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The Quality of Life of the Patients Under Palliative Care: The Features of Appropriate Assessment Tools and the Impact of Early Integration of Palliative Care

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Abstract

Based on the WHO definition, the primary objective of palliative care (PC) is to improve the quality of life (QoL) of the patients facing life threatening illness by means of a multidisciplinary approach. The assessment of QoL in patients under PC is an important process for the identification of patient's overall conditions including psycho-social, spiritual issues as well as the evaluation of the services provided to the patient. The ideal assessment tool the measurement of QoL in patients under PC should be patient centered and contain both subjective and objective domains and be able to correlate with the definition of QoL. The factors which positively influence the extend of the QoL include, good doctor-patient communication, economic status, education, socio-economic support and spirituality. The negative factors are social isolation, lack of employment, poverty, rejection and stigmatization and experience of symptoms, such as uncontrolled pain. Early Integration of PC leads to higher psycho-social support and acceptance of diagnosis, and severity of illness, which in turn helps for the better symptom management and reduces the disease related stress, which clearly associated with improved QoL. It provides more time for the end of life decision making, promotes self-efficacy and sense of control in decision with respect to individual values.

Keywords: quality of life, palliative care, early palliative care, QoL assessment, QoL tools, symptom management, psycho-social support

1. Introduction

Palliative care is a philosophy based approach in patient care not on physical facilities but on attitudes and skills [1] and is redefined by the World Health Organization (WHO) in 2002 and extended to include palliative care for children for the active total care of patients facing life-threatening illness through prevention and relief of sufferings by means of early identification and impeccable assessment and treatment of pain and other problems as physical, psychosocial and spiritual, with an aim to improve the quality of life of the patient and their families [2, 3]. Most of the developed and developing countries recognized palliative medicine for the improvement

of the quality of life of patients with chronic disease such as malignancy [4]. The primary goal of palliative care is the achievement of the best possible quality of life for the patients and their families and role extends to support on bereavement, if necessary. The term 'care' underpinned by the concept of total pain, defined as including not only physical symptoms but also mental distress and social or spiritual problems [5]. This concept of palliative care points to the need of holistic approach including symptom control for the management of the patients with terminal illness. Based on the above definition by WHO, the primary aim of palliative medicine is to prevent, treat the symptoms of patients with non-curable diseases as total care and to improve the quality of life (QoL) of the patient and their families.

The evaluation of QoL of patients in Palliative Care is an important procedure in the identification of a patient's overall condition as well as in the evaluation of the quality of service provided [6]. In patient's perspective, the following aspects such as physical abilities, personal autonomy, emotional state, socializing, spirituality, cognition, health care provision and preparation for death are important factors of quality of life in people with a life-limiting illness receiving palliative care [7] and to be considered during the assessment of quality of life in these patient cohort. The occurrence of incurable diseases can cause an enormous challenge to the patient, their family as well as medical professionals, affecting the QoL of patients in many ways [8]. With key components of systematic symptom assessment, pain control and other symptom relief, psychosocial support and family support, it is evident that early interdisciplinary palliative care and care givers' support help the patient to achieve effective symptom control and better quality in life [9]. However, usual practice to seek palliative care service is still limited to the terminal phase of illness. A coherent and empathetic communication of health professionals with the patient and their family has a major role in adopting patients' and their families' readiness for palliative care at the time of or shortly after diagnosis of incurable life-threatening illness [10–14]. In this context, this chapter highlights the facts with the primary objectives of:

1. To explain definitions and the variables for the terms “quality of life”, and “Health Related Quality of Life (HRQoL)” in the concept of “Health”
2. To suggest appropriate research tools for the assessment of QoL and HRQoL in patients under palliative care
3. To describe the influence of palliative care medicine in the improvement of QoL in these patients.

