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RETROSPECTIVE STUDY

Quality of life in end stage renal disease patients

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Abstract

AIM: To understand factors associated with quality of life (QOL), examine types of QOL instruments, and determine need for further improvements in QOL assessment.

METHODS: The method used databases (Pubmed, Google scholar) and a bibliographic search using key words QOL, end stage renal disease, Hemodialysis, Peritoneal dialysis, instruments to measure QOL, patients and qualitative/quantitative analysis published during 1990 to June 2014. Each article was assessed for sample size, demographics of participants, study design and type of QOL instruments used. We used WHO definition of QOL.

RESULTS: For this review, 109 articles were screened, out of which 65 articles were selected. Out of 65 articles, there were 19 reports/reviews and 12 questionnaire manuals. Of the 34 studies, 82% were quantitative while only 18% were qualitative. QOL instruments measured several phenomenon such as physical/psychological health, effects and burdens of kidney disease, social support etc. those are associated with QOL. Few studies looked at spiritual beliefs, cultural beliefs, personal concerns, as per the WHO definition. Telemedicine and Palliative care have now been successfully used however QOL instruments seldom addressed those in the articles reviewed. Also noticed was that longitudinal studies were rarely conducted. Existing QOL instruments only partially measure QOL. This may limit validity of predictive power of QOL.

CONCLUSION: Culture and disease specific QOL instruments that assess patients' objective and subjective experiences covering most aspects of QOL are urgently needed.

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Key words: Quality of Life; Hemodialysis; Peritoneal dialysis; Patient; End stage renal disease; Quality of life instruments

Core tip: Quality of life (QOL) in end stage renal disease patients is an important outcome measure. This study tried to understand the dimensions of various QOL instruments and association of various risk factors with QOL. Since each instrument measures specific aspect of QOL, use of any one of these instruments allows studies to measure QOL only partially compromising on the validity of the predictive power of QOL. Furthermore, less attention has been given on conduct of qualitative and longitudinal studies. There is an urgent need to develop disease and culture specific instrument that covers most aspects of QOL.

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INTRODUCTION

In medicine most assessments are conducted by laboratory tests or examinations from healthcare workers. Quality of Life (QOL), though equally important to assess the quality and outcomes of medical care, is not routinely measured. QOL instruments measure individ-



ual's own views of his wellbeing. The core components of QOL are physical, functional, psychological/emotional, and work/occupational^[1]. This review will discuss QOL of adult end stage renal disease (ESRD) patients. For this review, we used the World Health Organization' s (WHO) definition of QOL which is "individuals' 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". It is a broad ranging concept affected by the person's complex physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment^[2]. QOL can be used to gauge health system performance, mortality indicators, and compare health of groups^[3].

This review focused on adult ESRD patients since renal disease is a serious illness and treatment is challenging and prolonged. Globally, the estimated prevalence of chronic kidney disease (CKD) (the first four stages out of five) is 7.2% in adults over the age of 30 years^[4]. CKD is a major determinant of poor health outcome of noncommunicable diseases affecting 5% to 8% of world's population^[5]. Despite the substantial resources committed to the treatment of ESRD and significant improvements in the quality of dialysis therapy, patients continue to experience significant mortality and morbidity and a reduced quality of life^[6]. With improved medication, medical treatment, medical care and health technology, patients may be living longer but are they living a better life? The effect of the treatment is not only measured in terms of survival, but also in terms of well-being. There is an ever expanding body of literature related to various factors that affect QOL, like genetic, environmental, psychosocial, stress, emotional, and comorbidities. Findings have shown that lower scores on QOL were strongly associated with higher risk of death and hospitalization^[7,8] than clinical parameters such as serum albumin levels8 in cases of ESRD patients. It is also noticed that QOL in ESRD is most affected in the physical domains, and nutritional biomarkers are most closely associated with these domains compared to Kt/ V (marker of dialysis adequacy), mineral metabolism indices, and inflammatory markers which are poor health related quality of life (HRQOL) correlates^[9]. These findings demand more attention towards patients' essential QOL measures and indicators.

While assessing QOL, both subjective and objective information is necessary since they derive distinct types of information. Objective measures may be more suitable in detecting treatment effects, such as the number of days on dialysis. Subjective information (such as happiness, satisfaction, spiritual and religious beliefs) is also necessary to complete the QOL picture and enhance the interpretation of objective data. Both the illness and the treatment of ESRD influence subjective QOL factors.

