






BMJ Open Thematic analysis of spousal interaction patterns among Asian parents of children with chronic life-threatening illness

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ABSTRACT

Objective This is the first known study which examines the evolutionary nature of spousal interaction patterns among Asian parents of children with chronic life-threatening illness, from the time of providing care to their child through bereavement. This study is informed by earlier findings that when a child is diagnosed with a chronic life-threatening illness, parents are faced with multiple stressors, leaving them with little time to invest in their spousal relationship.

Participants and setting A constructivist-phenomenological research paradigm was adopted and meaning-oriented interviews were conducted with 20 parental units (i.e., 6 couples, 12 lone mothers and 2 lone fathers) of Chinese, Malay and Indian ethnicities who lost their child to chronic life-threatening illness in Singapore.

Results Qualitative thematic analysis of the data revealed four themes, which describe the evolutionary nature of spousal interaction patterns among Asian parents of children with chronic life-threatening illness, from caregiving through bereavement. Findings reveal participants' tendency to concentrate on pragmatic, solution-focused communication during the period of caregiving (pragmatic interaction), avoid discussion about their emotional pain as a means of protecting their spouse (partner-oriented self-regulation), respect and acknowledge their spouse's personal coping strategies (empathic responding) and show greater appreciation and emotional expression within the spousal relationship after their child's death (affective appreciation).

Conclusion Engaging in pragmatic discussions, deferring emotion-focused and potentially distressing conversations, and acknowledging their spouse's need for personal space are important coping strategies for Asian couples facing their child's chronic life-threatening illness and in the immediate aftermath of his/her death. Bereaved couples who have processed their grief individually feel ready to share their reflections with their spouse, deriving meaning and greater relational closeness through such disclosure. These findings are discussed from a cultural lens, with recommendations for healthcare professionals working with Asian parents of children with chronic life-threatening illness.

Strengths and limitations of this study

- This study fills a critical knowledge gap in our understanding of the evolutionary nature of spousal interaction patterns among Asian parents who experience the chronic life-threatening illness and subsequent death of their child.
- In liaison with three community research collaborators, 20 parental units (i.e., 6 couples, 12 lone mothers and 2 lone fathers) of Chinese, Malay and Indian ethnicities were purposively recruited.
- Adhering to a constructivist-phenomenological research paradigm, participants were invited to share their narratives of end-of-life caregiving, grief due to child loss and the evolution of their spousal relationship and communication styles via a semi-structured, meaning-oriented interview.
- Qualitative thematic analysis of the data was carried out with stringent mechanisms to ensure research rigour and trustworthiness of the findings (including maintenance of an audit trail, peer debriefing, checking preliminary themes and interpretations against data obtained in subsequent interviews, inter-researcher consensus in finalising of themes, achievement of data saturation and theory triangulation).
- Future studies should have a more balanced representation of genders, and draw links between the developmental trajectory of spousal interaction patterns over the lifespan of a couple and its impact on their interaction patterns during the stressful period of caregiving and bereavement.

Globally, the number of children living with chronic life-threatening illnesses is increasing.^{1,2} In Singapore, there was a 20% rise in child and youth deaths which climbed from 120 in 2014 to 152 in 2016.³ Chronic conditions such as congenital anomalies as well as cardiovascular and cerebrovascular diseases are prevalent causes of child and youth mortality in Singapore.⁴ Due to rapid

advancements in health and medical technologies, many such children are able to live longer lives, but consequently also face the accompanying challenges of prolonged dependency and disability for several years.¹ The responsibility of providing them with emotional and practical support, assistance and comprehensive care lies with their family caregivers (usually parents),^{5 6} who now face additional stressors over and above the typical challenges of parenting.⁷

In a typical family where a child has diverse and chronic medical needs, the primary family caregivers are usually stay-at-home mothers who are engaged in a kind of unpaid work as required by the numerous psychological and practical demands of caregiving.^{5 6 8} The responsibility of earning income is often shouldered entirely by fathers who need to balance familial and employment responsibilities.⁹ Thus, regardless of their role in supporting the family, both parents are presented with similar levels of challenges and stressors including emotional distress surrounding their child's prognosis, the practical and financial demands of caregiving, strain in marital relationships, neglect of other healthy children and physical exhaustion due to their round-the-clock caregiving duties.^{10–15} Furthermore, caring for a child with a chronic life-threatening illness involves close liaison and communication with medical professionals, but such interactions could increase parents' anguish if they are made to feel disconnected from their child's treatment decisions.^{14 16} In sum, the challenges of caregiving and strain on resources puts parent-caregivers at greater risk of psychological distress, fatigue and poor quality of life.^{5 17 18} This can leave parents with little or no time and energy to invest in their spousal relationship.¹⁹

