SYSTEMATIC REVIEW

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# The Transition of Patients with Special Health Care Needs From Pediatric to Adult-Based Dental Care: A Scoping Review

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Abstract: Purpose: The purpose of this study was to explore the breadth and extent of evidence regarding the transition of health care from pediatric to adult-based care for patients with special health care needs (SHCN), including evidence-based protocols to guide future research for the care of these patients. Methods: A scoping review protocol was used. A comprehensive literature search was completed for the relevant keywords and in multiple databases. Additional literature was identified from references within these articles. The inclusion criteria included both medical and dental literature to capture all pertinent information. Resulting article abstracts were screened and a full article review was performed to determine final inclusion. Results: Twenty-four articles were included. There is more medical literature for transition care for patients with chronic medical conditions than for oral health care. While there have been policy statements and guidelines published, these are not supported by high-quality evidence. There are no evidence-based protocols to guide this process. Conclusions: There is limited information within the current literature to guide the transition process for patients with special health care needs from pediatric to adult-based dental care. This is an area of study that can be explored in more depth to help improve dental management and care for patients with SHCN. (Pediatr Dent 2020;42(2):101-9) Received September 27, 2019 | Last Revision January 3, 2020 | Accepted January 6, 2020

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People with special health care needs (SHCN) face difficulty obtaining health care services when compared to the general population. SHCN is defined as "chronic physical, developmental, behavioral, or emotional condition(s) that require health and related services of a type or amount beyond that which are generally required. Dental care is the most prominent unmet health care need among this population. There are multiple reasons for this:

- 1. There are not enough dentists willing and able to treat patients with SHCN. 1-5
- 2. Patients with SHCN experience increased barriers to care (e.g., physical, financial, geographic).<sup>2,3-5</sup>
- 3. Families and caregivers of patients with SHCN have more difficulty facilitating dental care. <sup>2,3,6</sup>

Pediatric dentists have increased training for the provision of care of patients with SHCN.<sup>7,8</sup> However, adult patients with SHCN have an adult dentition and adult dental needs. The scope of care that pediatric dentists can provide does not include many of the adult dental care services that general dentists provide.<sup>5,7</sup> This treatment paradigm is problematic because if most dental providers who are willing and able to treat patients with SHCN are pediatric dentists, then adult

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patients with SHCN may not be receiving optimal care. However, even if dental care is not optimal, some dental care may be better than no dental care. While not ideal, pediatric dentists managing adult patients with SHCN provide these patients with some level of dental care.

The current state of dental care for patients with SHCN raises questions regarding the patient transfer from pediatric to adult-based care. If pediatric dentists are typically the dental providers for patients with SHCN into adulthood, but there are some general dentists who provide care for patients with SHCN, how are these patients transferred and transitioned from one provider to another? Is there adequate evidence to guide and support the transition of dental care for patients with SHCN as they age into adulthood? What impact does this transition of care have on health outcomes?

The purpose of this study was to explore the breadth and extent of evidence regarding the transition of care from pediatric to adult-based care for patients with special health care needs, including any evidence-based protocols to guide future research for the care of patients with SHCN.

#### Methods

This scoping literature review was completed following the protocol detailed by Pham, et al.<sup>13</sup> The following research question was formulated: What literature exists to guide the transition of health care from pediatric to adult-centered care for children with special health care needs? A comprehensive literature search was completed for the following keywords: continuity of patient care; transition; transfer; handoff; dental; disabled persons; neurodevelopmental disorders; pediatric dentistry; dental care; and general practice. These search headings were exploded to include subcategories (Figure 1). Further, the authors utilized the Boolean operators 'and' and 'or' to identify combinations of these words. The search was limited to literature in the English language and studies that included children ages zero to 18 years. Searches were completed in

OVID Medline, EMBASE, Cumulative Index to Allied Health Literature, and EBSCOhost.