Recently (2014), Boudreau JE has talked about the functional definition of concept of QOL by discussing three attributes: (1) the ability to engage in vigorous ac-

tivities; (2) the ability to engage in social and occupational roles; and (3) the ability to perform activities of daily living (ADL)^[10]. Reviews were conducted that included the type of measures, the instrument development process, study sample characteristics, particular quality of life domains, and reliability and validity testing. Some reviews provided an overview of the instruments used and judged the instruments in terms of their comprehensiveness, reliability, and validity^[11]. Few studies sought to establish which domains of QOL are most affected by ESRD^[9]. Review by Gentile^[12] did provide a variety of generic and disease targeted health related QOL instruments for patients suffering from ESRD. Yet, reviews have rarely discussed whether existing QOL instruments have covered both objective and subjective patient experiences as per the WHO definition of QOL.

Based on this background, the aim of this review was to understand the factors associated with QOL of adult ESRD patients, examine the various dimensions that QOL instruments measure, and identify if there is a need to expand the measurements of QOL.

MATERIALS AND METHODS

The search strategy detailed in Figure 1 was used to identify published literature in the English language during the years 1990 to June 2014. The search was conducted during March - June 2014 using the search criteria (key words, year and language) as mentioned in Figure 1. The search was conducted with MEDLINE, PubMed and was further expanded with Google Scholar using the same search criteria mentioned above. Title and abstracts of the studies were checked with the key words to screen the articles. This process generated 109 studies including research papers, reviews, reports and manuals relevant to our scope of interest.

Inclusion and exclusion criteria (as mentioned in Figure 1) were applied to the selected abstracts for relevance. If the author was not satisfied with the content of the abstract, the full paper was accessed and the same inclusion/exclusion criteria were applied. A total of 62 research papers met the criteria. The bibliography of the research papers was then reviewed to identify additional literature published in English that met the inclusion criteria. Three more research studies were identified by this process. In total, 65 research papers, reports, reviews and quality of life questionnaire manuals were included in this review

These 65 research papers were then arranged into four principal categories as follows: (1) Reports, reviews, published series, discussion articles; (2) Quantitative studies; (3) Qualitative studies; and (4) Quality of life questionnaire manuals (Table 1).

RESULTS

For this review 109 articles were screened, out of which 65 articles were selected. Out of 65 articles, there were

