EVALUATION OF QUALITY OF LIFE INSTRUMENTS IN A PALLIATIVE CARE CONTEXT: AN INTEGRATIVE LITERATURE REVIEW

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Abstract

Quality of life (QOL) research has been identified as a priority for nursing. A wide variety of QOL instruments have been developed to address a number of domains such as physical, functional, emotional, and social well-being (Corner & Baliey, 2008, & Stewart). It has been proposed that meaning should also be included, as well as purpose, spirituality and grief (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). Evaluation of QOL instruments in palliative care is an important research priority. Considerable research has addressed the QOL and quality of care aspects for palliative patients, but there has been limited evaluation of the measurement technique for both in the Middle East. To the authors' knowledge no studies have been conducted to explore this issue in the Middle East, and certainly not in Qatar. Therefore, this project promises to develop a new insight into the importance of evaluating the QOL measurement instruments that could potentially be used in the palliative care unit in Qatar. The overall objective of this paper was to examine the findings of an integrative literature review for the purpose of determining cultural adaptations and validations of instruments needed to evaluate the QOL of patients in palliative care, and to discuss the use of these instruments in the Middle East context.

Introduction

The known lifestyle changes required for health, and the scientific advancements made in the health care system to date, have increased life expectancy among cancer patients in developed countries (Bingley, & Clark, 2009, Jassim, & Whitford, 2013). The incidence of people living longer with a diagnosis of cancer has increased, and as a result, there is a greater need for cancer care (Bingley, & Clark, 2009, Jassim, & Whitford, 2013). Palliative care is a very important part of this cancer care.

Palliative care is a philosophy of care whose efforts improve the QOL of patients and their family members. This is done in the process of coping with death through early identification, prevention and relief of suffering, evaluation of treatment appropriate to physical, psychosocial and spiritual problems (Corner & Baliey, 2008). Palliative care is defined as an approach that improves QOL for patients and their families who face the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). The goal of palliative care is recognized to include health related quality of life (HRQOL), as well as spirituality, loss and grief, family involvement and coping.

In palliative care QOL is an important concept and a center of focus in the identification of the overall patient condition, and is an outcome measurement process (Kaasa, & Loge, 2003). The quality of care that is provided to patients in the last few months of life has a significant influence on both patients and their families (Stewart, Teno, Patrick, & Lynn, 1999). QOL has a wide range of different complex concepts that fall under it. These have led to the development of different measurements instruments (O'Boyle, & Waldron, 1997). Because of this, it is important to document the QOL experiences of dying patients and their families. As such, this information could help in the assessment of quality of care outcomes across the setting. It could also evaluate efforts to improve quality of care, which would in turn improve QOL (Kaasa, & Loge, 2003).

Despite the widespread use of the QOL concept, no standardized or precise definition exists (Kaasa, & Loge, 2003). The concept of QOL has been defined as an individual's perception of his/her position in life, in the context of a culture system value, where the individual lives in relation to his/her goals, expectations, concerns and standards. It is also connected to the individual's physical health, psychological state, and level of independence, social relationships, environmental factors and personal beliefs (World Health Organization, 1997). In the health care system QOL is a concept that is related to symptoms, functioning, psychological and social wellbeing, and not fully related to meaning and fulfillment (Kaasa, & Loge, 2003). This definition is a multidimensional health-oriented concept which has been named HRQOL (Kaasa, & Loge, 2003).

Despite a lack of consensus for a definition of the term QOL, there are various instruments intended to measure such a construct from different perspectives. In this context, studies have been developed to validate instruments to evaluate QOL in the field of palliative care. The purpose of this study is to explore these various instruments that have been tested to measure QOL, and to determine the adequate QOL instruments in the palliative context. This information will then be used to facilitate the decision making process about the most appropriate instruments to be used in clinical practice and research in Qatar.

