

## Determining the Factors Contributing to Quality of Life of Patients at the End -Stage of Life: A Qualitative Study

<sup>1</sup>Fatemeh Estebsari, <sup>1</sup>Mohammad Hossein Taghdisi, <sup>2</sup>Davood Mostafaei and <sup>3</sup>Ensiyeh Jamshidi

<sup>1</sup>Department of Health Education and Promotion, School of Public Health,  
Tehran University of Medical Sciences, Tehran, Iran

<sup>2</sup>Department of Health Management, School of Health Management and Information,  
Tehran University of Medical Sciences, Tehran, Iran

<sup>3</sup>Community Based Participatory Research Center, Tehran University of Medical Sciences, Tehran, Iran

**Abstract:** Quality of life end stage patients are different from quality of life from other people and patients. The aim of this study was to Determining the factors contributing to quality of life of patients at the end -stage of life patients in order to provide higher quality care for these patients. This is a qualitative study by the thematic framework method based on analysis qualitative data. 23 participants including patients, their families, nurses, physicians, psychologists and clergymen were selected by goal based sampling. Data were collected through semi – structured interview. We used the thematic framework method for analyzing qualitative data. Seven subject was extracted from the data as factors shaping quality of life end stage patients included: stress reduction, participation, homecare, education, independency, support, resources and facilities. According to the findings factors shaping quality of life end stage patients are multiple. Pay attention to the end stage quality of life especially from the health professionals can provide appropriate services for patients and their families.

**Key words:** End of life • Quality of life • Care • Concept • Theme • Thematic framework

### INTRODUCTION

Addressing the issue of quality of life (QOL) and promoting healthcare have always been a topic of great import for health service providers [1, 2]. According to the WHO definition, health “is a state of complete physical, mental and social well-being not merely the absence of disease” [3]. QOL is influenced by demographic, social, economic, cultural, ill- health-related variables [3, 4]. Experts believe that the concept of QOL of patients at the end- stage of life is different from that of the others and is more affected by experiences and activities overshadowed by a life-threatening factor, ie. death [4-6]. The *end-stage of life* is a phase during which a person is approaching death [7, 8]. Quality of healthcare at the end-stage of life presents a major challenge for patients and their families as well as health professionals and policy-makers Quality of healthcare is a right that should be provided equally to all [4, 9-12]. So far in Iran, there has not been a comprehensive study on the QOL of end-stage of life

patients. Most studies have dealt with the Q OL of end-stage patients with chronic diseases or healthy people and have been primarily concerned with determining the relationship between QOL and factors such as nutrition, physical activity, pain control and the like. This study explored the perceptions and views of participants about the factors contributing to QOL of end-stage patients with the aim of providing care of higher quality and variety.

### MATERIALS AND METHODS

This research is a qualitative study carried out in Iran in 2012. Participants ( $N = 23$ ) included patients hospitalized at the oncology ward ( $n = 7$ ), their companions ( $n = 4$ ), nurses ( $n = 3$ ), physicians ( $n = 3$ ) psychologist ( $n = 3$ ) and clergymen ( $n = 3$ ) in two major hospitals, namely Taleghani and Shohada-ye Tajrish in Tehran, the capital city Iran. The two hospitals were selected due to being a reference for patients with various