Communication patterns and interpersonal exchanges between spouses have not been studied among parents whose children are living with chronic life-threatening illness. However, there is research that address communication patterns among bereaved parents after their children died due to a chronic life-threatening illness. These studies found that bereaved parents who communicated their grief openly to their spouse, provided each other with consolation and jointly remembered their deceased child experienced greater relationship closeness, trust and security.¹¹ Bereaved couples who avoided talking about the loss of their child and attempted to remain strong in each other's presence experienced greater grief.²⁰ Among family caregivers of adult patients, patterns of communication that are associated with better spousal adjustment include open discussion of illness-related concerns and listening and responding supportively to one's spouse, while maladaptive spousal relationship functioning is linked to hiding concerns from one's spouse, perceiving one's spouse's responses as discouraging and responding negatively to one's spouse's disclosure.²¹ The benefits of feelings-centred spousal communication have also been affirmed by a randomised controlled trial on the usefulness of emotionally focused interventions for couples with chronically ill children.²²

However, the notion that emotional sharing is key to satisfactory spousal relationship when faced with illness of a family member, as proposed by studies from the USA, Canada, Switzerland and the Netherlands, has not been unanimously supported. In a study with Flemish-speaking couples in Belgium, grieving parents refrained from in-depth communication with their spouse to regulate emotions in daily life, to respect that their spouse faces the same loss but experiences a different grieving process, or because they were not ready to share their emotions with their spouse.²³ Other Canadian studies propose that communication styles of bereaved parents may be related to their gender, whereby mothers desire emotional expression of their intense feelings while fathers prefer to limit talking about their sorrow, instead choosing to keep busy and adopt more solution-focused strategies to cope with their loss; such asymmetry between bereaved spouses' grieving styles can result in secondary losses such as marital disruption if unaddressed.^{10 24}

RESEARCH GAP AND CURRENT STUDY

The reviewed literature highlights two important research gaps. First, the authors were unable to find any study which addressed spousal communication patterns and interpersonal exchanges among parents providing care to their child living with chronic life-threatening illness before bereavement. Second, there is no known Asian study which sheds light on the spousal communication patterns and interpersonal exchanges among parents who experienced their child's chronic life-threatening illness and subsequent death. This means that there is little evidence-based guidance for healthcare professionals providing care to Asian parents whose children have paediatric palliative care needs. Given that Asian family caregivers can be reluctant to engage in in-depth emotional sharing even during times of loss and separation,²⁵ the idea that emotion-focused communication among spouses is essential for healthy adaptation and relationship satisfaction may not hold true for the Asian population, and this could have a bearing on the way healthcare professionals perceive and approach these families. This paper presents selected findings from a larger study that was undertaken to enhance understanding of the experience of Asian parents who lived through their child's chronic life-threatening illness and subsequent death.¹³ The objective of this paper is to examine the evolutionary nature of spousal interaction patterns (defined as interpersonal exchanges and communication patterns between partners in a married relationship) among Asian parents of children with chronic life-threatening illness, from the time of providing care to their child through bereavement.

METHODOLOGY

This study is guided by the consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist for reporting qualitative studies involving interviews

and focus groups²⁶ (refer to online supplementary material for the completed COREQ checklist).

Research approach and design

The study adopted a constructivist-phenomenological research paradigm. The researcher invited participants to share their narratives of end-of-life caregiving, grief due to child loss and the evolution of their spousal relationship and communication styles. The emphasis of this facilitated dialogue was on the meaning that participants ascribed to their experiences. Common themes within these narratives were later extracted for data analysis. Thus, the coconstructive paradigm of this study ensured moderatum generalisation, whereby replication is contingent on shared cultural norms, values and similarity of physical experiences.²⁷

Participant recruitment

Purposive sampling was adopted to recruit family units of lone or couple parents who had lost their child to a chronic life-threatening illness from among the Singapore public. Participant recruitment was carried out in liaison with three community research collaborators, namely HCA Hospice Care (HCA), Children's Cancer Foundation (CCF) and Club Rainbow Singapore (CRS). This allowed the research team to examine spousal interaction patterns due to a wide spectrum of chronic life-threatening illness. The inclusion criteria for study participants were: (1) parents who previously had a child diagnosed with a chronic life-threatening illness between the ages of 0 and 19 years, (2) their child had passed away due to such conditions in the subsequent years, (3) they had been married at the time of their child's diagnosis and at the time of the interview and (4) a minimum period of 6 months had elapsed between their child's death and the study interview. Parents who could not communicate in English, Mandarin or Malay, could not provide informed consent, or showed signs of depressive symptoms or any other major mental illness were excluded from the study.

