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Deathbed experiences and meaning-making: Perspectives of family caregivers of patients who received cancer palliative care

Original Article

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Corresponding author: Irene Teo;
Email: irene.teo@duke-nus.edu.sg

Irene Teo, PH.D.[1,2], Keerthana Paramasivam, B.SOC.SCI[1], Wai Yee Chee, M.SC.[3], Carolyn Ng, PSY.D.[4], Patricia Soek Hui Neo, M.B.B.S., M.R.C.P.[5] and Geok Ling Lee, PH.D.[6]

[1]Department of Psychosocial Oncology, National Cancer Centre Singapore, Singapore; [2]Lien Centre for Palliative Care, Duke-NUS Medical School, Singapore; [3]Grief Matters, Montfort Care, Singapore; [4]Portland Institute for Loss and Transition, Portland, OR, USA; [5]Department of Palliative Medicine, National Cancer Centre Singapore, Singapore and [6]Department of Social Work, National University of Singapore, Singapore

Abstract

Objectives. The deathbed symbolizes a time when the patient is dangerously ill and where death is imminent. The memories of family caregivers during this time can potentially shape their meaning-making of the patient's death and bereavement adjustment. We aimed to understand the experiences of family caregivers at the deathbed of patients receiving palliative care. We also examined caregiver's meaning-making that occurred after the patient's death.

Methods. In this retrospective qualitative study, family caregivers of cancer patients who received palliative care in Singapore were recruited through purposive sampling. In-person, semi-structured interviews were individually conducted with study participants to understand their experiences from a caregiver's perspective before and after the death of the patient. Thematic content analysis method was conducted.

Results. A total of 25 bereaved family caregivers were interviewed, with spouses, adult children, and others comprising one-third each of the sample. Six themes emerged from caregivers' recollected experiences around the patient deathbed: *Lasting image of the patient, A time of intense emotions, Healthcare providers prepare caregivers, A time for saying goodbye, Rituals provide comfort*, and *Impact on family ties*. Four themes emerged surrounding post-loss meaning-making: *An end to the pain and suffering, "Have I done enough?," Significance in the timing of events*, and *Gaining strength and personal growth*.

Significance of results. The deathbed is a salient time for family caregivers as they prepare for patient's death. There are opportunities to provide support to the family based on the study findings.

Introduction

Cancer is the leading cause of death in many developed nations, including Singapore, and is responsible for about 28–29% of deaths in Singapore (Office NRoD 2015). Family caregivers are typically involved in end-of-life care of patients with cancer and can experience emotional distress as they confront the impending demise of patients (Teo et al. 2023). The patient deathbed symbolizes such a time when the patient is dangerously ill and where death is imminent, typically in days or weeks. The recalled experiences of family caregivers are remembered and interpreted subjectively, yet these recollections are important as they can influence caregivers' meaning-making of the patient death.

There is a large body of work understanding challenges faced by bereaved caregivers and what types of support caregivers require both prior to and post-patient death (Breen et al. 2017; Holtslander et al. 2017; Mack et al. 2021; Stajduhar et al. 2010; Wiener et al. 2019). A number of qualitative studies have highlighted the emotional distress experienced by caregivers brought about by witnessing patient suffering and by anticipatory grieving (Coelho et al. 2020; Tang 2019). Studies have also highlighted the importance of open, honest communication between the healthcare provider and patient, caregiver and family so that patients are able to live their best quality of life and families are prepared for patient death (An et al. 2020; Mack et al. 2021; Morris et al. 2020; Tang 2019). However, there is limited research or studies focused specifically on understanding the experiences of caregivers at patient deathbed or when patients are imminently dying.

According to Neimeyer's model of grief therapy, meaning reconstruction is central to the process of grieving and is a coping resource to the bereaved (Neimeyer 2001, 2022; Neimeyer and

Sands 2011). Important aspects to the meaning-making process include the processing of the death event, the realignment of the bereaved-deceased attachment, and the revision of the self-definition and life narratives (Neimeyer 2022). Barboza et al.'s study (2022) on meaning-making showed that a deep yearning for the attachment bond can manifest as grief when meaningful or close relationships are lost. Some bereaved individuals have also reported positive outcomes such as personal growth following a loss, while others reported more severe symptoms of grief and distress symptoms (Bellet et al. 2018).