diseases and from diverse cultures and authority. Based on the process of qualitative research, the sampling method was purposive sampling and the sample size was based on the data saturation. Therefore, the selection of eligible cases was continued until the point when further data collection ended in the repetition of previous data (Data saturation phenomenon). A total of 23 interviews were conducted. Participants were aged between 16 to 64, including 13 women and 10 men. The method of collecting data was semi-structured interviews, beginning with a number of general questions about the topic of the study. The questions were designed using related studies and texts, plus consulting advisors and academic experts. Concerning the objectives of the study, some of the questions were previously designed. The questions revolved around the factors contributing to QOL of patients at the end-stage of life. Efforts were made to win the confidence of participants in the study by explaining the objectives of the study. They were ensured that all information was completely confidential and was collected only for research purposes. The interview time spans varied between 30 to 45 minutes. Participants were notified that the conversations were recorded and, except one, the others expressed agreement. Every participant was interviewed only once. The interviews with the patients were conducted in private in their room. Interviews with their accompanying relatives were conducted in a place designated by them (the hospital courtyard, hall and hospital's restaurant). Appointments with the physicians, nurses, psychologists and clergymen were arranged in advance at their preferred location (their resting room, treatment, conference rooms, pavilions, or office). The data analysis framework adopted consisted of five steps, namely "familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation" [13]. All interviews were transcribed in fewer than 24 hours afterward. The researcher first got familiar with the range and diversity of the content and issues. Out of them, the key concepts and themes were identified, based on which, a thematic framework was then worked out. According to this framework, all the transcriptions were reviewed, annotated and categorized. Concepts, contradictions, theories, experiments and research carried out were compared and the patterns and relationships were inferred from the findings. Simultaneously, data was encoded. The main concepts were assigned the primary codes. The next step was putting together the codes similar to each other, which led to the categorization and sub-categorization of

data. This can be done via *Atlas.ti* or other popular software programs such as Microsoft Word [14]. The latter was used in the current study.

## RESULTS

The factors contributing to QOL of end-stage patients emerged as 7 main concepts and 28 themes were recognized (Table 1).

**Reducing Stress:** The eight themes were identified as factors which led to relieving patients' stress:

**Not Leaving the Patient Alone:** Participants believed that not leaving a patient alone, spending time with their spouse, children, relatives, acquaintances, friends and colleagues could significantly alleviate stress and ultimately improve patients' lives.

**Providing a Stress-Free Environment:** Patients at the end-stage need rest more than any other thing. A calm and cheerful environment has a great impact on raising their spirits.

**Avoiding Upsetting Events:** In order for our patient to enjoy life, we'll do whatever we can to avoid creating stress and anxiety. For example, never talk about treatment expenditures, cost of living, or the cost of children's education.

**Concealing the Truth:** Patients' companions expressed that they preferred not to mention the true diagnosis or details of the disease to their patient, just to reduce stress and anxiety.

**Resorting to Religious Beliefs, Praying and Asking for Forgiveness:** Another factor that contributed to the patient's tolerance toward stress and made it easier to cope with their illness was relying on religious beliefs and attitude toward the disease. Seeking forgiveness from friends and family before leaving this world was another technique practiced by the patients in the study.

**Resorting to the Clergy:** In this study, the main mental preoccupation of participants' was questions about death, the other world and one's life after death. This mental state appears more predominantly in case of sickness and hospitalization.

Table 1: The factors contributing to QOL of end-stage patients emerged as 7 main topics

Key concepts	Themes
1 Reducing stress	(a) not leaving a patient alone (b) providing an environment free of stress (c) avoiding upsetting events (d) concealing disquieting facts (e) resorting to religious beliefs, praying and asking for forgiveness (f) asking questions of a cleric (g) seeking counseling (h) planning for after death.
2 Participation and assistance	(a) participation of the end-stage of life patient in their treatment (a) the participation of their family in patient treatment
3 Home care	(a) Resuming treatment in the familiar environment of home and family (b) Relieving depression
4 Training	(c) Reducing costs (a) Training patients (b) Training families (c) Training the personnel (d) Raising the society's awareness
5 Independence	(a) self-reliance (b) having control over personal and family life and the surrounding environment and events.
6 Support	(a) Support from family and friends (b) financial support from the government to provide the costs of drug and cost of living (c) Support from private and non-private organizations or community groups
7 Resources and facilities	(a) increasing the number of public hospitals (b) equipping public hospital with specialized and diagnostic machines (c) increasing the staff especially experienced and trained nurses (d) providing chemotherapy drugs (e) proper insurance coverage.

**Seeking Counseling and Psychiatric Services:** The psychologists interviewed believed that coming to terms with incurable diseases, especially cancer, is difficult for patients and their families. These patients and their families undergo severe pressure and stress during the treatment and even after it.

