Transition to Adult Dental Care from a Pediatric Hospital Dental Home for Patients with Special Health Care Needs

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Abstract

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for Patients with Special Health Care Needs

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Purpose: This study describes patients with Special Health Care Needs (SHCN) transitioning from a pediatric hospital dental home to adult care and evaluates effectiveness of current transitions.

Methods: Demographics, medical/behavioral complexity, and documentation of transition processes were collected for patients who graduated between 10/01/2018 and 11/30/2019. A survey invitation was mailed to patients/guardians meeting criteria. The survey assessed progress and barriers in transitioning to an adult dental home.

Results: Seventy-nine patients graduated; 63 met survey criteria. Twenty-nine surveys were completed. Ninety percent of surveyed patients had established some/all adult medical care, 41% completed a dental visit, but less than 28% established a dental home. Medical/behavioral complexity, payor, and time since graduation did not impact having a visit.

Conclusions: This study demonstrates disappointing effectiveness in the transition to adult dental care from a pediatric hospital dental home for patients with SHCN. Medical transition programs may be effective models for dental transition.

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DEDICATION

To Joseph Mikkelson, my partner in life and love.

For creating space for my mind to soar, and for always being there when I come back down.

INTRODUCTION

The process of moving from pediatric to adult health care is described as “transition” and is necessary for those patients who establish their medical home with pediatricians and/or their dental home with pediatric dentists. The dental home is defined by the American Academy of Pediatric Dentistry (AAPD) as “the ongoing relationship between the dentist and the patient, inclusive of all aspects of oral health care delivered in a comprehensive, continuously accessible, coordinated, and family-centered way.” [AAPD 2020]. A key difference between pediatric and adult models of healthcare is an emphasis on family-oriented decision making in pediatric care versus more autonomous self-directed care for adults [Castillo 2015].

Transitioning from pediatric to adult healthcare can be challenging for any patient but adolescents and young adults with special health care needs (SHCN) often face additional barriers in transitioning to adult dental and medical care. The AAPD definition of SHCN includes “any physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs. The condition may be congenital, developmental, or acquired through disease, trauma, or environmental cause and may impose limitations in performing daily self-maintenance activities or substantial limitations in a major life activity.” [AAPD 2020]. A 2010 estimate of prevalence of SHCN among adolescents between 12 – 18 years in the United States (US) was 18.4% or 4.5 million individuals [McManus 2013]. Approximately 750,000 adolescents with SHCNs in the US reach adulthood each year [Scal 2005].

Patients with SHCN demonstrate a broad spectrum of care need complexity, and specialized knowledge may be required to adapt the dental experience to a patient’s unique SHCN. Pediatric dentistry residency programs include extensive training in the care of patients with SHCN, with an emphasis on acquiring the ability to provide “accommodative measures beyond what are considered routine” [AAPD 2020]. In a survey of practicing pediatric dentists, 84% received comprehensive didactic courses in the care of patients with SHCN, 97% had clinical training, and 89% felt proficient in treating children with SHCN upon completion of their formal training [Nowak 2002]. The AAPD recognizes the challenges of transitioning

from a pediatric-centered to an adult-centered dental home for individuals with SHCN. Dental transitions from pediatric dentists occur between 18-20 years for patients with SHCN and 15-20 for patients without SHCN [Nowak 2010]. An AAPD policy first adopted in 2016 includes goals for successful transition by the age of majority based upon a medical model and identifies transition barriers [AAPD 2020].

Major barriers to transitioning for patients with SHCN reported by pediatric dentists include: poor availability of general dentists (70%) and specialists (66%) willing to treat these patients, lack of insurance reimbursement for transition planning (36%), and breaking the bond with pediatric care providers (35%) [Nowak 2010]. Low dental reimbursement for patients with Medicaid has been cited by both pediatric and general dentists as a major barrier to care transition [Bayarsaikhan 2015]. Other barriers identified by pediatric dentists included insufficient staff time and skills for transitioning services, lack of knowledge about community resources that support young adults with SHCN, and inability of patients to self-advocate at dental visits [Nowak 2010]. Similarly, interviews with adolescents with SHCN and their families noted having Medicaid insurance, patient's lack of readiness, and "difficulty finding a knowledgeable general dentist willing to treat patients with SHCN" as key barriers to transition [Cruz 2015].

