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ORIGINAL ARTICLE

The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit

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Abstract
Background Existing bereavement literature focuses on the care provided in palliative care units or community settings. However, nurses in oncology units are in a unique position to provide bereavement care, which is care extended to the families after the death of cancer patients. This study aimed to explore the perceptions and experiences of bereavement care among nurses and bereaved family members in an oncology unit in Hong Kong.
Method Semi-structured qualitative interviews were carried out in one oncology unit in Hong Kong with 15 nurses and ten bereaved family members. All interviews were audio-taped, transcribed verbatim and analysed by using qualitative content analysis.
Results Among the bereaved family members, three themes emerged: being informed, being supported and being with the patient before and after the patient's death. Among the oncology nurses, however, the three identified themes were: elements of good bereavement care, emotional response in providing bereavement care and educational needs in the provision of bereavement care. Comparatively, the experiences of and the opinions on bereavement care identified by the bereaved were more specific than those identified by the nurses.
Conclusion The findings revealed that there is room for improvement in current bereavement care. Family members were committed to patient care and they expressed their need for more involvement in the patient care, which could result in a positive impact on their grief and loss experience. Nurses were committed to quality care, and they expressed their need for more training on knowledge, skills and attitudes to improve their readiness and competencies in the provision of bereavement care.

Keywords Bereavement · Oncology · Family · Nurse · Qualitative study

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Introduction

Cancer is the leading cause of death in Hong Kong, accounting for one third of deaths in 2011 [1]. At present, most of the attention of health professionals has been given to address the needs and concerns of patients. The literature shows that serious illness affects not only the patients but also their families. Care and support to patients, therefore, has to be extended to the family, particularly during the time following the patient's death, as it can be a devastating experience. Bereaved family members are at higher risk of mental and physical health problems, such as depression and anxiety, and some of them may even have suicidal thoughts [2–4]. Hence, bereavement care is crucial in supporting them to regain their emotional equilibrium during this difficult period [5].

Nurses who have the most frequent contact with patients and their family members are often in a unique position to provide bereavement care. However, several studies have found that nurses are uncomfortable in providing or are unprepared to provide bereavement care. For example, nurses working in the Accident and Emergency Department believe that leaving the bereaved families alone is an appropriate approach, and indeed they do not want to experience "sadness" [6]. Other studies have also shown that nurses

often distance themselves from emotionally stressful situations so as to protect themselves from burnouts [7, 8]. The discrepancy between the expected role of nurses in the provision of bereavement care and their actual practice hence gives rise to dissatisfaction and even hostility among family members towards the health care team [9, 10].

Several studies have reported that the bereaved families were not satisfied with the bereavement care they received. In Wong and Chan's study (2007), the informational needs of the bereaved were not met and they wished that the nurses would take an active role in informing them about the patient's condition [10]. Main reported that the bereaved expected nurses to listen and clarify their concerns [11]. In addition, the bereaved appreciated the chance to participate in the last office procedure and to accompany the patients after their death [10, 12].

Oncology units in Hong Kong are typically a fast-paced, busy, crowded and acute patient care environment. Although patient deaths occur often in oncology units, little attention has been given to explore how bereavement care is provided in this setting. While the bereavement care would affect the experience of the family members during this difficult time, the care quality depends on the readiness of oncology nurses to provide it. Therefore, it is important to understand the perceptions and experiences towards bereavement care from both perspectives. This study aimed to explore the perceptions and experiences of bereavement care among nurses and the bereaved family members in an oncology care setting in Hong Kong.

Methods

Design

This study employed a qualitative design that generated an in-depth understanding of the participants' experiences. The data were collected through in-depth interviews.

Participants

A convenience sample of oncology nurses and bereaved family members were recruited from an oncology unit of a local regional hospital. Recruitment was stopped when the data were found to be saturated. Nurses working in the unit for more than a year were eligible for the study. Fifteen female nurses were interviewed, with age ranged from 25 to 42 years. All have received either a bachelor degree or above. Their clinical experiences in oncology specialty ranged from 1 to 20 years, with eight have been working in this specialty for more than 10 years and seven have received specialty training in oncology. To understand the experiences of bereaved families, ten adult family members (five males and five females) of patients who died in the oncology unit were interviewed. All were children of the deceased patients, with age ranging from 22 to 46 years.

