

# Quality of life for transplantation patients: National Institute of Nursing Research Spring Science Work Group\*

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Quality of life for transplantation patients offers many opportunities for basic science and clinical researchers, ranging from biological and behavioral investigations to clinical interventions and population studies. Specific topics of interest for the field of transplantation research that have immediate application to studies of quality of life include signs and symptoms of chronic illness, biobehavioral risk factors for disease, functional disabilities, patient outcomes, adherence to treatment, care delivery, roles of families and caregivers, strategies of stress management, special needs of children and high-risk patients, health promotion and education, and long-term care. These topics offer investigators a unique opportunity to develop and apply integrated prevention and treatment strategies and to contribute valuable insights and skills to multidisciplinary research teams needed for quality-of-life studies of transplantation patients. (Heart Lung® 2001;30:5-8.)

**T**he National Institute of Nursing Research (NINR) sponsored a Spring Science Work Group, Quality of Life for Transplantation Patients, at the National Institutes of Health (NIH). The work group addressed the following topics: science gaps in the transplantation literature addressing quality of life for long-term survivors of transplantation, critical research questions which need to be answered to improve quality of life for long-term survivors of transplantation, and mechanisms to increase research training and career development, resource opportunities, and collaborative

strategies. Specific science areas and potential areas of research opportunity included special needs of children and adolescents, predictors of quality of life before and after transplantation, biobehavioral interventions to improve quality of life, and the use of telehealth interventions to improve the relationship between care delivery and quality of life. (For more information on telehealth initiatives, visit: <http://grants.nih.gov/grants/guide/pa-files/pa-00-138.html>.)

## SCIENCE AREAS AND OPPORTUNITIES

The work group addressed gaps and opportunities in 3 areas of research on quality of life for transplantation patients: signs and symptoms of chronic illness that impair quality of life, modulating physiologic and psychological complications to enhance quality of life, and effects of interventions to improve quality of life for long-term survivors of transplantation. Within each area, the work group identified compelling opportunities for research.

Transplantations are performed on children and adults with end-stage diseases of the heart, lung, liver, kidney, pancreas, and bone marrow, or with

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hematologic or immunologic disorders such as cancer and leukemia. The work group participants reported that quality-of-life outcomes after transplantation have been studied since the early 1970s. Interest in quality of life has come to the forefront because of increased survival of patients due to the success of transplantation for end-stage organ disease. Work group presenters noted that transplantation is far less risky today than it was 20 years ago; surgical procedures have been refined, a broad array of immunosuppressant agents is available, and rejection of grafts is frequently prevented. Because of these advances, quality of life has become a key indicator of the success of transplantation, joining the more traditional indicators of morbidity, mortality, and cost-effectiveness.

The work group noted that quality of life is a multidimensional concept that is inclusive of the following areas: physical/physiologic function, mental/psychologic status, social function/interaction, and global well-being. Various research projects have been conducted to assess these aspects of the lives of transplantation patients and have included cross-sectional analyses of life changes among transplant recipients, comparisons of the outcomes of transplantation with other treatments and control groups, comparisons of quality of life among patients receiving different organ transplants, identification of predictors of quality of life, and longitudinal investigations from pretransplant to several years posttransplant.

## RESEARCH DIRECTIONS

The work group identified several broad issues for future research to improve the quality of life for transplantation patients. In addressing these issues, the workgroup emphasized that this research requires approaches and multidisciplinary research teams that can answer both the biological and behavioral questions that arise regarding long-term transplantation survivors.

## Methods and measurements

Standard definitions of quality of life and standardized measures and instruments are needed to compare data within and between patient and transplant groups. Rigorous, well-designed, prospective, and longitudinal studies that evaluate improvement in the physiologic, psychologic, functional, and social aspects of quality of life among patients of different types of organ transplantation have not been completed. Efforts to develop generic and disease-specific measures and tools for assessing quality of life are under way and robust efforts should be continued.

## Predictors of quality of life

Standard predictors of quality of life need to be defined (in relation to expected outcomes) for all organ transplant categories. Specific research topics to be pursued include the following: the complex of factors and the interaction of body systems that give rise to metabolic change; the contribution of cardiac allograft vasculopathy, osteoporosis, and stressors that impede successful quality of life; changes in the predictors of quality of life over time; the effect of new and emerging treatments (eg, new immunosuppressants, biotechnology and nanotechnology devices, xenotransplantation, mixed chimerism); differences in predictors of outcome by age, gender, culture, race and ethnicity, and socioeconomic status of patients; and specific effects of transplantation (eg, work, sexual function, spirituality, and financial stability).

## Interventions to improve quality of life

Aggressive interventions to improve quality of life need to be developed, tested, and evaluated. Specific and comprehensive interventions are needed for all facets of quality of life including before and after transplantation. The effectiveness of interventions should be evaluated from both a biological and a behavioral perspective. Develop, test, and evaluate specific and comprehensive interventions for biological and behavioral components of quality of life for pretransplantation and posttransplantation. Design pretransplant interventions that maximize posttransplant outcomes.

Interventions may include, for example, dietary and nutritional strategies to mediate metabolic changes or reduce obesity, nonpharmacologic approaches to prevent or slow the progression of osteoporosis (particularly for women who are postmenopausal and osteopenic), education to increase physical activity, biobehavioral approaches to help patients and their families cope with stress, and comprehensive approaches that include multiple aspects of rehabilitation.