Health care transitions is a broad topic. However, there is limited research and knowledge regarding transitional dental care for children with SHCN. Thus, the inclusion criteria were expanded to include both medical and dental literature to capture all pertinent information. Inclusion criteria included references that were in English, published 1990 or later, and described concepts pertinent to transition from pediatric to adult care for persons with SHCN ages 18 years and younger. The authors used the following questions to determine inclusion: Did the article address the transition of clinical medical or dental care for adolescent patients transferring from pediatric to adult-based care? Did the article focus on patients with SHCN?

Inclusion criteria were limited to articles in English to avoid any biases introduced from a translation of non-English articles. Articles published prior to 1990 were eliminated to ensure that findings were timely and representative of the most current research and protocols. From this search, 236 deduplicated references were identified. An additional 37 articles were identified from references to these articles and other sources, such as Google Scholar. The authors completed independent title and abstract reviews to include or eliminate articles based on inclusion criteria. Then, independent full

article reviews were performed on the articles included from the initial review to evaluate for relevance to the research question. If there was disagreement about inclusion, the authors re-read the article and determined inclusion based on consensus.

### Results

Twenty-four articles were included from the initial search and from references within the articles (Figure 2). From the comprehensive literature search completed, 11 were unique small sample cohort studies, three were policy statements, four were literature reviews, three were clinical commentaries, one was a scoping review, and one was a systematic review. The characteristics of the included studies were summarized (Table 1). There is more medical literature for transition care for patients with chronic medical conditions than for oral health care. Within the published literature regarding the transition from pediatric to adult-based dental care for patients with SHCN, there are no evidence-based protocols to guide this process. While there have been policy statements and guidelines published in the medical and dental literature, these are not supported by high-quality evidence and there is a scarcity of research on this topic.

The literature identifies transitions occurring at various ages within adolescence to early adulthood, ranging from 14years and older. 14 The transition process is dynamic and multifactorial, as it involves communication, collaboration, and cooperation among several parties. A systematic review focused on the topic of transition of hospital care for adolescents with chronic conditions and purported that, for patients to successfully transition their care services from child-centered to adult-centered, several parameters should be met:

(1) there must be a good partnership between the pediatric and adult providers; (2) the patient and his/her family/caregivers should be prepared for the transition from pediatric to adult-centered care; (3) a transitional plan should be developed; and (4) the transition plan should be adhered to.<sup>15</sup>

Regarding dental-specific transitions, the American Academy of Pediatric Dentistry has published a policy statement regarding the transition of children with SHCN to adult-based care that relies on medical transition policies to apply to oral health care. A scoping review of the medical literature summarized that there is very limited evidence to indicate best practices or robust studies on the efficacy of protocols and policies for the transition of dental care for children with SHCN from pediatric to adult care. Based on this scoping review, there is minimal evidence to guide the process for transition from pediatric to adult-based dental care for patients with SHCN. This review resulted in categories related to transition concepts, facilitators, barriers, and existing protocols (Table 2).

#### Discussion

The transition from pediatric to adult care presents a significant point of instability for children with SHCN. There are several changes that occur during this period of adolescence into adulthood, such as changes in anatomy, social structure, social

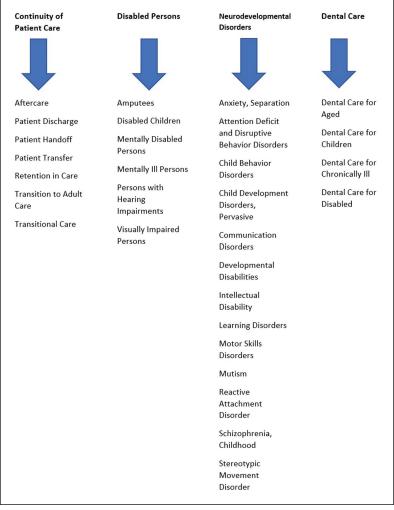


Figure 1. Subcategories of original search terms that were also included in the comprehensive literature search.

needs, level of independence, personal needs, and health care needs. 9,18,19 For children with SHCN, these transitions may require extra adjustment time and can be more difficult to manage and navigate. These efforts can be confounded by changes in community support, lack of continuity, changes in financial and insurance coverage, and barriers to access/utilization of adult-centered services. 12,20

