Transitioning health care from pediatric settings to adult health care settings has been investigated for years in an attempt to determine and decipher the appropriate method of approach and how to assure that this milestone achievement is seamless. Transition is defined as the time when an adolescent is progressing into young adulthood (Federal Partners in Transition Workgroup, 2015). During the transition process, the patient experiences changes in many areas of life not limited to health care (Federal Partners in Transition Workgroup, 2015). Further, patients with chronic illnesses have additional challenges that can affect the transition process and experience.

Although health care transition processes have been researched, formal recommendations and guidelines are not consistently applied with efficacious results (Prior, McManus, White, & Davidson, 2014). Acknowledging the barriers and appreciating the opportunities from prior transition program efforts can provide perceptions of how to improve transfers from pediatric to adult health care (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP], & American College of Physicians-American Society of Internal Medicine [ACP-ASIM], 2011b).

The objective of this integrative review was to identify and systematically review the published evidence focused on transitional care for adolescents and young adults to an adult health care setting. Additionally, examination of literature focused on the transitional care processes with an emphasis on pediatric, adolescent, and young adult patients with chronic illness were surveyed. This review was completed to provide insight for improving transitional care services for patients with spina bifida seen in a urology practice. Moreover, the intention of this review was to gain knowledge to improve a newly established urology transition program for patients with spina bifida and other congenital or chronic conditions.

**Background and Significance**

According to the Centers for Disease Control and Prevention (CDC) (2014), chronic disease management represents 75% of total health care costs. Moreover, the prevalence of children and adolescents with chronic illness or conditions has increased from 1.8% in the 1960s to more than 7% in 2004 (CDC, 2014). The CDC (2014) accentuated that 86% of all health care dollars are spent on treating chronic diseases across the lifespan. Between $25 to $45 billion health care dollars have been wasted due to incompetent transitional care processes, including preventable health problems and complications, such as hospital admissions (Health Affairs, 2012).

Transition-aged patients are
in a challenging developmental stage when compounded with chronic illness, which can result in monumental obstacles to an effective shift from pediatric to adult settings. Unfortunately, failure of transition in this vulnerable population is attributed to inadequate preparation and education for the transition process (Fagerskiold & Mattsson, 2010; Oswald et al., 2012). Research by McManus and associates (2013) highlight the devastating conclusion that only half of adolescents and young adults were formally and properly prepared for transition. Inefficient and inadequate transition leads to a variety of health complications and adverse outcomes that may otherwise have been prevented or detected earlier with consistent and uninterrupted health care (Callahan & Cooper, 2010; Crowley, Wolfe, Lock, & McKee, 2011). Advanced health care technology and intervention have led to improved survival of patients with chronic illnesses beyond adolescence and young adulthood, thereby multiplying the concern of insufficient transitions in this population (AAP, AAFP, & ACPASIM, 2011a).

Spinal bifida is a chronic condition derived from a congenital neural tube anomaly that affects approximately 1,500 infants born annually (CDC, 2013). The presence of spinal bifida is associated with lifelong urological implications, and effective transition of care from the pediatric to an adult urologist is imperative. Individuals with spinal bifida have many urologic issues across the lifespan, including bladder management, preservation of renal function, and overall quality of life (Spina Bifida Association, 2014).

**Search Methods**

A systematic literature search was conducted with the intention to identify research pertinent to the topic of transition care processes from pediatric to adult health services. The search engines of CINHAL, Medline, and ProQuest databases were utilized for this search. These databases were searched for articles between the years of 2009 and 2014. An emphasis was placed on the urological setting and chronic illness, specifically spinal bifida. Key terms used individually or in combination for the literature search included transitional care, chronic illness, pediatrics, adolescents, and young adults. The key terms were applied to the searches by the phrases pediatric transitional care, adolescent transitional care, young adult transitional care, chronic illness transitional care, and transitional care. Limiters were applied to include articles for English language, full-text, human, and peer-reviewed publication journals.

The initial search revealed 1,111 studies with discussion or emphasis on transition care processes from pediatric to adult health care settings from all the designated databases. The initial CINHAL database search yielded 799 articles; restricting the search to include transition identified 14 items reviewed. The initial Medline/OVID database using above limiters yielded 263 articles. After narrowing the search by date, 57 items remained. Specificity in the study inclusion criteria eliminated 40 articles, thus this search identified 17 articles for review. The final database used for the literature search was ProQuest. ProQuest initially retrieved 49 articles that were narrowed to 10 after applying full-text parameter. The total number of included articles for consideration from all databases was 41. The articles were then scrutinized to emphasize the transitional care process of patients with chronic illnesses from pediatric to adult health care services. Finally, the studies not specific to spinal bifida or generalized transition processes were excluded. The majority of articles focused on spinal bifida as the chronic illness of primary emphasis for discussion, and the total number of studies included in this review after all inclusion and criteria were met was N = 15 (see Figure 1).

