

**The 2020 National Nursing Research Roundtable: Care Transitions from Pediatric to Adult Care: Planning and Interventions for Adolescents and Young Adults with Chronic Illness, March 5-6, 2020**

The 2020 National Nursing Research Roundtable (NNRR) was co-sponsored by the National Association of Pediatric Nurse Practitioners (NAPNAP) and the National Institute of Nursing Research (NINR), part of the National Institutes of Health. Representatives from over a dozen professional nursing societies met to discuss opportunities and challenges in pediatric to adult healthcare transitions (HCT) for adolescents and young adults (AYA) with chronic illnesses.

NINR Acting Director Dr. Tara Schwetz provided an update on NINR research and current activities and outlined the topic of transitions from pediatric to adult care for AYAs with chronic conditions. She described the issues that all adolescents face as they enter adulthood, such as balancing growing independence with heightened vulnerability to health risks, and the frequent exacerbation of chronic conditions in patients age 12-25.

The process of AYA HCTs involves transferring care from a pediatric to an adult provider and facilitating appropriate levels of independence and support for youth, with the goal of achieving optimal health and quality of life. A lack of structured HCT interventions is associated with adverse consequences, such as discontinuity of care, difficulties with treatment adherence, excess morbidity, dissatisfaction and worry, and preventable emergency department and hospital visits.

Dr. Schwetz noted that the complexity of transition care underscores the need for health care professionals across subspecialties and care settings to work collaboratively. She identified nurse scientists as leaders in the development of evidence-based interventions that may be translated into clinical practice and policy to optimize transitional care health outcomes. Dr. Schwetz noted that the multifaceted roles of nurses and nurse scientists in team science—as clinicians, researchers, educators, coordinators—position them to face the pressing challenge of pediatric to adult transitional care.

In her keynote address, Dr. Cecily Betz of the University of Southern California described several pediatric conditions that were fatal in childhood until recent health care advances allowed survival into adulthood. As a result, patients and their families face new challenges with the transition from pediatric to adult healthcare. Dr. Betz cited research that revealed numerous, sometimes life-threatening problems that arise, including increases in health complications and adverse events, delays in seeking treatment, more mental health issues, and increased costs of care.

Dr. Betz noted that former Surgeon General C. Everett Koop drew attention to the matter with a 1989 conference, “Growing Up and Getting Medical Care: Youth with Special Health Care Needs,” which initiated a research agenda to better understand the situation and to develop, test, and implement service models. The important role of nursing was recognized in the early stages of research in these HCTs. Nurses contribute expertise in comprehensive, coordinated, and interdisciplinary care frameworks. Nurse scientists have published several systematic

reviews on HCT research in the past 12 years, however there are persistent gaps in knowledge, due to limitations in areas such as the scope of conditions and interventions studied, and applicability of findings to implementation.

Dr. Betz identified persistent gaps in HCT research, such as the lack of rigorous study design, organizational frameworks for outcomes measurement, and evidence-based standards. She enumerated future developments in HCT research that are poised to move the field forward, including the development of HCT tools, more rigorous research design and methodology, and evaluation of contributors to health care disparities and social determinants of care. She addressed the relevance of the field to nurse scientists involved in pediatric and adult care, the opportunities for them to develop and test innovative approaches and models of care, and the need for more collaboration between nurse scientists and colleagues from other disciplines in pediatric and adult health care settings.

Dr. Grayson Holmbeck of Loyola University Chicago discussed his HCT research in spina bifida (SB) patients, who experience multiple transitions due to the complicated nature of their conditions. Because SB affects several organ systems, patients must visit multiple clinics, and they may progress from pediatric to adult care with different specialists at different times. The condition can require significant self-care and medication responsibilities, as well, with potentially severe health consequences from non-adherence. Hence, parents of these patients often face conflicting interests: ensuring their child's health and adherence to treatment while fostering independence.

Dr. Holmbeck has led the ongoing Chicago Healthy Adolescent Transition Study (CHATS), which encompasses a longitudinal analysis of the social and neuropsychological difficulties in a cohort of youths with SB, the **transfer** of medical self-management from parent to child, and the **transition** from pediatric to adult health care. The study showed that some youths who were given self-management responsibilities lacked the skills for these responsibilities. In comparison with healthy adolescents, SB patients demonstrated a 2-year lag in the transfer of decision-making responsibility, with a more significant delay in decision-making autonomy in youths from lower socioeconomic status backgrounds. Recent data revealed that, at age 13, two-thirds of SB patients were able to take on more medical responsibilities from their parents, but one-third of patients did not progress to this level of responsibility. Predictors for an increase in autonomy included higher IQ, being female, and lower levels of family stress.

Although there are now SB research measures for HCT completion, CHATS initially adapted measures used for other chronic conditions, such as type I diabetes, for use with SB patients. However, the cognitive disabilities and multiple HCTs associated with SB generated a more complex picture. Dr. Holmbeck emphasized the ongoing research questions generated by the medical, physical, and cognitive challenges that youth with SB and their parents face that are coupled with social, psychological, familial, and maturation transitions.

Dr. Roberta Rehm of the University of California, San Francisco, described her research on AYA patients with chronic conditions and cognitive disabilities who cannot develop the skills

necessary for autonomy in self-management. Because of their reliance on complex medical technologies, they will need assistance well into adulthood to survive. Dr. Rehm advocated for increased inclusiveness in care, particularly community services, because these patients spend the majority of their lives at home and in the community. She proposed that it would lead to continuity in care, and high quality of life and well-being, in the context of complex conditions and entering adulthood.