2. Definitions and the variables for the assessment of QoL of patients under early palliative care

2.1 Definitions

Defining the QoL is challenging and many approaches based on human needs, subjective well-being, expectations and phenomenal viewpoints exists [15]. The available definitions of QoL that are useful in health care can be grouped into five categories:

1. Normal life
2. Happiness/satisfaction

3. Achievement of personal goals
4. Social utility and
5. Natural capacity [16].

As early as in 1949, Karnofsky outlined the necessity of assessment of patients' subjective improvement in terms of mood and attitude, general well-being and activity, appetite and alleviation of distressing symptoms such as pain, weakness and dyspnea in addition to performance status, length of remission and prolongation of life during the evaluation of new drugs in cancer chemotherapy and highlighted the importance of psycho-social and QoL variables in molecule development. In contemporary terms, these subjective improvement criteria can be considered as QoL measurements and can be considered one of the first description on QoL in health care [17]. The alternative approach is with a view that individuals are the centre point to judge their own experiences and referred to as subjective QoL of subjective well-being (SWB) [18]. The subjective approach defines QoL as the congruence between aspirations and accomplishments, as perceived by the person and measures of life satisfaction, happiness, and positive and negative emotions falling in this category of subjective well-being [19]. These approaches direct to the necessity of a patient-centered approach for the evaluation of quality of life in the health care system. Since the introduction of the term "quality of life" in the medical literature in the 1960s, a number of researches have been happening, especially in patients with malignancy.

Based on a review, Aaronson [20] suggested two common threads in the structure and content of measures that carry the quality of life label.

1. Such measures tend to reflect a multidimensional conceptual approach. The following health dimensions are frequently incorporated to a greater or lesser degree in assessment of QoL.
 - a. Physical health with variables such as somatic sensations, disease symptoms, and treatment related complications.
 - b. Mental health ranging from a positive sense of well-being to non-pathological forms of psychological distress to diagnosable psychiatric disorders.
 - c. Social health including qualitative and quantitative assessment of community contacts and interactions
 - d. Functional health which includes both physical functioning in terms of self-care, mobility and physical activity as well as social role functioning in relation to family and work

Beyond these dimensions, other variables specific to a given disease may be incorporated, for example, quality of life evaluations in breast cancer will often include measures of sexual activities and body image. Another example studies in rheumatoid arthritis may include expanded assessment of joint mobility and pain.

2. The patient focused approach is primarily reliance on the subjective judgment of the patient themselves, rather than on observations of physicians, nurses, family members or other third parties. Although this process adds complexity to the data collection, considering the manner in which this approach

addresses the psychosocial factors surrounding disease and treatment, it is generally considered as the most appropriate.

This concept on QoL is supported by Ware [21] who suggested that routine assessment of a fairly broad, comprehensive set of psychosocial variables may often be most appropriate given our limited knowledge of the impact of chronic disease on everyday functioning, and of the psychosocial tradeoff associated with alternative treatments. Marcel [17] highlighted the importance of having a definition of QoL that covers the topic of research. Alternatively, he suggested getting umbrella coverage for any aspect of living with illness or disability to the term 'quality of life' in a QoL article. He advised the reader to focus on the variables which are actually measured in the study rather than the terms used.

In 1993, the WHO Quality of Life Group clarified the definition of the term Quality of Life as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. This broad concept on QoL is influenced by the individual's physical health, psychological state, level of independence, social relationships and their relationships to salient features of their environment in a complex manner [22]. However, at this point, it is important to consider the fact that the term QoL does not have same meaning to every person [23] and it is suggested that there are some aspects of QoL that are universal, where as some of them would be important only to the individual [24]. The interaction between these aspects-general and individual- will also vary from individual to individuals and their correlation is not static and moreover, changes overtime in response to life circumstances such as life-threatening or severity of illness [25]. Based on the above concepts and hypothesis, a number of definitions for QoL exist and many of them focus on subjective judgments. In view of this, a number of researchers have argued for the importance of inclusion of objective factors in the assessment of QoL [15]. Including all these variables in to consideration, QoL has been defined as "an overall general well-being which includes the objective assessments and subjective measurements of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values" [26].