**Results**

The literature reviewed provided several applicable studies discussing transitional care processes, and in particular, patients with spinal bifida. The primary study designs of the articles reviewed included the use of questionnaires and surveys to evaluate the transition process. These studies demonstrated varying sample sizes for the reported findings; however, the majority were small sample sizes with varying age groups. These studies reported the sample ages as in adolescence or young adulthood ranging from 12 years of age to early 20s. However, several studies had mean average ages in the early 30s at the time of the study. Several studies included parents or health care providers as the sample participants. The primary settings of the studies were outpatient settings, such as clinics or other health care facilities.

A common denominator of several studies was that a formal transition program demonstrated decreased incidence of acute events and improved satisfaction of the patients with transfer of care from pediatric to adult health services. Callahan and Cooper (2010) documented findings of increased emergency department (ED) visits in young adults in contrast to adolescents with a designated medical home. The study data reported 40% of visits to the ED were for preventative care encounters (Callahan & Cooper, 2010). Armour et al. (2009) provided supporting data for prevention of hospital admissions as related to urinary tract infections (UTIs) with available outpatient resources and access to providers who care for and treat this common complaint.

A chief topic identified from the results was that no transition model was superior to implement; however, any degree of transition education and monitoring was beneficial for the transfer and change process. Brustrom,
Thibadeau, John, Liesmann, and Rose (2012) reported a care coordinator as an instrumental asset to transitional care in patients with spina bifida to facilitate the transition process. Improved psychological impact, quality of life, or satisfaction with transition experience were the subjects highlighted in the literature. However, cumulatively, the studies provided minimal data to validate and support improved overall health outcomes as related to formal transition interventions. Overall, the studies used validated or reliable questionnaire and survey tools to assess patients’ experience, satisfaction, and quality of life as related to the patients’ diagnoses and transition experiences. The use of these instruments supports the implementation of such tools in the transitional planning and implementation development (see Table 1).

**Implication for Improving Transitional Care**

The integrative review suggests that the current state of transitional care in patients with chronic illness is deficient in providing consistent and sufficient transfer from pediatric to adult health care. The studies reviewed provided insight of patients with chronic disease interpretation of transition and areas of weaknesses in the system at this critical time of change. Patients with chronic diseases, such as spina bifida, have health care issues that require following up across the lifespan. Appropriate and reliable transition programs are imperative to satisfactory transfer of care from pediatric to adult health care settings.

Transition periods in patients with chronic illnesses during adolescence and young adulthood require strategic preparation to facilitate efficient transfers. Basic acceptance of strategy includes applying structured and team-based transition programs that include the patients, parents, and/or caregivers in the process; application and instillation of resources that are severely lacking in this population; providing transparency and accountability of transition programs for exemplars for other health care programs; and decreasing preventable mortality and morbidity in adolescents and young adults with chronic illnesses (AAP, AAFP, & ACPASIM, 2011b; Callahan & Cooper, 2010; National Center for Cultural Competence, 2001; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011).

**Recommendations For Further Research**

Although there is significant research on transition processes, including evaluation of specific programs or models for transition, there is minimal literature indicating the optimum method or tool to employ for transitional care in patients with chronic illness. Additionally, understanding specifically why and when transition does not occur has not been thoroughly addressed. The probable themes have been identified but not meticulously investigated. The transitional period is at a critical developmental stage between adolescence and young adulthood. The magnitude of considerations imperative to the adolescent and young adult developmental stage are then compounded by the patients’ challenges of having a chronic illness. Discovery, identification, and implementation of a struc-
Table 1.
Articles Included in Integrative Review