In a 2001 American Dental Association (ADA) survey of general dentists, 10% reported that they saw children with SHCN very often or often, and about 25% reported having hands-on educational experiences with children with SHCN during dental school [Casamassimo 2004]. Almost 95% of pediatric dentists report routinely seeing patients with SHCN, and almost 71% continue to follow patients with SHCN beyond 21 years of age [Nowak 2002]. Many parents of adolescents with complex SHCN expressed belief that it was acceptable to continue seeing a pediatric dentist into adulthood [Cruz 2015].

Research about pediatric to adult dental transitions to date has focused on perceived barriers and facilitators of transitioning care. A 2020 scoping review concluded that, while there is medical literature which addresses transition care for patients with SHCN, there are no dental-specific evidence-based

protocols at this time. This review called for research focused on “testing the transition protocols and policy statements of professional organizations for efficacy with patients with SHCN” [Chavis 2020].

The purpose of this study was to 1) describe characteristics of adolescents with SHCN transitioning from a hospital-based pediatric dental home to adult dental homes, and 2) survey these patients at least one year after their final visit in the pediatric dental home to: determine efficacy of the current transition method, examine influence of selected patient characteristics on progress with transition, and identify barriers to successful transition.

METHODS

Study hospital description

Seattle Children’s Hospital (SCH) is a 407-bed tertiary care hospital which serves as the pediatric and adolescent academic medical center for Washington, Wyoming, Alaska, Montana and Idaho. The SCH pediatric dentistry team performs inpatient and emergency consultations and treatment and provides a dental home for patients with SHCN until age 17 years at a dental clinic within the hospital. Continuing dental care is provided for certain older patients actively receiving oncology or transplant services. Dentists first discuss the need for transition to adult dental home providers and clinics when a patient is 15 years old, culminating in a “graduation” appointment at 17 years of age. Patients are given a printed document identifying dental providers for adults with SHCN with verbal guidance towards the option(s) best suited for the transitioning patient. No further outreach is made by the SCH dental team following the graduation visit.

Graduating patient cohort EHR review

Study participants were identified via hospital reports. Inclusion criteria were: 1) SCH served as the patient’s dental home, 2) the patient had SHCN, and 3) graduated from the SCH pediatric dentistry clinic between October 1, 2018, and November 30, 2019. Exclusion criteria were: 1) SCH was not the patient’s dental home, 2) patient did not have SHCN, 3) graduated outside of study period, or 4) returned to SCH

following graduation due to ongoing treatment by medical or surgical subspecialty service. Characteristics of the graduating patients were collected from electronic health records (EHR) (IRB # 00002421). Data was collected and entered into a REDCap (Research Electronic Data Capture) database hosted at the University of Washington [Harris 2009, Harris 2019]. Data was collected by a single examiner with areas of ambiguity resolved by attending dentists familiar with the patients and research plan.

Patient demographics included gender, age at time of graduation, dental payor, guardianship status, residence type (living independently, with family, in a group home/health care facility), and language of care. Patients were classified as medically complex (e.g. hemophilia), behaviorally complex (e.g. physically resistant to care), or both. Further classification was made regarding the need for accommodation beyond that required by a typical patient in a general dental practice (e.g. extensive medical consultations, protective stabilization, or use of general anesthesia).

Indicators of patient readiness to cooperate for dental care were collected. Positive indicators included the ability to accept an examination in the dental chair, obtain intraoral radiographs, behavior rating of either Frankl +/+ (definitely positive) or Frankl + (positive), tolerance of rubber cup prophylaxis, and history of accepting treatment with local anesthetic in the dental clinic setting [Frankl 1962]. Negative indicators included the need for extra dental personnel, security team presence during appointments, protective stabilization use, or greater than three instances of dental treatment under general anesthesia.

Two data points relating to the transition process at the “graduating dental visit” were recorded: 1) presence or absence of narrative in the chart note of a transition discussion and 2) documentation in the same note that the graduation document identifying dental providers for adults with SHCN (Appendix A) had been given to the patient and guardian during the appointment.

