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Grief reactions of family members after the death of cancer patients: a phenomenological study

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ABSTRACT

Introduction. The death of a family member due to cancer is one of the most stressful events of life. The purpose of the present study was to investigate lived experiences of family members grieving after the death of their relatives from cancer in Iran.

Material and methods. A phenomenological study was performed. The seven-stage process of data analysis was employed. The study was conducted in two hospitals that have oncology wards in Tehran, Iran. We interviewed 14 bereaved family members. Participants went through semi-structured, in-depth, and face-to-face interviews.

Results. Study participants' lived experiences were classified into 2 main themes including 'grief management' and 'evaluating death'. 'Grief management' had two subthemes: 'cultural adaptation to death' and 'emotional reactions'. 'Evaluating death' also had two subthemes: 'good death' and 'bad death'. One constitutive pattern `families' effort to accept the cancer patient's death' was identified.

Conclusions. According to our findings, family members of cancer patients require more supportive programs such as supportive care. Our study indicated the need for culture-based care for the bereaved family members of cancer patients.

Key words: cancer, death, family, phenomenological study, supportive care

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Introduction

In 2020, 1,806,590 new cancer cases and 606,520 cancer deaths are projected to occur in the United States [1]. In Iran, cancer is the third common cause of death, after heart disease and road accidents [2]. The death of a family member due to cancer is one of the most stressful events of life [3]. In other words, the death of a family member is identified as an emotional crisis in life [4]. Many family members of cancer patients experience a major emotional imbalance after the death of a loved one [5]. When a patient is dying due to cancer, family members often put their lives on hold to give comprehensive care [6]. Bereaved family members of cancer patients have a lower health-related quality of life than the other people [7]. Therefore, the concept of bereavement in cancer is affected by a group of elements, including health concerns, social considerations, and family interactions [8].

A wide range of studies about bereaved family members has been published. According to the findings of a study in Denmark, relatives of terminally ill patients reported functional impairment at 6 months after bereavement [9]. Results of another study in Belgium demonstrated that the first moments of bereavement included feelings of disbelief, regret, and relief. Also, loneliness is considered a dominant feeling throughout the bereavement period [10]. The results of a study

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in Ireland indicated that factors that have a positive influence on bereavement among family carers of patients who died of cancer included patients having no preference for place of death and carers remaining in employment pre- or post-bereavement [11]. According to the findings of a British study, bereaved individuals reported a predominance of negative and upsetting memories and more negative intrusive imagery [12]. It seems that a complex of factors influences family members' experiences.

Reviewing the literature, we found that there is a lack of qualitative studies regarding the lived experiences of bereaved family members of cancer patients in the Iranian context. Respect for bereaved family members seems to be very important in Iranian culture. However, there are limited studies of bereaved families in this regard. Thus, it is important to comprehend the lived experiences of this group, as well as identify the bereaved family members' feelings and beliefs. Since the death of cancer patients can culturally affect family members, it is necessary to continue developing studies that evaluate and deepen our knowledge from the families' lived experiences. The present study aimed to explore the lived experiences of family members about grief reactions to cancer patient's death in Iran. Results of this study can promote awareness and respect for the opinions of families toward the death of cancer patients in clinical settings in end-of-life care.

Material and methods

The phenomenological methodology of the study was used to develop an understanding of the lived experiences of the individuals who have experienced the death of a patient. This is a good methodology for the study because the phenomenological approach can provide an answer to a research question that seeks to comprehend how people experience a common phenomenon [13]. This study was performed using a hermeneutic phenomenological approach. It assists us in evaluating the meaning of 'being in the world' [14]. Thus, contributing to the lived experiences of family members is a way of 'being in the world'. Furthermore, the hermeneutic approach in the present study would permit family members to concentrate on their lived experiences through an explanation of their individual experiences of cancer patients' death.

The study was conducted in two hospitals that have oncology wards in Tehran, Iran. Referring to the hospitals' and patients' documents, 14 bereaved close family members of cancer patients were identified. We employed a purposeful maximum variation sampling. The inclusion criteria specified that individuals must (a) be at least 12 months past the death of a cancer patient, (b) be young adult age or older and (c) receive no psychotropic drugs. Thanks to head nurses' coordination with the medical records unit, the families' phone numbers were obtained and the families were contacted. The participants were called by the second author. Accompanied by a letter including some information about the aim of the study, the interviews were done by the authors over 3 months (Oct-Dec 2019). The main criterion for inclusion was the experience of a cancer patient's death.

