intentions and caring processes and foster coping and positive reward in caring, thereby creating a context which is stress-reducing and therapeutic.

Keywords: cerebral palsy; family care-giving; phenomenology; mother; Taiwan, nurses, nursing

INTRODUCTION

Research studies indicate that barriers to maternal care-giving revolve around balancing relationships between family members and relationships with others outside the family (Sawin *et al.* 2003, Cole 2005). This is particularly the case in Chinese families. Chinese culture has been deeply influenced by Confucius. Confucius pays close attention to family and relationships, so Chinese culture can be regarded as a family culture. The family holds the highest value to an individual. The Chinese family is dominated by males in a patriarchal society, so grandparents, fathers and husbands are significant people who have the highest authority and impact on family life (Hui 2008). For a married woman, the relationship with her mother-in-law is the most important after marriage. Parents-in-law are her priority and present relational opportunities to demonstrate her obedience. Her husband is her second priority (Baker 1979).

Lindblad *et al.* (2007) argued that parents of children with disabilities feel gratified when their disabled children are accepted by other family members. In Chinese families, giving birth to a child with a disability is regarded as a disruption to ancestry, especially when the disability is visible. It leads to social stigma and loss of face, because it is contrary to the Chinese collective value and cultural expectation that professes the importance of not being different from others (Holroyd 2003, Pun *et al.* 2004). Chinese husbands have been reported to indicate that they would 'pay any price to have a normal son' to regain their reputations

(Holroyd 2003).

Realising children's disabilities also influences the quality of the child-mother relationship in a way that is different for a mother of a healthy child (Harden 2005). For Sawin *et al.* (2003), 'blended parenting' described the challenge of balancing the need to promote independence whilst maintaining close supervision and potentially becoming overprotective. Child-mother relationships with healthy siblings reveal feelings of ambivalence as mothers strive to avoid placing carer strain on siblings and balance this with a need to practically manage their load (Lindblad *et al.* 2007).

Relationships outside the family with significant others have been found to have a significant impact on the experience of maternal care-giving. Parents have been found to be dissatisfied with the quality of their relationships with health professionals. Denboba *et al.* (2006) who undertook surveys of 38,666 caregivers of children with special care needs found that poor participatory relations with health professionals resulted in increasing missed school days, difficulty accessing specialty care, dissatisfaction with services and disappointment with unmet needs.

With regard to relationships at school, Cole (2005) uses the term 'inclusion' to express mothers' inner voices that convey a need for their child to be included and welcome in the school environment. McCabe (2007) found that children with disabilities in China were frequently rejected and excluded at school owing to their lack of self-care skills. Such

interactions left parents and their children with pessimistic expectations that compounded the challenges of managing their situation.

International research that examines familial relationships and disability has primarily been undertaken in Western countries. The ethnic diversity of the population is a significant phenomenon in the United States, the United Kingdom and Australia, particularly with rapidly growing Asian populations (Hatton *et al.* 2003, Hsu *et al.* 2005, Hayes *et al.* 2008). It is important that health care professionals gain a better understanding of how Asian parents experience care-giving for a child with a disability, influenced by family and culture.

THE STUDY

Aim

The aim of this study was to describe a range of challenging care-giving experiences for Taiwanese mothers providing care for their children with Cerebral Palsy (CP). This study focused on mothers' experiences, as they have been shown to bear the primary care-giving responsibility in Taiwan (Liao 1995). Such experience emerged as one significant aspect of a larger hermeneutic phenomenological study of mothers care-giving experiences for disabled children in a Taiwanese family context. The larger study revealed four significant aspects: family and caring histories; engaging in everyday care-giving; barriers to care-giving and

seizing possibilities for future care-giving (Huang *et al.* 2008, 2010). This article focuses on barriers to care-giving.