Survey

A nine-item institutionally approved survey was developed through input of pediatric dentists, a survey research expert, and the parent of a young adult with SHCN (SCH IRB # 00002783) (Appendix B).

Survey questions inquired about patient or guardian recall of the transition guidance offered by the SCH dental team, progress towards establishing care with adult dental and medical providers, current dental insurance type, and perceived barriers to transitioning dental care. All respondents were given an opportunity to comment in a free response format about “anything else you would like us to know about your experience moving to a dentist who cares for adult patients”.

Not all graduated patients met criteria for follow-up contact. Patients were excluded if they had died since graduation, required a language of care other than English, or it was indicated in hospital records that the patient/family declined to be contacted for research. A packet with an invitation to participate in the survey and detailed study information written at a 7th grade reading level was mailed to potential participants per IRB protocol (Appendix C). Each patient’s guardianship status at the time of graduation was determined during review of the electronic health record, and correspondence was addressed to either the patient or their parent/guardian accordingly. Potential participants were given a phone number and email address contact to use if they wished to opt out of the study. After a period of at least two weeks, the patients/guardians were then contacted by phone to determine interest and obtain consent and/or assent as appropriate. Up to two attempts at phone contact were made. Per participant preference, surveys were administered by mail, telephone interview, or electronically via email using the REDCap survey function. One email reminder was sent to patients/guardians who requested an electronic version of the survey if it was not completed after a period of one to three weeks. Responses were collected in REDCap.

Statistical plan

Descriptive statistics were calculated for all graduated patients, for graduating patients who did not participate in the survey, and for survey respondents. Descriptive statistics were also completed for survey respondents who had a visit versus did not have a visit. Counts and percentages were used for categorical variables and analyzed with chi-square tests; means and standard deviations were used for continuous variables and analyzed by t-tests. Surveyed patients who did or did not have a dental visit after graduation from SCH dental clinic were further analyzed. Logistic regression examined the relationship between time since graduation and having/not having a dental visit. Multiple logistic

regression was used to examine relationships between type of SHCN, need for medical and/or behavioral accommodation, payor, and having a visit. Statistical significance was preset at < 0.05. The Stata 16 statistical package was used for analysis. (StataCorp. *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC;2019)

RESULTS

Graduating cohort EHR review results

During the study period, 79 patients with SHCN graduated from dental homes with SCH pediatric dentistry. The majority of graduating patients were male (65%). The patients ranged in age from 15-24 years and mean age was 19.5 years. Nearly all patients lived at home with family (92%). Parents were most frequently the patient's legal guardian (65%). The majority had Medicaid dental insurance only (67%), versus those with Private dental insurance only or dual Private/Medicaid dental insurance (33%). Thirteen percent of patients received care in a language other than English, seven languages were represented. Most graduating patients had experienced a dental home other than SCH at some time in their lives (65%); SCH had been the patient's one and only dental home for 35% of graduating patients. The number of visits with the SCH pediatric dentistry team in the graduating cohort ranged from 1-47 visits, with a mean of 15 visits, and years with an SCH dental home ranged from 1-23 years, with a mean of 10 years (Table 1).

Sixty-eight percent of graduating patients were given a positive Frankl behavioral rating of +/+ or + at their graduation visit. Frequency of positive readiness indicators to accept care in the community among graduating patients were acceptance of: examination in the dental chair (81%), rubber cup prophylaxis (70%), intraoral radiographs (58%), and treatment with local anesthetic in clinic (25%). The most common negative readiness indicator was more than three instances of dental treatment under general anesthesia (20%). Other negative indicators included requiring extra dental personnel (11%), use of protective stabilization (5%), and presence of hospital security team during appointments (3%).

Survey results

Sixty-three patients met criteria for the post-graduation survey. Between 01/30/2021 and 03/10/2021, 29 surveys were completed: 22 by phone interview, 4 electronically, and 3 by mail. The time between the graduation appointment and survey administration ranged from 15 to 28 months. For all but one measure, survey responders did not significantly differ from non-responders. The length of time SCH had provided the dental home was longer for patients who did not participate in the survey (mean 11.4 years) than for survey respondents (mean 8.1 years) ($p = 0.019$) (Table 2).

