

Short Communication

End of life care for terminally ill-patients in North West of Iran

Hossein Jabbari¹, Elham Khanlarzadeh², Fariba Bakhshian³, Dawood Agha-Mohammadi⁴,
Narjes Habibmogaddam⁵, Zhila Khamnian*²

¹ Associate Professor, Department of Community Medicine, School of Medicine, National Public Health Management Center (NPMC), Tabriz University of Medical Sciences, Tabriz, Iran

² General Practitioner, Department of Community Medicine, School of Medicine, Tabriz University of Medical Sciences, Tabriz, Iran

³ Department of Midwifery, Medical Philosophy and History Research Center, Tabriz University of Medical Sciences, Tabriz, Iran

⁴ Associate Professor, Department of Anesthesiology, School of Medicine, Tabriz University of Medical Sciences, Tabriz, Iran

⁵ General Practitioner, School of Medicine, Tabriz University of Medical Sciences, Tabriz, Iran

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Abstract

Introduction: Nowadays chronic disease and number of elderly population climb in low and middle-income countries and need for high-quality hospice care services for them. The aim of this study was to review the experience of hospitalized end of life (EOL) patients and their family's regarding hospice care.

Methods: In this qualitative study with the phenomenological approach, 20 patients and their families were chosen using purposive sampling to achieve data saturation from the Tabriz University of Medical Sciences Hospitals, Iran. The required data were collected using in deep semi-structured interviews and analyzed using Diekelmann method.

Results: Patients and their family's experiences included 7 main themes: lack of special education for healthcare providers, preferences, financial problems, health care quality, lack of providing information to patients and their families, limitation in life due to disease, burdens to EOL care for family.

Conclusion: Due to the lack of experience in hospice care in Iran, patients, families and health care provider not have adequate knowledge about hospice. The cost of this service is high, and qualities of these services are low. Furthermore provide educational courses for patients, families and health care provider and decrease of cost and improve of quality are necessary.

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Introduction

Nowadays, the burden and death of end-stage disease as cancer in the worldwide context continues to grow, with an increasing number of accidents as external cause of death, especially in many developing countries.¹ Older people and patients with life-threatening conditions are missing out on vital care and access to palliative care services; thus this central concern, suggesting end of life (EOL) care and hospice in this country. It includes management of pain and other symptoms and provision of psychological,

social, spiritual and practical support.^{1,2}

Life-treating conditions in recent decades, especially in developing countries; however there is not a Comprehensive palliative care strategy to give everyone nearing the EOL access to high quality care.³ As this demographic transition, many older people are living with and dying from multiple chronic debilitating Hospice need to improve the quality-of-life for older people living with life-threatening illnesses, as well as their families and careers, by addressing their physical, psychological, social and spiritual needs.^{3,4}

* Corresponding Author: Zhila Khamnian, Email: zhila.khamnian@gmail.com

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Despite this growing need, 42% of countries still have no identified hospice and palliative care service, whereas 80% of people globally lack adequate access to medication for the treatment of moderate to severe pain. This means millions of older people, especially in the developing world, are living and dying in unnecessary pain and distress.^{5,6} Quality of death index provides a snapshot of the provision of EOL care (EOLC) in each country, including the access to hospice care, the level of government involvement and public awareness.⁷ Although palliative and hospice care share the same principles of comfort and support, but should be noticed that palliative care is different from hospice care.⁸

The "EOLC or hospice care" since 1979 has been provided by an interdisciplinary team of doctors, nurses, social workers, chaplains, home health aides and volunteers who understand that when it can't be about curing, it must be about caring. Indeed it has the same principles of comfort and support of palliative care, but Methodist hospice services as a form of palliative care are approaching the EOL that is given to a person who has a terminal diagnosis (usually defined as having a life expectancy of 6 months or less) and medical or surgical therapies are no longer controlling the disease.⁸

Despite the success of the hospice sector in many countries; in others such as Iran still there are many people who face the EOL without specialist care and support. Improving EOLC demands that first we know contextual needs; thus in this hermeneutic phenomenological study, we intend to review the experience of hospitalized life-treating patients regarding their spiritual needs, which is presented in the form of a constitutive pattern as the spiritual needs of hospitalized patients as experience end-stage disease in their daily lives that has been issued in the challengeable field of EOL in Tabriz, Iran.