Research design

A hermeneutic phenomenological research approach was adopted to provide the researcher with theoretical guidance in understanding and interpreting the meaning ascribed to Taiwanese mothers' challenging experiences when raising children with CP. Several assumptions informed by the philosophical world views of Heidegger (1962) and Gadamer (1975) provided theoretical guidance in revealing and interpreting everyday experiences. Firstly, mothers as human beings possess the capacity to reflect on the nature of their existence in such a way that personal meanings are uncovered. Secondly, the essence of how mothers exist in the world is influenced by their background, shaped by a particular period of historical time, culture, language and family. Thirdly, the ways mothers engage in activities and relationships serves to illuminate the significance of everyday caring. Fourthly, understanding personal concerns provides access to the ways existence as a mother is deemed meaningful. And finally, seizing possibilities for meaningful existence is possible as mothers are temporal beings capable of attributing meaning to their involvement in present day practices, as influenced by the past and anticipated in the future (Kellett 1997).

In this paper, we focus on the mode of Being-concerned. Being-concerned reveals what matters and what motivates mothers to care, despite the challenges and barriers encountered that threaten everyday care-giving.

Participants

Mothers who were primary care-givers for children with CP ($n=15$) were recruited from a hospital in central Taiwan through the paediatric out-patients clinic, the Paediatric Rehabilitation Department and the Taiwanese CP magazine. This study purposefully sought out mothers who had experience of the phenomenon under investigation. Thus mothers who were primary care-givers for a child aged 0-18 years with a CP diagnosis, who were able to speak Mandarin or Taiwanese as their primary language and who were willing to share experiences, were recruited.

Ethical considerations

Data were collected from December 2005 - June 2006. The study received ethics approval from the participating Taiwanese hospital and Griffith University, Human Research Ethics Committee, where the first author was a doctoral student.

The first author introduced herself to prospective mothers following their clinic consultations. They were invited to a nearby private room to discuss the study and their

possible participation. The rationale for adopting this method was to get to know each potential participant, discuss the purpose, research process, potential risks and benefits of the study and offer the opportunity to raise questions and receive answers. Following such discussion participants were invited to sign an informed consent proforma which assured them that all information shared was anonymous and confidential and that they were free to withdraw their participation at any point during the study.

Data collection

Data were collected using two 1-2 hour in-depth audio-taped interviews with each mother. First interviews were initiated using broad open-ended questions, for example ‘can you describe a typical day providing care for your child?’ Immediately after each interview the researcher recorded journal notes to describe the context, personal responses, reflective thoughts and feelings (Smythe *et al.* 2008).

Follow-up interviews served two purposes. Firstly, an opportunity to share and validate developing interpretations of mothers’ experiences and secondly an opportunity to probe further those areas that had emerged as significant to issues related to barriers to care-giving. Follow-up interview questioning strategies included, ‘could you tell me about that challenging experience?’ (Rubin & Rubin 2005). Pseudonyms were used to protect the identity of participants, family members and institutions. After interviewing 15 participants, data

collection ceased as no new information, topics or shared meanings were revealed and saturation of interview data was achieved (Fossey *et al.* 2002).

Data analysis

All interviews were conducted by the first author and transcribed verbatim into Chinese to ensure subtle meanings were not lost in translation (Twinn 1997, Neubert 2003). Data analysis was also conducted in Chinese. Shared meanings and selected quotes were translated into English and translations were checked for meaning accuracy by a translator who was fluent in Chinese and English (Twinn 1997, Neubert 2003).

Data analysis involved the process of entering the hermeneutic circle. Firstly, the first author listened to the audio-taped interviews, read and re-read the interview transcripts and compiled whole summaries of impressions of each mother's experience of her everyday care-giving. Secondly, turning to the parts, line by line coding and labelling facilitated the identification of significant aspects of everyday care-giving that illuminated meaning relevant to the research question. Thirdly, engaging in hermeneutic analysis involved the researcher entering the hermeneutic circle, a process which describes the movement from forming a pre-judgmental notion of the meaning of the whole story, to a change in the sense of the meaning of the whole story because of confrontation with the detailed parts (Palmer, 1969). This process is characterised by an open process of dialogue between the expectations of the

researcher and the meanings embedded in the stories and served to illuminate how the mothers as human beings attempted to make sense of their everyday existence when challenged by barriers to care-giving.

