## **ORIGINAL ARTICLE**

Received: February 2014 Accepted: September 2014

# Concept Analysis of Family-centered Care in Cancer Using Hybrid Model: A Qualitative Study

Naimeh Seyedfatemi<sup>1</sup>, Marjan Mardani Hamooleh<sup>2,\*</sup>, Leili Borimnejad<sup>1</sup>, Mamak Tahmasebi<sup>3</sup>

# ABSTRACT

**Background:** Family-centered care is an essential concept in cancer but there is no consensus about its meaning and it remains an abstract concept. This study was conducted with the purpose of analyzing the concept of family-centered care in cancer.

*Methods:* Concept analysis of family-centered care was conducted using hybrid model that has 3 phases: theoretical, field work and final analytical phase. For the theoretical phase attributes of family-centered care were identified through a review of the literature (without time limitation). In second phase 6 nurses were interviewed. In third phase final analysis were extracted from the first and second phase.

**Results:** In general, original categories in the family-centered care context encompass; existence of family in clinic, family security and family support, communication between nurse and family, family participation in care, exposure to tension and family participation in decision making.

*Conclusion:* By identifying the facilitating and preventive factors about the concept of family care center in cancer, we will be able to run our activities based on scientific findings which could provide the necessary conditions for good implementation of family care center in cancer.

Keywords: Cancer, Concept analysis, Family-centered care, Hybrid model.

14

 Center for Nursing Care Research, Faculty of Nursing and Midwifery, Iran University of Medical Sci<sup>-</sup>ences, Tehran, Iran.

2. Faculty of Nursing and Midwifery, Iran University of Medical Sci-ences, Tehran, Iran.

3. Cancer Research Center, Cancer In¬stitute, Tehran University of Medical Sciences, Tehran, Iran.

#### \*Corresponding Author:

Marjan Mardani Hamooleh, Faculty of Nursing and Midwifery, Iran University of Medical Sci¬ences. Zafar Str, Vanak Sq, 1419733171, Tehran, Iran. Email:mardanimarjan@gmail.com



# Introduction

hronic disease such as cancer is one of the major causes of death in the world. Cancer occurrence in Iran is about 48 to 112 cases per million for females and 51 to144 cases per million for males.1 Cancer patients are unable to continue their lives as it used to be and the appearance of problems in all aspects of personal, familial, and social life eventually leads the quality of life to decrease.<sup>2</sup> Caring for cancer patients is one of the most challenging issues in nursing and family is a key part in appropriate caring for these patients. In family-centered approach it would be possible that family members try to hide final diagnosis from the patient and look at it as selfsacrifice to avoid stress in family.<sup>3</sup> Disease of a family member could affect all family. However, cancer patients would make changes in the family system and sometimes their special needs make caring services unpredictable in meeting their needs especially to support families. Therefore, the family will confront difficulties during hospitalization of the patient.<sup>4</sup> Moreover, family relationships would be different after cancer because of having degrees of dependence which limits his/her personal interactions with others. Thus, this group of patients need cares such as family-centered care.3 In fact, family structure affects severity of problems which the patient confronts and family attention has an important role in preservation mental stability and adaptation to the disease so the patients would experience less tension. Therefore, nurse should not neglect family needs when determine caring needs of patients especially when family is responsible for caring.<sup>4</sup> Meanwhile, it seems that family-centered care is a key element in nursing which is still not completely known.<sup>5</sup>

Sweden has assimilated more than 1.2 million immigraSince there has been no agreement on meaning of family-centered care it is necessary to know and clarify this concept.<sup>6</sup> Really, concept analysis is a valuable method to clarify nursing concepts with the purpose of finding attributes out to clarify concept in nursing.<sup>7</sup> In addition, describing concepts would lead to reveal meaning and promote theory development in nursing.<sup>8</sup>

In the meantime, role of nurses as a main supporter for family members of cancer patients make their view about the concept of family-centered care important.<sup>9</sup> Considering importance of family care, different ability of families in caring and tolerating disease-related problems, lack of enough studies on cancer patients' family-centered care in our country and its clarification, this study was conducted to clarify this concept in nurses' point of view. Regarding lack of the concept analysis in socio-cultural context of Iran, carrying out a research in this field seemed appropriate because family-centered care in cancer is affected by cultural context and its differences. This study was conducted with the aim of analyzing the concept of familycentered care in cancer using hybrid model.

