Transition Needs of Parents of Adolescents and Emerging Adults With Special Health Care Needs and Disabilities

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Abstract
The period of health care transition (HCT) for adolescents and emerging adults with special health care needs and disabilities involves a complex realignment of the parent–child relationship, including alterations in role responsibilities and decision making. The purpose of this systematic review was to analyze the research designs, methodology, and findings reported in studies of parents during this transition period to provide new insights for research and clinical practice. Results showed that parents were unable to clearly envision what the future held for their children and were not well prepared by the service system to anticipate future prospects. These parents have a myriad of needs that are not yet fully understood, as HCT research is in the early stages of development.

Keywords
parents, systematic review, health care transition

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Increased attention is being directed at the challenges of developing health care transition (HCT) service models to foster the transfer of adolescents and emerging adults (AEA) with special health care needs and disabilities\(^1\) (SHCN; hereafter referred to as AEA-SHCN) to adult health care. The growing body of literature reflects the expanding needs of this population (Bryant & Walsh, 2009; Christie & Viner, 2009; Crowley, Wolfe, Lock, & McKee, 2011; Jalkut & Allen, 2009; Kralik, Visentin, & van Loon, 2006; Pai & Ostendorf, 2011; Pai & Schwartz, 2011; Sawyer & Macnee, 2010; Wang, McGrath, & Watts, 2010; Watson, Parr, Joyce, May, & Le Couteur, 2011). The number of AEA-SHCN reaching their second decade of life is on the rise, more than 750,000 annually, due to improvements in their treatment and long-term management (Cystic Fibrosis Foundation, 2009; Ferris, Gipson, Kimmel, & Eggers, 2006; Mariotto et al., 2009; Oakeshott & Hunt, 2003; Quinn, Rogers, McCavit, & Buchanan, 2010; Scale & Ireland, 2005). There is a need for AEA-SHCN to be competent and literate health care consumers and transition successfully to adulthood.

The science of this field of practice is in the nascent stages of development. Currently, limited evidence is available to guide practitioners with service development, and the research is hampered by the lack of reliable and valid instruments to measure concepts relevant to HCT, as well as studies using research designs with small sample sizes that limit generalizability (Betz, 2004; Betz & Smith, 2010; Binks, Barden, Burke, & Young, 2007; Bryant & Walsh, 2009; Nakhla, Daneman, Frank, & Guttmann, 2008). The preponderance of scholarly and practice efforts have been directed at better understanding the service needs of AEA-SHCN and the models of care effective in fostering their transfer to adult health care and transition to adulthood (Betz et al., 2014; Bryant & Walsh, 2009; Christie & Viner, 2009; Crowley et al., 2011; Jalkut & Allen, 2009; Kralik et al., 2006; Pai & Ostendorf, 2011; Sawyer & Macnee, 2010; Wang et al., 2010; Watson et al., 2011).

There has been limited focus on investigating the service needs of the parents of AEA-SHCN. The period of HCT involves a complex realignment in the parent–child relationship. The realignment of responsibilities, although dependent on AEA-SHCN developmental and functional capabilities, involves alterations in role responsibilities, decision making, ongoing clinical management, and relationships of all family members, including parents who have served as the primary caregivers and support for AEA-SHCN during the formative years of childhood development (Kieckhefer & Trahms, 2000; Kieckhefer, Trahms, Churchill, & Simpson, 2009). It is during this period that AEA-SHCN should become responsible for self-management of their chronic condition and learn the skills necessary to become literate and competent health care consumers. For AEA-SHCN whose continued reliance on
their parents and other caregivers will not completely abate, the life circumstances of parents and those of their AEA-SHCN children will be altered by the transfer of health care to adult providers, changes in their daily routines, and the availability of employment and community resources to foster inclusive lifestyle choices.

Although there have been policy recommendations to incorporate support services for parents as a component of comprehensive HCT services, there is a dearth of literature available to inform and guide practice (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP], & American College of Physicians [ACP], 2011, AAP, AAFP, & American College of Physicians-American Society of Internal Medicine [ACP-ASIM], 2002). It is, therefore, necessary to examine more closely what evidence exists on parental needs and issues during HCT.

We conducted a systematic review for the following purposes: (a) to gain an understanding of the state of the science as it pertains to HCT needs and issues of parents of AEA-SHCN; (b) to compare and contrast the research designs, methodology, settings, and samples of parent-defined (study sample consisted of parents only) and parent-combined (samples consisted of combination subgroups in addition to parents) studies included in this review by quantifying the data using frequencies and percentages; (c) to explore the HCT needs identified by parents; (d) to investigate whether areas of study other than parental needs were investigated in parent-defined investigations as presented with the findings of the thematic analysis; and (e) to provide new insights for research and clinical practice. It is important to learn about the needs and issues of parents of AEA-SHCN whose children are preparing to transfer to adult health care providers and transition from adolescence to emerging adulthood and beyond for the purpose of developing evidence-based service support programs that can be tested and replicated for improved parental outcomes.

Method

The methods of this systematic review are similar to the procedure described previously in another systematic review examining AEA-SHCN HCT needs (Betz, Lobo, Nehring, & Bui, 2013). The MEDLINE, PsycINFO, and EBSCO databases were searched to locate literature from January 2004 through December 2013, using the following search terms: disability OR chronic OR special health care needs AND transition. This period was selected because the first author had previously published an HCT literature review in 2004 (Betz, 2004). Because the primary objective for this search pertained to parents of AEA-SHCN and health care, we focused on 13- to 18-year-old adolescents and 19- to 24-year-old young adults (up to 29 years of age in the
PsycINFO database). Other search strategies included the archival retrieval of references from research articles obtained from the three electronic databases and from major reviews of HCT literature (Bloom et al., 2012; Bryant & Walsh, 2009; Christie & Viner, 2009; Crowley et al., 2011; Jalkut & Allen, 2009; Pai & Ostendorf, 2011; Rapley & Davidson, 2010; Sawyer & Macnee, 2010; Wang et al., 2010; Watson et al., 2011; see Figure 1).

A total of 742 articles were located. The retrieved articles were reviewed using the full-text articles or abstracts if the full-text article was not readily accessible. Articles were excluded if they (a) were clinically oriented papers, (b) were abstracts of conference presentations, (c) had insufficient information about the research design or methodology, (d) were published in a language other than English, or (e) were published before 2004 or after 2013.

During this first phase of the screening, two members of the research team conducted separate reviews of each article or abstract to determine which of these articles met the review criteria for inclusion or exclusion for years 2005 to 2012. In instances of disagreement, discussion ensued until agreement was achieved. For years 2004 and 2013, the primary author identified these articles with team consensus. Based on this screening approach, we reduced the number of articles to 260. Next, we screened research articles that involved parents of transition-aged AEA-SHCN, either as the focus of the research study or shared their perceptions about their children. The primary author identified these articles with the consensus of the other two authors. A total of 47 articles met this criterion and were the subject of this systematic review.

All studies were reviewed by all members of the authoring team. Another screening of the 47 studies was performed to identify those in which parent findings were reported separately and not merged with other respondent types (i.e., AEA). We described articles wherein parent findings were presented in this manner as “parent-defined” studies. A total of 30 studies met this criterion. Articles that merged parent findings with other subsamples of the study were labeled parent-combined. A total of 17 studies were identified as parent-combined (Figure 1; Tables 1 and 2). The rationale for grouping the final set of studies included in this review as parent-defined and parent-combined studies was twofold. First, the intent was to be as inclusive with the selection of HCT studies that included parents in the studies’ samples, as presented in the profile descriptions of both parent-combined and parent-defined studies in Tables 1 and 2. Second, this inclusive approach was problematic with the analysis of the studies’ findings included in this review, as parent findings reported in parent-combined studies could not be separated from the merged findings of other subsample groupings. Therefore, the decision was made to analyze the studies’ findings wherein parental responses could be clearly described, which meant parent-combined studies were excluded from this analysis.
All members of the authoring team met to review and discuss the themes found in the studies included in this review. During the discussion among the authors, one or more of the authors initially identified a theme that was evident, which then was verified by locating examples in the studies that represented the selected theme. Determination of themes was reached with the consensus of all authoring team members. Table 5 depicts the presentation of themes together with the studies wherein these themes were found.

Figure 1. Search process.
ROL = Review of Literature.
<table>
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<tr>
<th>Study</th>
<th>Location</th>
<th>Parent-defined/parent-combined</th>
<th>AEA-SHCN condition</th>
<th>Settings</th>
<th>Research design</th>
<th>Research procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betz and Redcay (2005)</td>
<td>United States</td>
<td>Parent-combined</td>
<td>Noncategorical SHCN</td>
<td>Community</td>
<td>Retrospective chart review</td>
<td>Chart extraction</td>
</tr>
<tr>
<td>Betz, Smith, and Macias (2010)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Spina bifida</td>
<td>Clinical</td>
<td>Randomized controlled design</td>
<td>Questionnaires measuring psychosocial construct</td>
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<tr>
<td>Bindels-de Heus et al. (2013)</td>
<td>Netherlands</td>
<td>Parent-defined</td>
<td>Noncategorical I/DD</td>
<td>Clinical/ community</td>
<td>Descriptive</td>
<td>Web-based survey questionnaire</td>
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<td>Brodie et al. (2011)</td>
<td>Australia</td>
<td>Parent-combined</td>
<td>Noncategorical SHCN</td>
<td>Clinical</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
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<tr>
<td>Casillas et al. (2010)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Cancer survivors</td>
<td>Community</td>
<td>Qualitative</td>
<td>Mixed methods</td>
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<tr>
<td>Clarizia et al. (2009)</td>
<td>Canada</td>
<td>Parent-combined</td>
<td>Congenital heart defects</td>
<td>Clinical</td>
<td>Qualitative</td>
<td>Mixed methods</td>
</tr>
<tr>
<td>Craig, Towns, and Bibby (2007)</td>
<td>Australia</td>
<td>Parent-defined</td>
<td>Cystic fibrosis</td>
<td>Clinical</td>
<td>Program evaluation</td>
<td>Mixed methods</td>
</tr>
<tr>
<td>Davies, Rennick, and Majnemer (2011)</td>
<td>Canada</td>
<td>Parent-defined</td>
<td>Noncategorical I/DD</td>
<td>Clinical</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Dupuis, Duhamel, and Gendron (2011)</td>
<td>Canada</td>
<td>Parent-defined</td>
<td>Cystic fibrosis</td>
<td>Clinical</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
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<th>Study</th>
<th>Location</th>
<th>Parent-defined/ parent-combined</th>
<th>AEA-SHCN condition</th>
<th>Settings</th>
<th>Research design</th>
<th>Research procedure</th>
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<tr>
<td>Fredericks et al. (2011)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Liver transplants</td>
<td>Clinical</td>
<td>Descriptive</td>
<td>Survey questionnaire</td>
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<tr>
<td>Geerts, van de Wiel, and Tamminga (2008)</td>
<td>Netherlands</td>
<td>Parent-defined</td>
<td>Parent-defined</td>
<td>Hemophilia</td>
<td>Pre-testing and post-testing</td>
<td>Questionnaires measuring psychosocial construct</td>
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<td>Jivanjee and Kruzich (2011)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Mental illness</td>
<td>Community</td>
<td>Qualitative</td>
<td>Focus group</td>
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<tr>
<td>Jivanjee, Kruzich, and Gordon (2009)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Mental illness</td>
<td>Community</td>
<td>Qualitative</td>
<td>Focus group</td>
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<tr>
<td>Kingsnorth, Gall, Beayni, and Rigby (2011)</td>
<td>Canada</td>
<td>Parent-defined</td>
<td>Noncategorical; I/DD</td>
<td>Community</td>
<td>Qualitative</td>
<td>Focus group</td>
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<tr>
<td>Kirk (2008)</td>
<td>Britain</td>
<td>Parent-combined</td>
<td>Noncategorical SHCN</td>
<td>Community</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
</tr>
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<td>Latzman et al. (2010)</td>
<td>United States</td>
<td>Parent-defined</td>
<td>Sickle cell disease</td>
<td>Clinical</td>
<td>Descriptive</td>
<td>Questionnaires measuring psychosocial construct</td>
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<td>Study</td>
<td>Location</td>
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<td>Moola and Norman (2011)</td>
<td>Canada</td>
<td>Parent-combined</td>
<td>Noncategorical SHCN</td>
<td>Community</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
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<tr>
<td>Pickler, Kellar-Guenther, and Goldson (2011)</td>
<td>United States</td>
<td>Parent-combined</td>
<td>Noncategorical; I/DD</td>
<td>Community</td>
<td>Qualitative</td>
<td>Focus group</td>
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<td>Reiss, Gibson, and Walker (2005)</td>
<td>United States</td>
<td>Parent-combined</td>
<td>Noncategorical SHCN</td>
<td>Clinical/ community</td>
<td>Qualitative</td>
<td>Focus group</td>
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<tr>
<td>Rutishauser, Akre, and Suris (2011)</td>
<td>Switzerland</td>
<td>Parent-defined</td>
<td>Noncategorical SHCN</td>
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<td>Survey</td>
<td>Survey questionnaire</td>
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<th>Research procedure</th>
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<tr>
<td>Shaw, Southwood, and McDonagh (2004)</td>
<td>United Kingdom</td>
<td>Parent-combined</td>
<td>JRA</td>
<td>Clinical</td>
<td>Qualitative</td>
<td>Focus groups</td>
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<td>Shaw, Southwood, and McDonagh (2005)</td>
<td>United Kingdom</td>
<td>Parent-combined</td>
<td>JRA</td>
<td>Clinical</td>
<td>Descriptive</td>
<td>Self-report questionnaire</td>
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<td>Shaw, Southwood, and McDonagh (2007)</td>
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<td>JRA</td>
<td>Clinical</td>
<td>Instrument validation</td>
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<td>Shaw, Southwood, and McDonagh (2006)</td>
<td>United Kingdom</td>
<td>Parent-defined</td>
<td>JRA</td>
<td>Clinical</td>
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<td>Survey questionnaire</td>
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<td>Singh et al., 2010</td>
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<td>Community</td>
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<td>B. Williams, Mukhopadhyay, Dowell, and Coyle (2007)</td>
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<td>Williams et al. (2010)</td>
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<td>Wong et al. (2010)</td>
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<td>Young et al. (2009)</td>
<td>Canada</td>
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<td>Noncategorical SHCN</td>
<td>Community</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
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</table>