Of the 14 participants, there were 9 females and 5 males. The family members were aged from 19 to 60 years old. Eight of the participants were married; the rest were single. Four participants had a university education, seven of them had completed secondary education and three participants had lower than secondary education. Regarding the type of their relatives' cancers, 6 patients had breast cancer, 5 hematologic cancer, 2 colorectal cancer, and 1 patient had prostate cancer. The deceased relatives were mothers, husbands, brothers, or sisters of the participants.

We performed face-to-face, semi-structured interviews, lasting 55–65 minutes. The interviews were flexible enough to be conducted in a comfortable place based on participants' requests. Most participants preferred to be interviewed at home. Because of it, most of the interviews were conducted in private at their home. Since 2 participants were interviewed twice, a full number of 16 interviews were conducted. Each interview was transcribed word for word. The interviews were continued until no new data appeared. Data saturation was obtained after all the interviews. Our interviews were carried out using the opening question 'What is the meaning of grief for a bereaved family member of a cancer patient?' After they responded to the main question, additional questions were asked to gain more data, such as: 'Could you clarify this further?', 'What is the meaning of that idea?', and 'Could you please provide me an example to assist us in comprehending your point of view?'

The data gathering was performed after obtaining signed informed consent outline from the family members. Following all interviews, the researcher conversed with the family members about neutral topics to decrease any emotional distress that may have occurred that was related to the talk about death.

Data gathering and analysis occurred in parallel. Teamwork was used in our study to analyze the data. In this regard, we performed the seven-phase method of data analysis [15].

Stage 1: The authors read each interview transcript to gain an overall understanding of it.

Stage 2 and 3: Probable common meaning units were then recognized, using extracts for clarification. The authors frequently listened to the tape recordings to abstract the accurate meaning of the data.

Stage 4: The research group assessed their explanations for similarities and differences, getting more clarification and agreement by reconsidering the main transcript.

Stage 5: All transcripts were then reviewed to confirm emergent themes. Next, the emerging themes were categorized by the research team.

Stage 6: A constitutive pattern was identified that showed the connection between themes and subthemes.

Stage 7: The authors created a final report, including quotes that were permitted for confirmation by the reader.

The rigor of this study is assessed by 4 criteria: credibility, dependability, confirmability, and transferability [16]. To achieve credibility, authors' ideas were used in the interviews and data analysis. Interview transcripts, reduced meaning units, and themes were discussed by some family members. To determine data dependability, views of an outside viewer, who was a researcher familiar with the phenomenological approach and not a member of the research team, were used. There was an agreement on the findings. To obtain confirmability, all the procedures were documented, and a report was presented on the research progress. To obtain transferability, data gathered from 2 family members outside of the study who were in situations similar to those of the participants were discussed and confirmed.

This article is part of a research project with the number: IR.ZAUMS.REC.1399.350 approved by Zahedan University of Medical Sciences. The human subject protection committee at the ZAUMS approved this study. The study was conducted according to the criteria set by the declaration of Helsinki.

Results

Study participants' lived experiences were grouped into 2 main themes including 'grief management' and 'evaluating death'. 'Grief management' had two subthemes: 'cultural adaptation to death' and 'emotional reactions'. 'Evaluating death' also had two subthemes: 'good death' and 'bad death'. These themes reflected the meaning of cancer patient's death to our participants. The constitutive pattern of the study was families' effort to accept the cancer patient's death.

The study themes and the participants' views are explained below.

Grief management

This theme consisted of 2 subthemes: 'cultural adaptation to death' and 'emotional reactions'.

Cultural adaptation to death

The presence of the bereaved people in funeral and mourning ceremonies helped them to cope with grief. 'When my mother died, my attendance in different mourning ceremonies held on the third, 7th and 40th day after her death really helped me in dealing with it' [Participant (P) 6].

In addition, supporting a grieving person played an important role in adaptation. One of our participants expressed: 'When my husband died due to colon cancer, his family did not leave me alone. In fact, their support helped me to accept the reality of his death' (P3).

Some participants claimed that belief in death as an inevitable fact resulted in accepting the death of the patient. 'Death is a phase of our life process. When my son died, I told myself it was his destiny' (P10).

Moreover, reconciling oneself with the loss could be facilitated by visiting the grave. 'Date offerings, washing the gravestone of my father and leaving flowers on it are the things I do on Thursdays' (P14).

Emotional reactions

Generally, after loss, it can be hard to accept what happened and some participants had trouble believing that the loss really happened or even denied the truth. Below are some examples: 'In the hospital, when I heard that my father had died, I could not accept it and shouted angrily this can't be happening to me' (P9).