## Adherence to treatment

Identify the factors that affect patients' adherence to pretransplant and posttransplant regimens, determine the relationship between pretransplant and posttransplant adherence patterns, and evaluate the cost-effectiveness of different methods for monitoring compliance (including home monitoring). The relationship between pretransplant and posttransplant adherence requires further study.

## Special needs of children and adolescents

Compare and contrast the physiologic, psychosocial, cognitive, psychomotor, and affective milestones of children and adolescents who have received transplanted organs with those of children and adolescents who have not. Define the psychosocial development of children and adolescents during the periods before and after a parent, sibling, or caretaker receives a transplanted organ. Longitudinal studies need to be implemented to assess growth and developmentally appropriate trends in children who are recipients of a transplanted organ through adolescence, young adulthood, adulthood, and older adulthood.

## Influence of family dynamics on patient outcomes

Determine the effect of gender and social role in the family of a transplantation patient. Identify the evolving metamorphosis of social interactions within the family and among caregivers before and after the transplantation experience and correlate how these factors affect patient outcomes, including biobehavioral measures of quality of life. Of particular interest is the psychosocial adjustment of the sibling of a transplantation recipient.

## High-risk groups

Identify patients at high risk for poor quality of life after transplantation (eg, patients who are or become pregnant, children who are transplant recipients or have parents who are transplant recipients, persons with limited access to care). Appropriate, effective, and ethically sensitive interventions for these groups need to be developed. Assess patients' understanding of the possibility of developing chronic conditions, such as diabetes mellitus and osteoporosis, when teaching and counseling about the risks for these maladies. Conduct behavioral research in conjunction with biological studies to better develop a holistic approach for interventions for the disease mechanisms afflicting high-risk groups. Identify disease markers for high-risk patients and monitor the development and progress of symptoms to prevent or delay the onset of further illness.

## Effects of quality-of-life interventions and cost on long-term outcomes

Compare and contrast risk factor profiles for interventions that are directed toward modifying molecular, biologic, behavioral, environmental, and lifestyle factors to better manage symptoms, en-

hance long-term survival of transplantation patients, and prevent complications beyond 3 to 5 years for different transplant groups.

## Relationship between care delivery and quality of life

Design and test specific interventions such as counseling patients to take charge of their health. Determine the optimum setting for treatment (eg, home, clinic, or group) in terms of the needs of the patient. Develop clinical interventions for helping patients obtain information about resolving their clinical problems before and after transplantation.

## Educational interventions

Develop and test innovative strategies for educating patients and health care providers about the importance of quality-of-life outcomes for transplantation patients. Explore the use of innovative communication and information technologies (eg, telehealth) for educational interventions, care delivery, long-term follow-up of patients, and monitoring of patients' adherence to health care regimens. Consider the possibility of using the Internet to establish a "virtual" center for automated, long-term tracking of transplant recipients.

## RESEARCH TRAINING, RESOURCE OPPORTUNITIES, AND COLLABORATIVE STRATEGIES

The work group encouraged the use of a variety of research training strategies and career development opportunities. For example, efforts could be made to attract doctoral students, postdoctoral investigators, and faculty from clinical research fields such as nursing into transplantation research, and special action could be taken to increase the participation of minority investigators. In addition, transplantation coordinators, who are often nurses, could be encouraged to broaden their research training to enhance their participation in, and contribution to, research projects.

The work group noted that NINR and other institutes and centers at the NIH could be used to support research training in quality of life for transplantation patients. Nurse researchers, in particular, were encouraged to apply for the new NIH awards for clinical research training. These opportunities are listed on the NINR Web site at: <http://www.nih.gov/ninr>. Other possibilities for research training include summer postdoctoral programs, short-term courses in the evening and on weekends, and distance learning (eg, courses on the Internet).

The work group suggested that efforts to identify hindrances to research training in transplantation

and quality of life would be useful and could serve as a basis for developing strategies to overcome these obstacles for nurse researchers and other investigators. Two potential roadblocks are the dearth of quality mentors and the difficulty of creating linkages among the relatively few number of researchers in this field. Efforts to overcome these deterrents are needed. To enhance their expertise in transplantation research, scientists are encouraged to seek NIH and other sources of support for clinical research training and to take advantage of related research training and career development programs.

With regard to resource opportunities and collaborative strategies, the work group emphasized the need for comparative data on quality-of-life issues for and across organ transplant categories. Multicenter studies that use standardized protocols and measurement tools could accelerate compilation of such data and evaluation of the effectiveness of interventions. The work group noted that some research topics (eg, quality of life among pediatric or pregnant transplant recipients, cross-sectional analyses of quality of life among long-term survivors) can only be explored through multicenter studies. Collaboration between biological and behavioral scientists should be fostered. Scientists from multiple disciplines engaging in biobehavioral research was strongly encouraged.

The work group also suggested that patient support groups, nonprofit organizations, and industry be invited to participate in networking, education-

al, and outreach activities. For example, industry could be approached for support of prospective studies of quality-of-life issues, research training (eg, postdoctoral fellowships), workshops, and scientific meetings. Patient support groups could be invited to collaborate in the organization of networks to track patients' long-term outcomes. Non-profit organizations may be interested in supporting informational or educational efforts.

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