Table 1 First Author, year of publication, study design and questionnaire used

Ref.	Study design	
Reviews, Published series, Reports, Discussion articles		
Donald ^[1] , 2009	Published Series article	
POFS ABUSE ^[2] , 1997	WHOQOL Instruments Report	
Romero <i>et al</i> ^[3] , 2013	Discussion article	
EpiCast ^[4] , 2014	Report	
Couser <i>et al</i> ^[5] , 2012	Policy Forum	
Obrador <i>et al</i> ^[6] , 2014	Review	
Schatell <i>et al</i> ^[7] , 2012	Report	
Berman <i>et al</i> ^[9] , 2008	Systematic Review	
Edgell <i>et al</i> ^[11] , 1996	Review	
Gentile <i>et al</i> ^[12] , 2003	Review	
Kimmel <i>et al</i> ^[21] , 2006	Review	
Johansen ^[30] , 2007	Report	
Kutner ^[31] , 2010	Rehabilitation Report	
Valderrábano <i>et al</i> ^[46] , 2001	In-depth Review	
Fleck <i>et al</i> ^[53] , 2007	Discussion	
Carver <i>et al</i> ^[57] , 1995	Review	
Blinkhorn ^[61] , 2012	Review	
O'Connor <i>et al</i> ^[64] , 2012	Review	
Catania <i>et al</i> ^[65] , 2013	Report	
Quantitative	Study design	Questionnaire used
Mapes <i>et al</i> ^[8]	Longitudinal	KDQOLSF-36
Kao <i>et al</i> ^[13] , 2009	Cross sectional	SF-36
Abraham et al ^[14] , 2008	Case control, follow up	WHOQOL-BREF
Kimmel <i>et al</i> ^[15] , 2008	Prospective	Satisfaction with Life Scale (SLS), McGill QOL, Single item
Patel <i>et al</i> ^[16] , 2002	Prospective	McGill QOL, Beck Depression
Griva <i>et al</i> ^[17] , 2009	Cross sectional	SF-36
Elder <i>et al</i> ^[19] , 2008	Cross sectional, case mix	KDQOLSF-36
Sanner <i>et al</i> ^[20] , 2002	Cross sectional	SF-36, Nottingham Health Profile
Tondra ^[22] , 2014	Conceptual Framework, CS	Quality of Life Index Dialysis,
Mingardi et al ^[23] , 1999	Prospective	SF-36
Seica <i>et al</i> ^[24] , 2009	Cross sectional	SF-36, KDQOLSF-36
Bakewell <i>et al</i> ^[25] , 2002	Longitudinal / intervention	KDQOLSF-36
Theofilou ^[26] , 2012	Cross sectional/ Observational	WHOQOL-BREF, GHQ-28
Kim <i>et al</i> ^[28] , 2013	Cross sectional	KDQOLSF-36
White <i>et al</i> ^[29] , 2002	Retrospective cohort	SF-36
Painter <i>et al</i> ^[32] , 2000	Experimental/Intervention	SF-36
Ouzouni <i>et al</i> ^[33] , 2009	RCT	SF-36, Quality of Life Index
Agakhani et al ^[34] , 2012	Case control/comparative	SF-36
Hegazy <i>et al</i> ^[35] , 2013	Intervention/Pre-post	Karnofsky performance scale
Abraham $et al^{[36]}$, 2009	Prospective, intervention	Karnofsky performance scale
Moattari et al ^[37] , 2012	RCT	SF-12
Brennan <i>et al</i> ^[38] , 2007	Intervention, report	SF-36
Cukor <i>et al</i> ^[39] , 2013	RCT	KDQOLSF-36, Beck Depression Inventory
Lii <i>et al</i> ^[40] , 2007	Intervention/Experimental	SF-36
Sathvik <i>et al</i> ^[52] , 2008	Cross sectional	WHOQOL-BREF
Pagels <i>et al</i> ^[50] , 2012	Cross sectional	SF-36
WHOQOL-SRPB ^[54] , 2005	Cross cultural/sectional study	WHOQOL-SRPB
Yong <i>et al</i> ^[63] , 2009	Prospective cross sectional	SF-36, Charlson Comorbidity Index
Qualitative		
Baudeau <i>et al</i> ^[10] , 2014	Concept analysis	
Fennegan-John <i>et al</i> ^[18] , 2013	Interviews, FGD	
Arabi ^[41] , 2006	Interview	
Rygh <i>et al</i> ^[59] , 2012	Interviews with patients	
Stroetmann <i>et al</i> ^[60] , 2000	Observational	
Jablonski ^{102]} , 2007	Observational	
QOL instruments		
Choices for Healthy Outcomes In Caring for End Stage Renal Disease ^[27]		
Sickness Impact profile ^(*2)		
SF-36 ^[43]		
SF-12 ⁽⁴⁴⁾		
Nottingham Health Profile ^[#0]		
EQ-5D ^[147]		
McGill Quality of Life Questionnaire ^[40]		
GHQ-28 ⁽²⁾		
WHO-BREFICH		
Dialysis Symptom Index ¹⁰⁰		



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KDQOL-SF36^[56] CKD Questionnaire^[58]

QOL: Quality of life; CKD: Chronic kidney disease.



19 reports/reviews and 12 questionnaire manuals. Of these 34 studies, 82% were quantitative while only 18% were qualitative. Most quantitative studies were cross sectional. Only two studies used longitudinal design.

Association of various factors with QOL and outcome

The treatment for ESRD patients imposes heavy restrictions that affect QOL. QOL usually includes both objective and subjective evaluations of both the positive and negative aspects of life. Researchers have reported demographic, clinical, social, psychological, and treatment related associations with QOL^[1].

It has been proven that the patient's perception is more important than the clinical assessment in determining QOL^[15]. Figure 2 illustrates several factors having linear, inverse or no association with QOL. Studies have commented that QOL can be enhanced by intervention techniques as mentioned in Figure 2. The same figure further shows that lower scores on all three summary scores of QOL (physical component summary, mental component summary and kidney disease component summary) were strongly associated with death and hospitalization as revealed by Mapes in DOPPS study^[8] (predictive power of QOL).

Qualitative research

Qualitative research produces rich information that is not possible to get by quantitative research. Qualitative research conducted on ESRD patients has reported some of the themes (subjective measures) for QOL. These themes were physiological impact, impact of treatment, impact on daily life, psychological impact, impact on relationships, social impact and coping responses^[20]. Another study came up with three themes and sub themes as: (1) "life restricted" with sub-themes "being tied down", "feeling left out", and "doing without"; (2) "staying alive" with sub-themes "love from others", "accept illness as part of life", and "trust in God"; and (3) "feeling good" with sub-themes "personal satisfaction" and "being happy"^[41].