Note. AEA-SHCN = adolescents and emerging adults with special health care needs and disabilities; SHCN = special health care needs; I/DD = intellectual/ developmental disabilities; NS-CSHCN = National Survey of Children With Special Health Care Needs; CAHPS = Consumer Assessment of Health Plans Survey; NHIS = National Health Interview Survey; JRA = juvenile rheumatoid arthritis.
Table 2. Profile of Reviewed Studies (N = 47).

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Study</th>
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<tbody>
<tr>
<td>Country</td>
<td></td>
</tr>
<tr>
<td>United States (23)</td>
<td>(Betz, Smith, &amp; Macias, 2010; Betz &amp; Redcay, 2005; Casillas et al., 2010; Duke &amp; Scal, 2011; Fredericks et al., 2011; Jivanjee &amp; Kruzich, 2011; Jivanjee, Kruzich, &amp; Gordon, 2009; Knapp, Huang, Hinojosa, Baker, &amp; Sloyer, 2013; Latzman et al., 2010; LoCasale-Crouch &amp; Johnson, 2005; Lotstein et al., 2009; Lotstein, McPherson, Strickland, &amp; Newacheck, 2005; McManus et al., 2013; McPherson et al., 2004; Pickler, Kellar-Guenther, &amp; Goldson, 2011; Rehm, Fuentes, Fisher, &amp; Chesla, 2012; Reiss, Gibson, &amp; Walker, 2005; Scal, Davern, Ireland, &amp; Park, 2008; Scal, Horvath, &amp; Garwick, 2009; Scal &amp; Ireland, 2005; Vijayan, Benin, Wagner, Romano, &amp; Andiman, 2009; Wiener, Zobel, Battles, &amp; Ryder, 2007; Woodward, Swigonski, &amp; Ciccarelli, 2012)</td>
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<tr>
<td>International (24)</td>
<td></td>
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<tr>
<td>Canada (7)</td>
<td>(Clarizia et al., 2009; Davies, Rennick, &amp; Majnemer, 2011; Dupuis, Duhamel, &amp; Gendron, 2011; Kingsnorth, Gall, Beayni, &amp; Rigby, 2011; Moola &amp; Norman, 2011; Williams et al., 2011; Young et al., 2009)</td>
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<td>United Kingdom (8)</td>
<td>(Kirk, 2008; Shaw, Southwood, &amp; McDonagh, 2004, 2005, 2006, 2007; Singh et al., 2010; Tan &amp; Klimach, 2004; B. Williams, Mukhopadhyay, Dowell, &amp; Coyle, 2007)</td>
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<td>Australia (2)</td>
<td>(Brodie et al., 2011; Craig, Towns, &amp; Bibby, 2007)</td>
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<td>Netherlands (4)</td>
<td>(Bindels-de Heus et al., 2013; Geerts, van de Wiel, &amp; Tamminga, 2008; Sonneveld, Strating, van Staa, &amp; Nieboer, 2013; van Staa, Jedeloo, van Meeteren, &amp; Latour, 2011)</td>
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<td>France (1)</td>
<td>(Dabadie et al., 2008)</td>
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<td>Hong Kong (1)</td>
<td>(Wong et al., 2010)</td>
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<tr>
<td>Switzerland (1)</td>
<td>(Rutishauser, Akre, &amp; Suris, 2011)</td>
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<tr>
<td>Ethnic and racial diversity reported</td>
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<tr>
<td>National/state-level surveys (8)</td>
<td>(Duke &amp; Scal, 2011; Knapp et al., 2013; Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2009; Scal &amp; Ireland, 2005)</td>
</tr>
<tr>
<td>Qualitative (1)</td>
<td>(Casillas et al., 2010; Jivanjee et al., 2009)</td>
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<tr>
<td>Descriptive (1)</td>
<td>(Latzman et al., 2010)</td>
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<tr>
<td>Randomized control trial (1)</td>
<td>(Betz et al., 2010)</td>
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<tr>
<td>Diagnostic conditions</td>
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<tr>
<td>Noncategorical SHCN (22)</td>
<td>(Betz &amp; Redcay, 2005; Brodie et al., 2011; Dabadie et al., 2008; Duke &amp; Scal, 2011; Kirk, 2008; Knapp et al., 2013; Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Moola &amp; Norman, 2011; Reiss et al., 2005; Rutishauser et al., 2011; Scal et al., 2008; Scal et al., 2009; Scal &amp; Ireland, 2005; Sonneveld et al., 2013; Tan &amp; Klimach, 2004; van Staa et al., 2011; Williams et al., 2011; Wong et al., 2010; Young et al., 2009)</td>
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Sample characteristics | Study
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Diagnostic-specific (17): acute kidney disease (LoCasale-Crouch & Johnson, 2005), cancer (Casillas et al., 2010), congenital heart defects (Clarizia et al., 2009), cystic fibrosis (Craig et al., 2007; Dupuis et al., 2011; B. Williams et al., 2007), hemophilia (Geerts et al., 2008), HIV (Vijayan et al., 2009; Wiener et al., 2007), juvenile rheumatoid arthritis (Shaw et al., 2004, 2005, 2006, 2007), liver transplants (Fredericks et al., 2011), sickle cell disease (Latzman et al., 2010), spina bifida (Betz et al., 2010), asthma (Scal et al., 2008)
Intellectual and developmental disabilities (6) (Bindels-de Heus et al., 2013; Davies et al., 2011; Kingsnorth et al., 2011; Pickler et al., 2011; Rehm et al., 2012; Woodward et al., 2012)
Mental illness (3) (Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Singh et al., 2010)

Recruitment settings

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<tr>
<th>Study</th>
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<tr>
<td>Clinical settings (23) (Betz et al., 2010; Bindels-de Heus et al., 2013; Brodie et al., 2011; Clarizia et al., 2009; Craig et al., 2007; Dabadie et al., 2008; Davies et al., 2011; Dupuis et al., 2011; Fredericks et al., 2011; Geerts et al., 2008; Latzman et al., 2010; Shaw et al., 2004, 2005, 2006, 2007; Sonneveld et al., 2013; van Staa et al., 2011; Vijayan et al., 2009; Wiener et al., 2007; Williams et al., 2011; B. Williams et al., 2007; Wong et al., 2010; Woodward et al., 2012)</td>
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<td>Community-based settings (7) (Betz &amp; Redcay, 2005; Casillas et al., 2010; Jivanjee &amp; Kruzich, 2011; Jivanjee et al., 2009; Pickler et al., 2011; Rehm et al., 2012; Tan &amp; Klimach, 2004)</td>
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<tr>
<td>Secondary analysis of national/state-level data sets (9) (Duke &amp; Scal, 2011; Knapp et al., 2013; Lotstein, 2005; Lotstein, 2009; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2008; Scal et al., 2009; Scal &amp; Ireland, 2005)</td>
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<tr>
<td>Combined clinical and community settings (2) (LoCasale-Crouch &amp; Johnson, 2005; Reiss et al., 2005)</td>
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Research designs

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<td>Qualitative (19) (Brodie et al., 2011; Casillas et al., 2010; Clarizia et al., 2009; Davies et al., 2011; Dupuis et al., 2011; Jivanjee &amp; Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011; Kirk, 2008; Moola &amp; Norman, 2011; Pickler et al., 2011; Rehm et al., 2012; Reiss et al., 2005; Shaw et al., 2004; Singh et al., 2010; van Staa et al., 2011; Vijayan et al., 2009; B. Williams et al., 2007; Young et al., 2009)</td>
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</table>
Sample characteristics | Study
---|---
Secondary analysis of data (9) | (Duke & Scal, 2011; Knapp et al., 2013; Lotstein, 2005; Lotstein, 2009; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2008; Scal et al., 2009; Scal & Ireland, 2005)
Descriptive (8) | (Bindels-de Heus et al., 2013; Fredericks et al., 2011; Latzman et al., 2010; Shaw et al., 2005; Sonneveld et al., 2013; Tan & Klimach, 2004; Williams et al., 2011; Wong et al., 2010)
Surveys (3) | (Rutishauser et al., 2011; Shaw et al., 2006; Woodward et al., 2012)
Program evaluation (2) | (Craig et al., 2007; Wiener et al., 2007)
Mixed methods (2) | (Dabadie et al., 2008; LoCasale-Crouch & Johnson, 2005)
Pre- and post-testing (1) | (Geerts et al., 2008)
Randomized control trial (1) | (Betz et al., 2010)
Retrospective chart review (1) | (Betz & Redcay, 2005)
Instrument validation (1) | (Shaw et al., 2007)
Methods | Interviews (11) (Brodie et al., 2011; Davies et al., 2011; Dupuis et al., 2011; Kirk, 2008; Moola & Norman, 2011; Rehm et al., 2012; Singh et al., 2010; Tan & Klimach, 2004; van Staa et al., 2011; B. Williams et al., 2007; Young et al., 2009)
Mixed methods (7) | (Casillas et al., 2010; Clarizia et al., 2009; Craig et al., 2007; Dabadie et al., 2008; LoCasale-Crouch & Johnson, 2005; Vijayan et al., 2009; Wiener et al., 2007)
Focus groups (6) | (Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011; Pickler et al., 2011; Reiss et al., 2005; Shaw et al., 2004)
Surveys (15) | (Bindels-de Heus et al., 2013; Duke & Scal, 2011; Fredericks et al., 2011; Knapp et al., 2013; Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Rutishauser et al., 2011; Scal et al., 2008; Scal et al., 2009; Scal & Ireland, 2005; Shaw et al., 2006; Sonneveld et al., 2013; Woodward et al., 2012)
Instruments measuring psychosocial constructs (4) | (Betz et al., 2010; Geerts et al., 2008; Latzman et al., 2010; Williams et al., 2011)
Self-report questionnaires (2) | (Shaw et al., 2005; Wong et al., 2010)
Chart extraction (1) | (Betz & Redcay, 2005)
Instrument validation (1) | (Shaw et al., 2007)

