Transition of Care for Adolescent Patients With Chronic Illness: Education for Nurses

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abstract

Because of the longevity of children diagnosed with chronic illness, many adult institutions are now seeing an influx of adolescents with chronic illnesses. An urgent need exists to educate adult care nurses on adolescent development, childhood chronic illness, and techniques to guide young adult patients through illness and hospitalization. This article describes the development of an educational program for nurses who care for these chronically ill young adult patients who are transitioning to adult care.

in an adult oncology unit, stating that there is a nursing knowledge deficit in normal and abnormal adolescent behavior. The authors concluded by stating that nurses must have knowledge of normal growth and development to be able to care for adolescent patients effectively. Schidlow and Fiel (1990) also stated that adult health care teams have not been properly educated to work with these adolescent patients. Further, Bowen, Henske, and Potter (2010) stated that the transition of adolescent patients may require additional training for health care workers that should include the developmental, emotional, and social needs of these young adults. Therefore, it is imperative that education and professional development be available for ambulatory and acute care nurses who may encounter patients who have special health care needs and are transitioning from pediatric to adult health care.

Por et al. (2003) described communication, documentation, education, professional development, support, good handoff and plans of care, and time and patience as needs that nurses identified to improve their comfort level when caring for these patients. Additionally, Forbes et al. (2001) identified a lack of staff education in relation to transition of care as a barrier to transitioning patients, and there is a great need to provide education to the staff in adult health care settings who are involved in the care of adolescents with special healthcare needs.

The American Academy of Pediatrics (2011) explained that although adult health care professionals are required to assume the care of the adolescent patient, caregivers cannot be expected to be knowledgeable in how to do this without additional education. The report also stated, “Further work is needed to characterize, demonstrate, and teach an adult model of care that is responsive to the particular needs of all young adults and sensitive to the specific challenges associated with providing high-quality care to young adults with specific chronic conditions” (Academy of Pediatrics, 2011, p. 197). Educational programs for adult health care providers who care for transitioning patients are not widely available. However, patient outcomes will improve when nurses understand these types of transitions and are actively involved in the coordination of care processes (Betz, 1998). With this understanding, nurses can then suggest interventions to manage changes related to illness, both physical and psychological.

Transitioning of adolescent patients to adult health care is of special interest to nursing staff and nurse managers because of the increase in the number of young adult patients with special health care needs who present to the ambulatory and acute care adult settings. Many pediatric patients who have chronic health conditions and are now living to adulthood have cystic fibrosis, childhood cancers, congenital heart disease, and diabetes. The Cystic Fibrosis Foundation (2012) stated that there are more than 30,000 cases of cystic fibrosis in the United States and more than 45% of the population with cystic fibrosis is 13 years or older. It is estimated that there are 270,000 adult survivors of childhood cancer in the United States, and 1 in 640 young adults between the ages of 20 and 39 years is a survivor of a childhood malignancy (National Cancer Institute, 2006). Approximately 20,000 children with congenital heart disease live to adulthood per year, and approximately 50% require lifelong specialized care (Fernandes et al., 2011). The American Diabetes Association (2011) reported that approximately 1 in every 400 adolescents has diabetes and 25.6 million people 20 years or older have diabetes. These numbers support the idea that there is an increasing need for adolescents and young adults to transition to adult medical care centers to better meet their medical needs. Caring for adolescents and young adults may create new challenges not previously encountered by the adult care nurse. Aside from the disease-specific care required, adolescent patients have developmental needs that are different from those of the adult population, including physical, psychological, emotional, and sociocultural issues (Sturrock, Masterson, & Steinbeck, 2007).

**COURSE DEVELOPMENT**

At the time of course development, the transition of care committee predicted that more than 200 adolescents with diabetes who were treated at the local pediatric medical center would be transitioning to adult care within the next year. In light of the increase in the number of transition patients, coupled with the lack of education for adult health care providers, a task force was convened between an academic medical center and the local pediatric medical center in the Midwestern region of the United States. A needs assessment was conducted within the academic medical center, using a four-point Likert-type scale, to determine the preferred method of educational delivery. All registered nurses who worked full- or part-time were asked to participate in the survey. The final sample consisted of 254 registered nurses (22%). The survey results determined that the majority of respondents preferred online learning. These findings supported the hospital’s transition of the care team’s decision to provide education for ambulatory and hospital-based nursing staff through the use of computer-based training modules using the organization’s learning management system.
The computer-based training was developed with current literature on transition of care topics and normal adolescent development. Embedded in the module were knowledge assessment questions intended to provide instant feedback to the learners as they progressed through the computer-based training. The course was designed to take approximately 30 minutes to complete. The module could be bookmarked to allow the learner to exit and return to the course as needed. Ten final assessment questions were presented at the end of the education module to evaluate learning. Successful completion was demonstrated by achieving a score of 80% or greater. Associates, the patient care staff employed at the academic medical center, were given 30 days to complete the course. The computer-based module was completed by a total of 1,898 registered nurses, case managers, patient care assistants, and paramedics. The average score on the posttest was 95%. The next section explains the content of the education modules.