**Planning for After Death:** Participants in the study believed that people in every situation, whether healthy or sick, consider death and try to prepare themselves for it.

**Participation and Assistance:** The following themes were identified including: the participation of the end-stage of life patient and the participation of their family. According to the participants, patients will feel helpful when doing a share in their treatment. This will also inhibit the feeling of vagueness and hopelessness. Family participation in the treatment process was viewed as substantially effective for the QOL of end-stage patients.

**Home Caring: the Themes Included:**

**Resuming Treatment in the Familiar Environment of Home and Family:** In this study, most participants stated

that home treatment is tremendously effective in increasing the QOL of patients.

**Relieving Depression:** The physicians interviewed believed that resuming the treatment process at home, rather than in the isolated, impersonal environment of the hospital, can alleviate depression. When at home, the patient is once again placed in a familiar environment where they see their beloved ones. Psychologists held that the hospital environment creates stress and most patients want to escape from this situation without completing their treatment.

**Reducing Costs:** One major concern for patients and their families, according to the physicians and nurses, is the hospitalization expenditures. By carrying out some care services by trained nurses at home, a considerable amount of budget will be saved for the patient and their family.

**Training: the Following Topics Include:**

**Training Patients:** Participants in the study stated that self-care training is one of the factors that can improve QOL.

**Training Families:** The majority of patients and families expressed the need to learn homecare techniques and skill.

**Training the Personnel:** Another main concern raised by patients, families and medical staff was the need for especially trained nurses.

**Raising the Society's Awareness:** Patients' companions claimed that the community's view of patients with cancer is one with patronization and undue compassion.

**Independence:** It includes the issue of self-reliance and having control over personal and family life and the surrounding environment and events. Being independent in doing personal tasks was a key concerns raised by patients participating in the study. Moreover, having control over their personal and family life and the events in their surrounding environment leave a great impact on their QOL.

#### **Support: the Following Themes Were Identified**

**Support from Family and Friends:** Study participants deemed support from family and friends important for the QOL of end-stage patients. They believed that family and friends are the most crucial source of emotional and psychological support. In addition, participants called for the government to provide financial support for the costs of drug and cost of living. The main type of support viewed as necessary by patients and families was financial support. For financial support, some participants suggested that private and non-private organizations.

**Facilities and Resources:** The five themes included increasing the number of public hospitals, equipping them with specialized and diagnostic machines, increasing the staff especially experienced and trained nurses, providing chemotherapy drugs and proper insurance coverage. Patients and their families were not satisfied enough with the equipment of hospitals to specialized and diagnostic devices and machines. Supply of chemotherapy drugs, regardless of their cost, is one of the basic problems raised by patients and their companions. Another factor affecting the QOL of end-stage patients was quality of insurance services. In general, participants' evaluation of insurance organizations' performance was unacceptable.

## **RESULTS AND DISCUSSION**

According to the interviewees, several factors shape the QOL of patients at the end-stage. Reducing stress and

anxiety is one of these factors in providing better QOL for patients at the end-stage of life. Creating a stress-free environment, not mentioning the disturbing events and hiding distressing realities and not leaving the patient alone are some of the methods identified in this regard. A study by Mak and Clinton (1999) identified factors such as spending time with one's spouse, children, friends and family as effective in enhancing the QOL of patients facing death [7]. Findings of the present study are consistent with these. Having religious faith, saying prayer and asking for forgiveness and the presence of a cleric were some other factors to provide optimum QOL for patients at the end-stage. Seeking forgiveness, saying prayer and supplicating, talking with a cleric before death were some of the wants and needs of the participants, which they emphasized to be respected. Patrick (2001) confirmed that acknowledging patients' religious convictions and their dying demands and expectations were some of the factors that put their minds at ease [6, 15, 16]. Capitalizing on psychologist and therapists is not as common as it should be in hospitals and they are referred to only if and when the physician recommends. However, all patients, particularly those suffering from depression and their families need counseling. Counseling must begin as soon as the diagnosis has been. These patients need to be informed about the higher efficacy of the treatment if they keep their spirits high. Every human has the right to life and they must be supported to enjoy this right [17]. Prepared for death by planning beforehand, has been recognized as one of the elements that lead to an enhanced QOL for end-stage patients. Making arrangements for death is advisable for end-stage patients and their families alike as it can anticipate actions that are based on sentiment than reason [5]. Still, another factor that was said to be effectual for the QOL of end-stage patients was relatives' cooperation and patients' participation. Letting the patient do some of his personal chores on their own can give them a sense of accomplishment and usefulness. Similar studies have also come up with the conclusion that bilateral work of the patients and their family can be more effective on QOL [4, 18]. Hospitalization services for patients with cancer are increasingly exorbitant. Therefore, if these services can be delivered at home either by a family member or a nurse, it is strongly recommended that the patients be transited to home. The results would be the lowering of the costs incurred and, more importantly, the serenity of the patients and their families. In order for end-stage patients to experience appropriate treatment at home, first, their psychological, social, spiritual and economic needs must be perceived and addressed. Secondly, the patient