The term "Health- Related Quality of Life" appeared in published articles by the mid-1980s and it was defined as a subset of QoL, relating only to the health domain of that existence [15]. However, in 1994, Gill and Feinstein reviewed 75 articles titled with word quality of life and concluded that none of the article distinguished overall QoL from the HRQoL [27]. To reverse these situations, many theorists, researchers, organizations and the consensus groups have proposed definitions for QoL and HRQoL [17]. There are at least four definitions for HRQoL can be found in literature [15]. In 2010 Hays and Reeve defined HRQoL in terms of individual's functioning life and perception of well-being based on physical, mental and social domains of health [28]. Here functioning life represents the individual's ability to carry out some pre-defined activities, [28, 29] while wellbeing refers to an individual's subjective feelings [28].

In another article, Torrance WH, correlates QoL and HRQoL and quotes as "quality of life is an all-inclusive concept incorporating all factors that impact upon an individual's life. The Health Related QoL includes only those factors that are part of an individual's health". Non-health aspects of QoL are not included in HRQoL, for example economic and political factors [30]. Focusing on aspects of QoL affected by disease factors, in 1995 Ebrahim S provided a definition of HRQoL as "those aspects of self-perceived wellbeing that are related to or affected by the presence of disease or treatment" [31]. In another definition of HRQoL, Gold MR et al. focuses on the value of health and refer HRQoL to "the values assigned to different health states" [32].

2.2 Difference between the terms: Health, QoL and HRQoL

It is acknowledged that “health is only one dimension of quality of life” [16]. Satisfaction with life is influenced by health, but health status only explains a small part of life satisfaction outcomes [33]. Therefore we can consider the Health and QoL as distinct concepts [15]. As some of definitions of HRQoL indicate to health status of person and others resembles QoL, differentiation between HRQoL and both health status and QoL is more problematic [15]. Especially when considering, the first two definitions of HRQoL given above do not seem to add much to the concept of health. If HRQoL is considered as functioning and wellbeing in physical, psychological, and social domains, then we need to take HRQoL as a particular type of description of health, in view of the WHO definition of health. HRQoL describes health using functioning and well-being rather than, for example, in terms of clinical symptoms or biological variables [29]. It is thus should be considered as a type of health measure, but not a type of QoL measure. Similarly, if HRQoL is the health aspect of QoL then HRQoL should be considered as same as health condition. Particularly, the first two definitions of HRQoL, which included here do not distinguish HRQoL from that of health [15]. The third definition of HRQoL highlights the aspects of QoL that are indirectly influenced by health (e.g., health affects income and hence housing, education and so forth) [34]. Perhaps more reasonable is the variant of this definition, where HRQoL is the aspects of QoL most affected by ill health [15]. Qualitative research has observed that existence of a wide variety of non-health factors those are important to participants for evaluating their health states [35]. If the research participant’s preferences are based on how health affects the QoL and if respondents estimate the effect of health status on QoL correctly then the utility of a health state could be referred to as health-related quality of life or more accurate term of ‘health-adjusted quality of life’ [15]. In summary, the above definitions of HRQoL reflect the values of definitions of both QoL and health in to its considerations.

2.3 The importance of HRQoL questionnaires measure in palliative care

As stated above, WHO defines palliative care as “an approach that improves the QoL of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” [36]. Since the patients under palliative care with chronic illness or non-curable disease, most of the measures in palliatives address for the symptom control and help the patients and their family to improve the quality of life physically, psycho-socially and spiritually. Based on the concept of above definition, the HRQoL questionnaire, such as the Personal Wellbeing Index (PWI) asks about satisfaction with: the standard of living, health, achievement, personal relationships, personal safety, community connectedness, and future security [37] in its assessment of variables. All these variables are more or less likely to be affected by ill health status of the individual. Because of this correlation between the domains and patient’s perception on health status, it is recommendable that the QoL questionnaires could therefore be to measure self-perceived health status, unless the connection between measuring functioning and well-being and QoL is justified [15]. The domains of the two most validated assessment tools such as SF-6D and the EQ-5D would fit to the WHO health definition, although the questions range across the WHO classification scheme of impairment, activity limitation, and participation restriction. Yet, there have not been many explicit justifications for differentiating HRQoL from health status [15]. However, neither