Facilitators to transition. The literature supports the idea that transitional care should not take place at a single point in time. To facilitate a successful transition to adult care from pediatric care, the process should begin in early adolescence until a transfer of care is complete.<sup>21</sup> This process involves multiple support personnel to manage social services and healthcare needs.<sup>22</sup> A process of transition allows understanding, buy-in, familiarity, and comfort for all stakeholders involved. The Society of Adolescent Medicine states in a position paper regarding the transition of patients with chronic illnesses that improved level of comfort with the transition process helps to ensure continued care without lapse or referral confusion.<sup>23</sup>

The existence of a medical home/primary coordinating provider is a facilitator to a successful transition of care, and the concept of a medical home as being integral to positive health outcomes and transitions is well documented.<sup>18,23</sup> For adolescents to transition from pediatric to adult-based care, there should be a single facilitating provider who coordinates this process. The presence of a coordinating provider from a medical/dental home helps to establish a transition plan, create a foundation to educate the patient, their family, and caregivers, collaborate with a receiving provider, and complete the loop of communication for transition.<sup>15,18,23</sup> Having a medical home to quarterback a transition plan and the transition process helps to streamline a referral and successful transfer of care.

The Maternal and Child Health Bureau (MCHB) has instituted the delivery of transition services as a core performance outcome for care systems for children with SHCN.<sup>9</sup>

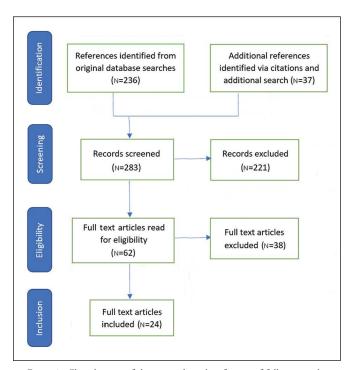


Figure 2. Flow diagram of the protocol to identify a set of full-text articles for inclusion in the scoping review.

Therefore, guidance, planning, and discussion of transitional care have become measurable aspects of health care for children with SHCN.<sup>24,25</sup> The American Academy of Pediatric Dentistry, American Academy of Pediatrics, and Society for Adolescent Medicine have policy statements recommending that professional societies and community practitioners focus on this topic.<sup>16,23,26</sup> The literature supports that these outcomes are enhanced when established working relationships and effective communication between pediatric and adult health providers exist.<sup>27</sup>

It has been shown that an important component of a successful transition is the understanding of why the transition should occur and patient/family/caregiver education is an integral component to enable this understanding. When awareness of the need for transition is communicated well, a patient and his/her family and social support group are more receptive and more likely to maintain continuous care throughout the transition to a new provider. <sup>29</sup>

Barriers to transition. The literature identified barriers to the transition of care. A documented barrier to a successful transition is the lack of willing and able providers within the community to whom pediatric dentists can transfer these adult patients with SHCN upon referral. 30,31 If a pediatric clinician does not have a relationship with a proper provider for patient referral, there can be no successful transfer of care.<sup>32</sup> Ten percent of general dentists provided dental care for children with SHCN "very often," while 70 percent of general dentists within the community rarely or never provided care to children with SHCN.<sup>12</sup> There is often a lack of coordination among providers as well as a lack of training for providers outside of pediatrics to provide care for adult patients with SHCN.15 Studies have shown that, without a base of clinicians to refer to, patients with SHCN tend to remain in the care of pediatric clinicians and pediatric dentists are impeded in their ability to successfully transition patients to adult-centered care. 32,33

