



Concept Analysis of Health Care Transition in Adolescents with Chronic Conditions^{1,2}

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Children with chronic conditions are living into adulthood and present with unique needs. One such need is their transition from pediatric to adult health care. This paper examined the literature to analyze and synthesize the concept of transition within two contexts, health care and adolescents with chronic conditions. Fifty multidisciplinary sources were included for analysis. A refined, working definition of the concept of health care transition in adolescents with chronic conditions is presented. Results will enable the scientific community to discuss salient issues using well-defined, uniform terminology. Nursing implications are delineated to ensure that these youths thrive into adulthood.
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WITH RECENT MEDICAL and technological advances, children with chronic conditions are now living well into adulthood. These children with previously labeled “childhood” diseases such as cystic fibrosis, congenital heart disease, and sickle cell disease are surviving and thriving into adulthood. Consequently, it is important that the health care system continues to ensure that their unique needs are met. One such need is the transition from pediatric health care to adult health care during their adolescent years. Although this transition has been identified as a health care priority for over two decades, no uniform mandate exists. Additionally, health care transition within the context of adolescents with chronic conditions has not been adequately evaluated, especially related to the clarification and definition of this seemingly nebulous concept. The purpose of this paper is to critically examine the literature to analyze and synthesize the concept of health care transition using Rodgers’ evolutionary

method (2000) in order to provide clear, well-defined language that facilitates discussion in the scientific community.

Introduction

Transition from pediatric health care (PHC) to adult health care (AHC) is an eminent issue in the health care community. It is estimated that 15.6% of adolescents in the United States have special health care needs attributable to improved survival rates (Lotstein, McPherson, Strickland, & Newacheck, 2005). Ninety percent of all children born today with chronic conditions or disabilities are expected to reach the age of maturity (Blum, 1995). This translates to approximately 750,000 adolescents with chronic conditions (i.e., cystic fibrosis, sickle cell disease, cerebral palsy, etc.) crossing over the threshold into adulthood annually (Goodman et al., 2011; Scal & Ireland, 2005). With timely diagnosis, innovative treatments, and improved health service infrastructure, children who did not live past their first decade of life now have the ability to live fully as adults.

This change in epidemiological profile poses corresponding challenges in meeting these adolescents’ unique needs as they transition from PHC to AHC. Governing bodies and health care organizations are in agreement that health care transition is a priority concern. Healthy People 2020

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identified five objectives related to healthy development, one of which states, “Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care” (HealthyPeople, 2020, 2020, 2014).

In 2002, a joint position statement was released by the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians (ACP), and American Society of Internal Medicine delineated that adolescents with special health care needs (ASHCN) should have a written health care transition plan by the age of 14, and that by the year 2010 all health care providers who deliver primary or subspecialty care to ASHCN must have developed a transitional program (Blum, Hirsch, Kastner, Quint, & Sandler, 2002). More than a decade later, pediatric and adult health care providers have not demonstrated adequate progress towards accomplishing the aforementioned goals (Agarwal et al., 2015; Schor, 2015). A follow-up statement by the AAP, AAFP and ACP released in 2011 provided an updated toolkit for health care transition, and revised the target age of transition discussion to age 12 (AAP, 2011).

The literature is replete with associated barriers and facilitators to health care transition; however, its properties need to be analyzed to more clearly define the concept. This will enable the scientific community to discuss relevant issues related to health care transition using a common set of defining attributes. Using the rigorous principles established by Rodgers (2000), a concept analysis on transition within the contexts of health care and adolescents with chronic conditions will be presented.

Review of the Literature

Transition is a central concept in nursing (Schumacher & Meleis, 1994). In fact, the history of nursing itself is a story of transition. Nursing as a discipline continues to evolve and engage in transitional activities through the work of its practitioners, scholars, educators, and scientists. Meleis, Sawyer, Im, Messias, and Schumacher (2000) and colleagues studied transition as a critical phenomenon in nursing. Their prolific work has resulted in a middle range theory (MRT) of Transitions, which is recognized as an emerging theory in its early stages of development (Meleis et al., 2000). Although a significant contribution in the study of transition, this MRT does not focus on health care transition pertaining to any specialized population, and as such is used as another source in this literature review. The goal of this paper is not to reformulate the work already done by the above authors. Rather, it is to present a more specific scope (health care transition) that is conducive to a more in-depth examination. Although transition from PHC to AHC occurs in the context of broader transitions (i.e., developmental, vocational, educational), it is beyond the scope of this paper to include all of the above with adequate rigor.

A preliminary online search of the words “transition” and “health care” (or two separate words, “health” “care”) using

InfoTrac OneFile database revealed 106,748 results. These results came from various governmental, industrial, business, and health care sources. It was evident that in order to complete this formidable task of concept analysis, it was crucial to institute certain inclusion and exclusion criteria.

“Transition” as a root word in the title was used to ensure that it was the main focus of the literature. Another titular keyword used was “health care” in order to exclude works on other types of transition. Other keywords used were “chronic illness(es)”, “chronic disease(s)”, “chronic condition(s)”, “adolescence”, “adolescent(s)”, and “youth(s)”. Other limiters were imposed to extract written works in English only. Published dissertations were excluded from review due to time and resource constraints. Parameters were not imposed on dates as most of the works noted were from 1990s and onward. Using the above criteria, the following databases were utilized: CINAHL, Medline, PsycARTICLES, PsycINFO, Academic Search Premier, and Health & Psychosocial Instruments.

The initial number of sources generated was sixty-four. After reviewing the abstracts for appropriateness (e.g., specifically discussed transition in health care context) and discarding duplicate sources, 38 articles remained which were deemed fit for further study. Twelve more sources were added after ancestral review of bibliographies revealed seminal works and consensus papers by major stakeholders in health care transition. A final number of 50 sources were used for literature review.

Representative disciplines included nursing, medicine, and “other” which comprised social work, psychology, and public health. Eighteen sources were research articles, thirty were review articles, and two were position statements. Countries included were the United States, United Kingdom, Canada, Italy, and Australia. Tracer chronic conditions included cystic fibrosis, congenital heart disease, sickle cell disease, diabetes mellitus, cancer, inflammatory bowel disease, endocrine disorders, renal disease, arthritis, and other unspecified disabilities or special health care needs. See Table 1 for reviewed literature.

Concept Analysis

Transition is broadly defined in the dictionary as “the passage from one state, stage, subject, or place to another” (www.m-w.com). This etymological definition stems from the Latin word “transire”, with synonyms including “change”, “movement”, “development”, and “evolution”. Subsequently, it is only fitting to use Rodgers’ evolutionary method of concept analysis. Rodgers’ method is also chosen because of its context-driven properties, inductive approach, and philosophical underpinnings (Rodgers, 2000).

Rodgers posits that concepts are “not static, timeless entities with identifiable boundaries” (Rodgers, 2000, p. 84). Rather, concepts are dynamic, context-dependent, and pragmatic serving a purpose (Rodgers, 2000). This is in stark contrast with the Wilsonian view of concepts in which

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