Palliative care in the Middle East

Palliative care is a new philosophical understanding or concept in health care within the Middle East. It was in Saudi Arabia where the notion of palliative care was pioneered, and where palliative care as a concept, was first introduced into the health care system in 1992 (Zeinah, Al-Kindi & Hassan, 2013b). The concept of palliative care was only recently introduced into the health care systems of the majority of countries in the Middle East including Qatar, United Arab Emirates, Bahrain, Palestine and Iraq, Oman and Lebanon. These countries are establishing a localized provision, or are in the building phase of introducing palliative care (Zeinah, Al-Kindi & Hassan, 2013b). As such, the integration of palliative care services in most of the Middle East countries has been shown to improve QOL for both the patients and their families. (Zeinah, Al-Kindi & Hassan, 2013b). In knowing this, assessment of QOL at the end of life is an important aspect to measure; however, researchers continue to struggle with the best way to measure QOL (Bentur, & Resnizky, 2005). This may be related to the unique characteristics of patients treated in palliative care making QOL a subjective concept.

Palliative Care in the State of Qatar

The State of Qatar is a wealthy country and is making tremendous strides in health and research innovation, yet it is considered to be in the developing phase in relation to palliative care (Zeinah, Al-Kindi, & Hassan, 2013A). The National Center for Cancer Care and Research (NCCCR) was established in Qatar in 2004, with a forty six bed capacity that provides cancer care. It is the only advanced cancer center in Qatar, and it is treating more than six hundred cancer patients each year from various nationalities and cultural backgrounds (Zeinah, Al-Kindi & Hassan, 2013b). The NCCCR offers advanced medical oncology care, radiotherapy, chemotherapy and pain management, as well as specialized laboratory services. The vision and mission of the NCCCR is incorporated within the Qatar National Cancer Strategy. For example, excellent standards, patient centered care and promotion of collaborative multidisciplinary team work are the key for the achievement of the best outcomes for patients.

The concept of palliative care was established in the State of Qatar in July 2008 with a ten bed unit specialized in caring for patients within the philosophy of palliative care. The objectives of the care provided within this unit are to improve the QOL for cancer patients and their families, and to achieve the best QOL outcomes by relieving suffering, controlling unrelieved distressing symptoms associated with cancer such as pain, and restoring physical and functional abilities.

The information on QOL in the Middle East region is extremely specific in characteristics because of the unique cultural norms and values of the people living in this region (Jassim, & Whitford, 2013). Therefore it is essential that both researchers and practitioners ensure that whatever tool is used, it is measuring the goals of the services offered, and is valid for the country, culture and target population (Bentur, & Resnizky, 2005). Most of the QOL measurement tools were developed or designed for the English language, and because of this, evaluating the QOL in terminally ill patients in the Middle East may be difficult as there is a need to adopt and translate these tools, and test the reliability and validity of the intended tool. However, to date, little information of this nature is available in the Middle East.

Objective of the project

The overall objective of this project was to complete an integrative literature review to analyze International studies for the purpose of determining cultural adaptations and validations of instruments needed to evaluate the QOL of patients in palliative care. The project then explored the use of these instruments in the Middle East context.

Research Question

To achieve the main objective the following research question will be addressed.

1) Which instruments used to evaluate the QOL for patients in Palliative Care have been validated and published?

2) Which instruments, if any, have been used to evaluate the QOL for patients in Palliative Care units in the Middle East?

3) Which instruments could potentially be used to evaluate QOL for patients in the Palliative Care unit in Qatar?