More survey respondents reported having established some or all adult medical care (90%) than adult dental care (41%). The majority of survey respondents had not had a dental appointment since their graduation visit at SCH Dental Clinic (59%). At the time of the survey, 14% percent were on a waitlist and 7% had their initial appointment scheduled. The number of dental visits at SCH was higher for survey responders who had a visit (mean 17.8 visits) than for those who did not have a visit (mean 9.35 visits) ($p = 0.046$). For all other measures, no significant differences were found between those who did or did not have a visit (Table 3).

Logistic regression including payor and two categories of accommodations (medical only versus medical + behavioral) found neither a significant effect of the payer status ($p=0.356$) nor a significance in the accommodations status ($p=0.507$) to result in a visit as the end outcome. Regression analysis did not show a significant relationship between having a visit and time elapsed between graduation visit and survey administration ($p=0.229$).

Of the 12 patients who had completed dental visits, six were seen in clinics primarily designed for the care of patients with SHCN, and six saw dentists at private or public health clinics in their communities. Four of the six patients who had a dental visit in their community commented that the first dentist they saw was not a good fit, and that they were seeking care elsewhere.

The main barriers to finding a new dentist reported by the survey respondents included finding a dentist who understands SHCN (66%), COVID-19 virus (38%), and finding a dentist who accepts their insurance (34%) (Table 4).

The graduation EHR notes for the 29 surveyed patients specified discussion of transition for 25 patients (86%) and that the graduation document had been given to 12 patients (41%). Patients were less likely to remember having a discussion with their dentist about the care transition (15 of 25 patients, 60%) and were more likely to remember whether they were given a graduation document (11 of 12 patients, 92%) (Table 5).

Narrative comments from survey respondents

Twenty-four survey respondents (83%) chose to provide additional comments when asked “Is there anything else you would like us to know about your experience moving to a dentist who cares for adult patients?” The majority of this feedback was shared during phone interviews, which ranged from 10 to 30 minutes. Several themes emerged during these conversations, which are reflected in the representative comments included below.

The strongest theme was that the adult clinics were not able or willing to take patients with SHCN:

> “Basically, I think most of the dental clinics I went to were hesitant to do anything on me because of my medical background. One that I tried going to wouldn't do any treatment on me.”
>
> “Finding a dentist who has room to take medically fragile patients has been our biggest burden.”
>
> “We can only go to public health or International Community Health Services (ICHS), but they can't handle special needs. They tried to take an x-ray, but she needs some extra time and they don't know how to wait for her.”
>
> “We were to the ADA website and found a dentist that was willing to come to the home, but then we ended up going to their office. We just spoke with them and they referred us back to Seattle.”
>
> “We went to a new clinic, but they didn't have any coordination and didn't communicate with Seattle Cancer Care Alliance (SCCA) [his medical specialists], so they didn't know about his medical problems and how to take care of him... Some of the clinics are not ready to receive the patients who are transitioning.”

> “They will say that they can take them, but it's not always true, first they will use insurance as a reason to not see them, and then the hospital won't see them… because they are worried about her medical needs after the surgery.”

The lack of local dentists available to see patients with SHCN was noted by several respondents:

> “I was trying to find somebody closer to us so we didn't have to go to Seattle every time.”

> “We are hoping to find a dentist closer to home so we don't have to drive to Seattle.”

Medical transition programs and medical providers were cited as helpful in finding dental clinics:

> “I waited over a year for an appointment, but then I called the University of Washington (UW) Transition Program and they got me an appointment.”

> “We reached out to a transition group through Multicare. The transition has gone well this time because we [at the medical group home] learned what questions to ask - not being shy or hesitant, but asking "what's next?" or saying "where should we go?" The Seattle Children's and Multicare clinics have been helpful answering these questions and giving us direction on where to go.”

> “The UW Hospital Transition Program helped me make an appointment… Everyone is different, but for me I was really scared, because I had all of these crazy procedures done and it wasn't clear if I had to go to a specialized surgeon or just a regular dentist.”

> “I just found out I was supposed to take [my son] to the [Dental Education in the Care of Persons with Disabilities] DECOD clinic and not the UW School of Dentistry. He was referred by his primary physician to the DECOD dental clinic.”