and their family need to be trained properly so that the home-based treatment will be as much efficient as possible. Designing an educational program and setting out homecare guidelines are the first step for the transmission of treatment from hospital to home [9]. Training the patients for self-care and training family members for assisting the patient are the initiatives thought to be practical and worthwhile according to the participants [19]. Apart from these, physicians and the nursing staff would also need to be trained and receive adequate information about end-stage patients. End-stage patients are different from others in that they are more sensitive and need gentler handling. Factors such as psychological support, counseling, professional conduct toward patients and their families, respect and kindness, common understanding, teamwork and medical support were said to be effective on the QOL of patients at the end-stage. Budis (2003) and Levin (2010) emphasized the interdisciplinary nature of care and explained that the training program for taking care of patients at the end stage of life should include the concepts of good health care, end-stage detection, detecting sorrow and melancholy, advanced care planning, pain management, emotional and spiritual care and taking care of the care-takers themselves [4, 20, 21]. Society should change their views toward patients with cancer. In this regard, the role of the mass media, particularly television and radio, were considered more notable. Having independence as a factor that could impact the QOL of end-stage patients for the better. Patrick (2001) and Gallagher (2001) found that the participants in their study wanted to have control over their lives and their environment [6, 12, 18]. The strategies for gaining more control over life included accessing support from professional staff, identifying individuals' coping skills, ensuring patient and family participation in care-taking, considering the family as a unit and maintaining open communication. Encouraging patients to participate in self-care is a way of empowering and increasing QOL [20, 22]. Support was also recognized as a factor that could elevate the QOL of patients. Support may come from political, economic, social, cultural and environmental areas and may involve awareness-raising, training, mutual assistance, counseling and intervention. Thacker (2008) discovered that supportive practices of the nurses taking care of patients at the end-stage of life could increase the QOL [21, 22]. The most important kinds of support include psychological support by family and friends; governmental support in financing healthcare costs and pensioning patients; support from social and charity organizations such as private, non-private,

insurance companies and NGOs. Economic problems and medicine supply were the major concerns of patients and their families. Governmental support, negotiation with insurance companies, revising the insurance laws particularly special patients' insurance can be beneficial. Some of the care services that must be provided to patients at the end-stage life by health care system based on Joint Commission International and Accreditation Standards (COP. 7) include sympathetic and feeling treatment, respecting religious values and cultural preferences of patients, having patients and their families participate in all possible aspects of care-taking and responding to their mental, emotional and spiritual concerns [23]. Factors obtained from this study are consistent with hospital accreditation standards for patients at the end-stage. Everyone has the right to die comfortably. Therefore, patients at the end-stage of life deserve the same attention that a healthy individual does and all aspects of their life and their relatives and family must be intended to. It is hoped that the information presented in this paper be of help to healthcare policy-makers and planners in providing a better QOL for patients at the end-stage of life. It is noteworthy that this study was a qualitative study and conducted on a small scale and with a small sample size, hence the limited generalizability of the findings.

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