

Are the Existing Quality of Life Measures Appropriate for Muslim Patients with Cancer?

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Purpose: This article aims to review the appropriateness of five general quality of life (QoL) measures for the Muslim patients with cancer.

Method: The literatures related to QoL in patients with cancer, published between 1981 and 2011 were critically reviewed. Several database databases including CINAHL, MEDLINE as well as PUBMED, ProQuest, Elsevier, Google scholar and reference list were included. There were 25 articles best fit the inclusion criteria. Books and journal articles addressing Islamic principles were also reviewed.

Result: QoL is a complex, multidimensional, and subjective phenomenon. It has been defined differently but overlapping by many scholars in the field. The patient's QoL is important since it is one of the indicators of quality cancer care. The EORTC QLQ C30, FLIC, McGill QoL are the examples of widely used QoL measures which are appropriate to be applied in Muslim cancer population, while the FACT-G and CARES SF need to be revised in some of their items. Issues related to Islamic principles are discussed to support needs of further revision of these QoL measures.

Conclusion: Most of the QoL measures' items are not conflicting with the Islamic principles, except some items. Psychometric properties of the revised measures appropriate for Muslim cancer population should be further examined so that applying these measures can provide valid findings. Furthermore future cross cultural study may be possible.

Key words: quality of life, QoL measures, Islam principles

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Introduction

In the last decades, cancer disease has become a major health problem. With the advancement in health sciences and equipments, new complete treatment for cancer have enhanced the possibility to cure some and also prolong cancer patients' lives. Many patients with cancer have to fight the disease for several months to years with complex toxic therapies (Williams & Pazdur, 2005). The cancer therapies for patients with cancer have been developed for several decades. The therapies are not only beneficial for the patients' lives but there are some consequences towards the patients' quality of life (QoL) (Osoba, 2004; William & Pazdur, 2005). These have to be assessed carefully by the healthcare providers.

The QoL of patients with cancer is considered very important in the cancer care. It is ranked in the second list of the quality care indicators after the mortality and morbidity of patients with cancer (Kuenstner et al., 2002). Assisting patients with cancer to achieve a better QoL has been appreciated as the best achievement of cancer care, particularly in the palliative area (Flanagan & Holmes, 2000; Jocham, Dassen, Widdershoven, & Halfens, 2004). This aspect has also presented as a prominent importance, such as to predict survival and to promote well-being of patients with cancer (Halyard & Ferrans, 2008). In addition, nurse and other healthcare providers have to understand clearly the concept of QoL to prevent unnecessary bias measurement, evaluation and over judge towards the patients' needs (Anderson & Buckhardt, 1999).

The application of the QoL measures in cancer patients is fundamental to achieve the desired outcomes. QoL is influenced by many factors such as physic, social, patients' characteristics, culture and religion (Ferrell et al., 2003; Ferrell, Smith, Cullinane, & Melancon, 2003). These factors determine how the QoL is contracted. Following that, the QoL of patients

with cancer has to be measured appropriately as its construction. There have been many measurement tools of QoL being developed for patients with cancer, for instance the Functional Assessment for Cancer Therapy General version 4 (FACT-G version 4), the European Organization Research Therapy for Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ C-30), the Functional Living Index for Cancer, the McGill QoL questionnaire and the Short Form (CARES SF). These tools have been tested for its reliability and validity. Nevertheless, would the widely known QoL measures be suitable for religion specific population, such as Muslim patients? This would be further reviewed.

Muslim patients as a religious specific population have taken a numerous number in the world. Muslim population reaches approximately 23.4% (1.6 billion people) of the world population (Pew Research Center's Forum on Religion & Public Life, 2011). The population is expected to increase 3x higher in the next two decades (Pew Research Center's Forum on Religion & Public Life, 2011). The majority of Muslim people live in Asian and African countries while the rest are in the Europe and America. Muslim people live with certain specific rules based on the Islamic concepts. Islamic values are guided by the Al-Quran (the Holy Book) and the As-Sunnah (prophet Muhammad Peace Be Upon Him [PBUH] saying). For instance, Islam teaches Muslim to be thankful to the God (Allah Subhanahu Wata'ala [SWT]) in any condition. This is stated in 52 verses (suraah) of the Quran, for example Al-Baqarah: 52, Al-Imran: 123 and An-Nisa: 147. Acceptance, having a positive thinking (husnu dzan) and relieving everything to God are also the philosophy of Muslim people (Al-Quran Al-Baqarah: 216; Asy-Syarah: 5-6). Being in a tough situation such as suffering from cancer disease can be regarded as a test, warning or prove of God's love for Muslims (Al-Quran, Al-Baqarah: 286). Having this guidance, Muslim patients might appreciate their QoL differently from other patient

populations. Raising a question to ourselves whether the general QoL measures are suitable for this specific population is very important, because many of the QoL measures were developed in the western countries which are noted having very large number of non-Muslim population.