<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Design</th>
<th>Setting</th>
<th>Sample</th>
<th>Findings</th>
<th>Strength</th>
<th>Weakness</th>
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<tbody>
<tr>
<td>Armour et al. (2009)</td>
<td>MarketScan Commercial Claims and Encounters database 2000-2013</td>
<td>Inpatient admission</td>
<td>Spina bifida patients and UTI diagnosis</td>
<td>Spina bifida with UTI average 0.5 hospitalizations versus 0.44 in general population if prevent admission decrease cost $4.4 million per 1,000 patients.</td>
<td><strong>Strength</strong>: Good data on UTI in spina bifida population, costs associated with decreasing hospital admissions. <strong>Weakness</strong>: Specified to UTI, non-specific with relation to transition.</td>
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<tr>
<td>Betz, Smith, &amp; Macias (2010)</td>
<td>Prospective randomized control trial</td>
<td>Spina bifida clinics at 2 hospital settings; letters of invitation</td>
<td>(N = 65) 31 youth in treatment group; 34 in control group</td>
<td>No significant findings between intervention group with formalized transition program and control.</td>
<td><strong>Strength</strong>: Applied dedicated transition education program to evaluate improvement in transition. Good sample size. <strong>Weakness</strong>: No significant conclusions provided to support this type of formalized program.</td>
<td></td>
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<tr>
<td>Brustrom, Thibadeau, John, Liesmann, &amp; Rose (2012)</td>
<td>Qualitative semi-structured interviews</td>
<td>75 spina bifida clinics</td>
<td>43 clinic staff and 38 focus group and caregivers</td>
<td>Care coordination is essential; beneficial dedicated care coordinator in spina bifida clinic beneficial.</td>
<td><strong>Strength</strong>: Good evaluation of staff and caregiver insight. Good discussion on care coordination. <strong>Weakness</strong>: Semi-structured qualitative interviews, no quantitative analysis provided of how care coordination provides improvement in transition.</td>
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<tr>
<td>Callahan &amp; Cooper (2010)</td>
<td>National Ambulatory Medical Care Survey data analysis</td>
<td>Ambulatory health setting</td>
<td>13- to 18-year olds and 19- to 24-year olds</td>
<td>Increase in emergency department visits in young adults versus adolescents; preventative care visit in 40% of emergency department encounters.</td>
<td><strong>Strength</strong>: Good data on transition aged population and emergency department visits; most visits were for preventative health care services that could be accommodated with routine care in a transition clinic. <strong>Weakness</strong>: Non-specific to chronic disease but on adolescent-aged population in general</td>
<td></td>
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<tr>
<td>Cox et al. (2011)</td>
<td>Ambulatory Care Experience Survey and Transition of Care Survey</td>
<td>Spina bifida clinic at one institution</td>
<td>105 patients identified with spina bifida, with only 24 participating in survey</td>
<td>Physical health correlated with lack of employment; parents reported more physical limitations; outcomes no significantly affected SF-36 score; key barriers identified with transition.</td>
<td><strong>Strength</strong>: Excellent evaluation of quality of life and physical health with comparison of social barriers including lack of transition in spina bifida population. <strong>Weakness</strong>: Although 105 identified, only 24 participants in study, small sample size.</td>
<td></td>
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<tr>
<td>Fagerskiold &amp; Mattsson (2010)</td>
<td>Phenomenology study: Explorative and descriptive design</td>
<td>Swedish hospital</td>
<td>13 participants ages 10 to 18, 8 girls, 5 boys, 10 MMC</td>
<td>Patients felt like outsiders in the community. Major themes: constraint and togetherness. Constrain r/t catheterization and bladder management. Togetherness r/t families, peers, and significant people</td>
<td><strong>Strength</strong>: Subjective and emotional themes provided for patients with MMC or spina bifida. Importance of support identified. Chronic disease management had barriers to transition or involvement in community activities. <strong>Weakness</strong>: Small sample of 13. Non-specific to a transition program.</td>
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Notes: UTI = urinary tract infection, MMC = myelomeningocele.
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<tr>
<td>Gleeson, McCartney, &amp; Lidstone (2012)</td>
<td>Review and recommendation of transition</td>
<td>Pediatrics and adults</td>
<td>Adolescents and young adults</td>
<td>Continuum of transition is continuous and working as team between pediatric and adults is essential.</td>
<td><strong>Strength:</strong> Insight to importance of evolution and continuity in transition programs. <strong>Weakness:</strong> Not specified to spina bifida or identified population; only review of recommendations available over transition.</td>
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<tr>
<td>Liptak, Kennedy, &amp; Dosa (2010)</td>
<td>Prospective cohort data from national survey analysis</td>
<td>Outpatient</td>
<td>130 mean age of 15 with SB diagnosis ages 12 to 18 with special health care needs</td>
<td>Followed for 4 years with general health declination in 4 year period; imperative continuum of care with successful transition is imperative.</td>
<td><strong>Strength:</strong> Good sample size and average transition aged identified. Prospective into how general health can decline without transition. <strong>Weakness:</strong> Ambiguous on recommended transition program.</td>
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<tr>
<td>McManus et al. (2013)</td>
<td>2009-2010 National Survey of Children with Special Health Care Needs</td>