Method

To address the questions as stated above, a complete analysis of the literature was conducted. The literature review stages for problem formulation, data collection methods, data evaluation, data analysis and interpretation and data presentation were complied for research synthesis (Cooper, 1998). These Cooper Stages (Cooper, 1998) for research synthesis were adapted to interpret and analyze the selected papers in order to extract the needed information to answer the research questions. To determine the sample, scientific papers published in periodicals electronic databases were searched, such as CINAHL, Medline, Family & Society Studies Worldwide; Health Source: Nursing/Academic Edition; Middle Eastern & Central Asian Studies; Psychology and Behavioral Sciences Collection; SocINDEX with Full Text and PubMed from 1995-2014. The descriptors and search terms were identified with the University of Calgary in Qatar public services librarian. The descriptors which included hospice care, palliative care and terminal care were associated through the Boolean connector "AND", with QOL in English. The search was restricted to validation studies and to studies whose full text was available online. Literature was reviewed from the Western World as well as from the Middle East in the English language. The guiding questions of the study were taken into consideration during the search process. A total of 297 papers were found from the identified databases. The titles and abstracts were screened, and as a result, twelve articles were identified to be duplicated under more than one descriptor. The duplication articles were identified by using the RefWorks process. In the end, 271 articles were excluded as irrelevant according to inclusion and exclusion criteria as described in the method section. Twenty-one (21) articles met the inclusion criteria for this study.

All of the selected papers were quantitative validity studies which were conducted to validate various QOL instruments in the palliative care context. The studies were conducted in different countries; three studies were conducted in the United Kingdom, three in South Korea, two in Canada, two in Spain, one in German , one in Poland, one in Greece, one in India, one in France, one in Mexico, one in Taiwan, one in Israel, one in Italy, one in Sweden, and one in Norway. Thirteen different instruments were translated into various languages and validated in these different cultural contexts. A total of 13 different QOL instruments used in the area of palliative care were obtained for the purpose of this project.

Quality of Life Assessment Instruments

Studies have shown that many QOL instruments have been developed and are used to assess the QOL for cancer patients in the palliative care context (Catania, Costantini, Beccaro, Bagnasco, & Sasso, 2013, O'Boyle, & Waldron, 1997, Singh, 2010). The purpose of these QOL instruments are defined for research purposes, to assess cancer patients' QOL, support clinical practice, measure care outcome and improve patient's QOL at the end of life (Catania et al., 2013, Salisbury et al., 1999). Multidimensionality and subjectivity are the main standards for the QOL measurement tool in the health care system (O'Boyle, & Waldron, 1997, Salisbury et al., 1999). Most of QOL instruments cover the following main domains: physical, psychological, social, body image and sexual functioning (O'Boyle, & Waldron, 1997). Cancer patients' QOL measurement in palliative care need to be covered by different domains which help to determine the type of instruments required (Patrick, & Deyo, 1989, Wiebe, Guyatt, Weaver, Matijevic, & Sidwell, 2003). There are two different types of QOL instruments; generic and disease specific QOL instruments (Patrick, & Deyo, 1989, Wiebe et al., 2003).

Generic QOL instruments are applicable for a wide range of diseases and across different medical interventions (Coons, et al., 2000). These identified instruments are multidimensional that include different QOL domains like physical, psychological and social aspects (Patrick, & Deyo, 1989, Wiebe, et al., 2003). The instruments measure the concept of the QOL in a broad way across various health condition types and severities, therefore these instruments are applicable to patients with more than one medical condition but often lack to responsiveness to change (Patrick, & Deyo, 1989, Wiebe, & et al., 2003, Kaasa, & Loge, 2003). An example of the generic measure is the Sickness Impact Profile (SIP). The SIP measures sickness impact on the physical, psychological and social aspects of patient life (Patrick, & Deyo, 1989).

Disease Specific QOL instruments are designed to measure the QOL of patients with specific disease categories and are focused to evaluate clinically important changes (Patrick, & Deyo, 1989, Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). These instruments provide great details about the impact of illness on patients' QOL (Patrick, & Deyo, 1989, Wiebe, & et al., 2003, Garratt, & et al., 2002).