Although these cancer measurement tools have been widely tested for its reliability and validity, the specific review of these tools for the Muslim population is rare. Whether the existing QoL measures for cancer patients are appropriate in the Muslim population is yet known. Therefore the aims of this paper are to review the specific concept of Quality of Life, evaluate the widely existing QoL measures and evaluate the appropriateness of those QoL measures in the Muslim patients.

Method

Literatures related to QoL in patients with cancer, published between 1981 and 2011 were critically appraised. The articles were retrieved from several databases including CINAHL, MEDLINE as well as PUBMED, Proquest, Elsevier, Google scholar and reference list. The literatures reviewed were about the concept of QoL and the widely used QoL measures for patients with cancer. The key words used to retrieve the articles were quality of life, measurement, patients with cancer, and Muslim. There were 25 articles best fit the inclusion criteria. Books and journal articles addressing Islamic principles were also reviewed. A synthesis of literature was performed to answer to the proposed questions.

Result

What is Quality of Life?

Definition of QoL is drawn by several scholars. It is varied in the clinical practice and research area (Anderson & Burckhart, 1999). Some widely used concepts of QoL are life satisfaction and happiness (Kimura & Silva, 2009; Schipper, Clinch, McMurray, & Levitt, 1984, Wilson & Clearly, 1995), individual perception towards life (the World Health Organization [WHO], 1997) and well-beings (Cohen, Mount, Tomas, & Mount, 1995; Ferrell, Smith, et al., 2003). Many studies and measurement tools have used these terms to define QoL. . However, the question is raised towards the real concept of QoL, whether it is relevant, appropriate or we mix up with other variables out of QoL.

Definition of QoL has to be conceptually clear. QoL concept is sometimes confused with other terms. The terms mostly used to relate with QoL are functional status, general health status, mood and symptom. Anderson and Buckhart (1999) delineated that QoL comprises of satisfaction and well-being in life. The satisfaction or well-being is achieved when the expectation towards the important domains in the patients' lives is accomplished (Anderson & Burckhart, 1999). These life's domains are comprehensive covering the patient as a human being (WHO, 1997). However, there could be a difference in valuing the satisfaction or well-being towards important domains in life among the patients. Only the patients who can judge his/her own QoL (Wilson & Clearly, 1995). Therefore, healthcare providers cannot over judge towards one domain, for instance physical domain, is more important and rely on only one or two domains to value the patients' QoL.

The important domains of life, which contribute to QoL, are crucial to be conceptualized. In the cancer field, the attributes of QoL are explained by Ferrell, Smith, et al. (2003) in the

study on ovarian cancer survivors. Four well-beings in life, which are considered very important for patients with cancer, had been captured through correspondence and news-letters called CONVERSATION from January 1994 until December 2000 between the authors and these survivors (Ferrell, Smith, et al., 2003). The ovarian cancer survivors shared their feelings, experiences, understanding, distress, coping and their life changing throughout the disease trajectory. These four well-beings are physical, psychological, social and spiritual well-being (Ferrell, Smith, et al., 2003). These were proposed as the attributes to delineate patients' QoL.

Furthermore, to have a better understanding, other concepts related to QoL will be discussed in brief. The health concept is described by WHO as a "state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO as cited in Anderson & Buckhart, 1999, p.301). The state of being healthy is achieved when these variable are well-balanced and wealthy. Health related to quality of life (HRQOL) is also sometimes used to relate the QoL of the patients. This concept particularly covers health and illness status, such as physical and psychological states. However, this status is not always reported by the patients themselves but also by the healthcare providers. According to Wilson and Clearly (1995), the assessment of the physical and psychological abnormality as the objective data may also help to investigate the overall QoL of the patients.

Furthermore, other term related to QoL is symptom. Concept of symptom as conceptualized by the health scholars is the perception of an individual towards an abnormal physical, emotional or cognitive state (Dodd et al., 2001). While the functional status term is merely about the abilities of people to fulfill their basic needs, accomplish their roles as well as to maintain their health and well-being (Dodd et al., 2001; Wilson & Clearly, 1995). Therefore, the concept of QoL is more comprehensive compared to other terms related to QoL.