Data collection

Because the topic of this study involved recalling the painful memory of a deceased relative, the interviewer should be experienced and well-trained in communication and counselling skills. Therefore, the second author, who had been working in the oncology unit for 7 years, conducted all the interviews. Individual interviews were arranged for a time and a place convenient both to the participants and the interviewer. A semi-structured interview guide with open-ended questions was formulated based on the study objectives. Chinese people in Hong Kong usually believe that after the seventh set of 7 days, that is on the 49th day following death, the grieving process should end [13]. So, 6 weeks after death was chosen as the appropriate time to conduct an interview with family informants. The length of the interviews was about 30 to 45 min. Field notes were taken during or immediately after the interviews. Data analysis was conducted concurrently with the data collection. Data collection was continued until no new themes emerged.

Ethical considerations

The study was approved by the Clinical Research Ethics Committee of the hospital cluster. All participants were provided with information about the study purpose. Written consent for the audio-recorded interviews was obtained. Confidentiality was assured. All participation was voluntary and participants could withdraw from the study at any time. Counselling was provided if negative emotions were noted in the informants.

Data analysis

All interviews were audio-recorded and transcribed verbatim. Qualitative content analysis was performed [14]. The analysis involves multiple reading of the transcripts to identify significant statements, phrases and sentences among the data in the transcripts. When the categorisation scheme was developed, all data were reviewed again and coded for correspondence to or exemplification of the identified categories. Following this, the core categories were identified. The data collected from the nurses and the bereaved were analysed independently and then integrated in the interpretation of them in discussion.

Rigour

The rigour of the study was achieved through the following strategies. To enrich the data by including multiple and

diverse perspectives, nurses with different demographic variables, including age, gender, educational background, and length of clinical experience in oncology, were recruited to ensure maximal variation in the sample. The interview guide was given to an expert in the area to ensure that the questions were in line with the study aim. All interviews were conducted by the first author to ensure consistency in the manner of data collection. Transcribed data were checked against the interview recordings to ensure accuracy. Member checking was conducted by asking the participants of both bereaved family and nurse groups to verify the transcript of their own interview and the interpretations.

Findings

This study explored the perspectives of bereaved families and nurses towards bereavement care in an oncology unit by conducting individual in-depth interviews.

From the bereaved families' perspective

As shown in Table 1, three core categories emerged from the bereaved families' accounts relating to bereavement care: being informed, being supported and being with the patient.

Being informed

Generally the family informants craved information about every aspect, from the patient's condition, their treatment plan and to future funeral arrangements, and they hoped that the health professionals would provide information to them proactively.

> I wanted to know the patient's condition…I was afraid that I had missed something to ask. I hoped that nurses could tell me something that I didn't know such as the treatment plan. (B2)

Family members believe that the information can help them to relieve their worries and anxiety, and such preparation can also help to resolve the conflicts within the family.

> We didn't understand why morphine should be given to mom, we worried morphine would worsen her condition, nurses explained to us patiently that morphine could help her shortness of breath and we thought that the most important thing was mom's comfort. Initially father insisted not to give morphine to mom and worried that morphine would make mum die. The nice nurse talked to father for 10 minutes and father finally accepted it. (B5)

Being supported

Support to both the dying patients and their family members at the difficult time was perceived by family informants as one of the important components in the bereavement care. On the one hand, the family members were concerned about the quality of care provided to the patients.

> I wish the health care staff could have been more attentive and careful…it was difficult because there were too many patients. If there were more staff to care for the patients, relatives would feel better because the patients could receive better care (B1)

On the other hand, the family members appreciated the support provided to them. Some informants recalled the kind words from nurses, who recognised their feelings and efforts. Furthermore, the family members advocated the need for a supportive physical environment that facilitates them to accompany their loved ones.