Disease specific QOL instruments focus on health aspects which are important to specific health problems in regard to cancer (Patrick, & Deyo, 1989, Wiebe, & et al., 2003, Garratt, & et al., 2002). The items in these instruments are designed to use various wording for items and instructions that are tailored to specific diseases. For example, cancer specific instruments items are focused on nausea, vomiting and cancer treatment related side effects (Patrick, & Deyo, 1989, Wiebe, & et al., 2003, Garratt, & et al., 2002). Disease specific instruments are multidimensional as they evaluate physical, social, and psychological aspects. These instruments are based on the nature of subjectivity to report symptoms and feelings of wellbeing (Kaasa, & Loge, 2003). Domain specific instruments evaluate specific health related QOL domains such as fatigue, pain or psychological distress and are sensitive to detect changes in the QOL related to the specified domain (Kaasa, & Loge, 2003). Assessments of the QOL often require a combination of generic, disease specific and domain specific instruments based on the study aim and purpose (Kaasa, & Loge, 2003).

Through this integrated literature review, the following QOL instruments used in the palliative care context have been selected for a closer review. They include:

1. The EORTC QLQ-C15-PAL (The European Organization for Research and Treatment of Cancer)
2. The Palliative Care Outcome Scale (POS)
3. The Support Team Assessment Schedule (STAS)
4. MC Master Quality of Life Scale (MQLS)

5. The McGill Quality of Life Questionnaire (MQOL)
6. Hospice Quality of Life Scale
7. Quality of Life at the End of Life (QUAL-E)
8. Palliative Care Quality of Life Instrument (PQLI)
9. Functional Assessment of Chronic Illness Therapy (FACIT)
10. MVQOLI (Missoula Vitas Quality Of Life Index)
11. Edmonton Symptom Assessment Scale (ESAS)
12. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30)
13. European Organization for Research and Treatment of Cancer - Lung Cancer (LC13) questionnaire

Discussion

Multidimensional Aspect of QOL Instruments

Thirteen different QOL instruments were identified and thoroughly reviewed for this integrated literature review, and were acknowledged for their ability to measure various aspects of QOL. The number of various instruments could be related to the concept of QOL itself, as it is a difficult concept to be defined. Because of this, different QOL instruments exist to measure various aspects of QOL (O'Boyle, & Waldron, 1997, Salisbury et al., 1999). All of the instruments examined captured the physical, psychological, and social aspects of the QOL. However, measurements of suffering and the meaning of life were not acknowledged. Failure to recognize these important aspects of QOL is therefore recognized as a limitation to the use of most of the tools described (Moro, & et al., 2006).

The meaning of life is considered to be an important determinate for QOL measurement in the palliative care context. However, only 2 QOL instruments, the McGill QOL questionnaire and the Palliative Care Outcome Scale (POS), captured or addressed this aspect in their measurements. For instance, the McGill QOL questionnaire captured 4 domains of QOL: physical, psychological, existential well-being and support. The existential well-being domain included meaningful existence, control over own life, feeling good about oneself and feeling that every day is a gift/burden (Cohen, Mount, Strobel, & Bui, 1995). The support domain included achieving one's goals, feeling that life is worthwhile, feeling that the world is caring and feeling supported (O'Boyle, & Waldron, 1997, Cohen et al., 1995). The authors acknowledge that the failure to address the patient's meaning of life is a limitation to the use of their instruments. In the current review four studies addressed the validity of the McGill QOL instrument.

First, the McGill Quality of Life questionnaire (MQOL-Taiwan version) validated the instrument on a sample of 64 Taiwanese patients with terminal cancer. The study validated the (MQOL-Taiwan version) for clinical and research use in Taiwan. The second study validated the McGill Quality of Life Questionnaire in hospice settings in Israel on a sample of 160 advanced cancer patients. The study concluded that the instrument is appropriate, reliable, and valid for the culture and Language of the Hebrew patient population. The third study validated the McGill Quality of Life Questionnaire in the palliative care setting in Canada on 143 patients with advanced cancer patients. The study findings suggest the tool is valid for the palliative care context in Canada. The fourth study validated the Korean version of the McGill Quality of Life Questionnaire on a sample of 140 palliative cancer patients. The study findings demonstrate strong reliable and validity scores for the instrument.