the EQ-5D nor the SF-6D contains patient valuation. Measures of HRQoL describe health status in terms of functioning health and wellbeing of individual than clinical parameters, and with a broad description of health condition than the measures of QoL. It is therefore more justified to classify typical HRQoL measures as measures of self-perceived health status [15]. So the ideal questionnaire should cover the concept of WHO definition along with patient self-evaluation on all aspect of QoL measures in relation his or her present health condition.

Spitzer et al. introduced a concise QL-index for measuring quality of life in cancer patients in 1981. This QoL instrument was based on the assessment of socio-personal variables and included physical, social, and emotional functions; attitude towards illness, personal features of patient's daily lives, including family interactions and the cost of illness. The considered items measures activities, self-care, general health, social support and out-look on life [38].

The findings in a systematic review by Nicola et al. [7] in 2016, with an objective to identify the aspects of QoL, which are important from the perspective of palliative care patients, suggests the following aspects as important for the quality of life in people with a life-limiting illness receiving palliative care on their own perspective: physical abilities, personal autonomy, emotional state, socializing, spirituality, cognition, health care provision and preparation for death. He also suggested a refinement of existing QoL measures in palliative care setting to improve the sensitivity and concluded with an opinion of generic preference based, HRQoL measures commonly used to inform public funding decisions do not include the domains such as cognition, emotional, physical, preparatory, social and the spirituality. Because of the existence of this mismatch between the domains available in assessment tools and the reality on the context of patient considerations, the assessment with the tools may fail to inform adequately on the money decisions about palliative care. Because of these mismatching facts, Carr and Higginson suggested for a patient-centered outcome measures (PCOMs), which capture the health status and well-being form the patient's perspective and focus on concern important to patient [24]. This point supported by Etkind et al., in a systematic review on the impact of PCOMs on processes and outcomes of palliative care, concluding that these type of measures raise the awareness of unmet need, improve recognition of symptoms and communication about QoL and benefit patient's emotional and psychological quality of life [39]. In short, during the selection of assessment tools for the evaluation of quality of life in patients under palliative care, it is recommendable for a patient centered outcome measuring questionnaire which correlate with definition of QoL.

3. The improvement of QOL of patients and their families under early palliative care

During early decades, palliative care services were initiated to provide a medical alternative to questionable medical practice regarding the end of life period: abandonment, euthanasia and inappropriate aggressive therapy and palliative care are usually offered late. Recently WHO recommends palliative care introduction as early as possible in the course of illness to increase the quality of life of patients and to positively influence the course of illness, in conjunction with other therapies, which are intended to prolong the life; such as chemotherapy or radiotherapy [40]. Palliative care is a multi-disciplinary approach that aims to improve the quality of life of all patients including both children and elderly and their families who are facing the challenges associated with life-threatening illness. These objectives of PC are achieved through the prevention and relief of sufferings, by means of early identification, assessment and treatment of pain and other physical, psychosocial

and spiritual distress [40]. The WHO recommendations also support the use of necessary laboratory investigations for the better understanding and management of distressing clinical complications in these patient group.