> A quiet environment free from disturbance from others is the basic need. It would be better if we could have sufficient space and privacy…I could stay with my mother and I don't need to worry if I had disturbed other people. (B2)

Table 1 Bereaved families' perspective towards bereavement care

Core category	Subcategory
Being informed	• Information about the patient's condition
	• Information about the treatment plan
	• Information about funeral arrangements
Being supported	• Questioning the quality of care given to patients
	• Attitude of the healthcare staff
	• Lack of privacy in a ward environment
Being with the patient	• Flexible visiting hours
	• Being informed in time
	• Participating in last official duties

Being with the patient

The family informants cherished the time with the patients, particularly accompanying the patients when they passed away. They expressed the need to have flexible visiting hours and the need to be promptly notified if the patients' condition deteriorated so that they could visit them in time. Sharing of information by the family informants showed that whether they could "see the patient for the last chance" or "do something" for the patient at the last moment greatly influenced their bereavement experience.

> I really thanked the nurse. On the day of my mother's death, a nurse found her condition changed and advised me to call all other relatives and friends to come to the hospital if they wanted to see the patient for the last chance. Two hours later, my mum passed away… all of us could see her. (B5)
> It was a long road from the ward to the mortuary…I would have felt guilty if I was not with her to walk this last road as a final farewell. (B9)

However, family informants who missed the chance were regretful.

> I wished the health care staff could have informed me earlier about the deterioration of my mother's condition, then we could….I felt regret that we were not there [when she passed away]. (B2)

From the nurses' perspective

On the nurse informants' account of bereavement care in the oncology unit, three core categories were identified: elements of good bereavement care, emotional responses in providing bereavement care and educational needs in bereavement care. The subcategories of each core categories are illustrated in Table 2.

Table 2 Nurses' perspective towards bereavement care

Core category	Subcategory
Elements of good bereavement care	• Providing good nursing care to the dying patient
	• Informing progress/prognosis on time and regularly providing updated information on a patient's condition
	• Providing physical comfort to the bereaved
Emotional response in providing bereavement care	• Feeling wronged and helpless
	• Coping with grief
	• Feeling frustrated and having a lack of support
Educational needs of bereavement care	• Feeling inadequately prepared
	• Lack of counselling skills in relation to the bereaved
	• Need for further education

Elements of good bereavement care

The nurse informants acknowledged the fact that good bereavement care is not only aimed at promoting the comfort of the dying patient in their last phase of life, but also to provide relief to the bereaved family members and to address their concerns, for example, the nurses regularly update the family members about the patient's condition.

> For the relatives, they would feel less worry when they knew that nurses were helping the patient and the patient has not been ignored. (N1)

They also believed that the physical environment may affect the quality of the bereavement care.

> When the patient passed away…due to lack of resources, we could not provide a quiet environment to the bereaved to vent their emotions. It's better if we have a single room for them. (N7)

Emotional responses in providing bereavement care

Despite knowing that bereavement care was beneficial both to the patients and their family members, the nurse informants generally expressed that providing bereavement care is emotionally draining. This is caused by their being acquainted with the patients and developing relationships with them throughout the days, that it was not easy to witness their death, and that negative emotions, such as feeling wronged, helpless and frustrated, are inevitable. They were also perplexed at that moment. Yet they know they need to remain calm and provide support to the bereaved family members.

> Some relatives agreed to giving supportive care and not resuscitation to the patient…but when the patient died, they questioned that we had done nothing to sustain the patient's life…scolded us for being apathetic to the patient's death. At that time, I felt wronged and didn't know what to do. (N1, 25)

The difficult situation is further aggravated by strained manpower and a heavy workload because they also need to continue their work as usual. Hence, nurses expressed that they were exhausted by a sense of powerlessness, grief, frustration and a lack of support.

> After the patient died, I, as a nurse, needed to explain the procedures on collecting death certificate to the relatives. But, I wanted to cry with the relatives when I

saw them crying. At that time, the relatives needed time to calm down, and so as I. (N3)

Educational needs in bereavement care

The nurse informants considered that they were inadequately prepared to provide bereavement care. They expressed the need for further education both on the knowledge related to bereavement care and on counselling skills, regardless of whether or not they had received specialty training.