Procedure

Appointed psychosocial staff at HCA, CCF and CRS identified and contacted potential participants via telephone to introduce the study and its rationale. The purpose of this telephone screening was to verify that the participants met the inclusion criteria for the study. Those who agreed were referred to the researchers. The researchers then established contact with the participants through telephone and an interview appointment was arranged. A total of 26 family units who met the criteria for the present study were referred to the research team, of which 22 agreed to participate. During the interview, two family units showed depressive symptoms; their data were removed from the final analysis and concerns about their well-being were expressed to the referral organisation for subsequent follow-up.

Data collection

Guided by the meaning-reconstruction framework,²⁸ a semi-structured interview guide was developed and pilot-tested. The questions were designed to elicit participants' experiences of caregiving and child loss and examine the nature of their spousal interaction patterns throughout this process. Sample questions included: (1) What has life been like for you after your child was diagnosed with the illness? (2) How has your life changed after the passing of your child? (3) How has your relationship with your spouse evolved throughout this journey? (4) How have you supported each other through this time? (5) Were there differences in how the two of you experienced loss and grief? If there are, how do you reconcile such differences?

Each interview comprised a single family unit, with either one or both parents present. Participants first read and endorsed an informed consent form and participant information sheet which provided an overview of the research, its' objectives and procedures and the rights of research participants. Following this, they engaged in a 60-min to 90-min interview facilitated by a primary interviewer and an assistant interviewer (both of whom were members of the research team). After each completed interview, debriefing was conducted among the interviewers in the absence of the participant. Such an approach allowed for investigator triangulation and encouraged multiple perspectives in observation and data interpretation. The venue for the interviews was either a quiet interviewing room at HCA or at the participants' homes. All interviews were audio-recorded and transcribed verbatim. The transcripts were supervised for quality assurance. Eighteen interviews were conducted in English; two interviews were conducted in Mandarin whose transcripts were later translated to English and verified by two researchers for accuracy. All interviewed family units received a SGD 30 cash voucher as a token of appreciation.

Further, the research team members had received extensive training in the field of death, dying and bereavement, and were qualified to provide on-site emotional support to participants during data collection to ensure their well-being. A referral system with HCA, CCF and CRS was also developed so that participants could obtain further psychosocial support if required.

Patient and public involvement

The design and planning of this study was informed by a comprehensive review of relevant literature as well as the research team's previous work in parental grief and bereavement.¹⁹ Participants were not involved in designing the research. All study participants were members of the Singapore community and no patient was involved in this study. Participants were informed that study findings would be disseminated to them via the community collaborators who referred them to the research team.

Table 1 Demographic information of participants

	Age (years)	Sex	Ethnicity	Child's diagnosis	Years since demise
P1	50–59/50–59	M/F	Ch	Cancer	2
P2	50–59/50–59	M/F	Ch	Cancer	2
P3	50–59	F	Ch	Cancer	1
P4	60–69/50–59	M/F	Ch	Cancer	2
P5	40–49	F	Ma	Cancer	4
P6	40–49/30–39	M/F	Ma	Cancer	2
P7	30–39	F	In	Cancer	1
P8	30–39	F	Ma	Cancer	2
P10	40–49	F	Ch	Cancer	4
P12	40–49	M	In	Brain tumour	4
P13	40–49	F	Ch	Brain tumour	4
P15	40–49	F	Ma	Cancer	5
P16	60–69/60–69	M/F	Ma	Kidney failure	3
P17	50–59	F	Ch	Cerebral palsy	2
P18	50–59	F	Ch	Blood clot in the brain	3
P19	30–39/30–39	M/F	Ch	Spinal muscular atrophy	2
P20	40–49	F	In	Cerebral palsy	1
P22	30–39	F	Ma	Multiple diagnoses	0.5
P24	40–49	F	Ch	Congenital heart disease	3
P25	30–39	M	Ch	Cancer	0.6

Ch, Chinese; F, female; In, Indian; M, male; Ma, Malay.