Methods

This qualitative study was approved by the Ethics Committee at the Tabriz University of Medical Sciences and was Conducted using

interpretative phenomenological analysis. We selected 20 Interviews from Gazi hospital (n = 4), farmanfarmayan hospital (n = 3), Imam Reza hospital (n = 11) and (n = 2) Razi hospitals based on inclusion criteria definition about terminally ill patients. We used Phenomenology as a method of the qualitative study to concentrate on patient perception, emphasized the patients' personal experiences of those whom EOLC affected. In this Phenomenological interview, we wanted to establish the context of patients' experiences constructs experiences and finally, enable reflection on the meanings these patients or families were asked to describe their experiences of being at the EOL.

All interviews took one session, that each been lasted 45 min. Finally; the transcripts with inferred themes been received to the interviewees to assure that there were no ambiguities and to improve the validity of the research. All these groups of participants agreed with the themes. Researchers that were independent of our study analyzed part of our data to the credibility of the findings we reestablished. Final codes were determined and then two researchers checked the codes to determine the presence of super-ordinate and sub-ordinate themes that were related to each other Themes were merged to create a new description. At last stage; data were reviewed by a supervising researcher and the objectivity of the data was enhanced by ensuring theoretical sensitivity whereby the researchers put aside preconceived ideas about the topic when he analyzed.

Results

After forming themes by merging the sub-themes according to the interpretive team's opinion, and finally, the constitutive was yielded (Table 1). In this section, the resultant themes were explained.

A 15th interviewer reflected on the experience: "I feel that caregivers themselves deserve a break. I feel the entire burden for about 2 or 3 years now. So that's what I wanted to speak on. We show some of the important themes that we acquired this study:

Table 1. Sub-ordinate and super-ordinate themes developed for patients

Number of quotations	Relevant quotations	Analyzer's interpretation	Subordinate themes	Super-ordinate themes
34	I knew that every nurse come in our house do not have adequate knowledge	She thinks nurses do not have knowledge	Provider of care	Lack of special education
120	The disease affected me in a very positive way, it ceased until I know my God more and to love Him more	She believes that disease helps her to know God more	More closeness to God	Preferences
31	I understood his purpose is perfect, but I think if my husband was not sick we are not Taste poverty and its problems	Disease to poverty	Financial problems	Lack of insurance support
24	If my father rest at home he is better than now	We do not receive all care in one health center	The place provided health care	Health care provider
12	If my father's doctor gave me aware I found that I am decided better than what I thought before	The health care The provider did not give information about disease course	Knowledge about disease	Lack of necessary information
41	I just realized that my daughter shame me because I loosed my hair due to disease	The disease cause my daughter have not come with me to school	Family anxiety	Limitation due to disease of life

A theme that translated across many participants was that the concern of becoming a burden to one's family at the EOL. We identified three types of burdens to EOLC that included:

- Physical caregiving burdens,
- Decision making for making difficult treatment choices,
- Financial stressors.

Lack of awareness of hospice palliative care (HPC) services. In patients, lack of knowledge of HPC services was expressed as the main reason why palliative patients and families did not EOLC.

No 7 said that: "we do not have knowledge about my father's disease and how to manage it". No 13 said: "when you mention care to EOL, they don't know what about this?". Participants pointed out that minority patients and families are not only aware of what they could about the disease. Thus; they expressed that health care services should always aware them and never benefited from specific care. No 8 suggested that: "Patient that came to the hospital with terminal illnesses someone should be there

that explains the disease and its course".

No coverage, no service.

Another barrier identified was the high cost of health care services perhaps it is not surprising that all of 20 participants and families reflected this problem due to context of healthcare in our country. They referred to health insurance and limited personal incomes specially affected their access to health care. As the No 20 stated, "I always could not come to the hospitals because of the cost."

Discussion

Twenty patients and their family experiences for hospice care were study and themes that arose out of the interviews with the 20 participants who they had end-stage disease. Furthermore, participants experienced barriers, which affected their access to the health care system and barriers to utilization of it not all participants addressed each of the themes identified, although there was much crossover for some of them. Many of the findings that described the barriers that determinant access and utilization of palliative care are not

surprising to others. Phenomenological analysis was identified the fundamental structure of the patient and family experiences of hospice caregiving. In our study, six dominant themes were identified.