FINDINGS

The mothers' ages ranged from 27-42 years and their education level from junior high school to college. Twelve were not employed, two worked full-time and one worked part-time. The children's ages ranged from eight months - 14 years, with education levels from preschool to junior high school. Their type of CP ranged from monoplegia to severe quadriplegia. Eight families were extended and lived with their parents-in-law and seven belonged to nuclear families. Analysis of interview data and journal notes revealed four shared meanings related to Being-concerned (Table 1).

Experiencing burden as a sole primary care-giver

Poor relationships with their parents-in-law or husbands was a significant issue for the mothers, because giving birth to a child with CP can bring social stigma, shame and disgrace to a traditional Chinese family:

My mother-in-law was hiding my child (with CP) in order to avoid our relatives. I had to take my child to my sister-in-law's house quickly... as my

child would make her lose face and feel inferior to other people. (No.9)

Some parents-in-law clearly communicated their lack of acceptance of the child with CP by communicating their concern over resources being used to support the child's daily care:

If my son had to be hospitalised owing to sickness my parents-in-law scolded me for spending money and needing someone to look after my son at the hospital. So someone had to also take over my job at home. ... My mother-in-law didn't agree with letting my son go to school. For him to go to school was just a waste of money. (No.7)

To regain the family's reputation and to keep the family's honour, some parents-in-law wanted the mother to have another healthy child, especially when the disabled child was a boy. The need to keep their family name into future generations was significant:

My mother-in-law asked me to have another child, because I only have one boy to keep on the family name and he is lame. She is very concerned about what others will think about having a lame boy in the family into the future. (No.6)

Some mothers not only lost support from their parents-in-law, but also their husbands:

My husband's interest was raising pigeons. ... He treated his pigeons nicer than our son ... Sometimes I asked him to take our son to the doctor. He wouldn't do it, so I had to do it myself and I felt very angry. I just ignored him. The only person you can count on is yourself. (No.7)

Managing the challenges of balancing demands

Maintaining a balance between being protective and promoting independence created a challenge. One mother said:

One time I tried to let my son change his T-shirt on his own. He fell down and had concussion. He couldn't stand well due to his legs problems. I was terrified after seeing that, so I won't let him do that again. (No.11)

Some mothers felt guilty and blamed themselves for their child's disability. Such beliefs resulted in difficult and manipulative relationships between the growing child and the mother:

She will turn 15 next year. ... Sometimes she would scold me that I caused her CP, that it was all my responsibility. I felt very sad when I heard that. (No.3)

The mothers realised that overprotection could result in their children losing the possibility of developing skills that would enable them to live independent lives in the future. They questioned themselves as to whether they had done enough for their child and had met traditional Chinese expectations of being 'good' mothers. A loss of perspective in dealing with their child's daily care could influence the quality of care their child received:

I just tried to do my best when I had this kind of child. It wasn't good to spoil her all the time, but she was quite pathetic if I didn't dote on her. You see, with her physical disability she wasn't able to catch up with others without a great deal of

support. (No.3)

Providing a balance between the attention and care provided to both their healthy and disabled children created tensions and strain in the family:

I felt sorry for my eldest son, because I ignored his feelings and needs since I needed to give all my attention to caring for Shui-Bian (child with CP). For example, when his brother was too young to go to school, I had to bring him and Shui-Bian with me to the hospital. At home, I also focused on doing rehabilitation exercises with Shui-Bian and teaching him. One day, my eldest son told me 'if he die, I may feel easier.' I was shocked and felt sad when I heard that. (No.11)

Family tensions were compounded by sibling rivalry when the disabled child's wants were always favoured:

Sometimes she (with CP) would argue with her younger brother over watching a different TV channel. I told her brother he should let her sister choose first because of her physical problems. ... My son questioned why he should always let her do what she wanted to do. I said no one would give her first priority, if you didn't. (No.3)

Maintaining a balance between different roles created tensions. Balancing the role as care-giver providing home therapy and the role as a parent created strain on family relationships:

I could feel the parent-child relationship becoming poor because of a focus on the need for therapy within our family home ... My husband felt resentful and angry and just gave up doing it. So we spent a lot of time looking for outside help from therapists. (No.14)