The role of the family in patient care changes from childhood to adulthood. Typically, as children without SHCN age, they have increasing individualized control over their health care. However, for children with SHCN, there is minimal transitioning of the ownership in managing health care from the parent(s) to the patient with SHCN because patients with SHCN still rely on their support systems.<sup>34</sup> Pediatric dentistry is the only dental specialty required by the Commission of Dental Accreditation to be trained in the provision of care for patients with SHCN.<sup>6,8</sup> Because pediatric dentists have more specialized training in the care and management of children with SHCN during residency, they have historically been viewed as the predominant providers for patients with SHCN of all ages. Furthermore, seniors and graduates from medical and dental schools felt that they were not competent to care for patients with SHCN and that curricula on this topic was not a priority for the schools; these gaps in education contribute to a workforce not prepared to manage adult patients with SCHN.<sup>33</sup> When pediatric dentists do not have knowledge or a working relationship with general dentists who treat patients with SHCN, communication is limited among providers regarding transition, the patient, and their families/support networks.

Lack of preparation for the patient and their family/support network constitutes a significant barrier to patient transition. It was found that pediatric providers have an important role to initiate the discussion for transition in the early teen years to prepare patients and their families for the change. When this discussion is approached closer to adulthood, it

| Table 1.            | CHARACTERISTICS OF INCLUDED STUDIES*            |      |           |   |   |
|---------------------|---|------|-----------|---|---|
| Reference<br>number | Author(s)                                       | Year | Origin    | Aims/Purpose  | Methodology   |
| 2                   | Cruz S, Neff J,<br>Chi DL                       | 2015 | USA       | Understand parent and adolescent perspectives about the transition from pediatric to adult dental care.   | Focus groups and interviews with 59 parents and 13 adolescent-parent pairs  |
| 5                   | Nowak, AJ                                       | 2002 | USA       | Determine the involvement of practicing pediatric dentists of managing patients with special health care needs.   | Survey to 950 randomly selected AAPD members who are actively practicing  |
| 6                   | Kennedy A, et al.                               | 2007 | Australia | Outline the process, importance of, and barriers to successfully transitioning pediatric patients with chronic conditions to adult-centered care.                                   | Clinical commentary   |
| 7                   | Waldman HB,<br>Rader R, Sulkes S,<br>Perlman SP | 2016 | USA       | Discuss and review the difficulties facing patients with SHCN and the need for pediatric dentist involvement in this transition to expand.  | Commentary  |
| 11                  | Waldman HB,<br>Ackerman MB,<br>Perlman SP       | 2014 | USA       | Understand the disparities of utilization and access to dental care based on different demographic features across the USA population.  | Cross-sectional study   |
| 14                  | Williams A,<br>Lewis DA                         | 2015 | UK        | Explore the literature for current practice concerning the transition of dental care for patients with SHCN.  | Literature review   |
| 15                  | Fegran L, et al.                                | 2016 | Denmark   | Identify and collate evidence from studies regarding<br>the transition from pediatric to adult care for<br>patients with chronic conditions.  | Systematic review protocol  |
| 16                  | AAPD Council<br>on Clinical<br>Affairs          | 2018 | USA       | Address the transition of children with SHCN and identify barriers to oral care for this population.  | Policy statement  |
| 17                  | Watson R, et al.                                | 2011 | UK        | Identify successful models of transitional medical care for adolescents with complex health care needs.   | Scoping review  |
| 18                  | Thrall RS,<br>Blumberg JH,<br>Beck S, et al.    | 2012 | USA       | Discuss a new model of integrative care established at the Hospital for Special Care in New Britain, Conn., USA.  | Implement a new model in the Special Care Family Academy at the hospital to facilitate the continuation of medical home services into adulthood for patients with SHCN. |
| 20                  | Wang G, et al.                                  | 2010 | USA       | Organize concepts of environmental factors impacting the health care transition of youth with SHCN.   | Literature review   |
| 21                  | McManus MA, et al.                              | 2013 | USA       | Examine and analyze the practice of transition from pediatric to adult-based health care and investigate strategies for improvement.  | Data analysis from the 2009-2010 National<br>Survey of Children with Special Health Care<br>Needs   |
| 23                  | Rosen DS, et al.                                | 2003 | USA       | Offer a construct to provide a basis for transition practices for children with SHCN.   | Position paper  |
| 25                  | Reiss J,<br>Gibson R                            | 2002 | USA       | Review the development of health care transition policy and research since the 1980s.   | Literature review/focus groups  |
| 26                  | AAP, AAFP,<br>ACP-ASIM                          | 2002 | USA       | Address the need for an organized method of transitioning care, define health care transition, and define necessary steps health care providers should take to transition patients. | Policy/consensus statement  |
| 28                  | McDonagh JE                                     | 2006 | UK        | Discuss the multifaceted elements of a successful transition of care.   | Literature review  Table continued across the page.   |