Data analysis

All audio recordings were transcribed using Microsoft Word and imported into QSR NVivo V.11 for analysis. Thematic analysis was adopted to identify, analyse and report patterns and themes which emerged within the data.²⁹ Such an approach involved the development of ‘themes’ which represented a patterned response or meaning within the dataset, capturing an important aspect of the data in relation to the research question.³⁰ Research rigour and trustworthiness of findings were ensured by adopting stringent mechanisms including

maintenance of an audit trail, peer debriefing, checking preliminary themes and interpretations against data obtained in subsequent interviews, inter-researcher consensus in finalising of themes, achievement of data saturation and theory triangulation.^{31 32}

RESULTS

The sample comprised 6 couples, 12 lone mothers and 2 lone fathers (n=20 parental units) who were citizens or permanent residents of Singapore. No mixed-race marriages were reported by participants. Table 1 provides an overview of the demographic details of the participants.

Figure 1 captures the four themes which describe the evolutionary nature of spousal interaction patterns among Asian parents of children with chronic life-threatening illness, from the time of providing care to their child through bereavement. This includes participants’ tendency to focus on pragmatic and solution-focused communication during the period of caregiving for their child, with lower priority assigned to emotional sharing within the spousal relationship (*pragmatic interaction*), participants’ tendency to avoid discussion about their grief and emotional pain as a means of protecting their spouse (*partner-oriented self-regulation*), participants’ respect for and acknowledgement of their spouse’s personal coping strategies (*empathic responding*) and participants’ tendency to show greater appreciation and

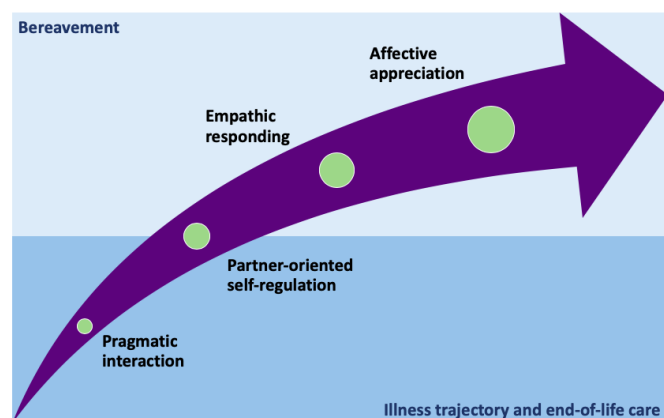


Figure 1 Evolution of spousal interaction patterns among Asian parents of children with chronic life-threatening illness.

emotional expression within the spousal relationship after acceptance of the loss (*affective appreciation*). These themes have been described below in detail and illustrated with relevant quotes from participants.

Pragmatic interaction (number of transcripts theme appeared in; N=13)

Participants explained that throughout their child's illness trajectory and end-of-life, spousal support was predominantly pragmatic and solution-oriented in nature. Most participants reportedly prioritised discussion of caregiving responsibilities over engaging in in-depth sharing of thoughts and feelings with each other.

Functional needs first; survival mode. Emotional needs sometimes. [We] don't have to say much [about] the pain or the struggle or the doubts that we're going through. [We] talk a bit about the diagnosis or what we think is the best place to go next [...] practical things. (P1, father)

However, despite not engaging in much emotional sharing within their spousal relationship, participants valued the pragmatic support which they received from their spouse.

We may not be communicating that much, but when he needs to help me, he helps me, while I go and rest, and it is his turn [to care for the child]. (P22, mother)

Other participants shared that dedicating all their physical and mental energy to caregiving meant reduction in quality time spent with their spouse. But this constraint in time spent with their spouse was perceived to be temporary, that is, until the inevitable death of their child.

There were some [work] trips he wanted me to go with him, I told him 'I cannot' [...] if anything goes wrong with [child], who is going to be responsible? [...] I promise you, once [child] goes back to the Lord, I will go with you. (P17, mother)

Partner-oriented self-regulation (N=11)

This refers to participants' tendency to protect their partner from further emotional distress by refraining from talking about the psychological pain that they were experiencing at an individual level. During the period of caregiving for their child, participants perceived that a discussion about their child's prognosis would be uncomfortable for both parties involved since it would bring to surface fears and worries about the impending deterioration of their child's health. Hence, they preferred to avoid it.