QOL instruments

Some QOL instruments provide a standard assessment of health. These instruments include questionnaires designed to be applicable for general population such as the Sickness Impact Profile (SIP)^[42], the SF-36^[43], SF-12^[44], the Nottingham Health Profile^[45,46] (used for primary care), the European Quality of Life Instrument - EQ-5D^[47], the McGill QOL (MQOL)^[48] scale



Figure 2 Factors associated with quality of life and predictive power of quality of life. Quality of life (QOL) is assessed based on several factors that show linear / inverse/no relationship with QOL. Based on these relationships QOL predicts Hospitalization or death. QOL: Quality of life; PCS: Physical component summary; MCS: Mental component summary; KDCS: Kidney disease component summary.

and GHQ- 28^[49]. Instruments designed by WHO such as WHOQOL^[50] WHOQOL-BREF^[51,52] are used by researchers. WHOQOL-SRPB^[53,54] is also used to assess spiritual, religious and personal beliefs (SRPB) within quality of life. In the CHOICE study, the research team is conducting several research projects for the development of patient-centered instruments for assessment of health-related quality of life^[27].

There are three disease-targeted questionnaires developed for ESRD patients undergoing dialysis. Dialysis Symptom Index (DSI)^[55], the Kidney Disease Quality of Life instrument Short Form- KDQOL-SF36^[56]. The Choices for Healthy Outcomes in Caring for End-Stage Renal Disease ([ESRD] CHOICE)^[27]. Additionally, few researchers use The Kidney Disease Questionnaire -KDQ^[58], Renal Quality of Life Health Profile (RQLP), and Quality of Life Index-D. Each QOL tool covers a number of domains (measurements of different characteristics) and they measure quantitative outcomes¹³. Culture specific validation has been reported for these instruments in many countries. Every instrument is scored on different domains. There is no one instrument that measures all the domains or most of the patients' perceptions towards their disease or life. The most common instruments used were SF-36 and KDQOL. Data collected by administering these questionnaires was analyzed using quantitative methods. Most studies use descriptive cross sectional design^[57]. In this review, out of 65 articles, 48% had used SF-36, 20% had used KDQOL, 16% had used WHOQOL and the remaining 16% had used GHQ-12, GHQ-28, McGill, DSI, QOLI (Table 1).

DISCUSSION

Researchers have reported a linear or inverse relationship between factors that improve or lower QOL. Researchers have defined attributes^[10] or used frameworks^[22] or models^[3] that encompasses certain aspects of QOL, such as demographic data, information on diet, treatments and their impact, anthropometric biomarkers^[50], and data related to mental health such as depression or anxiety. Most of the existing QOL instruments derived mainly quantitative information. Since QOL is subjective, more qualitative evidence needs to be gathered, assessed and understood. Although it is expensive and time consuming, incorporating qualitative methods will generate rich information.

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Considering the WHO definition of QOL and its multidimensional aspects, the instruments and models reviewed only partly assess QOL. Some of the domains were omitted, such as patients' thinking, learning, memory concentration, self-esteem, patient's perception about his body image, patient's feelings about his health and the surrounding environment, patient's age, patient' s dependence on medication or treatments, financial burden of treatment, and spiritual/religious beliefs^[27]. While studies that have used WHO QOL have covered some of the above-mentioned characteristics, they have not specifically covered these in relation to kidney disease. Although Paul Kimmel has commented that there is a need for proper measurements for judging QOL for chronic kidney disease patients^[21], not much attention has been given. There remains a need for an instrument that will capture the greatest number of QOL characteristics to get a broader understanding.

The results also reveal the need to conduct more longitudinal studies where researchers are able to detect changes in the characteristics of the population at a group level. Few longitudinal studies were conducted to report the usefulness of these instruments to find improvement in QOL over time. With longitudinal studies it would be possible to detect Minimal Clinically Important Difference (MCID) *i.e.*, a smallest change in treatment outcome that a patient himself would identify as important.

Culture plays a vital role in shaping individual QOL. An individual's values affects perception of QOL and this can differ between cultures as shown in DOPP study^[8].