<sup>\*</sup> Abbreviations used in this table: SHCN=special health care needs; CP=cerebral palsy; ASD=autism spectrum disorder; AAP=American Academy of Pediatrics; AAFP=American Academy of Family Physicians; ACP=American College of Physicians; ASIM=American Society of Internal Medicine; MCHB=Maternal and Child Health Bureau; SN=special needs.

| Table 1.            | CONTINUED*   |   |
|---------------------|--|---|
| Reference<br>number | Results  | Key findings  |
| 2                   | Parents believe it is acceptable to continue seeing a pediatric dentist; SHCN adults are motivated to transition when they felt out of place at the pediatric dental office  | Pediatric dentists are in a good position to implement family and adolescent centered policies to transition SHCN adults  |
| 5                   | 51% survey response rate of surveyed members, among whom $71%$ continue to follow and treat patients with SHCN after the age of $21$   | Most randomly sampled pediatric dentists who responded take an active role in the management of patients with SHCN into adulthood.  |
| 6                   | Four key elements of a successful transition are identification that patients need to be formally transferred, advocacy by the health care team, staffing to facilitate the transition, and collaboration between pediatric and adult providers involved in the transition.  | Despite barriers to the transfer of care, a defined protocol and care team can successfully transition patients with chronic conditions from pediatric to adult-centered care in a systematic and successful manner.  |
| 7                   | General dentists have little formal training for managing patients with SHCN; there is limited or a total lack of funding for adult dental Medicaid coverage.  | The major barriers to transition to adult care for patients with SHCN include a lack of providers to transition patients to and a lack of public insurance coverage for these adult patients.   |
| 11                  | There is a general increase in the utilization of dental services for children, but this increase is not evenly distributed across demographics.   | Children with SHCN still face disparities in access and utilization to dental care, particularly in the period of transition to adulthood. Low-income, minority, and medically compromised children also face this disparity.   |
| 14                  | Barriers to transition include poor communication between pediatric and adult providers and lack of transition plan. A transition plan and successful transition are beneficial to patient outcomes.   | Transition planning is critical to a successful transition of care for patients with SHCN.  |
| 15                  | Patient/family education, pediatric and adult clinician communication and involvement, and transfer of care responsibility have been discussed in the literature as facilitating a good transition.  | Despite the presence of discussion of the transition of care being prevalent in research, transitions still tend to be "ad hoc" and not well communicated or planned in practice.   |
| 16                  | Recommending steps to take to ensure the transition of children with SHCN to adult care as well as an accounting of barriers   | The transition of care for children with SHCN remains a concern to the health community; a coordinated transition of care is critical for maintaining health.   |
| 17                  | There are no robust studies of existing models for the transition of care, and there is limited literature of models of the transition of care for patients with CP, diabetes, and no existing documented models of transition for ASD.  | There is very limited evidence to inform best practices for the transition from pediatric to adult-centered care for adolescents with complex health care needs.  |
| 18                  | Participation by over 600 individuals in the Special Care Family Academy in 2011 at the Hospital for Special Care; the academy has foci on home/community, education, and medical/dental care.   | Implementation of supportive services and paradigm shift to the coordination of transitional care was widely utilized at the Hospital for Special Care.   |
| 20                  | There are three existing documented models of the transition of care that provide documentation to facilitate a smooth transition.   | The transition process requires active management and should be flexible to accommodate patient and family needs.   |
| 21                  | 40% of SHCN youth meet the transition core outcome standards as set by the Maternal and Child Health Bureau. Female gender, younger age, white race, non-Hispanic ethnicity, and greater than 400% poverty income are associated with transition preparation.  | Less than half of children/youth with SHCN are prepared for health care transition per core outcome standard. There are several positive factors associated with adequate preparation for the transition, as well as negative barriers.                                       |
| 23                  | The primary care provider (medical home) should coordinate the needs for transitional care. There should be ongoing patient/family education. All health care needs should be addressed during the transition process. Protocols that inhibit or impede transition should be eliminated, and it should be a collaborative process. | Several factors impact transition, and there are several parties involved that must be coordinated by the primary care provider and patient/caregiver for a successful transition. Limiting factors, such as prohibitive policies and protocols, should be eliminated.        |
| 25                  | The three major challenges in health care transition policy and program development are health care systems barriers, person-level barriers, and complexity of the health care transition process.   | Despite improvements in transition policies and practices over the year, there are still barriers to smooth transition and complexities of transition that have limited robust research and policy development.   |
| 26                  | An organized and well-timed transition from child-centered to adult-centered care can facilitate continuous, comprehensive, coordinated care into adulthood for patients with SHCN.  | Key steps to successful transition include the foundation of a medical home, knowledge of the provider of the patient's health care needs, preparation of medical documentation, development of transition plan by age 14, and facilitation of continuous insurance coverage. |
| 28                  | The barriers and challenges of transitional care are not specific to demographics or medical conditions but span the population of adolescents and are made better by coordination and communication.  | Transitional health care is faced with several significant barriers that make a successful transition challenging.  Table continued on the next page.   |