Being marginalised by others

Mothers felt disappointed and frustrated when school staff failed to provide their child with what they perceived to be basic personal care and adequate physical support:

Sometimes my son came home and his diaper was crooked or the diaper wasn't wet but his pants were wet. ... My son needed an 'H' safety harness and separator when he sat in his wheelchair, but his teachers never helped him to do that. ... When I saw him after school, his body was just totally in the wrong posture and distorted. (No.12)

Some mothers shared how their children with CP were not able to share personal experiences with classmates, which resulted in feelings of isolation and an unhappy school life:

Because she couldn't manage moving from place to place she just stayed in the class. In time her interactions with her peers have changed. Her classmates now think she is different and she is feeling isolated. One day, she told me tearfully that she had no friends so she didn't want to go to school. (No.14)

Mothers felt powerless when the school failed to provide a disability-friendly environment and ignored their child's personal disability and needs, creating a barrier to school attendance and integration into school life:

The school lacks a ramp to access the classroom and she is too heavy to be carried upstairs. The classes are mostly upstairs. So she has missed a lot of classes.

(No.3)

Some mothers were also concerned about what was going on while their disabled child's was at school. They experienced great anxiety and worry about their child's physical safety at school:

I really felt sad when I looked at those wounds and bruises on her knees. She was knocked down by a child on the second day of school. I could only turn my tears in on myself. (No.14)

Anger and frustration was experienced when the poor design of public facilities affected their disabled child's involvement outside of home. The attitude of others could harm their dignity and force them to further withdraw from social engagements:

Some bus drivers have treated us very badly as we are slow to access and leave the bus. He said 'last time it was my bad luck to drive you. My bad luck is back because I have encountered you again. You had better be quick. Don't waste time.'

How can a bus driver be without any sympathy? (No.3)

Some disabled children were verbally rejected by other children in public areas:

I took my son to the shop where some children played. One boy pointed to my son and said 'You are a monster. Go away. Don't stand here.' At that time the squint in his eyes was very severe. I was very angry. (No.13)

Encountering limited or no professional support

Some mothers lost trust in health professionals and their own ability to make care decisions.

When they felt mistrust, mothers would visit other hospitals in an attempt to regain control over the quality of care, but this was time and energy consuming:

I started taking him for treatment when he was about ten months old. ... The doctor told us he had a Trigger Finger. We went to (a second) hospital to receive surgery and when they performed surgery, the doctor found that it wasn't a Trigger Finger. Some one introduced us to (a third) hospital. The doctor suggested we go to (a fourth) hospital, because he didn't know what the problem was. The doctor (at the fourth hospital) advised my son to wear rehabilitation gloves first and my son's hand was able to open after wearing them. (No.11)

Some mothers felt dissatisfied when health professionals showed their impatience, lack of empathy and unwillingness to communicate with mothers and their disabled child to provide a better personal care:

The dentist didn't use a fixer to open my son's mouth and then my son accidentally bit him. He asked me angrily 'does he have a mental illness?' ... After that I never visited the dentist again. ... I just felt he lacked patience. (No.7)

Mothers felt frustrated and sad when their 'local' knowledge was not valued, recognised or acknowledged in supporting the quality of rehabilitation or medical care. Mothers also felt sad and frustrated when therapists lacked enthusiasm. This made them feel that there was little hope for their child's developmental progress in the future:

I could only wait outside the rehabilitation room as he thought I might disturb the therapy. The therapist just let her choose what she wanted to practice. I couldn't say to him that my daughter already knows how to do it. ... I believe my daughter chose a tool that was too simple for her. The session only took half an hour, but it took us more than two hours to travel there and back home. I felt depressed that my daughter couldn't get anything from her rehabilitation session. (No.14)

A shortage of therapists and the length of rehabilitation sessions also became obstacles to optimal rehabilitation care. One mother commented:

The therapist at the hospital got married so there were no therapists in that period of time. ... My husband worried that it might stop our son's progress, so we looked for a clinic near our home. When we found a clinic we made a request for a lesson and we were told that we might only be able to get one lesson per week. We

could not ask for more lessons because the therapists were fully booked. (No.6)

DISCUSSION

Family roles and relationships

Mothers felt hurt, helpless and powerless when their children were marginalised because of their disability, there was great distress when parents-in-laws believed that the disabled child caused them to lose face, placed a burden on the entire family, refused support for treatment or education or believed such input was worthless. Such findings are culture-specific as Lindblad *et al.*'s (2007) study of Swedish families found that grandparents gave support to parents caring for disabled child and this presented a basis for developing a close relationship.