Note. SHCN = special health care needs.
The articles included in this review demonstrate the breadth of this emerging field of practice and research. The research methods of the studies in this mixed methods review include quantitative, qualitative, program evaluation, pre- and post-testing, instrument validation, and secondary analysis of large data sets (Tables 2 and 3). In addition, the diagnostic categories of parents of AEA-SHCN are representative of a wide range of diagnostic categories, as evidenced in Tables 2 and 3. However, given the diversity of this mixed methods review, the commonality shared by all studies is the focus on the process of HCT, which includes the transfer of care from pediatric to adult health care that parents and children experience. The findings of this review illuminate the parental issues of concern and their needs for HCT services that can be applied to the development and implementation of evidence-based models of care to improve parental outcomes and those for their children.

Results

The findings of this systematic review begin with an examination of the samples and settings, research designs, and methods of all 47 studies reviewed. Next, an overview of the characteristics of both groups of studies “parent-defined” and “parent-combined” is provided. The parent-defined sample studies are then compared and contrasted with the parent-combined sample studies with regard to the studies’ designs, methodology, settings, and samples, followed by a discussion of the common concerns found in the parent-defined sample studies (Tables 1 and 2).

Sample Characteristics

Nearly equivalent numbers of studies were conducted in the United States ($n = 23; 49\%$) and in other nations (Tables 1 and 2). Fifteen (65\%) of the parent-sampled studies published in the United States were parent-defined, and 8 were parent-combined; of the studies from other countries, 14 (58\%) were parent-defined, and 10 (42\%) parent-combined (Tables 1-4).

Few of the studies, whether parent-defined or parent-combined, reported ethnic and racial characteristics of the parent samples (Tables 3 and 4). Ten of the parent-defined studies, all of which were conducted in the United States, reported ethnic and racial characteristics of the parent samples (Tables 1 and 2). Authors of the national surveys reported differences in services as they pertained to ethnicity, which reflected disparities in access to health care and HCT services (Tables 3 and 4). Socioeconomic status was also rarely addressed. For studies that reported ethnicity, racial composition, and socioeconomic status,
Table 3. Parent-Defined Studies.

| Sample characteristics | Canada (5) (Davies, Rennick, & Majnemer, 2011; Dupuis, Duhamel, & Gendron, 2011; Kingsnorth, Gall, Beaïni, & Rigby, 2011; Moola & Norman, 2011; Williams et al., 2011) | France (1) (Dabadie et al., 2008) | Hong Kong (1) (Wong et al., 2010) | Netherlands (3) (Bindels-de Heus et al., 2013; Geerts, van de Wiel, & Tamminga, 2008; Sonneveld et al., 2013) | Switzerland (1) (Rutishauser, Akre, & Suris, 2011) | United Kingdom (4) (Shaw et al., 2006, 2007; Tan & Klimach, 2004; B. Williams, Mukhopadhyay, Dowell, & Coyle, 2007) | United States (15) (Betz, Smith, & Macias, 2010; Casillas et al., 2010; Duke & Scal, 2011; Fredericks et al., 2011; Jivanjee & Kruzich, 2011; Jivanjee, Kruzich, & Gordon, 2009; Knapp, Huang, Hinojosa, Baker, & Sloyer, 2013; Latzman et al., 2010; Lotstein et al., 2009; Lotstein, McPherson, Strickland, & Newacheck, 2005; McManus et al., 2013; McPherson et al., 2004; Scal, Horvath, & Garwick, 2009; Scal & Ireland, 2005; Woodward, Swigonski, & Ciccarelli, 2012) |
| Diagnostic conditions | Noncategorical SHCN (10) (Dabadie et al., 2008; Duke & Scal, 2011; Lotstein et al., 2009; Lotstein et al., 2005; Rutishauser et al., 2011; Scal et al., 2009; Scal & Ireland, 2005; Tan & Klimach, 2004; Williams et al., 2011; Wong et al., 2010) | Diagnostic-specific (10) cancer (Casillas et al., 2010), cystic fibrosis (Craig, Towns, & Bibby, 2007; Dupuis et al., 2011, B. Williams et al., 2007), hemophilia (Geerts et al., 2008), juvenile rheumatoid arthritis (Shaw et al., 2006, 2007), liver transplants (Fredericks et al., 2011), sickle cell disease (Latzman et al., 2010), spina bifida (Betz et al., 2010) | Mental illness (2) (Jivanjee & Kruzich, 2011; Jivanjee et al., 2009) | Intellectual and developmental disabilities (4) (Bindels-de Heus et al., 2013; Davies et al., 2011; Kingsnorth et al., 2011; Woodward et al., 2012) | National surveys (7) (Duke & Scal, 2011; Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2009; Scal & Ireland, 2005) | State-level survey (1) (Knapp et al., 2013) | Qualitative (1) (Jivanjee et al., 2009) | Descriptive (1) (Latzman et al., 2010) | Randomized control trial (1) (Betz et al., 2010) |

(continued)
### Table 3. (continued)

| Sample characteristics | Clinical settings (14) (Betz et al., 2010; Craig et al., 2007; Dabadie et al., 2008; Davies et al., 2011; Dupuis et al., 2011; Fredericks et al., 2011; Geerts et al., 2008; Latzman et al., 2010; Shaw et al., 2006, 2007; Sonneveld et al., 2013; Williams et al., 2011; B. Williams et al., 2007; Wong et al., 2010; Woodward et al., 2012) Secondary analysis of national data sets (8) (Duke & Scal, 2011; Knapp et al., 2013; Lotstein, 2005; Lotstein, 2009; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2009; Scal & Ireland, 2005) Community-based settings (7) (Casillas et al., 2010; Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Knapp et al., 2013; Kingsnorth et al., 2011; Rutishauser et al., 2011; Tan & Klimach, 2004) Clinical- and community-based setting (1) (Bindels-de Heus et al., 2013) |
| Research designs | Secondary analysis (8) Duke & Scal, 2011; Knapp et al., 2013; Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Scal, 2009; Scal & Ireland, 2005) Descriptive (7) (Bindels-de-Heus et al., 2013; Fredericks et al., 2011; Latzman et al., 2010; Sonneveld et al., 2013; Tan & Klimach, 2004; Williams et al., 2011; Wong et al., 2010) Qualitative (7) (Casillas et al., 2010; Davies et al., 2011; Dupuis et al., 2011; Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011; B. Williams et al., 2007) Survey (3) (Rutishauser et al., 2011; Shaw et al., 2006; Woodward et al., 2012) Program evaluation (1) (Craig et al., 2007) Instrument development/program development(1) (Shaw et al., 2007) Mixed methods (1) (Dabadie et al., 2008) Pre- and post-testing (1) (Geerts et al., 2008) Randomized control trial (1) (Betz et al., 2010) |
| Methods | Survey questionnaire (14) (Bindels-de Heus et al., 2013; Duke & Scal, 2011; Fredericks et al., 2011; Knapp et al., 2013; Lotstein, 2005; Lotstein, 2009; McManus et al., 2013; McPherson et al., 2004; Rutishauser et al., 2011; Scal et al., 2009; Scal & Ireland, 2005; Shaw et al., 2006; Sonneveld et al., 2013; Woodward et al., 2012) Mixed methods (3) (Casillas et al., 2010; Craig et al., 2007; Dabadie et al., 2008) |
The implications of these demographic characteristics were not discussed in terms of practice or future research (Duke & Scal, 2011; Jivanjee, Kruzich, & Gordon, 2009; Latzman et al., 2010; Scal, Horvath, & Garwick, 2009; Scal & Ireland, 2005).

The parents of AEA-SHCN enrolled in the studies in this review provided information and insights about their lived experience of parenting a child with a chronic condition, which reflected commonalities, despite the diversity of diagnostic conditions represented, as well as unique perspectives based on their children’s specific condition and level of severity. The childhood-acquired conditions of the AEA-SHCN included a variety of chronic disorders, although not a broad-based representation of the range of SHCN affecting youth in both types of parent studies (Tables 1-4). As demonstrated in parent-defined and parent-combined studies, a noncategorical approach to sampling was used most frequently, followed by samples with diagnostic-specific conditions.

**Settings**

As a whole, samples were recruited from a variety of settings in both types of parent studies, although clinical settings were used more often in studies of other countries than in those conducted in the United States (Tables 1-4). The contrast of differences between U.S. and other national health care service systems may account for the divergence found in sample recruitment. The clinical setting was used most often (15 studies; 50%) in the parent-defined studies as well (Tables 1-4).

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**Table 3.** (continued)

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<th>Sample characteristics</th>
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<tr>
<td>Instruments measuring psychosocial constructs (4) (Betz et al., 2010; Geerts et al., 2008; Latzman et al., 2010; Williams et al., 2011)</td>
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<tr>
<td>Focus groups (3) (Jivanjee &amp; Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011)</td>
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<td>Semi-structured interviews (4) (Davies et al., 2011; Dupuis et al., 2011; Tan &amp; Klimach, 2004; B. Williams et al., 2007)</td>
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<td>Self-report questionnaires (1) (Wong et al., 2010)</td>
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<td>Instrument validation (1) (Shaw et al., 2007)</td>
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*Note. n = 30. SHCN = special health care needs.*
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<tr>
<th>Study</th>
<th>Purpose</th>
<th>Sample/setting</th>
<th>Research design/method</th>
<th>Findings</th>
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<tr>
<td>Betz, Smith, and Macias (2010)</td>
<td>Tested the effectiveness of the Transition Preparation Training program for adolescents with SB in combination with SB management compared with adolescents with SB who received SB management only</td>
<td>31 parents enrolled in treatment group (M age = 45.25), 87% Latino; 34 parents enrolled in control group (M age = 40.15), 91% Latino; 31 adolescents with SB enrolled in the treatment group; 34 adolescents with SB enrolled in control group</td>
<td>Randomized controlled trial Data collected pre- and post-transition intervention to measure psychosocial adjustment using the PARS III and investigator-developed demographic tool</td>
<td>1. No significant differences were found between treatment and control groups 2. Treatment and control groups had comparable scores on the highest (hostility) and lowest (peer) subscale scores</td>
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<td>Bindels-de Heus et al. (2013)</td>
<td>Investigated the parental experiences of their YYA with PIMD with their transfer from pediatric to adult health care</td>
<td>131 parents of YYA with PIMD (response rate, 24%); inclusion criteria: (a) 16 to 26 years of age, (b) IQ below 30, (c) developmental age of ≤2 years, and (d) GMFCS Level IV or V</td>
<td>Retrospective cross-sectional design; online self-reported questionnaire with closed- and open-ended items; data were collected on parents’ and YYA demographic characteristics, Katz ADLs, health care utilization, perceptions of and satisfaction with health care utilization and transfer of care, and HCT recommendations and preferences</td>
<td>1. Twenty-two percent (29) reported pediatrician continued to be coordinating MD. 2. Twenty-two percent reported having no coordinating MD. 3. M = 2.47 (SD = 1.45) specialists involved in care during past years. 4. Pediatric neurologist most frequently identified as specialist during past year of care. 5. Forty-seven percent of parents satisfied with adult coordinating MD, 33% no opinion as to level of satisfaction, and 20% disagreed. 6. Low scores on parental perceptions of transfer emotional impact and information provision. 7. Twenty-two percent of parents reported YYA who transferred only received transfer announcement. 8. Themes generated from two open-ended items answered by 86% of parents were (a) continue care (as it used to be) with the pediatrician and (b) listen to parents and value their expertise. 9. Parental recommendations for improving care were (a) more information, (b) gradual process for transfer, (c) joint consultation with pediatric and adult MDs, (d) copy of medical records, and (e) comprehensive HCT approach needed.</td>
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### Table 4. (continued)