Furthermore, some families reacted to the death of a family member by bargaining with God. 'My daughter was really kind. When she died I complained to God, why my daughter should die while there are many bad and sinful people all over the world. She was really meek and her death was unfair' (P1).

A group of participants experienced shock and disbelief after loss. One participant said: 'chemotherapy was not effective for my brother. After his shocking death, I experienced sleep and appetite disturbances and lack of concentration' (P5).

Evaluating death

The main theme 'evaluating death' included two subthemes: 'good death' and 'bad death'.

Good death

It seems that some factors such as providing ongoing support to grieving families and the patient receiving narcotics resulted in the death being evaluated as an easy going out of the world. 'My sister experienced a good death. All family members took care of her and met her needs. We wanted to help her enjoy the last days of life' (P11).

'My father experienced severe pain. Receiving narcotics was effective in him having a good death' (P8).

Also, the participants mentioned the death at home as a good experience because of the opportunity of providing care to the patient in the last hours of his/her life: 'My husband died at our home. Despite many bad

memories, I have good memories of his presence at our own house in the last moments' (P2).

Bad death

According to our participants, one factor which played an important role in evaluating death as a bad experience was dying in the prime of life which resulted in depression of family members: 'My young brother died from Leukemia, his death was really difficult and resulted in depression of my parents' (P12).

Grieving people mentioned death as a bitter experience because it prevented the deceased from fulfilling his/her wishes: 'My mom wished to celebrate the wedding party of her children and have grandchildren… it is a sad fact' (P4).

In addition, some participants experienced death as a catastrophic event. One of them stated that: 'When I was a child, my mother died in an accident and my sister played the role of a mother for us… her death due to breast cancer was really tragic … I feel alone' (P7).

The constitutive pattern: families' effort to accept the cancer patient's death

In the social context of Iran, families manage grief based on cultural adaptation to death and emotional reactions, but on the other hand, they experience it as an inevitable stage in life.

Discussion

The experiences of the participants showed that they have grief reactions regarding the death of cancer patients. The perspective on death among individuals with diverse socio-cultural contexts has key differences. Since death is an important part of life, understanding this phenomenon is essential. On the whole, cultural adaptation to death was a strategy to deal with grief in the families of cancer patients. They believed that being offered support was a key factor that led to acceptance. Results of a study carried out in Taiwan indicated that providing support to caregivers of cancer patients results in a shorter grieving process [17]. Iranian people often meet the family of the deceased in the period following the death.

Appropriate care after the cancer patient's death is needed to facilitate family members' acceptance of the loss of their relative. Also, some participants accepted death as a part of life that stems from destiny. Results of research in Lithuania demonstrated that people who had accepted death as a part of life showed fewer grief symptoms [18]. In the Islamic culture of Iran, Islam deliberates remembrance of death as a part of life journey. Thus, people are created for a life duration, and death is a part of the contract with God. Considering several rituals in the 3rd, 7th, and 40th days after death in Iran, the presence of the bereaved in funeral and mourning rituals for the deceased had a positive effect on the cultural adaptation to death. In Iranian culture, the mourning period officially lasts for 40 days. Also, visiting the place where the body is buried, on Thursdays, could facilitate acceptance of the reality of the loss. Thus, health professionals should be aware of the diversity of cultural values surrounding death and assess the values of cancer patients' families. In Iranian culture, bereavement is an element of death, so expressing sadness is suitable in prescribed ways [19].

On the other hand, some participants refused to accept the death of their relatives and experienced severe distress and anger. Results of the study in Taiwan showed that bereaved families of cancer patients had experienced severe distress [20]. In this regard, a multicenter survey of bereaved families in Japan showed that family distress was experienced when the physician stated that nothing could be done for the patient [21]. In this study, death has been a serious challenge for family members. In this situation, people started bargaining with God as a way to manage grief. In addition, death was a shocking event for them which resulted in sleep and appetite disturbances, lack of concentration, and confusion. This is consistent with the results of a systematic review that said people experienced sleep disturbances and anxiety in confrontation with death [22]. As several families experienced a psychological crisis when their relatives died, the psychological context of bereavement for family members is uniquely challenging and must be considered when providing care. Generally, our findings demonstrated that participants have experienced death as an inevitable stage in life. Bereaved families believed that taking care of patients, meeting their needs, and helping them to enjoy the last days of life resulted in a good death. According to American study, care for terminal phase of cancer patients was categorized into some themes such as support of daily life [23]. Moreover, based on the experiences of bereaved families, narcotics resulted in the good death of patients. Results of a study on cancer patients in Belgium showed that sedation was a key factor in a good death [24]. In addition, the results of another study demonstrated that reducing the pain of cancer patients helped them to enjoy their final phase of life [25].