# **Material and Methods**

In this qualitative research, concept analysis was performed using the hybrid model. It is one of the conceptualization, concept involution, and theory development methods, which is used to modify the abstract concept in nursing. In other words, it is especially valuable in studying significant and central phenomena in clinical nursing. This model merges theoretical analysis with empirical observations and emphasizes on important aspects of the definition and measurement.<sup>10</sup> Since this study aims to show essential characteristics of definition and measurement of family-centered care in cancer, the hybrid model of concept analysis would be the best method to choose. The method of the hybrid model is oriented toward developing concepts through a qualitative analysis using participant observation and interviews of phenomena taking place in situ. This model is composed of 3 phases including theoretical, fieldwork, and final analysis phase. In this research, the 3 phases for concept analysis of family-centered care in cancer were used as follows.

To review studies in the theoretical phase, articles published in "family-centered care in cancer" were sought using websites such as Ovid, Pub Med, and SID with key words "Cancer" and "Family centered care" in the title and abstract without time limitation. To search the articles, manual search method is used, too. In reviewing of studies, all the articles with the above mentioned keywords were first sought. Then, articles focusing on the family-centered care were selected. Field work phase started with data gathering. In this phase, data are gathered through face to face interviews. The interview conducted with 6 nurses working in cancer wards of the one educational hospital. In this study, sampling was done from nurses to the point of data saturation. The interviewees scrutinized the informed consent forms. Nurses were offered some information about their freedom of choice to either participate or leave the research at any moment, and finally, the permission for recording their voice was acquired. To respect privacy of the information, participants' names were removed. Data were analyzed by content analysis approach. Finally, categories and sub categories were obtained. To determine data dependability, findings are constantly compared. In the final analytical phase, the categories emerged from fieldwork were compared and contrasted with the data from theoretical phase and combined as clusters for a thorough analysis.

#### Theoretical phase

This phase starts with a concept selection. Review of studies not only causes more searches for concept of family-centered care, but also considers its usability as a key concept in cancer. Review of the literature : In South Korea researchers suggested a framework to concentrate on family based on family-centered care in families with special educational needs which some factors such as information exchange, understanding cultural differences, family needs for educational, emotional and financial support were considered.<sup>11</sup> In Cyprus, researchers emphasized some points in concept analysis of family-centered care including evaluation of family members' roles, evaluation of the family in its own context, involving first caregiver in care design and evaluation, and continuing support to the family after clearance.12

Houldin introduced family-centered care as a comprehensive approach and another study introduced this concept as a philosophy which supports patients in their caring roles.<sup>13, 14</sup> Family-centered care was regarded as a way to prevent or reduce patient's stress.<sup>15</sup> Researchers mentioned wide application of family-centered concept while reviewing qualitative studies in caring for patients.<sup>16</sup> Findings of a study in Spain revealed that family-centered care concept is correlated to nurses, family and relatives of the patient.<sup>17</sup> Iranian researchers in a study stated that empowerment of patient caregivers' leads to raising their awareness, perception and skill and assist them in efficient and effective caring and end up in improvement of their caring role.<sup>18</sup> Grinyer in a study to investigate family view about caring for patient remarked that identifying and managing conflicts about disease by family members of cancer patient would help them to confront crisis caused by disease diagnosis.<sup>19</sup>

Considering determined attributes for family-centered care its operational definition involves collaboration of patient's family and health care professionals which needs supporting families by caring staff such as nurses to promote caring quality.

#### Field work phase

In this phase the data were collected via semi-structured and in-depth interviews with 6 nurses with an average time of 40 minutes for each one. Participants were bachelor of nursing with 3 years working background in caring for cancer patients. Some interview questions included: what's your description of family-centered care as a nurse? What should family members do for health promotion of the patient? What are contributing factors in family-centered care? What are inhibitor factors in family-centered care? What are outcomes of family-centered care? In this study interviews were analyzed via constant comparison qualitative data analysis.

## Results

Finally, 155 primary codes were extracted which lead to formation categories and subcategories. The categories included existence of family in clinic, family security and family support, family participation in care, communication between nurse and family, exposure to tension and family participation in decision making.

## Existence of family in clinic

Results showed that majority of families have mentioned family members presence at patient's beside as one of effective categories on family-centered care which includes presence of main family members and relatives of patient as subcategories.