Being devalued by their family reinforced the mothers' feelings of hopelessness, since relationships with grandparents and husbands in a traditional family are so important in Chinese culture. The family has a higher value than the individual in terms of providing access to resources such as economic support, religion, warmth and affection (Hwang 1987, Lee 1999). Holroyd (2003) indicated a disabled child in Chinese culture meant 'disruption to parent-child order' since the child could not return or reward their parents for their parenting and there existed the perception of a lack of a reciprocal relationship. Several family members in this study did not anticipate that their disabled children could experience independence and live 'useful lives'.

Family members of some mothers were unwilling to be involved in providing care for the child with a disability, so mothers were left to bear all care-giving responsibilities alone. Sallfors and Hallberg (2003) labelled fathers of chronically ill children as ‘the waiting fathers’ since they only passively engaged in their child’s caring activities. Most fathers in Harden’s research (2005) believed that caring was not their primary role, rather their wives’ responsibility, justified on the basis of gender differences. In contrast, mothers of children with CP in Glasscock’s (2000) USA study stated that care-giving help from their husbands, allowed them to have more time and energy to provide care for their children.

Care-giving responsibilities for mothers in Chinese society are influenced not only by gender but by the expectation that mothers will perform this family duty as their primary role. As a married woman, in accordance with the family hierarchy and the obligation to respect and comply with her parents-in-law and husband wishes, asking for help would be socially unacceptable. Furthermore, mothers would not complain about their situation to ensure harmonious interpersonal relationships in the family were maintained (Hwang 1987, Lee 1999). Maintaining harmony and stability in family relationships is considered to be more important than serving individual need. This is a key difference between Taiwanese and Western family values.

Balancing protection and independence promotion

In this study, maintaining a healthy and harmonious balance between being protective and promoting independence was experienced as a challenge for all mothers in Taiwanese families. They were struggling with wishing their disabled child would become more independent while actively attending to all their child's needs. In Chinese families there is a moral duty to care for family members grounded in the Confucian ethical system of roles and familial relationships. It is considered a moral failure if families do not assume parenting and care-giving responsibilities (Harden 2005). Harden found that parents had a problem with letting their children gradually become independent, with tensions increasing when there was no consensus between parent and child on the level of independence. Pascall and Hendey (2004) argued that relationship tensions became more obvious when mothers push their children towards being independent, but regard their children as vulnerable and worry about their ability to live independently.

Therapy at home

The mothers in this study were concerned with their children's abilities to perform rehabilitation therapy at home. Their children would cry during stretching exercises and display a lack of motivation to actively engage in program schedules. When the child was unable to develop the same attitude towards rehabilitation and positively anticipate the same goal as the mother, then tension increased and the child-parent relationship was negatively

affected. Mothers felt not only frustrated and powerless, but also worried that progress was being hindered. Although Hinojosa and Anderson (1991) found that mothers were willing to implement rehabilitation programs at home, in contrast, Leiter (2004) found that mothers experienced ineffective therapy when they tried to integrate therapy into their daily life at home. Reluctant mothers indicated that they preferred to 'just' stay in the role of mother and refused to take on the therapist role at home. Similarly, Larson (1998) found mothers were felt incompetent and demotivated when they had negative experiences or were unable to perform a prescribed program according to a health professionals' advice.