The current study sought to understand the experiences of informal family caregivers as they witnessed cancer patients' end of life in a palliative care setting (i.e., hospital, hospice, or home hospice care programme) in Singapore and made meaning after the death of the patient. We anticipate that our findings can inform how palliative healthcare teams can provide death preparation support and the subsequent bereavement care and support to families of cancer patients.

Methods

Study design and participants

In this retrospective qualitative study, bereaved family caregivers of cancer patients who received palliative care were recruited through stratified purposive sampling as part of a larger project to understand the bereavement care needs in Singapore. Recruitment was conducted via study investigators (consisting of medical social workers, psychologists, and palliative care specialists) and community agencies between October 2017 and April 2018. The inclusion criteria included adult individuals who lost a family member from cancer between 6 months and 4.5 years ago and were able to communicate in English, Chinese Mandarin, or Malay. Individuals who were known to have a mental health condition were excluded.

Procedures

Ethics approval was obtained from the Centralized Institutional Review Board (Ref: 2017–2807). Individuals who were identified as being potentially eligible were contacted by phone by the study coordinator to verify their eligibility and to schedule an initial meeting. Written informed consent was obtained prior to the research activities. Participants completed a demographic survey before participating in an individual semi-structured in-depth interview to understand their caregiving experiences before and after the death of the patient. Each interview was audio-recorded with participant consent. Interviewers consisted of research assistants trained by IT and LGL. After the interview, each study participant received $30 and a number to call should they need a referral for bereavement support. Study participants were further contacted over the phone within 5 days after the interview for a check-in to ensure their well-being and need for further support.

Data analysis plan

All interviews were transcribed for analysis. Braun & Clarke's thematic content analysis (Braun and Clarke 2006) was conducted, and we focused on experiences of caregivers at the patient's deathbed and post-loss meaning-making. As part of the larger project, open coding was conducted by a team of four researchers using a subset of the transcripts for initial codes to arise inductively from the data. Discrepancies from the initial codes were resolved through team consensus to develop a codebook. The codebook served as a guide for coding the remaining data; every transcript was coded by at least two independent researchers to enhance coding reliability, and inter-coder discrepancies were further reconciled. For this study, the authors (IT and PK) organized the codes pertaining to caregivers' experiences at the patient deathbed and post-loss meaning-making into meaningful categories and themes. Iterative coding and revision of the themes occurred. NVivo software was used to facilitate data management. Finalized themes are presented with illustrating quotes. Edits to the quotes were made to correct grammar and omit extraneous words to improve readability.

Results

Participant profile

There were 25 bereaved caregivers, majority of whom were Chinese (80%), female (72%), and aged above 40 years old (72%). They were relatively diverse in terms of their religion, marital status, and relationship type with the deceased, although plurality of them were Buddhist/Taoist (40%), single (40%), and children or children-in-law to the deceased (Table 1). The cancer diagnoses of the deceased patients were also varied, with the most common being lung cancer (24%), breast cancer (16%), and head and neck (16%). Time since patient death ranged from 6 to 37 months (M = 14 months, SD = 8 months).

Thematic analyses

Six themes emerged from family caregivers' recollected experiences around the patient deathbed and four themes around meaning-making post-patient death. A summary with exemplars are presented in Table 2.

Deathbed experiences

The deathbed is defined as the time when patient is dangerously ill, and death is imminent. The patients are usually bedbound, symptomatic, and weak. We focused on what caregivers remembered during this critical period of time in a palliative care setting or home hospice care programme.

Lasting image of the patient. The last encounter(s) with the patients were visually recalled by caregivers, some with clarity and detail. These included the location, changes to patient's physical appearance (e.g., cachexia, being on feeding/oxygen tubes), and patient's suffering from pain (C14, 17, 44, and 50). One caregiver described a comforting memory of her loved one's facial expression: *"When he passed on, he still smiled, in a very peaceful manner. I told him, 'I love you.' Then he smiled"* (C05).

For some caregivers, these images were often accompanied by a remembered emotion, as indicated by the following quotes: *"I could not bear to see him like that. He had lost so much weight that his pants were too big for him"* (C10) and *"The biggest shock for me was seeing my dad on oxygen [tubes]. That image was so scary"* (C44).

A time of intense emotions. Intense emotions such as sadness and helplessness were commonly reported by the bereaved caregivers. Such emotions emerged mainly due to the contrasting image of the person prior to the illness and to the person at the deathbed, as exemplified by the quote: *"He's a very strong person. And then to see that person suddenly become so weak, you feel so helpless"* (C44).