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<tr>
<th>Study</th>
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<th>Sample/setting</th>
<th>Research design/method</th>
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</table>
| Casillas et al. (2010)     | Explored the perceptions of HCT facilitators and barriers to accessing adult survivorship care of Latino AYA cancer survivors and their parents | 27 of 37 eligible AYA ≥ 15 to 30 years  
21 of 52 eligible parents | Qualitative study using mixed methods; focus groups with parents; parent demographic questionnaire; key informant interviews with AYA  
Parents participated in one of four focus groups  
Questions for focus groups based on questionnaire content originally developed by Children’s Oncology Group on long-term follow-up care | Major themes emerged from data analysis:  
1. Survivorship care facilitators:  
   a. Emphasis on symptom communication in late effects discussion  
2. Survivorship care barriers:  
   a. Recalling the cancer experience as traumatic  
   b. Cancer stigma |
| Craig, Towns, and Bibby (2007) | Evaluated the effectiveness of a transition program for AEA with CF as measured by levels of satisfaction, QoL, and disease severity | Two groups comprised the sample of 45 AEA with CF and their 45 parents, who participated in a structured transition program between pediatric and adult Australian hospitals with CF programs | Program evaluation using cross-sectional design and the use of self-reported questionnaires measuring transition concerns, participation, and level of satisfaction; data were collected on AEA with CF on QoL and demographics | 1. Items of greatest parental concern in transferring to adult care were as follows:  
   Pre-transition (n = 45): leaving pediatric care (73.3%), changing relationship with pediatric staff (68.9%), and unfamiliarity with adult staff (64.4%);  
   Post-transition (n = 20): child assumes care responsibility (70%), unfamiliarity with adult staff (65%), and child makes own decisions (63.2%)  
2. Parents reported significantly more items of concern pre-transition than AEA-CF; post-transition, no differences noted  
3. 55% of parents expressed satisfaction with transition program |
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<tr>
<td>Dabadie et al. (2008)</td>
<td>Investigated perceptions of French patients with IBD and parents about the transition from pediatric to adult care GE and between those who received a joint (adult/pediatric provider) visit vs. those who did not</td>
<td>34 youths with IBD who transitioned to adult care; 34 parents One patient alone, one set of parents alone—the other 33 both parent and patient</td>
<td>Retrospective analysis, cross-sectional study Retrospective perspective from patients/parents already transitioned Mailed questionnaires to youth/parents on perceptions of the transition to GE adult care and offer service recommendations</td>
<td>1. All parents felt they had received sufficient information about transition. 2. Parental reasons for not being ready for transition to adult GE: difficulty with changing physicians, beneficial relationship with pediatric gastroenterologist, transition occurred near time of surgical procedure, and young age of child. 3. Seventy-nine percent of parents reported accompanying child to adult GE visit. 4. Four (13%) parents phoned pediatric gastroenterologist after leaving. 5. Twenty-three (77%) parents were involved with the adult care services. 6. All parents (11) involved with joint visit said they were positive; 7 reported one visit was inadequate.</td>
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<td>Davies, Rennick, and Majnemer (2011)</td>
<td>Described the experiences of parents whose children, ages 18-21 years with a neurological disorder and intellectual impairment, had undergone transition to adult health care services</td>
<td>17 Canadian parents of 11 18- to 21-year-olds with neurological disorders and intellectual impairment who had transitioned to adult health care services</td>
<td>A qualitative interpretive design using a semi-structured, in-depth interview guide; each interview lasted an average of 1 hr; data were collected over 8 months</td>
<td>Four themes emerged from the data: (a) A sense of abandonment by health care professionals, the system of care, fear, and uncertainty (b) Facilitation of transition, factors that limited transition success (c) Parental health affected by stress (d) Vulnerability and health status of the young adult</td>
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<td>Duke and Scal (2011)</td>
<td>Studied the relationship among family-centered care, transition counseling, and an usual source of care for 12- to 17-year-olds with SHCN</td>
<td>18,198 parents/guardians of 12- to 17-year-olds with SHCN who responded to the 2005-2006 NS-CShCN (a national U.S. survey completed by telephone between April 2005 and February 2007)</td>
<td>Secondary analysis of NS-CShCN</td>
<td>1. Youth with an identified source of care were more likely to receive transition counseling and be more independent in their health care. 2. FCC also influenced transition planning and accountability for care. 3. FCC accounted for 39.1% of the effect of having a usual source of care on transition counseling.</td>
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<td>Dupuis, Duhamel, and Gendron</td>
<td>Examined the pre-transfer experience of Canadian adolescents with CF and their parents</td>
<td>7 of 26 eligible families participating consisted of 11 parents (7 mothers, 4 fathers); 7 adolescents between 15 and 18 years of age</td>
<td>Qualitative study using semi-structured interview guides</td>
<td>Findings presented based on one of four major themes generated from the data, Parents’ experience: Living with the disease and supporting their teenager, which consisted the four subthemes: (a) Parents and adolescents living with CF: a dynamic of normalization, (b) Parents confronted with adolescent’s urgent desire to live, (c) Parents experienced ongoing suffering, (d) Suffering unrevealed to HCP</td>
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</table>
| Fredericks et al. (2011)      | Examined the perceptions and attitudes of parents and adolescents and young adults with liver transplants about HCT process | 31 LTR (ages 12 to 17 years) and their parents/guardians 15 LTR (≥18 years) without parent/guardians Recruited from pediatric liver transplant clinic 92% recruitment rate | Cross-sectional surveySurvey was compilation of items adapted from other questionnaires using Likert-type scale with 3-, 4-, and 5-point scales | 1. Forty-eight percent (15) of parents had not thought about HCT.  
2. Sixty-one percent (19) of parents reported “some” to “a lot” interest with learning about HCT.  
3. Parents’ level of HCT knowledge was limited: (a) 29% (9) understood insurance transferability and (b) 17% (8) were knowledgeable about targeted adult services.  
4. Parents expressed greatest concern about leaving pediatric care.  
5. Most important LTR SM task identified was knowing when to access emergency department.  
6. Parents perceived less shared management responsibility than LTR.  
7. Forty-eight percent (15) of parents offered suggestions for HCT improvements.  
8. Most frequently identified suggestion for HCT improvement was general information.  
9. Fifty-one percent did not express HCT concerns. |
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<tr>
<td>Geerts, van de Wiel, and Tamminga (2008)</td>
<td>Investigated the effects of the HCT to adult health care services in Dutch hemophilia patients and their parents on transition worries and QoL</td>
<td>Nine pre-transition children with hemophilia (mean age = 15.3) and their 18 parents Eight post-transition children (M age = 19.4) and their 21 parents (not clear how many mothers and fathers in each group)</td>
<td>Cross-sectional study Pre- and post-transition measures collected were as follows: (a) worries about the transition (a Dutch translation of the John Hopkins Adult Cystic Fibrosis Program Survey) (b) health-related QoL (a Dutch translation of the Haemo-QoL-A) (c) parents’ illness-related distress concerning their children</td>
<td>1. Worries of both pre- and post-transition patients and their parents did not differ. 2. Mothers’ worries exceeded both sons’ and fathers’ concerns. 3. Parental ratings of sons’ QoL negatively correlated with their illness-related distress and transition worries.</td>
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<td>Jivanjee, Kruzich, and Gordon (2009)</td>
<td>Reported the perceptions and experiences of family members of youth with mental illness during the youths’ transition years</td>
<td>Participants were recruited from the National Alliance for the Mentally Ill and local family advocacy organizations in the United States.</td>
<td>Focus-group design; eight focus-group sessions composed of parents; additional 12 focus groups consisted of youth, aged 17-24 years, not reported in this article</td>
<td>Parental themes revealed their perceptions and transition experiences: 1. Find opportunities for their children to reach goals, have peer relationships, and achieve community integration 2. Wanted their youth to experience success, independence, overcome stigmatization, and prepare for adult life 3. Lack of financial assistance, psychiatric and community services, supportive mentoring available 4. Appreciated helpful professionals but felt transition planning began late 5. “Letting go” was difficult; had feelings of exhaustion and disappointment; laws prohibited family from helping child after age 18</td>
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<tr>
<td>Jivanjee and Kruzich (2011)</td>
<td>Described the experiences and perceptions of young people of transition age (ages 17-24) and parents in relation to informal supports and mental health services</td>
<td>Parents were recruited through family support organizations and their children through educational settings, support groups, mental health agencies, and employment agencies in the United States</td>
<td>Focus-group design; 8 focus groups with parents and 12 focus groups with young people were held; not all parents were related to the young people who participated</td>
<td>Significant parental findings included the following: 1. Valued practical resources and help (i.e., respite care) 2. Distressed by eligibility service termination after age 18, negative relationships with providers, and lack of access to treatment 3. Difficulty knowing when to let go 4. Appreciated the effectiveness of advocacy services and activities</td>
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<td>Kingsnorth, Gall, Beayni, and Rigby (2011)</td>
<td>Measured the impact of the Transition Peer Support Focus Groups led by a family facilitator on participant parent’s level of support, skill, and knowledge for future transition planning</td>
<td>30 Canadian parents of 12- to 18-year-olds who received augmentative communication support (most had developmental or physical disabilities)</td>
<td>Focus-group design; over 12 months, 11 sessions were held</td>
<td>Three themes were identified: awareness, experiential knowledge, and active planning: 1. Awareness identified levels of stress for parents in planning and providing daily care. 2. Experiential knowledge revealed that parents learned and motivated to advocate for their child’s transition needs. 3. Active planning revealed need to learn more to support transition service needs, and promote independence and community inclusion.</td>
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<td>Knapp, Huang, Hinojosa, Baker, and Sloyer (2013)</td>
<td>Investigated the extent to which HCT discussions had occurred with parents and their ASHCN</td>
<td>376 matched pairs of parents and their ASHCN (ages 15-18 years) who were enrolled in the Florida’s Children’s Medical Services Network (Title V Program for Children With Special Health Care Needs); response rate: parents, 61%; ASHCN, 77%</td>
<td>Secondary analysis of data gathered state-level data set, Consumer Assessment of Health Plans Survey Cross-sectional telephone survey composed of three questions that queried about discussions with HCP about HCT</td>
<td>1. Parents indicated with greater frequency HCT with HCPs than ASHCN, except for nurses 2. Ethnic differences among parents who had discussions with their ASHCN with HCT discussions with MD were not evident: White non-Hispanic (34%); Black non-Hispanic (30%); Hispanic (34%) 3. Forty percent of parents stated they discussed HCT with their ASHCN; 32% had this discussion with MD 4. Parental and ASHCN responses to HCT discussions (yes/yes [62%-67%] and no/no [44%-66%]) were similar</td>
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<td>Latzman et al. (2010)</td>
<td>Explored the concerns of AEA with SCD and their caregivers pertaining to transition and the relative importance of services offered in the SCD transition clinic</td>
<td>41 parents of AEA with SCD; 20 pre-transition and 21 of transition aged 71 AEA with SCD, ages 17 to 26 years, in various stages of transitioning (pre, during, and post)</td>
<td>Descriptive study using cross-sectional design Several instruments used to collect demographic and transition concerns</td>