Siblings

In this study, sibling involvement in caring ranged from sibling jealousy to sharing caring responsibility. Hartley *et al.* (2005) found that mothers felt stressed and sorry for the healthy children who had to share their caring responsibility. In agreement, Fleitas (2000) stated that siblings of a child with disability would be expected to take on more caring responsibility or housework. The siblings seemed to have no opportunity to negotiate their new role of 'parentification'. This role has also been found in traditional Chinese culture. The eldest daughter was expected to take care of her younger siblings for her parents (Lee 1999). Sibling jealousy placed mothers in a difficult situation when their healthy children were angry or resentful toward their disabled siblings (Fleitas 2000, Barr *et al.* 2008). Sibling jealousy

prevented healthy siblings from developing a human connection with their disabled brother or sister. Sibling jealousy and fighting were particularly problematic and stressful for Chinese mothers living in a traditional cultural context that valued harmony, cooperation and sharing among siblings in terms of emotional ties (Lee 1999).

Relationships with professionals

Mothers in this study felt confused and angry when receiving inconsistent medical information that disempowered them and denied them access to joint decision making. This threatened their role as a mother, reducing the possibility of ensuring that their disabled child had access to potential opportunities of receiving the best available treatment. They were also unable grasp new possibilities when physicians provided them with limited treatment information, devoid of caring and empathy. Similarly, Harden (2005) found that parents felt isolated when health professionals took over their parenting decision-making responsibilities and did not engage them in their child's care.

The medical system in Taiwan has a tendency to be paternalistic, supported by a traditional patriarchal culture that shapes the doctor-patient-family relationship and medical decision-making that fails to emphasise the significance of parent or patient involvement in their own health care (Tsai 2001). Mothers as female family care-givers are expected to be subservient and compliant and are not considered partners in care and decision making. This

dynamic typically keeps authority and power in a male health practitioner's hands and has been referred to as a therapeutic privilege (Young & Klinge 1996).

School life

Mothers in this study experienced marginalisation in a variety of ways, both inside and outside the family. Mothers felt powerless and frustrated when their disabled children were the victims of personal prejudice, had difficulty relating with their peers or were excluded by teachers who did not give them individual help to improve their academic performance. McCabe (2007) found that parents in China with children with disabilities experienced rejection from school due to their lack of self-care skills. Cole's (2005) research in the UK describes the term 'inclusion' to express mothers' inner voices that express a need for their children to be included and welcomed in the school environment. However Cole (2005) explained that so often they encountered passive, resistant and non-accepting attitudes from school.

CONCLUSION

Being-concerned is experienced when mothers encounter challenges and barriers in taking care of their children with CP. This study highlights the importance and significant of the family as a resource and the impact of traditional Chinese families where the parents-in-law

and husband are the highest authority. Such authority when shared with participating mothers can influence opportunities for treatment and the acceptance of their children into the family. This study revealed that poor support and dynamics will emerge when family members regard disability as a loss of face or a stigma. In these circumstances, the families may be unwilling to engage in child care. Marginalisation can occur in public places where the rights of their disabled children are invisible. The challenge experienced by caregiving mothers is compounded when society fails to acknowledge the importance of the rights and needs of their disabled child.

Limitation and future research

Future research needs to investigate how the role of mothers can be enhanced by providing amenities to enhance family care, offering counselling services, supporting nursing staff through staff development that assists them to understand and accept the place of the parental care-giver in the process of disability care and treatment.

Future research needs to involve family members to explore experience of disability, creating a genuine family context. A whole of family approach will ensure all family members' voices are heard, offering a better understanding of the phenomenon of raising children with CP from a family perspective in a Taiwanese context.

RELEVANCE TO CLINICAL PRACTICE

Learning from those Taiwanese mothers who accommodate barriers to care-giving on a daily basis nurses are encouraged to seize the impetus to explore new ways of reconceptualising nursing practice with families and disabilities. The aim is to explore ways which will ultimately realign intentions and caring processes which foster coping and positive reward in caring, thereby creating a context which is stress-reducing, manageable and therapeutic.

CONTRIBUTIONS

Study design: YPH, UK; data collection: YPH, UK; data analysis: YPH, UK, WS; manuscript preparation: YPH; UK; WS.

Conflict of interest: No conflict or interest has been declared by the authors.

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Table 1

Overview of Being-concerned and shared meanings

Mode of Being	Shared meanings
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Being-concerned

- Experiencing burden as a sole primary caregiver
 - Managing the challenges of balancing demands
 - Being marginalised by others
 - Encountering limited or no professional support
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