Another factor that caused the good death of the patients was the death at home. To provide care to the patients at home and the opportunity to say goodbye to family was valuable for the patients and helped them to have a good death. Results of a study carried out in Norway showed that bereaved family members of cancer patients preferred to provide care to the patient and experience his/her death at home [26]. On the other hand, some of our participants had a negative evalua-

tion of death because it resulted in the depression of bereaved families, prevented patients from fulfilling their dreams, and deprived the survivors of the support of the deceased. A study in Germany showed that family caregivers of cancer patients had experienced depression at the final phase of life and after the death of their patients [27].

In general, the results of this study showed that there are cultural customs related to mourning ceremonies and grief reactions in Iran. Given that the results of the present study highlighted the role of culture in the lived experiences of bereaved family members about cancer patient's death, further studies are recommended with an ethnographic approach to explain how the culture of family members influences this phenomenon. It is also recommended that studies with an action research approach should be conducted to address the problems caused by this phenomenon.

This study had some limitations as well. The small participant size and the nature of the phenomenological research restricted the ability to generalize the results. However, as with all qualitative research, the findings were not intended to be generalized.

Conclusions

This study highlighted reactions to grief of bereaved families of cancer patients and their need for psychological support during the bereavement period. Understanding the bereaved family's lived experiences can lead to the development of psychological approaches to relieve their grief reactions. The findings of our study indicated the need for culture-based care and supportive services for the bereaved family members in Iran. Oncology nurses should assess the effect of death and the cultural background of the families. They should focus more attention on this vulnerable group. According to the findings, oncology nurses can design a care model for these families, which includes cultural elements for caring for bereaved families.

Conflicts of interest

There are no conflicts of interest.