<td>1. Findings revealed that caregiver and AEA with SCD did not significantly differ. 2. Major pre-transition parental concerns were as follows: leaving the pediatrician, adult caregivers not perceived as caring, and receive emergency room care. 3. Major parental transition concerns were as follows: receive emergency room care, admission into adult hospital, and meeting adult providers. 4. Post-transition feelings significantly improved.</td>
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<td>Lotstein, McPherson, Strickland, and Newacheck (2005)</td>
<td>Identified the number of 13- to 17-year-olds with SHCN who receive medical transition services with a secondary purpose to assess what health care and sociodemographic factors are correlated with the use of transition services</td>
<td>5,533 parents of 13- to 17-year-olds with SHCN were asked to respond to three transition questions that composed the HCT core outcome on the 2001 NS-CSHCN</td>
<td>Secondary analysis of NS-CSHCN; a national survey was conducted by telephone by the National Center for Health Statistics between October 2000 and April 2003 among parents of 13,885 adolescents; the transition questions were first asked in July 2001; therefore, the sample size for these questions was 5,533; the questions related to the HCT core outcome were changing health needs as an adult, transfer to adult providers, and having a HCT plan</td>
<td>1. Only 15.3% had met the MCHB’s core outcome for HCT; these youth were older and had a medical home. 2. Following topics were discussed: Fifty percent of respondents stated that they had discussed their CSHCN with their MD; 59% had transition plan, and 42% transfer to adult providers. 3. Parents of Hispanic youth reported significantly less discussion with MD. 4. About 42% had discussed the transition to adult providers; discussions increased as youth aged. 5. Families of Hispanic and Black youth reported less MD discussion about HCT.</td>
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<th>Purpose</th>
<th>Sample/setting</th>
<th>Research design/method</th>
<th>Findings</th>
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| Lotstein et al. (2009)       | Identified changes in the 2005-2006 HCT core outcome compared with 2000-2001 NS-CSHCN; reported survey results of HCT core outcome and sociodemographic variables | A total of 40,723 parents or legal guardians completed the survey; 18,198 were parents of youth, ages 12-17; 1,862 parents of children without SHCN in comparison group | Secondary analysis of NS-CSHCN; respondents asked four HCT questions that compose the HCT outcome; about future health care providers and needs, enrollment in adult health insurance plan, and facilitate youth's assumption of SM | 1. Forty-one percent met HCT core outcome.  
2. Following topics were discussed with pediatric provider: 42% transfer to adult care, 62% future health care needs, 34% enrollment in adult health insurance plan, and 78% SM.  
3. Non-Hispanic Whites were more likely to meet HCT core outcome than non-Hispanic Blacks and Hispanics.  
4. No significant differences with HCT core outcomes between parents of youth with and without SHCN. |
| McManus et al. (2013)        | Examined the HCT findings of the 2009-2010 NS-CSHCN                     | 17,114 parent/guardian respondents of YSHCN between ages 12 and 18 years        | Secondary analysis of NS-CSHCN; respondents asked four HCT questions that compose the HCT core outcome; about future health care providers and needs, enrollment in adult health insurance plan, and facilitate youth's assumption of SM | 1. Forty percent YSHCN met core HCT outcome.  
2. Following topics were discussed with pediatric provider: 44% transfer to adult care, 59% future health care needs, 35% enrollment in adult health insurance plan, and 78% SM.  
3. Non-Hispanic Whites were more likely to meet core HCT outcome than Hispanics and non-Hispanic Blacks.  
4. YSHCN whose condition significantly affects activities were more likely to not meet HCT core outcome. |
| McPherson et al. (2004)      | Obtained baseline measures of 6 MCHB core outcomes for CSHCN, of which HCT is 6th core outcome | 54,445 parents/legal guardians (38,866 NS-CSHCN; 13,579 NHIS)                   | Secondary analysis of NS-CSHCN and NHIS data; queried respondents about transfer of care; HCT planning and implementation | 1. 15.3% of YSHCN received HCT services based on 3 criteria: (a) MD raised issue of changing needs, (b) HCT plan developed, and (c) transfer of care.  
2. 25.5% received career/vocational counseling.  
3. 3.8% YSHCN, ages 13 to 17 years met this core outcome. |
| Rutshauser, Akre, and Suris (2011) | Explored HCT expectations of chronically ill AEA and their parents prior to the transfer to adult health care; transition obstacles compared AEA and parental responses | 283 Swiss AEA with chronic disorders, aged 14-25 years  
318 parents                                                                 | Cross-sectional study Similarly mailed questionnaires sent to AEA and parents to explore provider relationships, transition process, and issues | 1. Sixty-nine percent of parents preferred a joint transfer meeting with adult and pediatric specialists.  
2. Thirty-seven percent felt pediatric care is inappropriate for age; 34% said transfer at chronological age.  
3. Most frequently cited obstacles were (a) not feeling at ease with pediatric specialist (38%) and (b) lack of information (27%). |
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<td>Scal, Horvath, and Garwick (2009)</td>
<td>Explored the scope of HCT services adolescents with arthritis received compared with adolescents with diabetes and those with SHCN</td>
<td>1,052 parental respondents of adolescents with arthritis ages 12-17 years 389 parental respondents of adolescents with diabetes requiring insulin ages 12-17 years 17,137 parental respondents of adolescents with SHCN, ages 12-17</td>
<td>Secondary analysis of 2005-2006 NS-CSHCN Analysis of 4 items pertaining to HCT and associated with selected demographic variables</td>
<td>1. Seventy-five percent of adolescents with arthritis encouraged to acquire SM skills, 55% counseled on adult health care, 22.5% on adult insurance plan, and 19% on transfer to adult care 2. Adolescents with diabetes were more likely to receive counseling on 3 of the 4 elements of HCT than those with arthritis 3. HCT counseling rates were similar for adolescents with SHCN and with arthritis</td>
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<td>Scal and Ireland (2005)</td>
<td>Identified the socioeconomic, condition-specific, and health care system that supports or inhibits the transition from child-centered to adult-centered care</td>
<td>4,426 parental respondents of children with SHCN ages 14 to 17 years</td>
<td>Secondary analysis of 2000-2001 U.S. NS-CSHCN Analysis of 3 items exploring HCT and the associated with socioeconomic status, condition-specific variables, and health care services</td>
<td>1. 50.23% discussed changes in health care needs during adulthood; 29.93% discussed adult provider care; 30.08% had HCT plan. 2. Older age, White race, higher level of needs, and higher quality of relationship between parent and provider are associated with higher HCT scores.</td>
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<td>Shaw, Southwood, and McDonagh (2007)</td>
<td>Described the development and validation of the “Mind the Gap” tool designed to measure adolescents with chronic illness and parents’ satisfaction with HCT services</td>
<td>359 families were invited 308 adolescents with JIA (ages 11-17 years) 303 parents/guardians recruited from 10 pediatric rheumatology centers in Britain</td>
<td>Instrument validation testing</td>
<td>Findings reported are part of a larger study: 1. Cronbach’s α for parent form was .94; for each subscale was .83 (management of environment), .91 (provider characteristics), and .94 (process issues) 2. Parents’ subscale scores: highest satisfaction with provider characteristics, lowest satisfaction with process (p &lt; .001)</td>
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<td>Shaw, Southwood, and McDonagh (2006)</td>
<td>Examined the adolescent and parent transition expectations; investigated adolescent and parent satisfaction pre- and post-transition program implementation (part of larger study)</td>
<td>359 families invited 308 (86%) of adolescents with JIA (ages 11, 14, or 17 years) 303 (84%) parents enrolled recruited from 10 pediatric and adolescent rheumatology centers</td>
<td>Survey research Use of self-report questionnaires measuring satisfaction with care, health-related QoL, and arthritis-related knowledge</td>
<td>1. Parents (and youth) rated HCT best practice as important; rated HCT services worse than best practices. 2. Parents had higher HCT expectations than their children. 3. Parent (youth) service satisfaction significantly better after 12 months.</td>
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| Sonneveld et al.      | Explored adolescents with JRA, NMD, T1DM, their parents and providers' perspectives concerning the quality of the initial implementation of HCT care and the extent to which these perspectives are condition-related | 166 parents of adolescents with JRA, NMD, and T1DM  
127 adolescents with JRA, NMD, and T1DM  
19 providers  
34.7% parental response rate | Survey research  
Online versions with backup paper versions were available for adolescents and parents.  
Paper versions of survey were completed by providers.  
22-item questionnaire was composed of three dimensions: (a) provider characteristics (Cronbach's $\alpha = .92$), (b) HCT delivery, (c) environmental management (Cronbach's $\alpha = .64$); used 7-point Likert-type scale that compared perspectives pertaining to "best care" and "current care."  
Provider 52-item survey checklist was developed based on these domains: providers’ characteristics, HCT process, and patient/parent characteristics using a 5-point Likert-type scale. | 1. Parents ranked provider characteristics higher than adolescents.  
2. Parents ranked provider communication skills and interpersonal interactions higher than adolescents.  
3. Parents reported lower levels of satisfaction with HCT care and were less satisfied than adolescents.  
4. No differences were noted with satisfaction with scheduling appointments, waiting times, and the setting environment.  
5. Although differences between groups were slight, parents of adolescents with NMD were less satisfied with HCT care than parents of other groups. |
| Tan and Klimach       | Assessed AEA and their parents’ opinions about the feasibility of using health portfolios for the transfer to adult care | Eight parents of AEA with complex learning/health conditions  
10 youth, 17 years of age with complex learning/health conditions | Descriptive  
Semi-structured interview conducted in the home setting with parents/youth | 1. Seven (88%) were satisfied with the use of the health portfolio.  
2. Four (50%) parents thought the report should include summary information from other programs (education, social services).  
3. Parents provided other suggestions to improve the quality of the report, such as additional details about needs of their children. |
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<td>Williams, Mukhopadhyay, Dowell, and Coyle (2007)</td>
<td>Examined the process of shifting responsibilities of Scottish parents and children/youth with CF pertaining to CF physiotherapy.</td>
<td>31 parents of children/youth with CF, 32 children/youth with CF, ages 7-17 years</td>
<td>Qualitative study, Interviews individually conducted with study subjects</td>
<td>4. Parents would have appreciated additional guidance in contributing to the portfolio. 5. All parents supported continuing the provision of health portfolios for transfer.</td>
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<td>Williams et al. (2011)</td>
<td>Examined youth and parent (mother) responses on a self-developed medical SM questionnaire to assess initial psychometric properties and SM association with independence.</td>
<td>Convenience sample of 49 Canadian youths with neurological conditions (ages 11-18 years, M = 15.58) and their parents enrolled in transition program</td>
<td>Descriptive correlational study, Administration of 3 instruments: (a) Self-Management Skills Assessment Guide, (b) Scales of Independent Behavior—short form, and (c) demographic questionnaire</td>
<td>1. Major themes emerged from data pertaining to six parental roles during process of shifting responsibilities: (a) complete directing, (b) partial directing, (c) passive supervising, (d) partial initiator, (e) directed assisting, and (f) noninvolvement. 2. PTs seen as having important role in facilitating transfer of responsibility by providing information, training, monitoring, and emotional and positive support</td>
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<td>Wong et al. (2010)</td>
<td>Explored the attitudes of adolescents with chronic illnesses and parents living in Hong Kong toward transition</td>
<td>137 16- to 19-year-olds with chronic illnesses, 67 parents recruited from 7 hospitals that are part of the Hospital Authority in Hong Kong</td>
<td>Descriptive, cross-sectional study, Used self-report questionnaire to examine attitudes toward HCT care</td>
<td>1. 82.5% of the parents desired a transition to adult care compared with 85.3% of the adolescents 2. 11.5% of the parents had discussed or received information about HCT from MDs compared with 8.1% of adolescents 3. The only significant barrier to the HCT was the strong desire not to change</td>
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**Table 4. (continued)**