<sup>\*</sup> Abbreviations used in this table: SHCN=special health care needs; CP=cerebral palsy; ASD=autism spectrum disorder; AAP=American Academy of Pediatrics; AAFP=American Academy of Family Physicians; ACP=American College of Physicians; ASIM=American Society of Internal Medicine; MCHB=Maternal and Child Health Bureau; SN=special needs.

| Table 1.            | CONTINUED*                |      |           |  |   |
|---------------------|---------------------------|------|-----------|--|---|
| Reference<br>number | Author(s)                 | Year | Origin    | Aims/Purpose   | Methodology   |
| 29                  | Schwartz LA,<br>et al.    | 2013 | USA       | Validate the social-ecological model of adolescent and young adult readiness to transition.  | Focus groups and semi-structured interviews   |
| 30                  | Bayarsaikhan Z,<br>et al. | 2015 | USA       | Understand dentist perspectives about the transition from pediatric to adult dental care.  | Semi-structured interviews of 7 pediatric and 6 general dentists  |
| 31                  | Friedman RB               | 1990 | USA       | Discuss the aspects that impact referral of patients with SHCN.  | Conference paper  |
| 32                  | Chi D                     | 2014 | USA       | Assess whether SHCN youth with a medical care transition plan are more likely to use dental care during the transition and what factors are associated with this dental utilization. | Analyze the National Survey of Children with SHCN (2001) and Survey of Adult Transition and Health (2007) via a retrospective cohort study. |
| 35                  | Lotstein DS, et al.       | 2009 | USA       | Describe the results of the Maternal and Child Health Bureau's core performance outcome of transition services.  | Data analysis from the 2005-2006 National<br>Survey of Children with Special Health Care<br>Needs   |
| 36                  | Strickland BB, et al.     | 2011 | USA       | Assess and measure the health status of children with SHCN based on 6 quality indicators developed by MCHB.  | National survey of families of children with SHCN in 2005-2006  |
| 39                  | Lotstein DS, et al.       | 2008 | USA       | Describe access to care and identify factors associated with access for low-income young adults who aged out of the public program for children with SHCN.                           | Cross-sectional survey of 77 graduates of a public program for children with SHCN   |
| 41                  | Borromeo, et al.          | 2014 | Australia | Determine the nature of transition practices of pediatric and special needs dentists in Australia.   | Survey to all pediatric and special care dentists in Australia.  Table continued across the next page.                                      |

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may be too abrupt for families and impede a smooth and timely transfer and continuous care.