Discussing that [child's prognosis] can be unpleasant sometimes, so we would rather not do that, so we rarely talked about it. (P4, mother)

Participants reported that they would make decisions independently, where possible, to reduce the load of caregiving that their spouse bore.

Things which I believe I can take the lead in the decision, I just carry on, because I don't want to overwhelm her [...] there's a lot of things that she has to handle [...] not sleeping well, taking care of the child, battling the adverse effect on the child in terms of chemotherapy [...] I want to give lesser stress to her. (P25, father)

In the aftermath of their child's death, participants continued to protect their spouse by avoiding conversations that revolved around their deceased child.

I was worried about stirring up his feelings, he was worried about stirring up my feelings. So, we didn't talk about it for about a year, didn't talk about our son. (P13, mother)

Empathic responding (N=12)

Although participants and their spouses jointly experienced the phenomenon of child loss, they acknowledged and accepted that they coped with their grief through different means and at separate times. Participants thus empathetically responded to their spouse by providing him/her with space and time to grieve.

His running time is the time that he has an outlet [...] my outlet time is when I'm home on my own bed. (P1, mother)

I wanted to go for the [bereaved parents' group therapy] session, he encouraged me to go... And then... we always tell each other, 'If you want to go for holiday, you want to take a break, go ahead'. (P7, mother)

Some participants chose not to broach the subject of loss as a recognition of their spouse's grief and pain as well as respect for the choices that were the most comfortable for their spouse.

I know he doesn't have it easy working outside. So, I don't talk too much when it comes to certain things [referring to deceased daughter], because I know how tough it is for him. (P4, mother)

Affective appreciation (N=13)

Participants reported that after their child's death, they felt a greater sense of appreciation towards their spouse and the support provided by him/her during the challenging period of caring for their sick child.

I explained to him, 'Without you, we would not have this quality of life. You must always remember. How I could have every minute with [child]? It's because you supported the family [...] you contributed a lot to my life so that I can walk this path easily'. (P24, mother)

Participants also reflected on their newfound ability to openly communicate with their spouse about the thoughts and emotions surrounding their child's absence and the meaningful memories associated with their deceased child.

[We] started to talk. As we talked, surprisingly, we became happier. We spoke about what he [child] loved the most, what he was best at. We talked less about his least happy stuff, or the process of his illness. (P13, mother)

Other couples engaged in grief rituals which allowed them to foster closer emotional bonds with each other through grieving together for their deceased child.

When he goes to the cemetery, I accompany him. We have long walks. We take a date at the cemetery. (P8, mother)

DISCUSSION

This is the first known study to examine the evolutionary nature of interpersonal exchanges and communication patterns between spouses among Asian parents of children facing chronic life-threatening illnesses. Such spousal interaction patterns have been detailed from the time of providing care to their child through bereavement. Findings show that during the period of caregiving, end-of-life and to some extent, bereavement, spousal interaction patterns tended to be pragmatic in nature, with each individual in the spousal relationship protecting the other from further emotional distress by refraining from talking about the psychological pain that they were experiencing at an individual level. In the aftermath of their child's death, participants began to acknowledge their spouse's need for personal space and respect their spouse's unique ways of coping with grief. They also began to show greater appreciation and emotional expression within the spousal relationship after the death of their sick child.

Participants in the present study 'did not want to add on to their spouse's burden' and so they avoided talking about their child for 'fear of stirring up each other's pain' (P13, mother), which is similar to findings with Flemish-speaking Belgian participants.²³ These findings differ from the bulk of literature which shows that open communication and emotional engagement with one's spouse is key to adjustment of both partners when faced with a life-threatening diagnosis in the family.^{11 21 22} It is interesting to interpret these findings from a cultural lens. Flemish people are not known to be emotionally expressive, and not talking about their grief was perceived to be a culturally appropriate way of responding to the loss, a trait that is similar to the Asian population.²³ When participants in the present study were asked how they coped with their caregiving challenges as a couple, they responded that they refrained from deep emotional sharing for worry about bringing to surface their spouse's

distress. In the midst of their hectic caregiving schedules, participants found it more meaningful to support each other in pragmatic and solution-oriented ways rather than initiating a conversation about their grief that was likely to upset both spouses. These findings support the collectivistic Asian values of showing consideration for the needs of others and containing one's emotions in order to maintain harmony with others,³³ thus providing further evidence that even during times of grief, in-depth emotional sharing is not in tune with the needs and practices of Asian family caregivers.²⁵