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| Woodward, Swigonski, and Ciccarelli (2012) | Assessed the health, functional characteristics, and health care service needs of youth and young adults with SHCN attending a comprehensive, noncategorical transition program | 198 parents of AEA-SHCN attending a transition clinic | Survey research, Self-administered survey developed from national health surveys and clinical experience to assess 44% (87) returned the questionnaires | 1. Reported higher needs for all services except mental health care and tobacco or substance use counseling compared with NS-SHCN parents.  
2. Forty-three percent reported at least one unmet health need, 69% reported need for personal care assistance, and 9% needed assistance with ADLs.  
3. Ninety-one percent needed assistance in managing SHCN.  
4. Forty-one percent of parents typified their children’s health as good or excellent. |

Note. SB = spina bifida; PARS III = Personal Adjustment and Role Skills Scale; YYA = youth and young adults; AYA = adolescents and young adults; PIMD = profound intellectual and multiple disabilities; GMFCS = Gross Motor Functioning Classification Scale; ADLs = activities of daily living; HCT = health care transition; MD = medical doctor; AEA = adolescents and emerging adults; CF = cystic fibrosis; PT = Physical Therapists; QoL = quality of life; IBD = irritable bowel disease; GE = gastroenterology; SHCN = special health care needs; NS-SHCN = National Survey of Children with Special Health Care Needs; FCC = family-centered care; LTR = liver transplant recipients; ASHCN: adolescents with special health care needs; HCP = health care provider; SCD = sickle cell disease; MCHB = Maternal Child Health Bureau; NHS = National Health Interview Survey; JIA/JRA = juvenile rheumatoid arthritis; NMD = neuromuscular disorder with chronic ventilation; SM = self-management; TIDM = type 1 diabetes mellitus.
Research Designs and Method

Only 1 of the 47 studies in this review used an experimental design in a randomized controlled trial (Betz, Smith, & Macias, 2010). The predominant research design used was qualitative ($n = 19$; 40%), followed by secondary analysis of data studies ($n = 8$; 17%). These studies were designed to describe HCT from the parents’ perspectives rather than to test intervention strategies (Tables 1 and 2).

In the following section, the thematic foci of the studies are presented. Seven areas of parental perspectives and concerns focused on role changes affecting them and their children, transition reflections and concerns, and service recommendations.

Thematic Foci

A number of common concerns were identified in the parent-defined studies in this systematic review: (a) changing expectations pertaining to future planning, (b) changes in the parental role, (c) changes in the children’s role, (d) exploration of parental perspectives of the transition experience, (e) parental stressors related to HCT, (f) perspectives about helpful support/services provided, and (g) parent’s perceptions of the child’s HCT experience. These concerns are expanded on and described in the following sections (Tables 4 and 5).

Changing expectations pertaining to future planning. Although not always studied explicitly, implicit within the responses shared by parents were their hopes and desires that their children’s futures would be successful (Jivanjee et al., 2009). Their worries and concerns, as discussed later in this section, were predicated on their fears that their children’s futures would be somehow unfulfilled and diminished. There were circumstances (e.g., intellectual disabilities or severe physical impairments) wherein these fears were realistic; in other situations, these concerns were based on parental acknowledgment of the uncertainties associated with living with a chronic condition (Craig, Towns, & Bibby, 2007; Dupuis, Duhamel, & Gendron, 2011). In a study of AEA with mental illness, parents expressed the hope that their children would achieve success in adulthood and live independently (Jivanjee et al., 2009). The concerns about the future of their children were consistent, whether children had mental or physical disabilities.

Changes in the parental role. As parents noted, the transition of their AEA to adulthood created significant changes in their lives as well. Parents shared that the “letting go” process was challenging (Dupuis et al., 2011; Jivanjee &
Table 5. Identification of Reviewed Studies Contributing to Each Thematic Focus.

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<tr>
<th>Thematic focus identified</th>
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<tr>
<td>1. Changing expectations pertaining to future planning</td>
<td>Craig (2007); Dupuis, Duhamel, and Gendron (2011); Jivanjee, Kruzich, and Gordon (2009)</td>
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<td>2. Changes in the parental role</td>
<td>Jivanjee and Kruzich (2011); Jivanjee et al. (2009); Kingsnorth, Gall, Beayni, and Rigby (2011); B. Williams, Mukhopadhyay, Dowell, and Coyle (2007)</td>
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<td>3. Changes in the children’s role</td>
<td>Craig, Towns, and Bibby (2007); Davies, Rennick, and Majnemer (2011); Jivanjee et al. (2009); Kingsnorth et al. (2011); Woodward, Swigonski, and Ciccarelli (2012); B. Williams et al. (2007)</td>
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<td>4. Exploration of parental perspectives of the transition experience</td>
<td>Bindels-de Heus et al. (2013); Dabadie et al. (2008); Jivanjee and Kruzich (2011); Knapp, Huang, Hinojosa, Baker, and Sloyer (2013); Lotstein et al. (2009); Lotstein, McPherson, Strickland, and Newacheck (2005); McManus et al. (2013); McPherson et al. (2004); Rutishauser, Akre, and Suris (2011); Scal, Horvath, and Garwick (2009); Shaw, Southwood, and McDonagh (2006, 2007); Sonneveld et al. (2012); Wong et al. (2010); T. S. Williams et al. (2010)</td>
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<td>5. Parent stressors related to HCT</td>
<td>Bindels-de Heus et al. (2013); Craig et al. (2007); Dabadie et al. (2008); Davies et al. (20011); Fredericks et al. (2011); Geerts, van de Wiel, and Tamminga (2008); Kingsnorth et al. (2011); Latzman et al. (2008); Sonneveld, Strating, van Staa, and Nieboer (2013); Wong et al. (2010)</td>
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<td>6. Perspectives about helpful support/services provided and parental strength</td>
<td>Casillas et al. (2010); Dabadie et al. (2008); Davies et al. (2011); Duke and Scal (2011); Jivanjee and Kruzich (2011); Jivanjee et al. (2009); Rutishauser et al. (2011); Shaw et al. (2006); Sonneveld et al. (2012); Tan and Klimach (2004); Wong et al. (2010)</td>
<td>11</td>
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<tr>
<td>7. Parent’s perceptions of the child’s HCT experience</td>
<td>Betz, Smith, and Macias (2010); Bindels-de Heus et al. (2013); Craig et al. (2007); Duke and Scal (2011); Knapp et al. (2013); Lotstein et al. (2005); McManus et al. (2013); McPherson et al. (2004); Scal et al. (2009); Scal and Ireland (2005); T. S. Williams et al. (2010); Woodward et al. (2012)</td>
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Note. HCT = health care transition.
Kruzich, 2011; Jivanjee et al., 2009). They remarked that the shift in their parental role from the responsible and accountable decision maker for health care and other services for their children to a supportive and consultative role was difficult as their children reached the age of majority (Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth, Gall, Beayni, & Rigby, 2011). In one study (Kingsnorth et al., 2011), parents were worried they would no longer be effective advocates for their children once the transition to adult services had been completed. As these findings indicate, parents experienced difficulties in adapting to the changes associated with HCT.

**Changes in the children’s role.** Parents expressed concerns about their children’s ability to assume responsibility for their care (Craig et al., 2007; B. Williams, Mukhopadhyay, Dowell, & Coyle, 2007; Woodward, Swigonski, & Ciccarelli, 2012). These concerns extended to uncertainties about their children’s abilities to make appropriate decisions pertaining to their health care (Craig et al., 2007). Parents of AEA with neurological disorders and intellectual disabilities viewed their children as being more vulnerable following the transfer to adult health care (Davies, Rennick, & Majnemer, 2011). They needed information about guardianship and other legal aspects to remain a part of their child’s health care. Parents of AEA with mental illness were concerned about their children’s abilities to have peer relationships and become fully integrated into the community to avoid social isolation (Jivanjee et al., 2009; Kingsnorth et al., 2011).

**Exploration of parental perspectives of the transition experience.** Parent perspectives regarding the transition experience were explored in several studies to better understand parents’ concerns and needs during transition, as HCT services are in the early stages of development. Many of the studies used qualitative designs to gather narrative data from parents to gain insight into what their experience had been during this time of service changes. Their comments were not only limited to their own personal experiences but also included their perspectives about their children. They shared opinions about both positive and negative experiences, gaps in services, and suggestions for improvement (Bindels-de Heus et al., 2013; Casillas et al., 2010; Craig et al., 2007; Davies et al., 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011; Shaw, Southwood, & McDonagh, 2006, 2007; Sonneveld, Strating, van Staa, & Nieboer, 2013; Woodward et al., 2012). Parental responses also included recollections of their pediatric experiences, which, for the most part, were positive (Bindels-de Heus et al., 2013; Rutishauser, Akre, & Suris, 2011; Sonneveld et al., 2013). Casillas and colleagues (2010) found that Latino parents of AEA cancer survivors continued to have difficulties in discussing
their children’s cancer experience, which parents described as traumatic. According to parents, the trauma of their AEA cancer experience continued as evidenced by the feelings of stigma and isolation they felt from others who believed that parents had a causative role in their children’s diagnosis. These parents suggested that providing information about late effects not only to the cancer survivor but also to the family would be helpful.

Positive experiences identified by parents included joint meetings between pediatric and adult care providers. Some pediatric providers began seeing the youth with their parents and then alone during a visit, thus, preparing the youth for an adult visit without parents, which parents identified as a strength (Bindels-de Heus et al., 2013; Dabadie et al., 2008; Rutishauser et al., 2011).

Concerns expressed by parents included making certain that transition did not occur during an acute episode requiring hospitalization. Some parents also thought transition should occur at an older age. Some felt excluded when their child was receiving care from adult providers (Bindels-de Heus et al., 2013; Dabadie et al., 2008; Jivanjee & Kruzich, 2011).