The importance of QoL

To present in general, the importance of QoL in the clinical setting will be explicated. The QoL has emerged as an outcome of healthcare intervention (Anderson & Burckhardt, 1999; Verrachio & Ferrans, 2010), particularly in the cancer care, it is counted as the second indicator after the mortality and morbidity (Kuenstner et al., 2002). For patients with advanced stage of cancer, full recovery might be away for the reality (Schipper, Clinch, McMurray, & Levitt, 1984), therefore, achieving the best quality during their life span would be imperative.

There are other significant reasons to measure QoL in the clinical setting. Measuring QoL is one of the variables to guide individualized the health care for each patient (Varrichio & Ferrans, 2010). The QoL assessment in the clinical routine care has also given benefits in choosing the best interventions for each patient, helping informed decision-making and enhancing the quality care which will generate better outcomes (Halyard, 2008; Sloan, 2006; Varrichio & Ferrans, 2010). Furthermore, measuring QoL provides information about the effects of health interventions from the patients' overview (Sloan, 2006). Routinely assessing the QoL will be able to enhance the patients' wellbeing (Velikova et al., 2004). The patient is able to report or response whether a statistically significant intervention is effective or not to improve a component of his/her QoL (physical, psychological, social, and spiritual well-being) (Halyard & Ferrans, 2008, Ferrans, 2010). Furthermore, Halyard and Ferrans (2008) reviewed that the baseline score of QoL could be used to predict the survival of the cancer patients.

Nowadays, this measurement has also become a means of communication between the patient and care providers, such as in what kinds of care that the patient actually needs (Anderson & BuckHart, 1999; Velikova et al., 2004; Perwitasari et al., 2011). This situation can

help both the patients and health care providers to make the best decision making for related issues.

It should be noted that having a clear definition is related to how the QoL will be measured. An appropriate measurement tool is needed by healthcare providers to report the patients' QoL. The measurement tools have to represent the QoL conceptualization as much closed as possible (Anderson & Burkhardt, 1999). It means that the QoL measures are able to cover all the dimensions, that the patients percept, are important in their lives. Moreover, the QoL measures have to rate the patients' satisfaction in a simple rating score which are not confusing for the patients. Above all, the measurement tools, either new or existing ones, have to be valid and reliable (Mainpour, 2011; Smith & Huntington, 2006). Nowadays there are many existing QoL measures, thus healthcare providers need to review the studies on the psychometric properties of those tools. Having all above criteria, the QoL measures will help healthcare providers to get clinically significant data as well as outcomes.

In order to choose appropriate existing QoL measure, there are at least four considerations. First is the consideration of the population which is going to be measured (Ferrans, 2010; Smith & Huntington, 2006). Specific group of patients with cancer, for instance patients with breast cancer, need specific measures which best represent their QoL. Second consideration is the expected outcomes or domains of QoL (Smith & Huntington, 2006). Healthcare providers might consider the kinds of QoL measures with each of their domains. Third consideration is the amount of question of the QoL measures (Smith & Huntington, 2006). For example, considering more than 50 questions might not be too many to measure QoL of patients with cancer at the end of life. Last consideration if the right timing and strategy to administer the QoL measures (Smith & Huntington, 2006).

QoL measures

This article would only briefly discuss five widely used QoL measures for general cancer population. These QoL measures would also be reviewed for its appropriateness for the Muslim patients. The existing measures are the European Organization of Research and Therapy of Cancer Quality of Life Core-30 (EORTC QLQ C-30) (Osoba, Aronson, Zee, Sprangers, & Velde, 1996), the Functional Assessment of Cancer Therapy General (FACT-G) (Cella et al., 1993), the Cancer Rehabilitation Evaluation Short Form (CARES SF) (Scagh, Ganz & Heinrich, 1991), McGill QoL Questionnaire (Cohen, Mount B, Tomas & Mount L, 1996), and the Functional Living Index Cancer (FLIC) (Schipper, Clinch, McMurray & Levitt, 1984).

