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Review article

Measurable Outcomes After Transfer From Pediatric to Adult Providers in Youth With Chronic Illness

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ABSTRACT

Children with chronic medical conditions are requiring transition services to prepare for transfer of care. There has been little data on what qualifies as a successful transition or how to measure this goal. The purpose of this review was to identify measurable patient-level outcomes for transitioning youth with chronic illness from pediatric to adult health care. An integrative literature search was conducted using CINAHL and OVID Medline. Key words included transition to adult care and health transition. Research articles published between 2002 and 2015 and reported on measurable patient-level outcomes in youth with chronic illnesses were included. The initial search yielded 556 articles and 19 articles were selected. Most of the research reporting on outcomes after transfer is nonexperimental using secondary data. Additionally, there is inconsistency in the use of term transition. In the specific outcomes identified, there is little uniformity in measurement both in terms of timing and standardization of measurement. Further research is needed on outcomes after transfer that includes standardized measures and time intervals in order to evaluate successful transition services. This research is essential for health care providers who are instrumental in supporting young people during this high risk period.

IMPLICATIONS AND CONTRIBUTION

Measurable outcomes for transition success should include: (1) clinic attendance and (2) hospitalizations pretransfer and at least 3 years post-transfer. Additionally, satisfaction should be measured using a standardized instrument. As outcomes differ based on diagnosis, professional organizations should develop standardized, consistent methods to measure disease-specific outcomes.

Before the 1980s, few children with chronic medical conditions survived into adulthood. Medical advances have changed the natural history of many chronic illnesses increasing the survival of children with conditions such as diabetes and congenital heart disease [1]. The increasing number of youth with chronic illness surviving to adulthood has national implications, as it is now estimated that there are more than 900,000 children with a chronic condition nationally [1–3].

The health care system has not prepared to effectively transfer the care of these young patients with complex health care needs from pediatric to adult health care services. Often, the transfer of care occurs during moments of crisis such as pregnancy, nonadherence, or periods of mental distress, when pediatric providers feel unprepared to handle these issues with young adult patients. When the transfer occurs during times of crisis, it leads to poor outcomes such as: an increase in disease complications, increase in noncompliant behaviors, and an increase in the number of patients lost to follow-up [4–6]. Since

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the mid-1980s, there has been an interest in medical transition services as a way to bridge the gap in care for youths with chronic illnesses. In 1989, Surgeon General Koop held the second Conference on Medical Care for Youths with Special Health Care Needs. During the conference, Koop [7] stated that smooth medical transition for children with chronic conditions was the one major medical issue for chronic conditions that had not yet been addressed. In response, in 1993, Blum et al. [8] defined medical transition services as the "...purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (pg. 570). Soon thereafter, the American Academy of Pediatrics, the American Academy of Family Physicians, the American Society of Internal Medicine, and the Society for Adolescent Medicine issued consensus statements on health care transitions for young adults with special health care needs [9]. These statements highlight the difference between "transfer" which is the act of changing from one provider to another and "transition" which is the process of preparation for patients, family members, and providers for the actual transfer of care. For the purpose of this review, "transition" refers to the process or program to prepare for the transfer of care, while the use of "transfer" relates to the actual event of transferring care from one provider to another.

The transition literature has primarily focused on the need for services, the basic concepts required for transition services, and identified barriers to the successful transfer of care. Most of the data remain anecdotal and there continues to be a significant lack of outcome data or recommendations about which outcome data are relevant for various populations [8,10–12]. A recent systematic review on transition programs, identified common components of transitional programs, and identified several areas for further research; most importantly, they concluded that there is no accepted way to measure transition success [13].

The overarching goal of any transition program is to optimize health and help each individual young adult achieve his or her maximum potential [10]. However, it is still not apparent what outcomes best measure this goal. Measuring outcomes of successful transition is difficult. As early as 1993, Blum et al. [8] stated, "Outcome measures should include rate of completion of referrals, functional outcomes, sense of well-being, and patient satisfaction" (pg. 573). Other potential outcome measures identified in the literature include educational success, employment status, insurance coverage, noncompliant behaviors, quality of life (QOL) measures, disease severity, and mental health status [14]. In 2015, Suris and Akre [15] published a consensus paper suggesting eight key indicators to assess successful transition: (1) patient not lost to follow-up; (2) attendance of scheduled visits in adult care; (3) the development of a trusting relationship with an adult provider; (4) continuing attention for self-management; (5) first visit to adult care no later than 3–6 months after transfer; (6) number of emergency room (ER) visits for regular care in the past year; (7) patient and family satisfaction with transfer of care; and (8) maintain/improvement of standard for disease control. These indicators were developed via Delphi methodology by 30 experts in adolescent health and are used as a framework for this current review analyzing how these indicators are currently being operationalized for evaluation of transition success. Therefore, the purpose of this review was to identify measurable patient-level outcomes using Suris and Akre's (2015) key indicators as a framework for transitioning youth with chronic illness from pediatric to adult health care.

Methods

This review used an integrative review process as described by Whittemore and Knafl [16] applying qualitative analysis techniques to assimilate a broad array of research findings to improve the validity of review findings. Using this method, "...a thorough and unbiased interpretation of primary sources, along with innovative synthesis of the evidence" is accomplished (p. 550). This integrative review process included two phases of literature selection (Figure 1).

In phase I of the search, an initial search of the literature was conducted using CINAHL and OVID Medline using keywords and MeSH headings of transition to adult care, health transition, and youth with chronic illness yielded 885 articles. The search was subsequently limited to only articles published in peer-reviewed journals, articles available in English, and those published since 2002, based on the consensus statements on health care transitions for young adults with special health care needs [9]. After applying these limits, the remaining 556 articles were divided among the three authors for review. Article titles and abstracts were reviewed. Articles were included if they were primary research articles that focused on outcomes after transfer of care to adult providers in youth with chronic illness. Exclusion criteria included articles that were (1) primarily descriptive or qualitative; (2) focused on transition readiness; (3) reported patient/family and provider views; (4) focused primarily on cost; or (5) that evaluated youth with a primary diagnosis of intellectual, psychiatric, or physical disabilities. At the conclusion of phase I of the review, 42 articles were selected.

During phase II of the review, the 42 articles were reviewed in their entirety. The three authors discussed if the article met the inclusion or exclusion (Table 1). Twenty-six articles did not meet criteria (Figure 1), and three additional articles were selected based on review of reference lists. After phase II, a total of 19 articles met inclusion and exclusion criteria.

For all 19 articles included, the strength of evidence was evaluated by using the Johns Hopkins Nursing Evidence Based Practice Rating Scale [17]. This scale is based on five levels of evidence (LOEs) and includes three LOE for research studies and two for non–research-based articles. Level I is the highest and includes experimental/randomized controlled trials (RCTs) or meta-analysis of RCT, while level V (opinion of individual expert based on nonresearch evidence) is the lowest. All three authors discussed and agreed on the strength of evidence based on the reported methods of the articles reviewed. Data from the selected articles were entered into a table including columns that identified the author (s), purpose of study, sample/setting, study design and level of evidence, findings/outcomes, time points, and information about transition programs (Table 2). The table allowed for analysis of data in an unbiased comprehensive approach. Data were categorized into themes using an "iterative comparison" approach [16]. Results will be presented by strength of evidence followed by the themes identified.

Results

Several themes were identified in this review: measureable disease-specific patient-level outcomes, measurable non–disease-specific patient-level outcomes, and the timing and frequency of outcome measurement. Findings on evaluation of strength of evidence will be presented first followed by results by theme.