Findings derived from large-scale national surveys provided quantitative information about the extent to which HCT services were provided. McPherson and colleagues (2004) conducted a secondary analysis of two national surveys: National Health Interview Survey and the National Survey of Children With Special Health Care Needs (NS-CSHCN) from 2000 to 2001. Receipt of HCT services was based initially on three criteria that were expanded and changed in subsequent surveys (Table 4). They found that 15.3% of youths with SHCN received HCT services, and 25.5% reported vocational/career counseling had been provided. This core outcome was met by 5.8% of youths with SHCN. Lotstein, McPherson, Strickland, and Newacheck (2005) also reported on their analysis of the 2000-2001 NS-CSHCN and found that of those 13- to 17-year-olds who received transition services, as reported by their parents, approximately 42% had discussed HCT, with the frequency increasing with age. Blacks and Hispanics were less likely to have discussed this topic with their physicians. Only 15.3% had met the expected core outcome for HCT, according to guidelines established by the Maternal Child Health Bureau (Lotstein et al., 2005). Four years later, data were reported from the 2005-2006 NS-CSHCN on the extent to which children with SHCN received HCT services (Lotstein et al., 2009). The methodology varied slightly from the earlier survey, as a fourth component was added to determine whether the youth were encouraged to assume self-management responsibilities. Findings revealed higher percentages of changes achieved pertaining to HCT services than in the 2000-2001 NS-CSHCN. For example, 41% had met the core performance HCT outcome. Continued racial disparities in meeting the HCT performance outcome were reported in this survey as well.
Another secondary analysis of the 2000-2001 NS-CSHCN examined the variables (socioeconomic, condition-related, and system of care) associated with promoting or inhibiting HCT. Higher rates of HCT services correlated with an older age of the adolescent, White race, and effective parent–provider relationships, as reported by parents (Scal & Ireland, 2005). Secondary analysis of the more recent 2005-2006 NS-CSHCN was conducted to explore HCT services received by adolescents with arthritis compared with adolescents with diabetes. Findings revealed that adolescents with diabetes were more likely to receive HCT counseling than were adolescents with arthritis; however, rates were similar for both adolescents with arthritis and special health care needs (Scal et al., 2009).

More recent data from the 2009-2010 NS-CSHCN showed that 40% of youths with SHCN had met the core HCT outcome (McManus et al., 2013). Variability among providers’ discussions of the four criteria was found, ranging from 78% of providers discussing the topic of self-management to 35% raising the issue of enrollment in an adult health insurance plan. Ethnic differences were found with regard to meeting the core outcome; non-Hispanic Whites were more likely to meet the core outcome than were Hispanics and non-Hispanic Blacks. Youths with SHCN with more severe conditions were less likely to meet the core outcome. Similar ethnic differences were found at the state level in Florida, wherein 30% non-Hispanic Blacks reported HCT discussions compared with 34% of non-Hispanic Whites and Hispanics (Knapp, Huang, Hinojosa, Baker, & Sloyer, 2013).

Parental stressors related to HCT. Parents shared their feelings of stress with researchers about the transfer to adult health care and the other components of the transition experience (Craig et al., 2007; Geerts, van de Wiel, & Tamminga, 2008). Foremost among the stressors shared about the transition experience was the termination of their relationships with pediatric providers and the uncertainty associated with forthcoming adult care (Bindels-de Heus et al., 2013; Craig et al., 2007; Dabadie et al., 2008; Davies et al., 2011; Fredericks et al., 2011; Latzman et al., 2011). In one study, parents expressed stressful feelings of loss associated with terminating relationships with pediatric providers (Kirk, 2008). In a study by Dabadie et al. (2008), several parents contacted the pediatric provider after the transfer to adult health care provider. Fifty-one percent of parents of adolescents with liver transplants did not reveal their forthcoming worries about the transition process; the remaining parents expressed their stress about leaving their pediatric providers, as they were concerned about the care received following the transfer (Fredericks et al., 2011). Parents shared their stress about the limitations and/or problems with the quality of transition services received (Kirk, 2008;
Wong et al., 2010). In a study by Davies et al. (2011), parents were stressed about the success of the transition process, as they believed they had received limited information and resources to assist them, and care was fragmented and not well coordinated. Problems with service coordination were mentioned by parents in other studies as well (LoCasale-Crouch & Johnson, 2005; Rutishauser et al., 2011). Parents were used to an interdisciplinary team approach by pediatric providers that was not evident with adult providers.

Other service problems identified by parents included difficulty with communication (Lotstein et al., 2005; Sonneveld et al., 2013) and inconsistency with the level of services received (Lotstein et al., 2005). Parents of AEA with mental illness noted the lack of psychiatric services and supports available in the adult system (Jivanjee et al., 2009).

Another source of stress expressed by parents was the delay in the initiation of transition services (Jivanjee et al., 2009). Parents also expressed the need to have more information about available community services and supports that would be of assistance to their children to become more independent (Kingsnorth et al., 2011; Sonneveld et al., 2013). In a study by Rutishauser et al. (2011), 37% of parents acknowledged that provision of care by pediatric providers to AEA with SHCN was inappropriate as their children aged.

Parents were worried that they would be identified as a “difficult parent” as they learned to navigate the new system of care and they continued to serve as advocates for their children who were unable to be self-sufficient due to their intellectual or physical disabilities (Kingsnorth et al., 2011). They expressed concern about the forthcoming changes they would encounter with the adult system, and they anticipated significant differences between service systems (Latzman et al., 2011; Jivanjee et al., 2009). They also expressed concern about being effective navigators because they did not understand the service system (Kingsnorth et al., 2011). These perceptions included feelings that adult providers were not as caring as pediatric providers were (Latzman et al., 2011). They were worried about the availability of medical, psychiatric, and comprehensive health services following transition (Jivanjee et al., 2009; Latzman et al., 2011; Woodward et al., 2012). Parents in a Canadian study reported concerns about access to adult services, including fears of their child being relegated to an agency waiting list (Kingsnorth et al., 2011).

In a study by Geerts et al. (2008), parents were queried prior to and following the transition experience regarding their perceptions of their illness-related distress, their transition worries, and their child’s quality of life. Parents with higher levels of transition worries and illness-related distress reported lower quality-of-life levels for their sons with hemophilia. Mothers’
worries exceeded those of the fathers and sons with hemophilia. In another study (Betz et al., 2010), parents of adolescents with spina bifida randomly assigned to either a transition training program and a control group were asked to rate the psychosocial adjustment of their children. Although no differences were found between groups, the highest subscale scores were associated with hostility and the lowest pertained to peer relationships.

Dupuis and colleagues’ (2011) study of parents of adolescents with cystic fibrosis found that these parents were fraught with concerns and stress about their children’s future. All of the parental respondents were cognizant of the shortened life expectancy of their children, which influenced their pessimistic view of the future. These views were in sharp contrast to those optimistic views of their children who had positive future aspirations for living. These pessimistic views permeated the parental lived experience of having an AEA with cystic fibrosis.

As the findings of these studies reveal, parents expressed a myriad of stressful feelings about their child’s forthcoming transition and transfer of care to adult health care services. Interestingly, in one study, these anticipated stressors were found to improve following the actual transition to adult care (Latzman et al., 2010), which suggests that additional insights may be gained with follow-up reports of parents following the transition experience.

Perspectives about helpful support/services provided. Besides identifying helpful service supports and resources, parents identified sources of familial, personal, and network strengths. Family support was identified by parents as helpful during transition (Casillas et al., 2010; Dabadie et al., 2008; Davies et al., 2011). The service model of family-centered care was identified as positively associated with the receipt of transition counseling (Duke & Scal, 2011). Advocacy services were viewed as helpful transition services by parents of AEA with mental illness (Jivanjee & Kruzich, 2011). Parents of AEA with mental illness identified supportive mentoring, programs for developing work skills, and respite care as important for successful adult transition (Jivanjee et al., 2009). A joint meeting with both pediatric and adult–pediatric specialists or meeting the adult provider prior to transfer was seen as a preferred service option for transfer of care to adult health care providers (Fredericks et al., 2011; Rutishauser et al., 2011). HCT preparation materials that provided transfer timelines and adult provider contact information were identified as helpful. A number of methods for disseminating this information were named, such as face-to-face discussion and online and printed materials (Fredericks et al., 2011). Parents were in agreement that a portfolio of the AEA health care information provided to the adult providers would be useful (Tan & Klimach, 2004). In a study by
Shaw et al. (2006), parents agreed that transition best practices were important services.

**Parent’s perceptions of the child’s HCT experiences.** In several studies in this review, the parents served as their children’s voice. Parents were asked to provide information or their perceptions of their children’s experience because their children did not have the capabilities to serve as respondents and/or it was not feasible to access AEA for study purposes, as evidenced in data collection for national surveys, such as the NS-CSHCN (Betz & Redcay, 2005; Duke & Scal, 2011; Knapp et al., 2013; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2009; Scal & Ireland, 2005; Woodward et al., 2012). In some studies, parents were asked to provide demographic or factual information about their children, such as access to community services, educational activities, and social relationships (Craig et al., 2007; Woodward et al., 2012). In other instances, parents were asked to provide opinions about their child’s level of functioning and reactions to events during the transition experience (Betz et al., 2010; T. S. Williams et al., 2010). For example, in Craig and colleagues’ (2007) study, parents were asked questions about their post-transition experience, HCT outcomes, and opinions about providers’ transition services. In the study by Bindels-de Heus and colleagues (2013), investigator-developed scales, titled *The Pediatrician Physician Evaluation Scale* and *Appreciation of Preparation for Transfer Scale*, were developed to elicit parental opinions about care provided by their child’s pediatrician and transfer services provided. In addition, parents were asked to provide responses to open-ended questions about suggestions for improving HCT services and preferences for adult health services.

Parents served as respondents in many HCT studies for the reasons previously identified. It is evident that parents provided important information, insights, and perceptions about the HCT experience, as it affected not only them and their family members but also their AEA-SHCN children. The following discussion incorporates a summary and synthesis of the findings presented, together with implications for practice and research.

**Discussion**

The discussion will first address the findings of the analyses of the research designs, methodology, and results reported in both parent-defined and parent-combined studies. Next, parent-defined and parent-combined studies will be compared and contrasted. Findings of the thematic analysis of parental needs.
and issues reported in parent-defined studies will be discussed, followed by
the implications of this mixed studies review for clinical practice and research.

As the findings of this review indicate, HCT research is in the early stages
of development. The findings of studies conducted from 2004 to 2013 continue
to be hampered by many of the same methodological and design limitations
identified in earlier and more current reviews of the HCT literature (Betz,
2004; Binks et al., 2007; Bloom et al., 2012; Crowley et al., 2011; Pai &
Ostendorf, 2011; Wang et al., 2010; Watson et al., 2011). These limitations
include small sample sizes, use of designs without comparison or control
groups, and the application of tools with weak or nonexistent psychometrics.
In addition, the sample of parents represented limited numbers of diagnostic-
specific conditions. Only 17 (36%) of the studies were conducted with the
following diagnostic groups: acute kidney disease, cancer, congenital heart
defects, cystic fibrosis, hemophilia, HIV, liver transplants, juvenile rheuma-
toid arthritis, sickle cell disease, and spina bifida. This same limitation of
diagnostic-specific conditions has been reported in other reviews as well
(Crowley et al., 2011). The selection of these diagnostic groups may have
been influenced by the ease of access for recruitment purposes. The remain-
ing studies used a noncategorical approach, which has been advocated by
experts based on the premise that AEA-SHCN share more commonalities
pertaining to psychosocial concerns than they demonstrate differences,
developed by various childhood-acquired chronic illnesses and disabilities (Stein & Silver, 1999). However, there is
another school of thought that recognizes the challenges of sampling rare
pediatric populations, suggesting alternative sampling and design approaches
(Hartling et al., 2012; van der Tweel et al., 2012).

