



Transition to Adulthood for Young People with Medical Complexity: An Integrative Literature Review

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This article explores how the empirical literature on the transition to adulthood for young people with medical complexity can inform nursing and advanced practice nursing. An integrative literature review informed by Meleis' Transition Theory and Bronfenbrenner's Bioecological Theory of Human Development was conducted including 11 studies and yielded three themes: it's like falling off a cliff, the paradox of independence, and it takes a village. The findings demonstrated a need for an increased focus on the process of transition and transfer for this complex population. Recommendations for pediatric nurses and advanced practice nurses based on these findings focus on advocacy, capacity-building, education, and program development and evaluation. Recommendations for future research are offered with a focus on determinants of health, psychosocial concerns, and program development and evaluation.

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TECHNOLOGICAL AND SCIENTIFIC advances for pediatric long-term conditions are transforming outcomes and increasing longevity for young people with the most complex and fragile conditions (Cook, 2013). This has resulted in a major gap in services for young people with medical complexity, who have significant complex needs and service involvement (Cohen et al., 2011), leaving many of these young people and their families ill-equipped to navigate the adult system to attain developmental goals while coping with the fragile nature of their conditions.

The transition to adulthood involves a developmental process and a care transition that occur simultaneously. In other words, movement between pediatric and adult services across sectors occurs in the context of a young person's developmental trajectory (Labhard, 2010; Stewart, Gorter, & Freeman, 2013; Stewart et al., 2010). Developmentally, the

transition to adulthood has been described as a time of identity exploration, increasing responsibility, and making choices for the future (Betz, Lobo, Nehring, & Bui, 2013). From a health care perspective, transition to adult care is a "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" (Blum et al., 1993, p. 570). Despite the multiplicity of the transition to adulthood, researchers have rarely considered this transition across developmental domains and service sectors simultaneously, instead focusing mainly on health care service transitions (Betz et al., 2013). Assuming the goal of nursing is to enhance health, quality of life and the human experience as a whole, these multiple simultaneous transitions must be considered together to enable the achievement of goals in all domains.

Transition experts have advocated for a holistic approach that spans developmental, behavioural, health and psychosocial aspects of a person's life with a goal of maximizing personal potential through flexible, comprehensive, and collaborative supports (Kaufman & Pinzon, 2007; Rosen,

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Blum, Britto, Sawyer, & Siegel, 2003; Stewart et al., 2010); however, syntheses of studies published over the last decade describe a lack of preparation, coordination and services for young people with chronic conditions and disabilities as they transition to adulthood (Doug et al., 2011; Stewart et al., 2010). In addition, few authors have considered the experiences and impacts of the transition process for young people with medical complexity (Cohen et al., 2011; Doug et al., 2011; Mesman, Kuo, Carroll, & Ward, 2013). With the numbers of this population increasing, it appears timely to explore the state of the science on transition for this population.

The purpose of this review is to explore and synthesize the literature on the transition to adulthood for young people with medical complexity from a nursing and developmental perspective. The results of this review will be applied to inform nurses and advanced practice nurses on the transition experience for young people with medical complexity to understand their situation and better support them.

Theoretical Perspective

Meleis' Transition Theory and Bronfenbrenner's Bioecological Theory of Human Development were used together to inform this review. Transition Theory is a middle-range nursing theory that describes the process experienced by individuals when changes occur in their lives and focuses on this process as central to the nursing role (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Schumacher & Meleis, 1994). Meleis et al. (2000) describe the types of transitions, patterns of multiplicity and complexity, properties of transition, transition conditions (facilitators and barriers), process and outcome indicators, and nursing therapeutics. In this review, the transition to adulthood was considered a developmental transition and an organizational/situational service transition.

Bronfenbrenner's Bioecological Theory of Human Development, hereafter referred to as Bioecological Theory, provides a framework for the study of human development over time (Bronfenbrenner, 2005). There are four properties in this theory: person, process (a form of interaction), context, and time. Bronfenbrenner has been credited with the introduction of context into commonplace developmental psychology focusing on reciprocal interactions with the environment at microsystem, mesosystem, exosystem, and macrosystem levels that lead to developmental outcomes (Bronfenbrenner & Morris, 2006; Darling, 2007). The use of both theories enabled consideration of the transition to adulthood in the context of health and human development simultaneously.

Approach to Inquiry

An Integrative Literature Review methodology was used to explore the literature on the transition to adulthood for young people with medical complexity as this approach allows for consideration of qualitative and quantitative studies simultaneously. The process of this integrative literature review was guided by Whittemore and Knaf's

(2005) five stages: problem identification, literature search, data evaluation, data analysis, and presentation of findings. The problem was identified in the purpose statement of this review, which guided all further stages.

Literature Search

The Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Medline were searched using key terms listed in Figure 1. An ancestry search of included articles was also completed. Young people in the context of this review were defined as adolescents and young adults, age 15–30. Since medical complexity includes a wide variety of diagnoses with diverse terminology used in databases and articles, Cohen et al.'s (2011) definitional framework was used to define medical complexity. According to Cohen et al., these young people have at least one complex chronic condition, significant family-identified service needs, functional limitations that are related to medical conditions, technology dependence, or developmental disabilities, and high health care service usage.

Included articles (1) were published 2003 or later; (2) consisted of empirical articles including evaluation studies; (3) included participants who fit Cohen et al.'s (2011) definitional framework. The year 2003 was chosen to align with two landmark papers published at that time calling for a renewed focus on the transition to adult care (American Academy of Pediatrics, American Academy of Family Practice, & American College of Physicians-American Society of Internal Medicine, 2002; Rosen et al., 2003). For studies not excluded through title or abstract review, participant characteristics were examined. Studies were included if 25% of participants could be considered medically complex. If proportions were unclear, personal clinical experience guided the decision on inclusion or exclusion based on descriptions of participant characteristics (Figure 1). Included studies are summarized in Table 1.

Data Evaluation

To evaluate included studies, frameworks for critiquing qualitative research (Streubert & Cameron, 2013) and quantitative research (Klein & Singh, 2013) were utilized based on the type of study being evaluated. A criterion of applicability to the review and to practice was added to each framework. Quality scores were assigned to each criterion in the frameworks to yield a total score out of 20, with a score of 10 as a cut-off for inclusion. All studies that fit the inclusion criteria exceeded this cut-off. Based on evaluation of the retrieved studies, provider perspectives were excluded from the analysis.

Data Analysis

In the data reduction stage, studies were initially classified as qualitative or quantitative and then further classified based on key informants. Data pertaining to the broad perspectives of young people or their parents on the transition process were extracted from the findings of each study and reduced to a

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