It seems like that many patients or their family is unaware as who pays for these services and willing to at least give them information about hospice care. However, much still needs to be done with respect to educating these health care consumers to help the provider and family by giving excellent and perfect care. At the same time, the themes of our study revealed that all patients with life treating disease that experienced as an attempt to express need of these patients and problems that in Iran there is yet. As we mentioned same study in Iran and especially in Tabriz about hospice care did not do, thus context difference causes we do not compare and discuss about it.

In regard to the conceptualization of HPC, there was significant data in the world generated that describes a holistic understanding of it. We try to address the findings of this study and link these with the other findings in articles. The findings of our study support the results of studies in other literature in other countries.^{6,9,10}

The statements made by the patients and their family in our sample demonstrate their understanding of this professional virtue for hospice care in our city (Tabriz). Furthermore, the delivery of adequate and relevant HPC services also depends on an appropriate comprehension of a patient's beliefs and values. Within these themes frequent experiences were made to most characteristics of the domain of themes as described in this study, which were a significance of these relationships in the finding of meaning and purpose.

The main focus of the experience of the family or patients was concerned with the relationship with themselves and with significant others. References to 'getting real about it', new understanding of health care providers (Theme 1), strengthening of more closeness to god and praying (Theme 2), giving financial support (Theme 3),

strengthening of bonds, allowing to have a centers to receive all hospice care (Theme 4), changed knowledge about disease with comprehensive information (Theme 5), a desire to 4reduce family anxiety about disease (Theme 6) are all examples of how the meeting contributed to strengthening the patients and hospice care providers relationship.

The major limitation of our study, pertaining to all qualitative focus group studies, is related to the number, size, and composition of focus groups. Although conducted in a large academic medical center, physicians practicing in the community were included. The strength of the study is that information was obtained directly from patients and their family involved with hospice care, and participants may have not sought cognitive dissonance in their recall of events.

Conclusion

This qualitative study suggests that for community especially patients, comprehensive information was generally a positive experience and provided opportunity to feel well-being and however, efforts should also be made of improve relevant education about EOL and hospice care to increase their competence in such discussions. At the same time; We hope the international research with focus on managing chronic illness and providing EOLC determined by the wants and needs of patients and their family because focusing more patient groups, and other demographic factors are important questions for future research and could be undertaken to provide the appropriate care and the long term benefits of the utilization of hospice care. This could be enhanced with a multicentric application of the car allowing application to a wider population with serious disease. Capacity building is needed to provide a more comprehensive and refined view of hospice-palliative care activity and advocacy, policy making and service development is necessary to hospice-palliative care activity.

Conflict of Interests

Authors have no conflict of interest.

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References

1. Degenholtz HB, Rhee Y, Arnold RM. Brief communication: the relationship between having a living will and dying in place. *Ann Intern Med* 2004; 141(2): 113-7.
2. Bryce CL, Loewenstein G, Arnold RM, Schooler J, Wax RS, Angus DC. Quality of death: assessing the importance placed on end-of-life treatment in the intensive-care unit. *Med Care* 2004; 42(5): 423-31.
3. Kumar SP, Jim A. Physical therapy in palliative care: from symptom control to quality of life: a critical review. *Indian J Palliat Care* 2010; 16(3): 138-46.
4. Shield RR, Wetle T, Teno J, Miller SC, Welch L. Physicians "missing in action": family perspectives on physician and staffing problems in end-of-life care in the nursing home. *J Am Geriatr Soc* 2005; 53(10): 1651-7.
5. National Hospice and Palliative Care Organization. NHPCO facts and figures on hospice care [Online]. [cited 2013]; Available from: URL: http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf
6. Cramer LD, McCorkle R, Cherlin E, Johnson-Hurzeler R. Nurses' Attitudes and Practice Related to Hospice Care. *Journal of Nursing Scholarship* 2003; 35(3): 249-55.
7. Centers for Disease Control and Prevention. National home and hospice care survey [Online]. [cited 1999 Oct]; Available from: URL: http://www.cdc.gov/nchs/data/series/sr_13/sr13_141.pdf
8. Elsayem A, Swint K, Fisch MJ, Palmer JL, Reddy S, Walker P, et al. Palliative care inpatient service in a comprehensive cancer center: clinical and financial outcomes. *J Clin Oncol* 2004; 22(10): 2008-14.
9. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000; 284(19): 2476-82.
10. Schofield P, Carey M, Love A, Nehill C, Wein S. 'Would you like to talk about your future treatment options'? Discussing the transition from curative cancer treatment to palliative care. *Palliat Med* 2006; 20(4): 397-406.