The Palliative Care Outcome Scale (POS) captures the meaning of life, life worthwhile and self worth aspects, however, it did not assess suffering (McMillan, & Mahon, 1994, Eischens, Elliott, & Elliott, 1998, Stevens, Gwilliam, A'hern, Broadley, & Hardy, 2005). One study that tested the POS reported some limitations in capturing the spiritual aspect for terminally ill cancer patients. It recommended the instrument to be expanded in certain areas to capture the spiritual domains and assess the patients' spiritual needs (Bausewein, & et al., 2005). In the review of four studies identified, the POS instrument proved to be a valid and reliable instrument to be used in the palliative care context. The first study validated the German version of the instrument on a sample of 118 advanced cancer patients. The authors concluded the instrument is valid and well accepted by the patients and staff. The second study validated the instrument in the United Kingdom on a sample of 262 cancer patients in the palliative care context. In this study the authors concluded the validity of the tool. A third study validated the scale in Argentina on a sample of 65 patients with cancer as well as 20 professionals. This study indicated that the Argentine POS is a valid and reliable measure of palliative care outcomes with advanced cancer patients. The fourth study validated the instrument in Spain on a sample size of 117 patients with advanced cancer. The results of the study proved a strong validity of instrument for use in the palliative context.

The Edmonton symptom assessment scale (ESAS) has identified that failure to address the meaning of life is a limitation in the use of this tool. In this study, authors reported that the ESAS has a limitation as it does not measure the suffering in cancer patients at the end of life (Moro, & et al., 2006, Nekolaichuk et al., 2008, Chang et al., 2000). The instrument measures the symptoms only in certain measurement levels and lacks the individual patient's experiences and expression (Moro, & et al., 2006, Nekolaichuk et al., 2008, Chang et al., 2000). In an additional study examining a review of the Italian version of the ESAS, a sample size of 83 in- patients and 153 home care cancer palliative patients were tested. The instrument was considered to be valid and reliable for physical symptoms assessment in the palliative context. The authors recommended the need for internal validity testing to be completed (Moro, & et al., 2006).

The Quality of Life at the End of Life (QUAL-E) instrument evaluates various important QOL domains at the end of life. These include the life completion aspect which explores the relationship with others, interpersonal connections, and the ability to help others (McAdams, & De St Aubin, 1992). The ability to help others is related to the generativity in the life span context theory of personality development (McAdams, & De St Aubin, 1992). The generativity has been identified as a concern in establishing and guiding the next generation, and it is considered as a key element in adulthood and in the end of life (McAdams, & De St Aubin, 1992, Steinhauser, & et al., 2004). Only one study in this author's review validated an instrument in Canada. This was completed on a sample of 464 patients with advanced cancer and concluded that the tool is valid to assess QOL for patients with advanced cancer.

Subjective Aspect of QOL Instrument

Thirteen QOL instruments identified the subjectivity of the QOL concept in that each patient has different values, needs and priorities in regard to QOL (Moinpour, Feigl, Metch, Hayden, Meyskens, & Crowley, 1989, Salisbury et al., 1999, O'Boyle, & Waldron, 1997). This is an important point for consideration in the palliative care context as it places patient value and autonomy as core to the concept of QOL (Salisbury et al., 1999). The use of subject language allows for the measurement of individual patient's experiences. With this understanding, care can be designed according to the patient's needs and preferences (Byock, & Merriman, 1998). Many QOL instruments have been used to measure the QOL for cancer patients who are not in terminal stages (Salisbury et al., 1999). It is important to understand the differences in QOL at the end of life, and that these differences will change for the same patient during the last days of life (Salisbury et al., 1999). Patient ratings for the symptoms assessment is considered to be the gold standard. However, in the current review, 6 studies acknowledged subjectivity a limitation of the study due to the often sudden deterioration in patient conditions at end of life (Salisbury et al., 1999, Nekolaichuk et al., 2008, Nicklasson, & Bergman, 2007, Bentur, & Resnizky, 2005, Kim et al., 2009, Kim et al ., 2006 Hearn, & Higginson, 1999). Measuring the QOL for terminally ill cancer patients is a challenge as with this stage of the disease, it can be difficult to get data from the patients themselves. This is often related to the dramatic changes in cancer patients' health status at the end of life (Catania, Costantini, et al., 2013, Salisbury et al., 1999). Measuring changes in the patients' health conditions over time will help health care providers to assess care and measure outcomes. However, the Palliative Care Outcome Scale (POS) instrument acknowledged this challenge of rapid changes in the health status of terminally ill patients and viewed this as an opportunity to assess patients at different time points. Therefore, health care professionals can tailor care according to patient and family needs (Hearn, & Higginson, 1999, Arraras, & et al., 1994).