"Several references to hospital make cancer patients impatient so accompanying a main family member could help the patient in fast adaptation to the disease" (Participants2).

"Sometimes presence of relatives like uncle, aunt or

others at patient's beside help the patient in caring and raise him/her satisfaction"(P4).

#### Family security and family support

Family security and support is another main category which included subcategories of spiritual and financial support.

"Counseling services for resolving family problems of the patient is considered as a spiritual support for the family to improve their caring" (P1).

"Regarding high expense of cancer patients, family financial support would lead to benefit from high quality care"(P6).

#### Communication between nurse and family

Communication between nurse and family was another category which was included subcategories of patient condition improvement and care coordination.

"Appropriate communication between nurse and family could cause improvement in cancer trend" (P3).

"Effective communication between nurse and family would lead to care coordination" (P5).

## Family participation in care

Family participation in care was a main category with subcategories of being beneficial of family for the patient and family participation in patient's clearance.

"Family participation in care is appropriate when could offer qualitative and beneficial care" (P1).

"Family participation means that family members could do the best care for the patient and prepare a condition for patient's clearance at the determined time"(P3).

#### Exposure to tension

Exposure to tension included difficulty in caring and family impressionability from disease.

"Concerning special difficulties in caring for patients, family members will be exposed to tension" (P4).

"Caring for patients affects personal life of caregivers as a source of tension" (P2).

#### Participation in decision making Family

Another category obtained from statements of partici-

pants was family participation in decision making which included appropriate care organizing and family members' satisfaction.

"Family participation in making patient-related decisions, organizes care in an appropriate way" (P6).

"Family participation in decision making increases their care satisfaction" (P5).

#### Final analytical phase

In this phase, considering results of previous phases, final description of the concept was represented: familycentered care in cancer is appealed by family collaboration with care professionals, family presence at patient's beside and family participation in making patient-related decisions. In this care, family will be exposed to tensions therefore family security and support is needed to promote care quality.

## Discussion

This study carried out to clarify family-centered care concept for cancer patients. This concept includes collaboration of family with health care professionals, family support by care staffs such as nurses and family participation to promote care quality which are all involved in mentioned categories. However, one of obtained categories was family presence at patients beside. Generally, a purpose of family-centered care is empowerment's promotion of family members in special fields to overcome obstacles in patient's health via continuous presence of family at patients beside.<sup>19</sup> In addition, patients value family-centered care and expect families to attend at their beside and answer their questions carefully and patiently.<sup>20</sup> It seems that family-centered care is a caring way with the presence of family members which forms care philosophy, programs and daily contractions of the patients and their families.

This study showed necessity of family security and support. On one hand, family-centered care have some benefits for families such as giving continuity to family relationships, gaining skill and merit to caring for patient and on the other hand, there are also some benefits for the patient such as feel secure.<sup>21</sup> Moreover, spousal support is also mentioned as an effective factor to reduce interpersonal conflicts in relationship with patient and empower him/her more in confronting disease.<sup>22</sup> Results of a study in Iran revealed that family members and spouse are the most important supporters for cancer patients.<sup>23</sup> Another study showed that cancer patient's family needs in caring and its continuity and spiritual needs are neglected. <sup>24</sup> In a study researcher stated that family members feel lonely in caring for patient which end up in dissatisfaction of present situation and affect their view based on lack of nurses' support.25 One of main categories was communication between nurse, family and patient, so family care is related to factors like relationship of family members.<sup>26</sup> A study in Japan showed that the most important problems in cancer patients are related to family members' relationships, patient's isolation and hopelessness.<sup>27</sup> Results of another study mentioned problems of family members in relationship with patient and confronting the disease.<sup>28</sup> Findings of a study revealed that although family-centered care contribute to family members and nurses in decision making, but lack of effective relationship of them, professional communications and issues such as power would be an obstacle in nurses and family members collaboration.29

Therefore, nurses should try to promote patient's health through a relationship with the family, responsibility and mutual collaboration of nurses and patient's family members.