Few authors recorded sociocultural and demographic data, such as ethnic-
ity and socioeconomic level. Currently, scant information is available on the
role of culture and socioeconomic status in accessing services and supports. Better understanding of these variables will help to inform practice.

Eighteen of the studies identified in this review merged findings of parents
with other subgroups in the sample, such as youth and/or providers. The find-
ings of these investigations were problematic to analyze because the within-
group differences were not reported. The researchers indicated that
between-group differences were not evident; however, the nuances associ-
ated with data gathered from each of the subgroups were not reported. It
would be expected that different sample subgroups (i.e., AEA-SHCN, health
care providers) would have unique perspectives that would be characteristi-
cally different from each other. For example, parents would be expected to
have more informed views of service quality than would AEA-SHCN, as
their consumer acumen would be more limited. A provider perspective would
not have the depth of the lived experience of managing SHCN, as would a parent or AEA-SHCN. These limitations led to the decision not to include these studies in the analysis of thematic foci.

The thematic foci of findings of this mixed methods review yielded seven themes: (a) Changing expectations pertaining to future planning, (b) Changes in the parental role, (c) Changes in the children’s role, (d) Exploration of parental perspectives of the transition experience, (e) Parental stressors related to HCT, (f) Perspectives about helpful support/services provided, and (g) Parent’s perceptions of their child’s experience (Tables 4 and 5). Changing expectations pertaining to future planning reflected parental concerns regarding their children’s futures, regardless of diagnosis. The future concerns expressed by parents varied depending on the study’s purpose, ranging from access to adult health care (Craig et al., 2007; Jivanjee et al., 2009) to being successful as an adult (Dupuis et al., 2011; Jivanjee et al., 2009). The findings reflect the impeding challenges that parents recognized their children would face as the transition period arrived. This parental theme was identified in a previous HCT literature review as well (Wang et al., 2010).

In several studies, the theme Changes in the parental role revealed the difficulties parents experienced in the alteration of their roles. It was apparent that the relinquishment of their long-standing functions had not been anticipated by parents, nor had they prepared for it (Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Kingsnorth et al., 2011). Similarly, as parents expressed their feelings about the role changes associated with HCT, another theme emerged pertaining to Changes in the children’s role. Parents expressed hesitation and concern about their children’s abilities to function independently. These concerns included parental reservations about their children’s decision making on health care matters and developing appropriate social relationships (Craig et al., 2007; Jivanjee et al., 2009; Kingsnorth et al., 2011; B. Williams et al., 2007; Woodward et al., 2012). This parental concern was particularly evident in parents whose children had intellectual/developmental disabilities (Davies et al., 2011). Their children’s prognosis in terms of life expectancy weighed heavily on the minds of parents in the B. Williams and colleagues’ study (2007). Several other HCT reviews, broader in scope, identified these themes as well (Binks et al., 2007; Bryant & Walsh, 2009; Rapley & Davidson, 2010; Wang et al., 2010).

Exploration of parental perspectives of the transition experience theme reflected both the positive and negative parental experiences during the HCT process. The positive experiences parents shared reflected the value of advanced preparation for the HCT experience, such as joint pediatric and adult clinic visits (Bindels-de Heus et al., 2013; Dabadie et al., 2008; Rutishauser et al., 2011). Negative experiences shared by parents were their feelings of
being excluded and the lack of their children’s readiness for HCT, which demonstrate the need for adequate preparation (Bindels-de Heus et al., 2013; Dabadie et al., 2008; Jivanjee & Kruzich, 2011). In large-scale studies (Lotstein et al., 2009; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004), over time with each subsequent survey, parents reported improvements in discussion of the topic of HCT by their physicians, although racial disparities existed, as Blacks and Hispanics were less likely to have had this discussion (Knapp et al., 2013; McManus et al., 2013). Other survey findings also revealed that HCT discussions differed according to diagnosis, with AEA with diabetes receiving more counseling than those with arthritis (Scal et al., 2009). Other HCT reviews reported, among other findings, that the quality of the transition experience as reported by parents was predicated on the extent to which they received HCT preparation instruction (Binks et al., 2007; Bryant & Walsh, 2009).

**Parental stressors related to HCT** reflected their feelings of stress pertaining to the quality and scope of services received that were perceived by parents to adversely influence their children’s health and developmental outcomes. Parents expressed stressful feelings of loss with the anticipated termination of pediatric care and anxiety with unknown adult providers based on the fear that adult care would result in untoward health outcomes for their children (Bindels-de Heus et al., 2013; Craig et al., 2007; Dabadie et al., 2008; Davies et al., 2011; Fredericks et al., 2011; Latzman et al., 2010). These stressors extended to the perceived inferior quality of HCT services received, including community-based referrals for adult services (Geerts et al., 2008; Kingsnorth et al., 2011). Similar findings were reported in other HCT reviews examining transition challenges (Bryant & Walsh, 2008; Rapley & Davidson, 2010; Sawyer & Macnee, 2010).

The findings associated with the theme **Perspectives about helpful support/services provided** provide suggestions from parents regarding the services and supports that were helpful to them during HCT (Casillas et al., 2010; Dabadie et al., 2008; Davies et al., 2011; Duke & Scal, 2011; Jivanjee & Kruzich, 2011; Jivanjee et al., 2009; Rutishauser et al., 2011; Shaw et al., 2006; Tan & Klimach, 2004). Although the findings are limited, they provide initial direction as to the development of HCT services. They reveal that parents’ recommendations aligned with the practice standards advanced by major pediatric associations, although yet to be empirically tested (AAP, AAFP, & ACP, 2011; AAP, AAFP, & ACP-ASIM, 2002). Similar parental recommendations were detailed in other reviews as well (Binks et al., 2007; Bloom et al., 2012; Bryant & Walsh, 2009; Crowley et al., 2011; Kralik et al., 2006; Rapley & Davidson, 2010; Stewart, Stavness, King, Antle, & Law, 2006). The remaining discussion focuses on parents’ perceptions of their
child’s experience and highlights the issue of the challenges of gathering research data from AEA-SHCN.

As the theme Parents’ perceptions of their child’s experience demonstrates, nine of the studies in this review elicited responses from parents about their children (Betz et al., 2010; Bindels-de Heus et al., 2013; Craig et al., 2011; Knapp et al., 2013; Lotstein et al., 2005; McManus et al., 2013; McPherson et al., 2004; Scal et al., 2009; Scal & Ireland, 2005; T. S. Williams et al., 2010; Woodward et al., 2012). There are a number of challenges that influence researchers to use parents as subjects, including capabilities and intellectual limitations of AEA-SHCN, limited number of psychometrically strong tools to use with AEA-SHCN, and human subject constraints in conducting research with minors.

Clinical and Research Implications

As the findings indicate, the improved survival of AEA-SHCN has created unanticipated challenges for AEA-SHCN and their parents. It is evident from parental responses that they were unable to anticipate the availability and types of transition and adult health care and community services, as they were not familiar with them. Unlike their long-standing experience in navigating the pediatric and child health systems of care, their previous experience did not fully prepare them for this new challenge. It is also evident that parents and their AEA-SHCN were not well prepared by the service system to anticipate future needs. Parents would benefit from the provision of ongoing and preparatory instruction to support them to better understand the process of navigation from pediatric and child health services to adult services.

Studies that investigated parental perspectives concerning the HCT process revealed the difficulties parents experienced in the process, as evidenced by their descriptions of “letting go.” Their concerns extended to their perceptions and worries about their children’s abilities to become responsible and competent with their self-management. Additional research is needed to fully explore these parental concerns, as these findings are based on few studies that used samples of AEA-SHCN with unique issues, such as those with mental illness. Additional investigations are needed to improve our understanding of the role and developmental changes that parents face during this period of transition. Evidence about parental development and role changes are needed for the development of anticipatory guidance to assist parents as their children transition into adulthood. There is a lack of information regarding adult development and morbidity and mortality for these groups that can be provided to parents for anticipatory guidance purposes. This understanding will aid in the development of evidence-based HCT support services to meet
parental needs pertaining to their role and developmental changes in their children as they age.

Other studies involving parents reported on parents’ opinions regarding their experiences with HCT services. Their reports of service gaps reflect the problems associated with the early developmental stage of this service model in the United States and elsewhere. It is apparent that the institution of the HCT service model is limited and sporadic in scope and lags far behind the service needs of parents and AEA-SHCN. Parental recommendations identified in these studies provide an initial window into the need for the development of service models responsive to the needs of this population. Research is needed to test the effectiveness of service models that will lead to the development and implementation of evidence-based approaches to facilitate the acquisition of measureable AEA-SHCN outcomes that are focused on quality-of-life parameters. Currently, this research is lacking; more studies using more rigorous research designs with methodologically strong instruments and larger samples are needed to advance the science and practice of HCT.

Finally, few of the studies involved culturally diverse samples. As mentioned earlier, racial disparities exist pertaining to the provision of HCT services. Research is needed to explore the social determinants associated with the provision of these services and AEA-SHCN outcomes.

The themes identified in this review are similar to those identified in an earlier review of the HCT literature (Betz, 2004), in which parental concerns pertaining to the transfer to adult health care providers and transition process were described. As in this review, those findings echoed the same concerns about letting go and the tensions parents felt because they were no longer the decision makers regarding care except in the circumstances when parents were conservators or guardians (Betz, 2004). Previously, and as this current review of the HCT literature reveals, parents recognized the importance of receiving services based on best-practice guidelines. Findings from the earlier review provided more specific parental service recommendations compared with the findings of this review. These differences may be attributable to the design and procedural differences between the two time frames of HCT reviews, based on widespread belief that parental service needs and recommendations now are well established, although service gaps and limitations persist.

Given the aforementioned limitations of the studies of this review, this initial evidence has application for practice. As the findings indicate, AEA HCT is a family-centered experience. Although, the clinical focus is directed to the AEA with SHCN, it is essential that parental needs are continuously considered and supported not only for their children but also for themselves as well. Parents emphasized the importance of preparatory efforts for the transfer to adult providers and the transition to adulthood. These efforts included ongoing and responsive communication that addressed their needs to share their
parental concerns about the HCT process, receive the information needed to navigate new systems of care, and to have the support and understanding for the stresses and challenges associated with lifestyle and personal changes associated with this transition, including feelings of loss associated with the termination of relationships with long-standing pediatric providers. In these studies, parents shared perspectives of specific services and supports, which were helpful, such as information about legal matters such as conservatorship, joint meetings with pediatric and adult providers, and referral information for transition and adult community-based resources. As this field of science evolves, evidence-based practices to effectively support parents, family members, and AEA with SHCN will emerge for implementation.

Conclusion

As this systematic review has demonstrated, parents of AEA-SHCN can provide HCT researchers with unique and seasoned perspectives concerning their needs during the HCT period. As the findings show, parents and AEA-SHCN have a myriad of needs that have yet to be fully understood, as HCT research is in the early stages of development. Additional research is needed to develop evidence-based services to support parents and AEA-SHCN through this important period of transition. These studies need to be methodologically sound, use valid and reliable tools, and clearly differentiate data obtained from parents, AEA-SHCN, providers, and others. The structure of the health care system in which the youth are participating needs to be considered. Great gaps in the literature exist, which need to be addressed in the future.

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1. Special health care needs is a definition used by the Maternal Child Health Bureau, term used to describe “those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998). For the purposes of this article, SHCN includes those with disabilities.
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References marked with an asterisk (*) indicate parent-defined studies included in the systematic review. References marked with two asterisks (**) indicate parent-combined studies included in the systematic review.


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