The EORTC QLQ C-30, FACT-G, CARES SF, FLIC and McGill QoL Questionnaire have some differences. These five general QoL measures are distinguished by their main features. The further details of each QoL measures are presented in the Table 1. The numbers of items of these measures are different. The QoL measures are rated by using the 4-point Likert scale unlike the FLIC and the McGill QoL. Only the EORTC does not measure the global or total score, whereas the others do. The FACT-G composes statements to measure patients QoL while the others list questions. Generally these QoL measures are compounded of some subscales, however only the FACT-G version 4 which is clearly comprises of 4 well-being subscales. These five QoL measures have been well tested for its psychometrics properties and the results are satisfying (Cella et al., 1993; King, Stockler, Cella, Osoba, Thompson, et al., 2010; Kuenstner, Langelotz, Budach, Possinger, Krause & Sezer, 2001; Schag, Ganz, Heinrich, 1991; Schipper, Flinch, McMurray & Levitt, 1984; Webster, Cella & Yost, 2003).

General information, the QoL of patient is influenced by many factors, both internal and external factors. The external factor, such as culture and religion have made the important

domain of life of people is different from one to another. Anderson and Burkhardt (1999) mentioned that the satisfaction of life for Chinese people is achieved when there is a balance between *Ying* and *Yang*. These two aspects, culture and religion are very close to influence the way people live. This can be possible that patients from different cultures and religions see their life satisfactions or QoL somewhat dissimilar. Consequently, a good QoL measure has to be able to capture and attend this cross cultural differences.

Table 1 Main Features of EORTC QLQ C-30, FACT-G version 4, FLIC, McGill QoL and CARES SF

Features	EORTC QLQ C-30	FACT-G Version 4	FLIC	McGill QoL	CARES SF
Number of items	30	27	22	16	59
Global score	No	No	Yes	No	No
Scoring	4-point Likert Scale (not at all-very much) and 7-point Likert scale	4-point Likert scale (not at all – very much)	7-point Likert scale ranging from 1 to 7 (never-continually)	11-point Likert scale (very bad-excellent)	4-point Likert scale (not at all – very much)
Subscales (No. of items)	Physical function(5) Social function (2) Emotional function (4) Cognitive function(2) Role function (2) Symptom (7) Global health status (2)	Physical well-being (7) Social/Family well-being (7) Emotional well-being (6) Functional well-being (7)	Health & Functioning (13) Social & Economical (8) Psychological/Spiritual (7) Family (5)	Physical (4) Emotional (3) Social (2) Spiritual (6) Financial (1)	Physical (13) Psychosocial (17) Medical interaction (6) Sexual (3) Marital (9) Treatment related problems (12) Questions
Syntax structure	Questions	Statements	Mainly questions	Statements	Questions
Item's content	Everyday situation, symptoms	Existential problems, satisfaction	Existential problems and symptoms	Existential problems	Existential problems, treatment problems, symptoms
Time scale	Past week	Past seven days	Past month, past two weeks, current status	Past two days	One month

These five QoL measures were firstly developed in the western countries. The FACT-G, CARES SF, FLIC and McGill QoL were originated from the United States of America, while the EORTC QLQ C-30 was constructed for European countries. Both the FACT-G and the EORTC QLQ C-30 has been translated into many languages. Related to a specific religion group population, the QLQ C-30 has been tested in a country which has a major Muslim population; Indonesia. Its validation was conducted in 2011 to Indonesian cancer patients who received chemotherapy, together with SF-36 (Perwitasari et al., 2011). Although this study did not discuss further to the specific value or concept of Islam related to this measurement tool, the QLQ C-30 has no major problem to be implemented in this cross cultural and religion. The FLIC has been tested in the Turkey population which the majority of its people are Muslim (Bektas & Akdemir, 2008). This QoL measure has been proven to be reliable in Turkish population and found to be valid in this cross cultural population.

Discussion

Are the Existing QoL Measures Appropriate for Muslim Patients With Cancer?

Muslim population spends their lives based on the basic rules and guidelines of Islam. Their ways of life is guided by two main basic guidance, the holy book “Al-Quran” and Al-Hadith (The practices and statements of Prophet Muhammad PBUH). In any situation, even before a Muslim is being born until the life after death and explanations and guidances are given in the Holy Book. In addition, the prophet Muhammad PBUH had also given many examples in how to live as a good Muslim. Living in the Muslim population, such as in the Middle Eastern countries and South East Asia countries could be completely different compared with the Western countries in which all of the QoL measures were firstly developed. In a Muslim society,

basic rules of Islam are used as the baseline in terms of culture and daily life activities of Muslim people. This religion also influences many life aspects of Muslim population. Therefore, measuring the QoL of Muslim patients with cancer disease is unique especially by using the general QoL measures.