Table 1. Demographic characteristics of study participants ($N = 25$)

ID	Age	Gender	Race	Religion	Marital status	Relationship to deceased	Cancer diagnosis	Time since death (months)
C01	61–65	M	Chinese	Free thinker	Widowed	Spouse	Colon	7
C02	61–65	M	Chinese	Christian	Married	Child	Breast	15
C05	46–50	F	Chinese	Buddhist	Widowed	Spouse	Nose	9
C06	56–60	M	Chinese	Buddhist	Married	Child	Leukemia	6
C10	71–75	F	Chinese	Free thinker	Single	Godmother	Nose/eye	8
C13	56–60	M	Chinese	Buddhist	Single	Sibling	Tongue	6
C14	56–60	F	Chinese	Buddhist	Married	Sibling	Throat	9
C16	31–35	F	Chinese	Buddhist	Single	Grandchild	Lung	12
C17	21–25	F	Chinese	Free thinker	Single	Child	Bile duct	12
C18	71–75	F	Chinese	Taoist	Married	Parent	Lung	12
C23	46–50	F	Chinese	Buddhist	Widowed	Spouse	Pancreas	10
C24	26–30	F	Indian	Hindu	Single	Child	Breast	27
C26	41–45	F	Chinese	Christian	Single	Friend	Stomach	12
C27	66–70	F	Chinese	Christian	Single	Child	Pancreas	16
C30	46–50	F	Chinese	Christian	Married	Child	Lung	7
C31	41–45	F	Malay	Muslim	Divorced/Separated	Child	Colon	11
C32	36–40	F	Chinese	Catholic	Single	Child	Stomach	30
C33	41–45	M	Chinese	Buddhist	Widowed	Spouse	Breast	15
C34	21–25	F	Malay	Muslim	Single	Sibling	Leukemia	13
C35	46–50	F	Chinese	Buddhist	Widowed	Spouse	Stomach	10
C36	31–35	F	Eurasian	Muslim	Married	Daughter in law	Lung	25
C43	41–45	M	Chinese	Christian	Widowed	Spouse	Breast	14
C44	21–25	F	Pakistani	Muslim	Single	Child	Lung	8
C45	51–55	M	Chinese	Buddhist	Widowed	Spouse	Lung	28
C50	41–45	F	Chinese	Free thinker	Widowed	Spouse	Lymphoma	37

Some caregivers felt emotional observing the pain and suffering experienced by the patient: “*You could see from his face that he really was in a lot of pain, to the point he would cry. Because he really, really was in so much excruciating pain. My niece, nephew, when they saw their uncle in that state, they all just hugged each other and cried together*” (C14).

One caregiver even described ambivalent feelings at the deathbed: “*It’s a tug-of-war inside. It’s this horrible feeling. You want him to go, but you don’t want him to go. [tears]. It’s tough*” (C30).

Healthcare providers prepare caregivers. Communication with and information from healthcare providers during this time was reported to be an important aspect of the deathbed experience for caregivers, such as preparing them for patient’s deterioration and death: “*They pre-empted us and let us know what to expect. These things really helped us psychologically. We were told that there are times he [patient] might see things and he really did. We were taught how to deal with such ramblings which were nonsensical.*” (C30).

A time for saying goodbye. The bereaved caregivers described how they had wished the patient a meaningful goodbye at the deathbed. Some had the opportunity to express gratitude for each other and meaningful wishes, with the most common form being “*I love* you” (C05, 18, 24). Others described saying *thank you* (C05), seeking *forgiveness* (C24), and reassuring each other *not to worry* (C05). One bereaved caregiver told the patient to “*see light, and just go towards it … do not look back*” (C50). Contradictorily, a few others expressed they were *too late* (C17) and were not able to say a *proper goodbye* (C34), which led to feelings of *guilt* (C44).

Rituals provide comfort. The bereaved caregivers described engaging in rituals, based on their own cultural and personal beliefs, during patients’ final moments that were meaningful. The rituals were reported to have provided some measure of “*comfort, especially those who share the same faith*” (C26). One study participant described saying a Buddhist prayer and chanting to “*lessen their* [the patient’s] *suffering*” (C06); another participant described the Hindu custom of pouring of milk to aid “*reincarnation into the next birth that is empathetic and compassionate*” (C24). One caregiver shared that her family recited words from a traditional cultural practice during the patient’s final moments (C24) and another described singing Christian worship music at patient’s bedside (C26).