3.1 The evidences supporting the early introduction of palliative care

The role of good doctor-patient communication is important in acceptance of illness, deciding the treatment options. With a focused intensified doctor-patient communication, early palliative care may lead to higher social support and increase the likelihood of the acceptance of the diagnosis and illness severity. This in turn improves the patient's openness to symptom control and psycho-social interventions, and thereby to reduce the disease related distress. The reduced distress itself associated with improved quality of life and consistently promotes survival [41–43]. Early palliative care intends to outline realistic and attainable goals of treatment and to facilitate patient's choices by providing adequate information and assessment of his or her values and preferences with regard to advance care planning [44, 45]. In a systematic review of a small number of trials, Haun MW et al. found that early palliative care interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Apart from small effect size of the studies, they observed the findings may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common [46].

There are evidences that under early palliative care patient and family members are better informed on disease symptoms and severity and treatment directives and are provided with more time for end of life decisions, which promotes the experience of higher self-efficacy and sense of control in decisions with respect to the individual values [47]. It is proved that, the effective use of palliative care is linked with less aggressive cancer treatment, such as reduced use of questionable chemotherapeutic agents and treatments and this practice will de-escalate treatment intensity in final, irreversible health conditions [48]. The above observations are also supported by Temel et al. in 2010 [49] with their findings in a randomized trial with participation of 151 patients of newly diagnosed metastatic non-small cell carcinoma. The primary objective of this study was improvement in quality of life and overall survival as secondary objective. In their study, it has been observed that the patients in group of early palliative care service along with standard oncologic treatment showed significant improvement in quality of life and in mood, than the patients in the group of standard oncology treatment only. In addition, the patients with early palliative care led a significantly longer survival ($p = 0.02$), despite less aggressive end of life care. In view of the observations in this randomized controlled trial, American Society of Clinical Oncology supported the combined use standard oncology treatment along with palliative care in the course of illness for any patients with metastatic cancer.

The early integration of palliative care service for the treatment of cancer patients especially with metastasis is also supported by, Pirl et al. [50] in 2012, with the observations in their trial. It claimed that early introduction of palliative care improved the result of medical comorbidity management, including depression and helps in the discontinuation of inappropriate and possibly detrimental cancer treatment at the end of life. Recently, Hutt et al. [51] conducted a phase III randomized trial in 2018, with an aim to test the hypothesis that the use of early palliative care provides greater clinical benefits than standard practice for a population of patients with metastatic upper gastro-intestinal cancers. The primary objective in this study was overall survival. The authors concluded with expectation of integration of earlier palliative care in oncologic care of patients with metastatic gastro-intestinal cancer.

3.2 The factors should be addressed under palliative care for the betterment of quality of life in patients

In 2011 Jacoba et al. [25] studied the effect of palliative care in a resource poor community in South Africa, with the themes of:

- a. the factors that had a positive influence on quality of life,
- b. factors that had a negative influence on quality of life
- c. experience of quality of life.

In their study, it is observed that: being able to work as a very important factor for all the participants involved in the study, as it keeping them busy and having no time to spend for unnecessary worries in addition to help in earnings. Support from friends and family as well as health care professionals was another major factor contributing for the improvement of quality of life. Spiritual activities such as going to church, participating church services, singing in choir and prayers made the participants to feel strong and comfort and gave them a feel of “alright”. Lastly, comes the symptom control. The poverty was the predominant negative factor on the quality of life of the study participants. Other negative factors were unemployment, separation from children, rejection and stigmatization and experiencing the symptoms with pain as mostly described symptom. It is observed that uplifting of education and economic status of the community will help for the improved psycho-social support extending to the terminally ill patients and there by their quality of life [52].

4. Conclusion

The primary objective of palliative care is to improve the QoL of the patients facing life threatening illness by means of a multidisciplinary approach. The process of QoL assessment identifies the patient’s overall conditions including psycho-social, spiritual issues as well as the evaluation of the services provided to him. So the ideal assessment tool the measurement of QoL in patients under palliative care should be patient centered and contain both subjective and objective domains and be able to correlate with the definition of QoL. It is evident that early integration of palliative care improves the QoL of patients with terminally ill condition and Early adaptation of palliative care is advisable for the management of patients with chronic conditions such as cancer.

Conflict of interest

None.

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