This does not, however, mean that emotional self-disclosure has no value for Asian couples. After their child's death, participants felt ready to share their reflections with their spouse. Similar to findings from Western studies,^{11 22} participants found that they derived meaning and greater relational closeness through such disclosure. Such couple-based coping strategies helped spouses to jointly maintain a bond with their deceased child and integrate memories of their deceased child into their present and onwards relationship with their spouse. One interpretation of this finding is that with Singapore being a cosmopolitan city that embodies Western modernity while retaining its Asian values,³⁴ there is an overlap between Western and traditional Asian communication styles in coping with loss. The unique ways in which this manifested itself can be seen in our study, although further research is needed to provide insight into the processes which influence such communication practices of grieving parents.

Clinical implications

While previous studies on family caregivers of patients with chronic life-threatening illness have cited emotional expression and communication between spouses as the key to relationship satisfaction,²¹ this study serves as a caution to healthcare professionals who may over-emphasise the need to openly express feelings and thoughts among Asian parent-caregivers of children with chronic life-threatening illness. We propose that in-depth sharing of thoughts and feelings may not be the priority for Asian couples during the period of caregiving and early bereavement. Rather, it would be useful for healthcare professionals to employ a time-efficient approach such as solution-focused narrative-based counselling^{33 35 36} when working with couples for whom functional needs such as providing care to their child take precedence.

A solution-focused approach to counselling would invite both spouses to reflect on 'what works',³⁷ that is, the strengths within themselves that have kept them going, the pillars of support (such as their spouse) that help reduce the strain of caregiving, and facilitate both spouses to think about what they can do to achieve more desirable outcomes within the context of their family life. Since parents of children with complex medical conditions often find themselves caught in a web of treatment and caregiving,^{13 19} the miracle question commonly used within solution-focused counselling^{38 39} could be

a useful tool for healthcare professionals. For instance, the miracle question can be employed to explore what would be different in the couple's life if they were to wake up one morning and find that their child was no longer sick. The counsellor could further explore how family life for the couple would be different with this miracle, and use the elicited information to explore how the couple can achieve their goal of a more satisfying family life. Solution-focused clinical work can thus address the culturally unique needs of Asian clientele⁴⁰ by highlighting self-efficacy and encouraging helpful styles of coping and goal setting.⁴¹

Narrative therapy⁴² could be useful for spouses facing their child's chronic life-threatening illness by helping to develop stories of strength and agency and facilitate the formation of a verbal legacy which can sustain the couple even after the death of their child.^{42–44} In the aftermath of their child's death, couples can continue to benefit from narrative therapy which can facilitate remembering their deceased child, acknowledging relational connections that helped smoothen the process of caregiving (such as support from their spouse) and revisiting the evolution of their spousal relationship with emphasis on expression of affection and appreciation towards their spouse. Thus, healthcare professionals can deepen therapeutic alliance with the couples that they work with by recognising the needs and priorities of couples at various stages and tailoring their counselling style to address these essential concerns.

Limitations and future directions

Since the purpose of this article was to examine spousal interaction patterns among Asian couples, it would have been useful if all participants could have been interviewed individually first, followed by a dyadic interview with their spouse, so that researchers could obtain richer data on the perspectives of both parties regarding the evolution of their relationship over time. The current findings also require a more balanced representation of genders. Further, this study was unable to draw links between the developmental trajectory of spousal interaction patterns over the lifespan of a couple and its impact on their interaction patterns during the stressful period of caregiving and bereavement. For example, do couples shift towards greater affective appreciation with the passage of time? How does the quality of the couple's relationship prior to their child's diagnosis affect their interaction patterns when faced with a stressor such as caregiving for their child with chronic life-threatening illness? These are pertinent questions that future research can seek to address.

CONCLUSION

Child death can impact relationship health for couples involved in caring for their child. Understanding the nature of spousal interaction patterns is the first step in helping couple parents heal together in the face of child loss. Although this study focused on the spousal interaction

patterns of Asian parents, it adds to the growing literature on the importance of cultural sensitivity among healthcare professionals working with diverse groups of parents. It is pivotal to recognise what keeps spousal relationships intact during stressful times so that interventions can be tailored accordingly to enhance resilience and coping among spouses facing crises such as impending and actual child loss.

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