Impact on family ties. Family ties were reported to be strengthened or weakened. For example, disagreement revolving around patient care resulted in tension and even fragmenting of family ties: *"My brother was against me, [he] thought that I was conspiring to kill my mom with the morphine. A lot of words were exchanged"* (C24).

On the other hand, the patient's imminent death also provided opportunities for the patient and caregiver to grow *closer* (C17, C24), as well as opportunity to heal rifts as the following quote illustrated: *"Because that was his final chance, father was going to pass away … at times they had argued, quarreled. So I think this was like, a closing ceremony … for the two of them to bond. And they managed to do that"* (C36).

Meaning-making during Bereavement

Caregivers' meaning-making of their loved one's death is characterized by their evaluation of the patient's end-of-life experiences and interpretations ascribed to the patient's death. This meaning-making occurred at post-loss, both in the immediate aftermath of the loss and subsequent post-loss adjustment phases, where caregivers started moving on with their lives, while reminiscing of their deceased loved one and what his/her death had taught them. Four themes are identified and are delineated below.

An end to the pain and suffering. Generally, caregivers reflected that they did not want their loved ones to continue *suffering* (C18, C36). Thus, they assured themselves and viewed their loved one's death as a way for the suffering to end for both the patient, as well as the family who bore witness to the pain but were not able to relieve it for them. This is illustrated by the following quote: *"I am glad that at least my dad is not sick anymore. It is a good feeling to know that he is not in pain … He was constantly complaining that he could not see properly … I am glad that it is over. It was better for everyone."* (C17)

"Have I done enough?". The perception of having done enough (or not enough) for the patient was something that came up among the bereaved caregivers. Caregivers who felt that they had done their best to care for their loved one were thankful that they were able to see to the patient's needs. They described feeling positive about their caregiving actions that helped mitigate the pain of their loss and reminisced about their gratitude for the opportunity to care for the patient and the satisfaction from providing care: *"I am really happy with what I have done for him"* (C18).

Contradictorily, there were caregivers who wished they had *done more* (C24). One caregiver said: *"I felt guilty because I shouldn't have gone on the trip"* (C44). Some caregivers described feelings of *regret* for not being physically present with the patient at the time of his/her passing (C30 and C34).

Significance in the timing of events. "Timing" was a significant factor reported to have influenced how the bereaved caregivers made sense of the death of their loved ones. This was reflected in two aspects, one of which was the availability of caregiver to provide care for patient. This is illustrated by the quote below by a caregiver who was single and working in a health-related profession: *"Before she [deceased mother] passed away, she made meaning of why I didn't get married. She said, "If you had gotten married, nobody will be here to take care of me." … God planted me in a cancer clinic, then a palliative clinic that gave me knowledge [to care for my mother]"* (C24). In such a case, being able to identify her purpose and role in her loved one's care both reaffirmed the caregiver's bond with the deceased while providing consolation.

Table 2. Themes and examplars reflecting the bereaved caregivers' deathbed experiences and meaning-making

	Theme	Exemplar
Deathbed experiences	▪ Lasting image of the patient	"That's the last time I saw him. He was sitting when I left … he wasn't looking at me. I am just left with that image." (C34)
	▪ A time of intense emotions	"I felt helpless. She was gasping and they said to let it be. It's very hard to see my mother gasping, panting away in her last moments." (C27)
	▪ Healthcare providers prepare caregivers	"… [the oncologist] helped us understand his condition better, even knowing how it would progress and what to expect. That was very helpful." (C44)
	A time for saying goodbye	"At the hospital, she wanted to throw a celebration with her friends and relatives. She was making a toast and saying goodbye to them. She said it was time for her to leave. Then, after an hour, her condition worsened." (C45)
	▪ Rituals provide comfort	"And that's my last prayer with him, and I will never forget. It's something I cherish until now. Even though we couldn't go to the mosque, we were still praying together, and to me that means a lot." (C44)
	▪ Impact on family ties	"When my father-in-law was sick, a family member came … she was so *manja* [affectionate], calling him 'father.' I was closer to him. It made me sick and jealous" (C36).
Meaning- making during bereavement	▪ An end to the pain and suffering	"When he was alive, I saw he was suffering. I did not want him to suffer so much. It was better for him to go earlier." (C18)
	▪ "Have I done enough?"	"I should have woken up earlier, I should have been there. Maybe I should have stayed over the night before. There is this sense of regret that I could have been there earlier" (C30).
	▪ Significance in the timing of events	"I told him that I not prepared to let go yet. If he can stay around for a week, I don't want to ask more than that … and it was exactly a week before he left" (C50)
	▪ Gaining strength and personal growth	"I learnt who are the people who are there for me and those who didn't help me. I have also grown more mature during this period" (C17).