Furthermore, the current instruments were developed some time ago. [KDQOL-SF36 (1995), KDQOL-36, SF-36 (2002), SF-12, EQ-5D (2004)] Since then (1995), medical technologies (e-health) and medical services have improved. Although telemedicine^[59], electronic/ digital processes in health, healthcare practice using the Internet, video conferencing with patients, and electronic medical records have been implemented, these services are not evaluated for QOL. For example, there is little published research on telehealth in renal units^[61]. Patients generally prefer to stay at home and telecare can extend homecare to peritoneal dialysis patients^[60], but use of telehealth is under researched^[61]. QOL instruments may be incorporated into telehealth assisted technologies for wider understanding and application.

For those who are not able to receive dialysis treatment, non dialytic management of ESRD seems to be a viable option. Patients managed conservatively had reported high symptom burden underscoring the need for concurrent palliative care^[64]. Hence, physicians are now considering palliative care services that specialize in symptom management for ESRD patients^[62,63]. This is especially important in frail, illiterate, elderly multimorbid patients with limited physical activity, where prognosis may not be altered by dialytic therapy. In such scenarios, palliative care will help improve quality of life. Though Catania G. has come up with a frame work to assess QOL with palliative care intervention^[65], he has explained the complexity involved in measuring palliative care as an intervention. The existing QOL instruments have rarely looked at palliative care aspects for improvement of patient well-being. Inclusion of newer technologies and therapies measured over time may also help to establish the minimally important differences that would constitute a real change in scores as well as clinically meaningful differences.

Studies have shown that QOL has improved with hemodialysis treatment as compared to peritoneal dialysis^[22,25]. Another study has shown that QOL is better for patients treated at home^[60]. In most cases peritoneal dialysis treatment is given at home. These two results may look contradictory but they are reported by two different studies. Is it the type of treatment or the place of treatment that affects QOL? It will be interesting to know what will be the result when both aspects are looked at by the same study. When several other factors are studied and included in the model, with the help of statistical analysis it will be possible to identify which factor affects QOL the most. Most instruments do not cover health literacy, which also has an impact on QOL. In the case of illiterate patients, sufficient data may not be available, so pictorial forms of the instruments may help.

Since patient-reported baseline QOL levels provide additional predictive information^[7], it is important to consider a patient's evaluation of their own QOL along with other aspects. A possible limitation of the study is that we were only able to review a portion of the research studies.

In summary, QOL is multidimensional where many indicators are intertwined and that affect person's overall QOL. Indicators based solely on certain characteristics of the patients pose serious restrictions to the measure of QOL. Ultimately, this may limit the predictive power of QOL. In examining QOL of ESRD patients, much work remains. The challenge for the next decade will be to continue to design a QOL instrument that takes both disease specific and culture specific subjective and objective factors into account so that it would be possible to get the complete assessment of QOL of ESRD patients.

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COMMENTS

Background

Quality of life (QOL) is considered as an important outcome measure. Researchers have claimed that it is even better than clinical parameters. Understanding QOL of end stage renal disease patients is necessary because renal disease is a serious illness and treatment is challenging and prolonged. Though there are various instruments to measure QOL, it is necessary to understand the dimensions used for assessment by these instruments and if there is a need to improve the existing QOL instruments.

Research frontiers

There are several instruments to measure QOL. Each instrument measures certain dimensions of human characteristics. Most of the instruments record objective information and measure QOL quantitatively. Most of the studies use cross sectional design that gives only snap shot information. An instrument designed by WHO measure subjective information but do not assess information related to kidney disease. These instruments rarely record the modern technologies such as telemedicine, e-health, conservative care *etc.*

Innovations and breakthroughs

There is an urgent need to develop QOL instrument that will try to look at the majority of (objective and subjective) characteristics of patients as well as the effect of new technologies like e-health and therapies like palliative care. QOL instruments, those are currently in use, have been developed some time ago. [KDQOL-SF36 (1995), KDQOL-36, SF-36 (2002), SF-12, EQ-5D (2004)] Since then (1995), medical technologies (e-health) and medical services have improved.

Applications

The newly designed QOL instrument that takes both diseases specific and culture specific, objective and subjective factors into account will help physicians to plan targeted intervention strategies based on strongest and weakest factors that affect QOL. With availability of complete QOL assessment, it will be possible to predict disease outcome effectively.

Terminology

Studies have reported that QOL can be used as an outcome measure in terms of hospitalization and mortality. The strength of this prediction would depend on how rigorously and comprehensively QOL was assessed. This is indicated as validity of the predictive power of QOL.

Peer review

This is an interesting topic.

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