EDUCATION MODULE DESCRIPTIONS

Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act (HIPAA) can be addressed differently in the adult health care setting than in pediatric institutions. HIPAA allows individuals to decide who can and cannot receive health information and requires institutions to ensure that health information is kept private and confidential (U.S. Department of Health and Human Services, n.d.). In the pediatric setting, parents and guardians make health care decisions for the child. In the adult care model, transitioning young adults make their own decisions about health care. Nurses must ask patients who are older than 18 years who they would like to have involved in their care, who can receive protected health care information, and who can be included in plan of care discussions. This could potentially be a change in culture for the adult care provider, who may be used to talking only to the patient about these topics. This could also be a culture change for patients and families, who were accustomed to having the parents and guardians make health care decisions when the adolescent patient was being treated in the pediatric facility. The learning objective for this content was to discuss HIPAA in relation to the adolescent transitioning patient.

Family-Centered Care

Most of the young adults in this study were transitioned from a local pediatric medical center that used the family-centered care model (Cincinnati Children’s Hospital Medical Center, n.d.). With this approach, the family is welcomed as part of the medical team. Because the family is the most constant support system in the patient’s life, family members are encouraged to advocate for the patient and to be uniquely involved in the health care decision-making process. The family-centered care model includes four concepts: dignity and respect, information sharing, participation, and collaboration (Cincinnati Children’s Hospital Medical Center, n.d.). Historically, the adult academic medical center had used an adult-centered care model that focused solely on the patient. In early 2012, the institution began to move toward implementation of a patient-family-centered care model. The transition of care education modules were part of the initial implementation of this new model of care. The learning objective for this content was to discuss family-centered care and its core concepts in relation to the transitioning adolescent patient.

Healthy Versus Chronically Ill Adolescent Development

The adolescent period marks a time of great change. This period involves the development of identity, the formation of moral values, the development of sexual orientation, separation from the parents, and the task of future life and career planning. In addition, this time may involve risk taking, feelings of invincibility, self-consciousness, impulsivity, and poor body image. Peers can be a major positive or negative influence on adolescents (Christie & Viner, 2005). Adolescents and young adults with a chronic diagnosis may be experiencing the same feelings, but often have additional stressors. These patients may try to “fit in” with their healthy peers and therefore may not be compliant with health care treatment. Adolescents and young adults may engage in risky behavior and struggle between independence and dependence on parents. Adolescents with chronic illnesses may be socially isolated from peers because of feelings of being different (Burns, Sadof, & Kamat, 2006). The learning objective for this content was to delineate the developmental differences between healthy and chronically ill adolescents.

Before the introduction of this educational program, yearly education on adolescent development was a requirement for all nurses and patient care assistants who worked at the institution. Therefore, completion of the developmental education module on healthy adolescents was required before completion of the transition of care education module. The first education module provided a good foundation on healthy adolescent development that allowed learners to focus on the unique issues facing adolescents with chronic illnesses.
key points

Transitioning of Adolescent Patients

1 An urgent need exists to educate adult care nurses on adolescent development, childhood chronic illness, and techniques to guide young adult patients through illness and hospitalization.

2 The education module is targeted to nurses who have little experience caring for the young adult patient with chronic disease.

3 Because of the large numbers of chronically ill pediatric patients surviving to adolescence in the United States, other health care institutions may want to replicate the transition education presented here to inform adult health care providers of the particular needs of this population.

FUTURE IMPLICATIONS FOR NURSING

Transition is a widely used term throughout the literature, but nurses working in adult health care facilities may not be familiar with the transition of patients from pediatric health care to adult health care institutions. To facilitate a smooth transfer for patients and to enable nurses to adapt to this emerging patient population, additional research and education are necessary. The current literature provides an overview of the general topics included in this article, but does not provide any specific findings in relation to the transition of pediatric patients with special health care needs to adult health care services. Further, more research is needed on the adolescent patient’s preferences and perceptions in transitioning from acute pediatric care to acute adult care. Information from these types of studies would provide additional insight into the needs of this growing patient population that could be used in future nursing professional development programs. In addition, results from preference and perception studies may lead to evidence-based refinement of inpatient and outpatient adolescent care practices to improve the patient experience. The growing number of chronically ill adolescents transitioning to adult health care necessitates the education of adult health care providers on the unique health care and developmental needs of these patients. Well-informed acute health care providers may provide better quality adolescent care with better patient perception of care. Health care administrators have an opportunity to develop excellence in the care of adolescents with chronic illness in their organizations, and this may lead to loyal adult patients with chronic illness. Prelicensure nursing programs and intercollegiate health care education should provide an introduction to adolescent transition to adult health care. Because of the large numbers of chronically ill pediatric patients surviving to adolescence in the United States, other health care institutions may want to replicate the transition education program presented in this article to inform adult health care providers of the particular needs of this patient population. Future programs designed to educate direct care providers on the subject of transition should be instituted and evaluated to provide adult caregivers with additional tools to care for these transitioning adolescent patients.

REFERENCES


