Quality of Life After Kidney Transplantation: The Bright Side of Life?

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This review describes the state-of-the-art on quality of life (QOL) in kidney transplant (KTx) recipients. More specifically, posttransplant QOL is compared with the pretransplant evaluation, with other chronically ill patient populations, and with healthy subjects. Determinants, consequences, and potential interventions to improve QOL are also summarized. However, because of the methodological diversity of published articles, this review starts with addressing some conceptual and methodological concerns surrounding research on QOL in general and in KTx recipients specifically. The ultimate goal of this review was to identify the gaps in the state-of-the-art evidence and to provide some guidelines for conduct of research in the future.

Index Words: Quality of life; Kidney transplantation; Well-being; Review; Life satisfaction; Perceived health status

Kidney transplantation (KTx) is a frequently performed life-prolonging procedure with excellent current survival rates. A functioning kidney graft offers patients the potential of freedom from frequent, time-consuming, and uncomfortable dialysis treatments. However, KTx recipients are confronted with side effects of the immunosuppressive regimen causing significant comorbidity, including cardiovascular complications,[1] de novo malignancies,[2] and infections.[3] Moreover, no satisfactory solution is available to prevent recurrence of the underlying cause of end-stage kidney failure[4] or to treat chronic allograft nephropathy.[5] If the benefits and costs of KTx are to be fully realized from the patient perspective, survival alone can no longer be the sole outcome measure of success.

Research on quality of life (QOL) has grown exponentially during the last 20 years, with numerous reports published. Dew and colleagues[6] very nicely described the QOL of several organ transplant recipients in a quantitative review published in 1997. Yet, recent reviews summarizing the state-of-the-art of QOL in kidney transplant recipients are absent. This review comprehensively describes the QOL of kidney transplant recipients based on studies performed in the last decade (1996-2006). The databases Medline, Cinahl, and Psyclit were searched for relevant articles written in English. In addition, the reference lists of retrieved articles were scrutinized for additional publications. The following search strategy was used: kidney OR renal AND transplant AND quality of life OR QOL OR HRQOL OR health status OR life satisfaction OR well-being. Out of 485 abstracts, 118 articles were selected for detailed analysis because their abstract indicated a review of the QOL literature in kidney transplantation or original QOL research in adult KTx recipients.

In the present review, posttransplant QOL will be compared with the pretransplant evaluation, with other chronically ill patient populations, and with healthy subjects. Determinants, consequences, and potential interventions to improve QOL are also summarized. However, because of the methodological diversity of published articles, this review starts with addressing some conceptual and methodological concerns surrounding research on QOL in general and in KTx recipients specifically. This critical appraisal of the methodological quality of articles will be provided initially because such concerns should be taken into account when interpreting the results of the

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information in the literature. The ultimate goal of this review was to identify the gaps in the state-of-the-art evidence and to provide some guidelines for conducting research in the future.

Conceptual and Methodological Quality of Publications on QOL in KTx

A first methodological drawback refers to the lack of a conceptual framework to define and measure QOL. Because of the lack of a universally accepted conceptual definition, it is difficult to determine what constitutes QOL. The concept is often used as an "umbrella term" that covers a multitude of aspects without exactly stipulating the significant components of QOL. Some authors used the terms QOL, health-related QOL or perceived health status interchangeably, although they have a different meaning and do not provide a definition of these terms. It has been argued that QOL is a complex, multidimensional concept encompassing the impact of disease on overall QOL and physical, mental, and social functioning.[6-9] These dimensions are derived from the World Health Organization's holistic definition of health as "a state of complete physical, mental and social well-being and not merely absence of disease or infirmary."[10-12] Typically, health care workers are interested in health-related aspects of QOL, although nonmedical aspects including family relationships, pet ownership, and spirituality can also influence QOL. Investigators should invest in a sound conceptualization of QOL to provide a framework for all future QOL research. By doing so, the concept of QOL can be made less ambiguous than it is currently.[13-19]

Second, in view of the lack of a conceptual definition, it is not surprising that QOL is operationalized and measured in multiple ways in the kidney transplant literature. The reasons for choosing a particular instrument and information on the psychometric properties of the measurement tools in terms of reliability and validity are usually not given. According to the landmark study of Gill and Feinstein[20] on the caliber of QOL assessments in different patient populations, an adequate measurement of QOL should provide patients the possibility to indicate the domains that are important for their QOL because QOL is a highly subjective concept. However, no reports on QOL in KTx recipients have used this approach.

Furthermore, a large methodological diversity among studies exists with respect to design. Qualitative research, allowing more in-depth analysis of what constitutes a patient's individual QOL, does not exist in the field of KTx. The majority of quantitative studies used cross-sectional designs and included patients with a varying posttransplant status, ranging from a few months to several years posttransplant. A baseline assessment of QOL in these studies is lacking. Although these reports provide summary data on overall QOL, it is difficult to conceive that the overall QOL of patients with widely ranging outcomes after transplantation will be the same. For instance, it is possible that QOL may change over time because of the emergence of infection, rejection, and side effects of immunosuppressive medications. No study looked at QOL during or immediately after a rejection episode. The majority of studies even exclude patients who are experiencing medical problems at the time of assessment. On the other hand, it is possible that patients maintain good overall QOL despite a deteriorating physical status (ie, the disability paradox).[21] The disability paradox refers to the view that individuals with disabilities experience a good or excellent QOL despite their physical disability, even though most external observers may assume that these people live an undesirable daily existence. The disability paradox, therefore, concerns the dissonance between objective conditions and subjective experiences.[21]

Longitudinal, prospective designs are preferred to prospectively evaluate QOL over time in the same cohort of patients. When a longitudinal study is not possible, cross-sectional studies should only include patients with similar posttransplant status (eg, 1 year posttransplant) in order to better reflect the QOL of KTx recipients at a given moment in time during their course after transplantation. In such studies, the majority focused data collection on the early posttransplant period. Because of improving survival rates, QOL research should broaden its focus to the period