Courses on bereavement care had not been provided for a long time. Our present skills and knowledge were from the coaching of our senior colleagues…but it's insufficient. I think good training on bereavement care should include theoretical backup in a systematic way. (N3)

Discussion

In this study, the perceptions of nurses and the bereaved were compared and contrasted. Their experiences during bereavement care in an oncology unit were complementary to provide a fuller picture about its provision, and this helps to reveal room for improvement in the current practices. The experiences of and opinions on bereavement care identified by the bereaved are more specific, such as drug side effects and visiting hours, than those identified by the nurses. It reinforces the need to provide more attention in these areas; this is because there may be discrepancies in the expectation between clients and care providers. It also reflects the oncology nurses' need to know more about the clients' specific needs instead of having a general belief and a recognition of the importance of bereavement care.

The findings found that family members wanted to know every detail about their loved ones, including their health conditions, their treatments and the preparation for funeral services, and for them to be kept immediately informed of any changes. This is in line with Wong and Chan's findings that the family members of the dying patients often have feelings of helplessness because they do not know what they can do [10]. In response to their informational needs, this study suggests that nurses have to place the concerns of the bereaved family members as the first priority when providing bereavement care, so as to prepare them to accept the loss and to cope with the grief. The attentiveness of the nurses towards the family members may also in fact partly help to address their need to be supported. The nurse informants in this study understood that their care is not only for the patients but also for their family members, and this means that they made an effort to maintain trusting relationships and effective communication with the family members in an attempt to clarify their concerns and queries. This was echoed by the sharing of the family informants that they were appreciative of the nurses when they acknowledged their feelings and concerns during the difficult time.

Despite their attempts to provide good bereavement care, the nurse informants were not satisfied with their care because it was limited by physical constraints. At present, the ward setting was standardised and several patients share a cubicle. Brereton et al. noted that privacy is considered by patients, families and nurses as part of the care context and that it is important to end-of-life care, particularly at the end stage of life and during the procedures of last office [15]. However, the current physical setting could not provide a quiet and private space for the family members to stay with the patients. Family members, therefore, place a heavy reliance on nurses to contact them whenever any changes in the patient's condition are detected. The nurses' assessment and their judgement about when to notify the family members thus become critical to whether the family members can accompany the patients at the last moment. In addition to the stress inherent in the nature of their work, the nurse informants generally agreed that providing bereavement care was emotionally taxing. Having taken care of the patients for some days, the nurses found themselves emotionally engaged with the patients, and they expressed the need to have time and support in coping with their own grief when the patients die. Wenzel et al. suggested that a supportive self-care environment can help to reduce compassion fatigue and enhance job satisfaction among oncology nurses [16]. For example, as proposed in the "Guide to good nursing practice in end-of-life care", the nurses have to conduct debriefing and provide support to colleagues and co-workers after they have cared for the deceased patient [17]. However, with the practical constraints in the present situation, the nurses were expected to assume their carer role and continue with their work immediately. It has been widely discussed in the literature that oncology nurses who are persistently exposed to emotionally stressful circumstances are at risk of burnout and vicarious traumatisation, and this may eventually result in a high turnover rate [18]. Further study should look into the impacts of working in an oncology unit on the well-being and intention to leave among nurses in the setting.

Furthermore, the nurse informants expressed the need for training to improve their readiness and competencies in the provision of bereavement care. They revealed that they lack the specialised training in this area. Their sense of inadequacies was consistent with the findings of previous local studies [19, 20]. Chan and associates noted that such need arises because teaching about bereavement care is insufficient in nursing education and organisational training [21]. This echoed with Liu et al. suggestion that continual training should be provided to oncology nurses to improve their knowledge, attitudes and skills in providing informational, emotional and practical support [22].

The limitations of this study should be acknowledged. All family informants were recruited from one oncology unit only, so that the experience of bereavement care in this sample may be relatively homogenous. In addition, the perception shared by the nurse informants might be similar because all of them were female and worked in the same unit. Further study is needed to understand the perspectives and experiences of family members and nurses in different hospitals.

Conclusion

This study used a qualitative approach to examine the experience and perception towards bereavement care both of oncology nurses and bereaved family members. It was found that the bereaved family members were in need of being informed, being supported and being with the patient. In response to those needs, nurses are committed to good bereavement care, but they also expressed their own emotional needs and educational needs in support of its provision.

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