It was identified that children with SHCN may have a myriad of providers and supportive resources to help manage social, financial, and clinical needs. 5,12,35 There are significant resources available to children with SHCN to obtain care and services needed throughout childhood. 6 However, the availability of health care, support services, and available funding tends to decrease in adult years. A national survey regarding children with SHCN found that 59 percent of parents reported that services were inadequate to prepare their children with SHCN for appropriate transition and adult-centered care. 11,24 Some of the lapses in necessary transitional care during the adolescent years were discussion of changing insurance coverage, discussion of the need for transition, lack of referral or completion of referral, and lack of an adult provider able to provide continued care. 22,37

Economic and financial issues are also documented barriers of pediatric to adult transfer and transition of care.<sup>38</sup> Pediatric dental insurance, which can extend to the age of 21 for children with SHCN, provides more coverage and reimbursement for dental procedures than insurance for SHCN adults.<sup>22,39</sup> There are very few services covered, if any, for dental care for

adults by Medicaid plans on a state-by-state basis.<sup>7</sup> The limited acceptance of Medicaid coverage by general dentists also encourages patients to stay with pediatric providers who often accept Medicaid insurance. <sup>7,11</sup> Lacking financial resources impedes patients from being able to maintain continuous care into adulthood by an adult provider once pediatric coverage is lost. <sup>7,35,38,39</sup> As a corollary, the literature supports that private insurance coverage in adulthood is a facilitator to transition to adult dental care. <sup>2</sup>

The final significant documented barrier to a successful transition is being a non-English speaker. For patients navigating the health care system, the barriers are exacerbated by non-English speakers. <sup>11,35</sup> Being a non-English speaker is associated with less dental care utilization, less discussion about health care transition, and deficiencies in meeting the MCHB core performance outcomes. <sup>35</sup>

Existing protocols and evidence for transition. There is little published on specific evidence-based protocols to facilitate the transition from pediatric to adult dental care for patients with SHCN. Most literature regarding transition protocols is based on expert opinions and anecdotal evidence.<sup>40</sup> There is more literature pertaining to transitions for medical care than dental care (Table 1). Few studies have been completed to

| Table 1.            | CONTINUED*   |  |
|---------------------|--|--|
| Reference<br>number | Results  | Key findings   |
| 29                  | The comprehensive methodical model of transition was validated and endorsed by stakeholders (patients, parents, and providers).  | Methodical models to transition adolescents with SHCN are testable and may be implemented, validated, and endorsed to facilitate transitional care.  |
| 30                  | Dentists think that transition from pediatric to adult care is important for patients with SHCN. Barriers include low reimbursement by Medicaid and a shortage of general dentists to treat these patients.                                | Dentists acknowledge the challenge of transitioning children with SHCN from pediatric to adult care but believe it is important for these patients.  |
| 31                  | Practitioner training and attitude, patient economics, and patient treatment needs are considerations for SHCN patient referrals.  | There are several parameters that influence provider referral of patients with SHCN, including provider training, economic considerations, and patient treatment needs.  |
| 32                  | For SHCN youth without functional limitation, having a medical care transition plan was associated with increased dental utilization but not for SHCN youth with a functional limitation.  | There are several factors that impact dental utilization during the transition to adulthood for patients with SHCN. Having a functional limitation is further associated with less dental utilization during the transition.   |
| 35                  | Forty-one percent of SHCN youth met the core performance outcome for transition, 42% discussed changing to an adult provider, 62% discussed children's adult health needs, and 34% discussed changes in health.                            | From 2005 to 2006, there were significant deficiencies related to meeting core performance metrics for children with SHCN to transition with barriers, including not having a medical home, lower income level, and not speaking English                                     |
| 36                  | The range of families receiving care for children with SHCN in 6 quality indicators developed by MCHB is 41.2% to 89.1%, with only 1 in 6 children with SHCN receiving consistent care in all 6 indicators.                                | There is a large disparity within children with SHCN receiving care in line with 6 defined quality indicators. There has been progress made in the care provided to this population since the institution of these indicators, but there are still significant gaps in care. |
| 39                  | Among the 77 subjects, 24% did not have health care, 27% went without some needed health care since turning 21, 39% delayed needed care, and 65% reported at least one adverse transition event that affected their access to health care. | Significant proportions of SHCN young adults experience difficulties in access to health care or lapses in coverage/care related to factors of transition from pediatric to adult-based coverage and care.   |
| 41                  | Eighty percent of responding pediatric dentists discussed future treatment options as part of transitional care; both SN and pediatric dentists treat patients over the age of 18 years.   | Transition discussion needs to occur with patients with SHCN and their families; the level of independence and financial consideration are the most significant barriers to transition.  |