Each research article in this review has been evaluated based on the instrument evaluation criteria. If an article recommended the combination of using two instruments to evaluate QOL for cancer patients at the end of life, this was credited as fulfilling a need to measure QOL from a different perspective or from a holistic approach (Gill, & Feinstein, 1994, Arraras, et al., 2014, Higginson, & McCarthy, 1994). In this current review, an examination of a study by Arraras, et al (2014) found a recommendation for using a combination of the EORTC QLQ-C15-PAL with another QOL instrument to ensure a comprehensive QOL assessment. Also, Higginson, & McCarthy (1994) recommended the combination of the STAS instrument with the Rotterdam Symptom Checklist and SF-36 in order to facilitate the inclusion of more appropriate measures to assess patients with advanced cancer. In an attempt to find a comprehensive instrument to measure QOL, authors recommend the EORTC QLQ-C30 instrument in certain aspects for comprehensive QOL assessment (Bausewein, et al., 2005, Fredheim, et al., 2007). Others recommended the development of a new QOL instrument to assess spiritual and social aspects in depth (Kim et al., 2007, Leppert & Majkowicz, 2013).

Recommendation from the Review

The availability and advancement of a well developed validated QOL instrument for use in the palliative care context in Qatar is a critical step to improve the QOL for cancer patients in end of life. This review identified the validated QOL instruments that are used in the palliative care context, and identified the lack of QOL instruments use in the palliative care context in the Middle East and in Qatar. This review will assist researchers in the Middle East and in Qatar to choose a preferred QOL instrument that could be trialed to assess palliative patients' QOL. The review concludes that there is no uniformly best QOL instrument and the decision to choose one over another, or combination of two QOL instruments, is based on the aim and purpose of QOL measurement. The review suggests every QOL instrument has its own strengths and weaknesses or limitation. As well, selecting QOL instruments for the palliative care context needs to be based on rigorous criteria rather than consensus (Simon et al., 2012). In order to adopt a validated tool to evaluate cancer patients' QOL in the palliative care context in Qatar, it would be crucial to take into consideration the instrument's evaluation criteria including the validity, reliability, psychometric properties of the instruments, responsiveness to change and respondent and administrative burden (Gill, & Feinstein, 1994, Kirkova, et al., 2006, Nekolaichuk et al., 2008, Simon et al., 2012). From this perspective, a result of this review recommends that health care professionals adopt and validate the palliative outcome scale (POS) in the palliative care context in Qatar, because of the multidimensional and the psychometric properties of the scale.

Conclusion

To conclude, QOL measurement research in the palliative care context helps to improve care outcome and enhance palliative patients' QOL. This review identified different validated QOL instruments in the palliative care context and highlighted the need to measure QOL in the palliative care context in the Middle East and in Qatar. The ideal instrument can be determined by the psychometric properties and the aim of the QOL measurement. Moreover, validity, reliability, responsiveness to change and respondent and administrative burden are the main instrument properties which need to be taken into consideration. The review also identified ideal instrument evaluation criteria and based on these criteria recommended the need to adopt and validate the POS instrument in the palliative care context in Qatar. POS is a useful multidimensional scale in the palliative care context in research and in clinical setting. The advancement of POS in Qatar may considerably advance and improve cancer patients' QOL measurement in Qatar.

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