References

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2020. CA Cancer J Clin. 2020; 70(1): 7–30, doi: 10.3322/caac.21590, indexed in Pubmed: 31912902.
2. Kalan Farmanfarma K, Mahdavifar N, Hassanipour S, et al. Epidemiologic Study of Gastric Cancer in Iran: A Systematic Review. Clin Exp Gastroenterol. 2020; 13: 511–542, doi: 10.2147/CEG.S256627, indexed in Pubmed: 33177859.
3. Sharp KM, Lindwall JJ, Willard VW, et al. Cancer as a stressful life event: Perceptions of children with cancer and their peers. Cancer. 2017; 123(17): 3385–3393, doi: 10.1002/cncr.30741, indexed in Pubmed: 28472536.
4. O'Sullivan A, Alvariza A, Öhlen J, et al. Bereaved Family Members' Satisfaction with Care during the Last Three Months of Life for People with Advanced Illness. Healthcare (Basel). 2018; 6(4), doi: 10.3390/healthcare6040130, indexed in Pubmed: 30404147.
5. Van Hout E, Peters S, Jansen L, et al. An exploration of spousal caregivers' well-being after the death of their partners who were older cancer patients - A phenomenological approach. Eur J Oncol Nurs. 2020; 47: 101779, doi: 10.1016/j.ejon.2020.101779, indexed in Pubmed: 32559712.
6. Galloway T, Horlick S, Cherba M, et al. Perspectives of Nunavut patients and families on their cancer and end of life care experiences. Int J Circumpolar Health. 2020; 79(1): 1766319, doi: 10.1080/22423982.2020.1766319, indexed in Pubmed: 32449489.
7. Wen FH, Chou WC, Chen JS, et al. Associations of preloss and postloss factors with severe depressive symptoms and quality of life over the first 2 years of bereavement for family caregivers of terminally ill cancer patients. Psychooncology. 2019; 28(11): 2157–2165, doi: 10.1002/pon.5201, indexed in Pubmed: 31418502.
8. Pottle J, Hiscock J, Neal RD, et al. Dying at home of cancer: whose needs are being met? The experience of family carers and healthcare professionals (a multiperspective qualitative study). BMJ Support Palliat Care. 2020; 10(1): e6, doi: 10.1136/bmjspcare-2016-001145, indexed in Pubmed: 28093387.
9. Nielsen MK, Christensen KS, Neergaard MA, et al. Exploring Functional Impairment in Light of Prolonged Grief Disorder: A Prospective, Population-Based Cohort Study. Front Psychiatry. 2020; 11: 537674, doi: 10.3389/fpsyt.2020.537674, indexed in Pubmed: 33362592.
10. Van Hout E, Peters S, Jansen L, et al. An exploration of spousal caregivers' well-being after the death of their partners who were older cancer patients - A phenomenological approach. Eur J Oncol Nurs. 2020; 47: 101779, doi: 10.1016/j.ejon.2020.101779, indexed in Pubmed: 32559712.
11. Roulston A, Campbell A, Cairnduff V, et al. Bereavement outcomes: A quantitative survey identifying risk factors in informal carers bereaved through cancer. Palliat Med. 2017; 31(2): 162–170, doi: 10.1177/0269216316649127, indexed in Pubmed: 27170617.
12. Smith KV, Rankin H, Ehlers A. A qualitative analysis of loss-related memories after cancer loss: a comparison of bereaved people with and without prolonged grief disorder. Eur J Psychotraumatol. 2020; 11(1): 1789325, doi: 10.1080/20008198.2020.1789325, indexed in Pubmed: 33062204.
13. Creswell JW. Qualitative inquiry and research design: Choosing among five designs. Thousand Oaks, CA: Sage 1998.
14. Heidegger M. Being and Time. Translated by Macquarie & Robinson, 1st ed. Basil Blackwell, Oxford 1962.
15. Diekelmann N, Allen D, Tanner C. The NLN Criteria for Appraisal for Baccalaureate Programs: A Critical Hermeneutic Analysis. National League for Nursing, New York 1989.
16. Lincoln YS, Guba EG. Naturalistic Inquiry. Sage Publications Inc, London 1985.
17. Tsai WI, Prigerson HG, Li CY, et al. Longitudinal changes and predictors of prolonged grief for bereaved family caregivers over the first 2 years after the terminally ill cancer patient's death. Palliat Med. 2016; 30(5): 495–503, doi: 10.1177/0269216315603261, indexed in Pubmed: 26311571.
18. Gegieckaite G, Kazlauskas E. Fear of Death and Death Acceptance Among Bereaved Adults: Associations With Prolonged Grief. Omega (Westport). 2022; 84(3): 884–898, doi: 10.1177/0030222820921045, indexed in Pubmed: 32326832.
19. Edalati A. Hooshmand Abarkouhye N. Death in Iranian Culture (A Case Study of Abarkouh, Yazd). Int Rev Soc Sci Humanit. 2012; 2: 200–202.
20. Wen FH, Chou WC, Shen WC, et al. Distinctiveness of prolonged-grief--disorder- and depressive-symptom trajectories in the first 2 years of bereavement for family caregivers of terminally ill cancer patients. Psychooncology. 2020; 29(10): 1524–1532, doi: 10.1002/pon.5441, indexed in Pubmed: 32539210.
21. Yamagishi A, Morita T, Kawagoe S, et al. [Talking about home hospices with terminally ill cancer patients -- a multicenter survey of bereaved families]. Gan To Kagaku Ryoho. 2015; 42(3): 327–333, indexed in Pubmed: 25812502.
22. Lancel M, Stroebe M, Eisma MC. Sleep disturbances in bereavement: A systematic review. Sleep Med Rev. 2020; 53: 101331, doi: 10.1016/j.smrv.2020.101331, indexed in Pubmed: 32505968.

23. Lavalley SA. Caregiver informational support in different patient care settings at end of life. Home Health Care Serv Q. 2018; 37(2): 97–112, doi: 10.1080/01621424.2018.1438951, indexed in Pubmed: 29424667.
24. Robijn L, Chambaere K, Raus K, et al. Reasons for continuous sedation until death in cancer patients: a qualitative interview study. Eur J Cancer Care (Engl). 2017; 26(1), doi: 10.1111/ecc.12405, indexed in Pubmed: 26515814.
25. Yamanaka M. A Concept Analysis of Self-Management of Cancer Pain. Asia Pac J Oncol Nurs. 2018; 5(3): 254–261, doi: 10.4103/apjon.apjon_17_18, indexed in Pubmed: 29963587.
26. Fjose M, Eilertsen G, Kirkevold M, et al. "Non-palliative care" - a qualitative study of older cancer patients' and their family members' experiences with the health care system. BMC Health Serv Res. 2018; 18(1): 745, doi: 10.1186/s12913-018-3548-1, indexed in Pubmed: 30268149.
27. Oechsle K, Ullrich A, Marx G, et al. Prevalence and Predictors of Distress, Anxiety, Depression, and Quality of Life in Bereaved Family Caregivers of Patients With Advanced Cancer. Am J Hosp Palliat Care. 2020; 37(3): 201–213, doi: 10.1177/1049909119872755, indexed in Pubmed: 31596115.