Reviewing the QoL measures for cancer patients from the point of view of Islamic concepts has to be carried out by looking at each measure one by one and further to each item or question. Basically, the majority of items questioned in those five general QoL measures have no contradiction toward Islamic guidelines. The EORTC QLQ C30, the FLIC, and the McGill QoL questionnaire are mainly appropriate to be applied in Muslim cancer population. As an example, the FLIC questionnaire has been tested in Turkey cancer population for its psychometric properties, it is then recommended to be used in the Muslim population (Bektas & Akdemir, 2008). Nevertheless, the FACT-G and CARES SF need to be revised in some of their items particularly the questions or statements about partner and sexual relationship.

Islamic teaching does not allow any sexual relationship between men and women out of marriage or zina. There are many suraahs in the Al-Quran which forbidding sexual relationship out of marriage. Suraah Al-Israa (ayaa 32) stated that “Nor come nigh to adultery: for it is an indecent (deed) and an evil way”. In addition, the Quran suraah An-Nuur (ayaa 2) saying that “The woman and the man guilty of illegal sexual intercourse, flog each of them with a hundred stripes, let not pity withhold you in their case, in a punishment prescribed by Allah, if you believe in Allah and the Last Day, and let a party of the believers witness their punishment (this punishment is for unmarried persons guilty of the above crime but if married persons commit it, the punishment is to stone them to death, according to Allah's Law). In addition, Islamic concept also forbids any sexual relationship in the same gender (lesbian or

homo) (Al-Quran Al-A'raf: 80-81; Ash-Shu'araa: 165-166). Thus the possibility of sexual relationship in Muslim population is only between man and woman and it has to be husband and wife.

The item related to the sexual life (GS7) asked in the FACT-G questionnaire should be specifically refer to marriage relationship. The GS 7 statement in the FACT- G (“I am satisfied with my sex life”) would be more appropriate if it is modified to be “I am satisfied with my marriage sex life”. The second choice in the 6th section “Are you married or in a significant relationship” in the CARES SF is not appropriate for Muslim population because sexually related or committed out of marriage such as dating is not allowed as well. It would be enough to ask “Are you married” for this section, the patients then are able to proceed to the questions related to the specific sexual activities in this section. Although the questions about sexual activities (questions number 28, 29, 42, 45 and 46) still can be kept in this questionnaire, it should be also anticipated that Muslim patients would feel reluctant to answer the questions. It is forbidden by Islamic concept to tell to other people about the sexual activities with their wife/husband as interpreted in one saying of Prophet Muhammad (PBUH) as narrated by Abu Hurayrah. It is obligatory for both spouses to keep the secrets of the marriage, especially anything that has to do with their intimate relationship in bed. The wife is entrusted with the husband’s secrets and the husband is entrusted with the wife’s secrets. It was narrated by Abu Hurayrah that the Prophet (peace and blessings of Allah be upon him) “turned to the men and said, “Is there any man among you who, when he comes to his wife, he locks the door, throws his blanket over himself and conceals himself with the cover of Allah?” They said, “Yes.” He said “And does he sit after that and say, “I did such and such, and I did such and such” They remained. Then he turned to the women and said, “Is there anyone

among you who speaks (of private marital matters)?” (Abu Dawood, 2174, Saheeh al-Jamai, 7037). “Do you know what the likeness of that is (disclosing husband and wife sexual relationship)? The likeness of that is that of a female devil who meets a male devil in the street and he fulfils his desire with her when the people are looking on.” The reluctance of answering the questions related to sexual activities might be also influenced by the Islamic culture in the Muslim population. The circumstance of this culture is more secluded or secret compared to the western culture, particularly about the sexual matter.

Furthermore, the 7th section which asks “Are you single or in a significant relationship” is also not appropriate or applicable in the Muslim population. As Islamic guidelines forbid any other relationship except marriage relationship, the questions related to significant relationship cannot be applied. Therefore this section as well as the two questions in this section should be deleted.

Conclusion

Most of the QoL measures’ items for cancer population are not conflicting with the Islamic principles, except some items. The items questioned in the EORTC QLQ C-30, the FLIC, the McGill QoL questionnaire are appropriate for Muslim population. The psychometric properties of the EORTC QLQ C-30 and the FLIC questionnaires are valid and reliable when they were tested in Muslim population. While some items in the FACT-G and the CARES SF need to be revised in order to be more suitable applying in the Muslim cancer population. These particular items are related to the sexual relationship and sexual activities. Therefore, further future cross cultural study may be possible to be conducted.

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