Another aspect of timing mentioned by bereaved caregivers pertained to the timing of the patient's death, where caregivers ascribed meaning. Several caregivers shared the patient waiting for their presence at bedside before drawing his/her last breath, which was meaningful to the caregiver: *"Once I kissed her, her heartbeat stopped. She waited for me for that last breath"* (C02). There were others who believed the patient timed his/her passing only when the family was absent to spare them the pain: *"When he [deceased father] passed away, no one was around from our family. If we were there, it will be very painful to watch. I told my mother that it is better that she was not home … if she was, it would be harder for him to leave"* (C44). In both instances, making sense of the timing of events enhanced their appreciation of the deceased and provided comfort in the midst of grief and loss.

Gaining strength and personal growth. Post loss, caregivers reflected how their loss changed the way they viewed life and how they gained an inner strength to move on. One caregiver described finding strength through *positive, motivational self-help books* (C05). Many found ways to move forward that honored the deceased patient, appreciated life more, and became purposeful in their actions: *"I felt that I really need to be more intentional and more disciplined because you really don't know when you will be gone. Live life without regrets"* (C26). A bereaved widow shared her efforts to carry on with life and raise her children: *"I hope to teach my children to be self-sufficient. So that we will always be capable and resilient in every walk of life"* (C50).

Discussion

Our qualitative interviews included 25 bereaved family caregivers of patients who received end-of-life care in a cancer palliative care setting, and where spouses, children, and others comprising one-third each of the sample. Six themes emerged around the deathbed: *Lasting image of patient, A time of intense emotions, Healthcare providers prepare caregivers, A time for saying goodbye, Rituals provide comfort*, and *Impact on family ties*. Four themes emerged surrounding post-loss meaning-making: *An end to the pain and suffering, "Have I done enough?," Significance in timing of events*, and *Gaining strength and personal growth*.

Themes from experiences around the deathbed that are consistent with the literature include the intensity of emotions leading up to patient death (Coelho et al. 2020; Tang 2019) and impact of the loved one's death on family ties (Steffen and Coyle 2017). Our findings also highlight the role of the healthcare providers in communicating prognosis and preparing caregivers of the impending death, meeting an important caregiver need (Breen et al. 2017; Mack et al. 2021; Stajduhar et al. 2010).

We found that the themes of *lasting image of the patient* and *a time for saying goodbye* were also important in the retrospective accounts of the bereaved. We could not find much accounts in the literature of lasting final image of loved ones, though a recent Chinese qualitative study described witnessing and remembering patient characteristics at the moment of death, such as shortness of breath and lack of responsiveness and being associated with distress among the bereaved (Tang 2019). Having the opportunity to say farewell has been examined previously, and our findings are consistent with prior reports of the salience of patient–caregivers wishing one another goodbye (Jeon et al. 2023). We expect that these emotionally salient, final memories of the deceased play an important role in the caregiver's perception whether the patient died a "good death" (Lee et al. 2013) and affect the bereavement adjustment of the caregiver (Oechsle et al. 2020). The theme of *rituals provide comfort*, although comprising varied cultural and religious practices showed the consistent value these rituals provided the bereaved – a way to honor their loved one and to do their best for the deceased's afterlife, which consequently offered them comfort.

The themes surrounding meaning-making illustrate the narratives constructed by the bereaved as they came to terms with the death of their loved one and looked for a silver lining. Interestingly, we found the theme of "*Have I done enough?*" presented as a double-edged sword as we observed that those who perceived themselves as having done enough subsequently reported better adjustment compared to those who conveyed guilt and regret for not having done enough. The literature have reported and focused more of the latter (Jeon et al. 2023; Mack et al. 2021), and we wanted to draw attention to situations where caregivers can derive sense of peace and satisfaction in their caregiving efforts. It is worth noting that "doing enough" (or not) is, of course, entirely subjective and may in part be shaped by societal and cultural expectations such as filial piety (Chan et al. 2012) or societal and personal expectations on life-stage appropriateness of patient death, such as in the case of losing children (Mack et al. 2021; Wiener et al. 2019).