Concerning family participation in caring a study in Japan revealed the relationship of the concept familycentered care and family participation in caring with effort to reduce patient's agony, family education about care and allow family to express its discomfort.<sup>30</sup> Really, family-centered care is a subjective concept which implicates family participation in caring.<sup>31</sup> Besides family participation in caring family-centered care needs time and ability to educate and observe family function in caring for patient. However, independence of the patient is also mentioned in family-centered concept.3 Therefore, family needs correct understanding from disease and nurses should contribute to raise hope and confidence in family which ends up in promotion of family health and welfare. Exposure to tension was a main category of the concept. Observing a family member in a critical situation would be a stressor for family.29 Researchers revealed that patient's family confronts numerous stressors in caring period which causes physical and mental reactions in them. In addition, factors such as giving appropriate information, religious beliefs and meeting family needs are effective in making family more patients in caring. Therefore, appropriate communication with patient and family caregivers plays an important role in caring team planning.<sup>32</sup> Families considered tension adaptation and confronting change and loss in family-centered concept. In fact, caregivers become vulnerable when find patient's caring needs higher than their own ability and supportive resources so not only looked at a situation as a stressor but also their mental health will be endangered.<sup>33</sup>

Generally, cancer patients need constant caring in a way which family is more responsible for caring and it causes severe limitations and concerns for families. Hence their view and way of confronting patient affects their health. In the meantime meeting patient's needs causes stress for family members and presence of supportive people would lead to their stress reduction. Moreover, numerous difficulties of cancer disease sometimes make family to withdraw from the patient so supportive resources such as nurses play an important role family members' empowerment. Furthermore, patient's family has ability to learn caring principles and it reduces their anxiety so nurses should educate families at the time of patient's hospitalization.

Concerning family participation in decision making knowledge, awareness, understanding the dander of cancer, cultural, economical and social factors are valuable elements to promote efficient caring strategies.<sup>31</sup> However, nurses are able to prepare knowledge, skill and required support for patient's family to motivate them for participation in making decisions about home care.<sup>25</sup> Regarding cancer chronicity, rise of cancer patients and high treatment expenses family participation in decision making is so important and lead to their efficacy in care and fast adaptation of the patient with the disease.<sup>30</sup>

Consequently, family as an informal system confronts different problems during all disease phases which would affect its daily function and next decisions about caring for the patient so it is necessary for nurses to pay more attention to cancer patient's family and preserve effective communication with the family via family-centered education and continuous visit of patient's at home after clearance. Also introducing supportive resources to the family contribute to tension adaption and changes resulted from the disease. Finally, it is suggested that next studies carry out family-centered concept analysis from patient's point of view.

#### Acknowledgement

The authors are grateful to all of the nurses who participated in this study. Without their help and cooperation, this research could not have been conducted.

# References

1. Mousavi SM, Pourfeizi A, Dastgiri S. Childhood cancer in Iran. J Pediatr Hematol Oncol 2010;32: 376-82.

2. Borimnejad L, Mardani Hamooleh M, Seyedfatemi N, Tahmasebi M. Human relationships in palliative care of cancer patient: lived experiences of Iranian nurses. Mater Sociomed 2014; 26:35-8.

3. Landier W. Adherence to oral chemotherapy in childhood acute lymphoblastic leukemia: an evolutionary concept analysis. Oncol Nurs Forum 2011; 38(3):343-52.

4. Hendrickson K, McCorkle R. A dimensional analysis of the concept: good death of a child with cancer. J Pediatr Oncol Nurs 2008; 25(3):127-38.

5. Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. Eur J Cancer 2008; 44(10):1414-24.

6. Duggleby W, Holtslander L, Steeves M, Duggleby-Wenzel S, Cunningham S. Discursive meaning of hope for older persons with advanced cancer and their caregivers. Can J Aging 2010; 29(3):361-7.

7. Longo CJ, Bereza BG. A comparative analysis of monthly out-ofpocket costs for patients with breast cancer as compared with other common cancers in Ontario, Canada. Curr Oncol 2011; 18(1):1-8.

 Rodgers BL, Knafl KA. Concept development in nursing: foundation, techniques and application. Philadelphia. W.B. Saunders; 2000.

9. Choi M, Bang K. Quality of pediatric nursing care: concept analysis. J Korean Acad Nurs 2010; 40(6):757-64.

10. Schwartz-Barcott D, Kim HS. An expansion and elaboration of Hybrid model of concept development. In: Rodgers BL, Knafl KA, editor. Concept development in nursing: foundation, techniques, and application. 2 ed. Philadelphia, London, Toronto, Sydney: W.B. Saunders Company; 2000.