<td>Survey review</td>
<td>21 hospital teams; 102/128 providers taking care of chronically ill</td>
<td>60% of transition experiences did not meet national transition core outcome measures.</td>
<td><strong>Strength:</strong> Identified crucial data on current transition experiences and outcomes. <strong>Weakness:</strong> Indistinct on chronic illness but focus on special needs. No formal recommendation or guidance provided on how to transition appropriately.</td>
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<tr>
<td>Nieboer et al. (2014)</td>
<td>Longitudinal study</td>
<td>Netherlands; ambulatory care</td>
<td>19- to 23-year olds that were from 14 to 17 at time of survey in 2001 with special health care needs</td>
<td>Significant variability in transition models; improved bottleneck with joint mission and improved patient experiences.</td>
<td><strong>Strength:</strong> Identified variability in transition approach and models. Collaboration to improve restrictions during transition will improve patient experience with transition process. <strong>Weakness:</strong> Inexplicit data on patient outcomes related to lack of unified transition. Inclusive on guideline on appropriate model or comparison of models of transition.</td>
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<tr>
<td>Oswald et al. (2012)</td>
<td>Survey of Adult Transitions Health and follow back 2001 and 2007</td>
<td>Outpatient ambulatory care</td>
<td>19- to 23-year olds with 1,865 respondents</td>
<td>21.6% made successful transition to adult health home after retrospective evaluation.</td>
<td><strong>Strength:</strong> Insight of how many special needs patients had transition to adult homes. <strong>Weakness:</strong> No direction provided on how to change poor transition.</td>
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<tr>
<td>Sawicki et al. (2011)</td>
<td>2007 survey adult transition and health</td>
<td>Outpatient survey</td>
<td>65 patients age 18 years and older</td>
<td>No common theme of non-transition preparation/discussion; medical home model promotes anticipatory guidance for transition.</td>
<td><strong>Strength:</strong> Large sample size. Good representation of common theme of lack of thorough preparation for transition. <strong>Weakness:</strong> Discussed medical home model and anticipatory guidance but no comparison analysis to other models.</td>
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<tbody>
<tr>
<td>Summers et al. (2014)</td>
<td>Retrospective patient review</td>
<td>Spina bifida urology clinic</td>
<td>80 patients with chronic conditions</td>
<td>Median age 30.6 years old; 17- and 12-month average last urology evaluation; 85% had presenting problem with chronic bladder conditions.</td>
<td>Strength: Identified lack of transition with specific time in patients with spina bifida and adequate urology evaluation. Highlighted significance of not having adequate urology follow up. Weakness: Median age was nearly 31 years old in population. Did not provide how transition could have significantly improved or prevented these health complications.</td>
</tr>
<tr>
<td>van der Toorn et al. (2013)</td>
<td>Pre- and post-test questionnaires of transfer of care</td>
<td>Urology department at one hospital; database at 1 center</td>
<td>24 young adults ages 15 to 22 years of age with chronic disease; 24 parents; 17 providers</td>
<td>No discussion about critical issues of adolescent and young adult sex, fertility, relationships; pediatric urologist relationship hinder transfer.</td>
<td>Strength: Recognized barrier of transition in relation to the pediatric urology provider. Common theme of fertility and sexuality in adolescence. Only post-transfer post-test to evaluate at one hospital urology department. Weakness: Small sample, only 24, non-specific to spina bifida; most data gathered from caregivers and providers.</td>
</tr>
<tr>
<td>van Staa, Jedek, van Meeteren, &amp; Latour (2011)</td>
<td>Qualitative semi-structured interviews</td>
<td>Tertiary referral center</td>
<td>Only one department had structured transition program; most not prepared for transition; need more organization with transition programs.</td>
<td>Identified the lack of consistent use of transition models or program regimens. Provided insight of lack of preparation and need for more structure to approach of transition.</td>
<td>Strength: Identified the lack of consistent use of transition models or program regimens. Common theme of fertility and sexuality in adolescence. Only post-transfer post-test to evaluate at one hospital urology department. Weakness: Small sample, only 24, non-specific to spina bifida; most data gathered from caregivers and providers.</td>
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Conclusion

Engagement and readiness assessment for transition is a multifaceted and intricate process (McManus et al., 2013). Development and interjection of scrupulous transition models will require meticulous consideration and collaboration of the entire health care team (Kennedy & Sawyer, 2008). Crowley et al. (2011) emphasized patient, staff, and service aspects of transition programs that encompass cooperative efforts from pediatric and adult health care teams. The coordination of the current pediatric setting to the introduced adult setting is an imperative component that is consistently lacking in transition programs (Kennedy & Sawyer, 2008). This integrative review provided insight of the continued struggle to determine the appropriate and indicated model for transitional care for adolescents and young adults with chronic disease or illness. The conclusive findings suggest continued endeavors and investments are evident and necessary in the critical area of transitional health care delivery.

References


Disability and Health Journal, 2, 145-152. doi:10.1016/j.dhjo.2009.09.001


Additional Readings