Dr. Rehm led the Transition to Adulthood Planning Study (TAPS), which examined planning processes for families of youth with complex chronic conditions who are entering adolescence and adulthood. Relentless care demands left little time for parents to consider the future and their child's transition to adulthood. They were committed to addressing their child's long-term needs in health, safety, housing, and financial support, and providing enrollment in meaningful educational or activity programs after high school. Planning became more specific at older ages, but support from schools and health care providers was inconsistent and uncoordinated.

Dr. Rehm and her colleagues applied the TAPS findings to the development of an intervention in a community-based research partnership with a Local Family Voices affiliate. The intervention created transition plans for a cohort of AYA patients needing ongoing care, with involvement of youths, professional case managers, teachers, and health care providers. Parents showed improved competence and confidence in finding and using services with the intervention, but they did not see reduction in worry or increased rewards in parenting.

Dr. Rehm extended the project to involve community partners, such as service agencies and parent organizations, in a mixed methods study to assist young adults with autism with skills to enhance health and QOL after exiting the school system. They identified the need for “soft” skills that are not emphasized in school-based curricula and they created a conceptual framework for further curriculum development. A program that addresses interpersonal skills, dealing with adversity, developing life goals, and managing feedback is being evaluated and refined with young adult cohorts.

Rounding out the formal presentations, Dr. Kathleen Grady of Northwestern University described her research with patients who received heart transplants (HT) as children and the psychosocial and self-management issues they face as they enter adulthood. Outcomes tend to be worse for HT recipients younger than 40 years old. Adherence to immunosuppressive medication is critical to survival. In addition, insurance policies may not cover the transfer from pediatric to adult hospital care.

Dr. Grady and her colleagues tested an intervention in the Transitioning to Adult Care (TRANSIT) study to improve outcomes and readiness to transition to adult care through enhanced HT education, self-management and self-advocacy skills, and social support. After the initial education module was administered, participants had periodic meetings with the adult HT coordinator to assess, tailor and reinforce the information towards self-care, self-advocacy, and support.

Although the participation and retention in the study exceeded expectations and indicated feasibility for future trials, outcomes were not improved for the intervention group in comparison with the usual care group. Most participants were still living with parents, which may have influenced adherence. There were no significant differences between knowledge and adherence between groups, but self-advocacy increased and there were some improvements in usual care participants over time.

The small sample size and short follow-up period after care transition were potential limitations that could be improved with a larger study. The homogenous cohort of primarily white males and subjective determination by pediatric cardiologists of transition readiness may have also affected the results. Supervised completion of education modules, additional educational content, and other teaching modalities are potential modifications for future studies. Other implications from the study were that transition planning should begin prior to transfer of care and continue for a period after the transition. Family-focused interventions, in which parents move from coordinating care to supporting care, may also be beneficial, as well as engaging adult clinicians in transition-related care.

The presenters answered questions collectively in a panel discussion moderated by Dr. Kathleen Sawin, Professor Emerita at the University of Wisconsin-Milwaukee College of Nursing. Some of the gaps in transition research are identified in practice, which, in turn, relies on research for evidence to inform practice. Emphasizing transitions in clinical education would stimulate interest in research that could support practice-related challenges that insurance

companies, health systems, clinicians, and patients face during transition. Qualitative research, which is often brought in by nurses in interdisciplinary research teams, is more prominent at the beginning of investigations. An international perspective on transition research brings attention to under-resourced populations, such as access for rural families; barriers to regular clinic visits can push care into emergency departments.

Issues in sexual and reproductive health are important in AYAs with chronic conditions, such as genetic counseling for those with heritable diseases and concerns about stamina for childbirth. In regions affected by restrictions to contraception access, clinicians in obstetrics and gynecology can intervene for these patients on the basis of health implications. Patients with cardiovascular risks are counseled not to get pregnant and HT patients are informed that medications can cause birth defects. More research is needed on the extra challenge female patients face about the role of women as beautiful and supportive.

Nurses and other disciplines bring new focus to QOL and other concepts that have been in the background. The federal government's Healthy People 2020 agenda states the importance of QOL and well-being, yet they are minimized in the transition care literature in comparison with medical science and transfer events. Measurement of QOL has been a challenge in transition research and Dr. Holmbeck's achievements in QOL measurements, such as SB patients' interest in employment, are significant.

Various methods for gathering data and testing interventions were discussed. Clinic visits were feasible because patients were in the hospital regularly. The software-based meeting platform Zoom was a good methodology for tech-savvy Japanese youth with SB. For ethnographic research, homes were the best study sites because it was where patients spent most of their time.

The Roundtable's break-out session and associated discussion concentrated on strategies organizations might use to facilitate research in pediatric to adult HCT for AYAs with chronic illnesses:

- Include transition research in organizations' strategic plans and develop collaborative goals across professional organizations with key stakeholders.
- Provide focused funding for transition research and consolidate funds from several organizations to have a greater impact.
- Facilitate transition research with:
  - electronic health record enhancements and improvements, to capture care across the lifespan.
  - encouragement of interdisciplinary research.
- Facilitate translation of transition research into practice and evidence-based policies, such as insurance continuity and telehealth.
- Increase awareness through:
  - academic programs and post-graduate training opportunities, for nurses, generalists, and specialists.

- partnerships with pediatric and adult health care organizations.
- special issues of professional journals.
- communications within nursing organizations.
- more exposure at conferences.