<sup>\*</sup> Abbreviations used in this table: SHCN=special health care needs; CP=cerebral palsy; ASD=autism spectrum disorder; AAP=American Academy of Pediatrics; AAFP=American Academy of Family Physicians; ACP=American College of Physicians; ASIM=American Society of Internal Medicine; MCHB=Maternal and Child Health Bureau; SN=special needs.

| Table 2. BARRIERS, FACILITATORS, POLICY CONSIDERATIONS                |  |   |  |  |
|---|--|---|--|--|
| Barriers  | Facilitators   | Policy considerations   |  |  |
| Financial (low income level, public insurance coverage)               | Financial (high income level, private insurance)                     | Pediatric age cutoffs for patient care (e.g., in hospital facilities)                         |  |  |
| Non-English speaker/Hispanic ethnicity                                | Coordination and collaboration between pediatric and adult providers | Changes in public insurance benefits upon turning 21  |  |  |
| Poor coordination/communication between pediatric and adult providers | Early age of transition discussion/planning                          | Changing social support/structure (e.g., graduation from school program to adult day program) |  |  |
| Lack of provider referral base  | Family/caregiver involvement with transition                         |   |  |  |
| Lack of medical home  | Presence of medical home   |   |  |  |
| Lack of patient/family education                                      | Patient/family education   |   |  |  |

assess how a transition should take place to ensure continuous comprehensive care for patients with SHCN.

A study investigated the transition practices of pediatric and special needs dentists in Australia, where special care dentistry is a recognized specialty. Among the options of age, maturity, level of independence, and financial reasons, age was the most prevalent factor for initiating a discussion about transition.<sup>41</sup>

In New Britain, Conn., USA, the Hospital for Special Care has implemented a Special Care Family Academy. This alternative model of a medical home provides four collaborative centers to provide comprehensive and continuous care for patients with special needs: (1) a Consumer Advocacy Center; (2) Life Skills Center; (3) Transition Care Center; and (4) Career Opportunity Center. This unique clinical site

serves as a potential model for collaborative integrative care for patients with SHCN and has been met with positive feedback by patients and families as well as positive patient outcomes 18

Despite the prevalent literature documenting the importance of continuous care and transition for SCHN patients from pediatric to adult-based care, there are few studies that have evaluated and assessed the effectiveness of transition protocols for these patients. Much of the existing evidence is found in the medical literature. The literature defines barriers, facilitators, and concepts regarding transitional care but is lacking in protocols that guide clinicians to perform a successful transition of care for patients with SHCN. This is an understudied area; based on the findings of this scoping review, there is a significant need for additional research. Future research should focus on testing the transition protocols and policy statements of professional organizations for efficacy with patients with SHCN. This study's limitations are primarily related to the minimal amount of literature published on the topic of this scoping review. The findings relied heavily on medical literature and could be limited in their applicability to dental care.

#### Conclusions

Based on this study's results, the following conclusions can be made:

- There is a paucity of literature that evaluates best practices or protocols to facilitate the effective transition of children with special health care needs to adult care from pediatric care.
- There is very limited information within the current literature to guide the transition process for patients with SHCN from pediatric to adult-based dental care.
- This is an area of study that can be explored in more depth to help improve dental management and care for patients with SHCN and potentially mitigate this unmet health care need.

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