11. Park SM, Kim YJ, Kim S, Choi JS, Lim HY, Choi YS, et al. Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. Support Care Cancer 2010; 18(6):699-706.

12. Papastavrou E, Charalambous A, Tsangari H. Exploring the other

side of cancer care: the informal caregiver. Eur J Oncol Nurs 2009; 13(2):128-36.

 Houldin AD. A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. Oncol Nurs Forum 2007; 34(2):323-30.

14. Shinjo T, Morita T, Miyashita M, Sato K, Tsuneto S, Shima Y. Care for the bodies of deceased cancer inpatients in Japanese palliative care units. J Palliat Med 2010; 13(1):27-31.

15. Splaine Wiggins M. The partnership care delivery model: an examination of the core concept and the need for a new model of care. J Nurs Manag 2008; 16(5):629-38.

16. Shields L, Pratt J, Hunter J. Family centered care: a review of qualitative studies. J Clin Nurs 2006; 15(10):1317-23.17. Alonso-Babarro A, Bruera E, Varela-Cerdeira M, Boya-Cristia MJ, Madero R, Torres-Vigil I, et al. Can this patient be discharged home? Factors associated with athome death among patients with cancer. J Clin Oncol 2011; 29(9):1159-67.

18.Valizadeh L, Zamanzadeh V, Rahmani A, Howard F, Nikanfar A. Cancer disclosure: experiences of Iranian cancer patients. Nursing and Health Sciences 2012; 14(2):250-6.

19. Grinyer A. Contrasting parental perspectives with those of teenagers and young adults with cancer: comparing the findings from two qualitative studies. Eur J Oncol Nurs 2009; 13(3):200-6.

20. Landier W. Adherence to oral chemotherapy in childhood acute lymphoblastic leukemia: an evolutionary concept analysis. Oncol Nurs Forum 2011; 38(3):343-52.

21. McIntosh J, Runciman P. Exploring the role of partnership in the home care of children with special health needs: qualitative findings from two service evaluations. Int J Nurs Stud 2008; 45(5):714-26.

22. Sun Y, Knobf MT. Concept analysis of symptom disclosure in the context of cancer. Adv Nurs Sci 2008; 31(4):332-41.

23. Rhee YS, Yun YH, Park S, Shin DO, Lee KM, Yoo HJ, et al. Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. J Clin Oncol 2008; 26(36):5890-5.

24. Heidari S, Salahshourian-fard A, Rafiee F, Hoseini F. Correlation of perceived social support from different supportive sources and the size of social network with quality of life in cancer patients. Iran J of Nurs 2009; 22(61):8-18. [Persian].

25. Choi ES, Kim KS. Experiences of family caregivers of patients with terminal cancer. J Korean Acad Nurs 2012; 42(2):280-90.

26. Harding R, Epiphaniou E, Hamilton D, Bridger S, Robinson V, George R, et al. What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. Support Care Cancer

#### 2012; 20(9):1975-82.

27. Carlander I, Sahlberg-Blom E, Hellström I, Ternestedt BM. The modified self: family caregivers' experiences of caring for a dying family member at home. J Clin Nurs 2011; 20(7-8):1097-105.

28. Miyashita M, Nakamura A, Morita T, Bito S. Identification of quality indicators of end-of-life cancer care from medical chart review using a modified Delphi method in Japan. Am J Hosp Palliat Care 2008; 25(1):33-8.

29. Spillers RL, Wellisch DK, Kim Y, Matthews BA, Baker F. Family caregivers and guilt in the context of cancer care. Psychosomatics 2008; 49(6):511-9.

30. Stajduhar KI, Martin WL, Barwich D, Fyles G. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. Cancer Nurs 2008; 31(1):77-85.

31. Shinjo T, Morita T, Hirai K, Miyashita M, Sato K, Tsuneto S, Shima Y. Care for imminently dying cancer patients: family members' experiences and recommendations. J Clin Oncol 2010; 28(1):142-8.

32. Mikkelsen G, Frederiksen K. Family-centred care of children in hospital - a concept analysis. J Adv Nurs 2011; 67(5):1152-62.

33. Nasrabadi A, Bahabadi A, Hashemi F, Valiee S, Seif H. Views of Iranian patients on life with cancer: a phenomenological study. Nursing and Health Sciences 2011; 13(2):216-20.