We highlight the one participant in our study whose young child had died; the bereaved parent described they did not want their child to suffer any longer and viewed death as *a way to end the suffering*; they further articulated they were happy with what they were able to do for their child. This parent's meaning-making of the death of their child is indeed exemplary in the face of such sorrow – to have the ability to shift perspectives and create coherence of why the death occurred, what it meant, and how this affects their life narrative. Indeed, we had reports of other caregivers describing *gaining strength and personal growth* in their attitudes about and way they lived life after losing their loved ones.

Our study presents novel information from a culturally and religiously diverse Asian setting where bereavement care of informal caregivers is an under-developed aspect of hospice and specialist palliative care services, though gaining recognition as being important. Palliative care service providers have been facing a number of obstacles in providing adequate bereavement care, including feasible models of caregiver follow-up/monitoring (Lee et al. 2022). Our findings on caregiver perspectives can be useful in informing the development of services that can meet the needs of these informal caregivers.

Clinical implications

Examination of these aspects of the caregiver experiences will enable understanding of their lived experiences and present opportunities to support them. This can include more upstream interventions at the patient deathbed to support and improve bereavement adjustment and coping after the patient's death. What would pre-loss caregiver support look like? Our findings suggest that being available to provide emotional and social support as caregivers experience intense feelings of anticipatory grief and come to terms with drastically changed appearance or functioning of the patient will be important. Caregivers also look to healthcare providers to guide them on what to expect – in providing timely information as well as preparing the family for imminent demise and last goodbyes. It is a time to be sensitive to potential tension among family members and, if necessary to mediate or facilitate discussions to reach an aligned goal concerning patient end-of-life care. For some families, the role of rituals may be comforting and the palliative care team can provide suggestions or refer to any appropriate services (e.g., for last rites).

In therapeutic bereavement work, processing imprinted last images of the patient with caregivers may be important. There may be powerful feelings that are associated with the meaning ascribed to perceived patient's suffering and whether or not they, as caregivers, had done "enough." We observed certain caregivers describing guilt and regret even years forward. Being able to utilize cognitive restructuring (Wagner et al. 2006) or meaning-making (Chan et al. 2005; Holland et al. 2006) bereavement coping strategies may be helpful in these instances. For caregivers who are ready, shifting the focus to daily coping or non-bereavement matters, reconstruction of positive meanings, and the future may be beneficial (Tey and Lee 2022). Studies in the USA and Hong Kong have shown that the Dual Process Model of Coping-guided bereavement interventions, which incorporate loss-oriented and restoration-oriented coping processes and the oscillation between the two orientations, are more effective than traditional bereavement intervention that focused on loss and grief only (Chow et al. 2019; Lund et al. 2010).

An important consideration is how to provide support to caregivers from the time patient is known to the palliative care service and to the subsequent bereavement period. Not all palliative care services have a formal protocol or process of assessing caregiver needs, which may result in caregivers "falling between the cracks" of the healthcare system, especially after the death of patient (who are the formal recipients of healthcare services). This is an area for service development in the future that will be important to explore and formalize.

Limitations

There are several limitations that should be acknowledged. Our study relied on a retrospective cross-sectional design, and thus could be susceptible to participants' recall bias. Our study also recruited participants from a wide range of settings that included inpatient palliative care as well as home hospice services. Different caregiving contexts may have different implications on the resources available and the stressors imposed to the caregivers. This in turn may create different deathbed experiences and affect the caregivers' post-loss adjustments differently.

Conclusions

This study offers a preliminary but important perspective of the lived experiences of caregivers at the patient deathbed and as they make meaning after patient death. We hope our findings are able to inform future studies that investigate interventions aimed at supporting caregivers of patients with terminal conditions in a continuous and comprehensive manner.

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Authors' contributions. IT was involved in study planning and design, IRB study preparation and led the data analyses and manuscript preparation. PK was involved in data analyses and manuscript preparation. WYC was involved in study conceptualization, study planning and design, IRB study preparation, data collection, and review of manuscript. CN was involved in study planning and design, data collection, initial data analysis, and review of manuscript. PSHN was involved in study conceptualization, study planning and design, IRB study preparation, and review of manuscript. GLL led the team in study conceptualization, study planning and design, IRB study preparation, data collection, initial data analysis, and review of manuscript.

Competing interests. The authors report no competing interests.

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