Quality of life of chronic kidney disease patients in developing countries

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In the developing world, the emphasis of care for the patient with chronic kidney disease is, in general, focused on the basics of care and patient survival; attention is not primarily focused on quality of life assessments. However, this arena is beginning to attract more attention. It is important to determine if standardized instruments are valid in the developing world and which unique assessments need to be utilized in individual cultural settings.

Kidney International Supplements (2013) **3,** 227–229; doi:10.1038/kisup.2013.20

KEYWORDS: cultural specificity; developing world; dialysis; quality of life

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Very little data are available concerning the quality of life (QOL) of patients with end-stage renal disease (ESRD) maintained on dialysis in the developing world. In contrast, assessments of the QOL of ESRD patients in the developed world have been recently attracting much attention and have been used as key outcome measures in several studies examining new approaches to ESRD care.[1–3] QOL assessments have generally relied on the use of standardized questionnaires that assess patient perceptions of their health and life.[1–3] However, the value and utility of these standardized instruments used to assess QOL in developed countries may or may not be applicable or relevant to patients in the developing world.

The World Bank classifies countries (for operational and analytical purposes) into four groups based on gross national income (GNI) per capita:[4]

(1) Low-income countries—GNI per capita of $1005
(2) Lower middle-income countries—GNI per capita of $1006 to $3975
(3) Upper middle-income countries—with GNI per capita of $3976 to $12,275
(4) High income countries—with GNI per capita of over $12,276.

The World Bank classifies all low- and middle-income countries as developing. The list of developing countries includes more than 100 countries, comprising about 80% of the world's population.[4] However, importantly, this classification does not necessarily reflect development status or imply that all economies in the group are at a similar developmental stage.

WHO defines QOL 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. It is affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment. Importantly, QOL needs to be thought of in relationship to the cultural milieu of the patient.

In the developing world, the emphasis is, in general, on patient survival—that is, simply getting some form of renal replacement therapy; attention is not primarily focused

on QOL. Care is often suboptimal by developed world standards. Hemodialysis (HD) is often done two times per week and peritoneal dialysis exchanges are frequently limited by costs. Standardized adequacy measures are often not targets of therapy and care is determined more by financial concerns rather than adequacy issues. The management of associated conditions, such as anemia, bone mineral disorders, cardiovascular problems, nutrition, and mental health issues, is limited by available resources and is, therefore, often suboptimal (at least by the standards of Western treatment guidelines) and thus can lead to further compromises in QOL. Preserving life is the concern—QOL is not the major focus.

However, investigators are now beginning to study the QOL of patients in the developing world. A variety of additional factors need to be considered in addressing the QOL of these patients. Lack of access to health care, in general, is a major problem. Few patients are followed in chronic kidney disease clinics and thus there is little preparation for developing an understanding of the impact of ESRD therapy. Often, the patient and his/her family have to assume the financial burden of care. This burden often comes at the expense of other family necessities, such as the care of other members of the family, education, nutrition, etc. The impact of these financial stressors on the QOL of the patient needs to be integrated into the understanding of the impact of ESRD and its treatment.

Recently, however, well-done studies from Iran, Brazil, the Philippines, India, and Turkey (among others), as well as studies involving indigenous and disadvantaged populations in developed countries, have examined patient perceptions of QOL.[6–11] In some studies, standardized QOL instruments have been modified; in others, they have not. Interestingly, when similar instruments are used, the scores on these HRQOL instruments are similar to the scores in developed countries, suggesting, not surprisingly perhaps, that the challenges for the patient with ESRD care may be independent of cultural background. The emotional burden of ESRD care for patients and the impact on their mental health may not be that different in developing and developed countries. However, what is most important about these studies is that they are laying the groundwork for future investigations by establishing baseline QOL scores for ESRD patients in these countries using standardized instruments. And, they have been important in setting the stage for intervention trials to improve the QOL of ESRD patients. Thus, randomized trials of exercise programs in HD patients in Turkey and cognitive behavioral therapy to treat depression in HD patients in Brazil have shown significant improvements in not only depression scores but QOL measures as well.[12,13] However, these assessments and treatment algorithms need to be understood in the cultural context of the patient, as emphasized above.

The burden of CKD in the developing world is expected to increase dramatically over the next several years. This relates to the increase in life expectancy, improved economic outlook, and dramatic increase in the incidence of hypertension and diabetes. In addition, the continued high incidence of infectious diseases (such as hepatitis B and C, HIV, malaria, skin infections, etc.) will continue to contribute to the high prevalence of renal disease. Expanded health-care services will also give a broader access to health care for individuals who now do not receive care. ESRD services will surely expand. Most recent studies indicate a dramatic increase in the prevalence of ESRD care in the developing world. It then will be important for each country to begin to develop acceptable methodologies for assessing the QOL of their patients. It remains to be determined if studies and instruments from the developed world will be applicable to the developing world. The different cultures, outlook on life, literacy, economic status, access to the basic needs of life (including clean water), nutritional status, mental health support, and involvement of national health systems all need to be taken into consideration.

Gender issues are also important. In many communities in the developing world, women are discriminated against, have limited support, and have limited access to health care and educational opportunities. QOL assessments need to take this problem into consideration.

Lastly, note needs to be taken of alternative health-care systems and social supports that are available in the developing world and have much more limited availability in the developed world. These include extended family, village, and tribal support systems, and traditional approaches to health-care delivery.

In conclusion, there is a need for more studies to assess the QOL of patients in the developing world. It needs to be determined if standardized instruments used in the developed world are applicable and useful in the developing world. It is likely that culturally specific instruments will need to be developed and validated in individual countries. It is important to keep in mind that a variety of factors that have an impact on QOL need to be considered in the developing world and that there are likely unique points to consider in each country. In many countries, providing basic care to sustain life takes precedence over QOL assessments. However, as ESRD care expands and the number of CKD patients increases, the focus will need to shift from simply prolonging life to providing a better QOL.

DISCLOSURE

All the authors declared no competing interests.

ACKNOWLEDGMENTS

Publication of this article was supported in part by the National Health and Medical Research Council of Australia through an Australia Fellowship Award (#511081: theme Chronic Disease in High Risk Populations) to Dr Wendy Hoy, School of Medicine, the University of Queensland, and the National Institutes of Health—NIDDK DK079709, NCRR RR026138, and NIMHD MD000182.

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