Patients and families expressed frustration at the long wait time for adult dental care:

> “A two-year waitlist [at DECOD] is really frustrating. That shows a lack of funding and advocacy.”

> “We are on the waitlist for DECOD clinic. All of our clients [at the medical group home] are overdue for dental care.”

> “It was a long waitlist - we were at the dental clinic at Seattle Children's Hospital in 2019 and last month [Feb 2021] was the first time we were able to get in to DECOD and have x-rays.”

> “[Our pediatric dentist] was warning us, try a year and a half before you leave us to find a dentist, and we didn't, so we haven't seen a dentist.”

Participants stated that they would like to have more information about the transition process and to start the discussion earlier:

> “There was no transition or preparation to guide you from Seattle Children's Dental Clinic, at the last visit, they just said we need to find a new dentist.”

> “Maybe spend a little more time explaining what happens when you have a transition.”

> “If Children's providers knew the UW was so slow, I would want to know early on what other options are so she doesn't go on to not have care for 2 years when she should have care every 6 months.”

> “Give information to families not only once, but 2-3 years ahead of time give information. Give a checklist at every appointment to see where families are with the progress in the transition. Just handing out information is not enough to prevent a long wait time for seeing a dentist.”

Several respondents commented on the desire for a provider-to-provider communication during the transition period – what is known as a “warm handoff:”

> “I didn't really get any information from SCH when I swapped over. I got information from my medical providers, but nothing from dental specifically. My medical provider recommended a specific doctor for me to see at UW.”

> “It would be great if they said "this would suit you the best" and then called to get it set up. With the medical doctors, his old doctor talked to his new doctor.”

> “With patients who have a higher level of disability and even a hard time coming in to the appointments, [the patient should be seen] until a point we can successfully transition and we are set to go, and not get to the point where you have to transition and then don't know what to do.”

COVID-19 was a novel concern unique to the graduation timing of this patient cohort. Some appointments were cancelled by dental clinics due to COVID-19 and families expressed concerns about exposure of medically fragile patients to the virus:

> “I had an appointment at a family dental clinic but it got cancelled due to COVID and I haven't called to reschedule.”

> “Because of COVID I don't want to expose her to any germs by going into the dentist.”

> “Mostly the barrier has just been the virus. His teeth are important, but due to his medical conditions, we are waiting until he gets the vaccine to go to a new dentist.”

DISCUSSION

This study demonstrates a disappointing level of effectiveness in the transition to adult dental care from a pediatric hospital dental home for a group of young adults with high acuity SHCN. A strength of this study is that the surveyed patients robustly reflected the graduating cohort. Unfortunately, the patients successfully transitioned to adult care at a low rate, with only 41% of surveyed patients having completed a visit with a dentist who cares for adult patients since graduation, and less than 28% establishing care consistent with the definition of a dental home. This is in stark contrast with the high rate at which the same patients had established some or all adult medical care (90%).

Health care transition

The challenges of young adults with SHCN include their ability to navigate independence, education/employment/vocational opportunities, community support and program availability, insurance coverage, financial considerations, and other social dynamics. A 2001 national consensus conference involving the American Academy of Pediatrics (AAP) and The Health Resources and Services Administration of the Department of Health and Human Services resulted in a policy statement on health care transition for adolescents and young adults with chronic health conditions. Six “critical first steps” have been adopted by the AAPD in their transition policy.

1) A healthcare provider taking specific responsibility for an individual’s transition

2) Teaching transition skills to primary care providers as part of their certification process

3) Developing a medical summary to facilitate smooth transfer of care between health care providers

4) Developing a written transition plan in collaboration with the patient and their family

5) Applying the same standards of primary and preventive health care to people with chronic conditions as their peers

6) Availability of affordable, comprehensive, and continuous health insurance [Rosen 2003].

Resources for implementing and expanding on these steps are available through Got Transition®, the federally funded national resource center of health care transition, which has created a set of tools named the Six Core Elements of Health Care Transition” [White 2020].

Medical transitions start early with teaching adolescents to manage health on their own between ages 10-12 and spending some appointment time alone with adolescents between 12-14 years, for an age 17-18 transition [Geenen 2003]. Despite the early introduction about transition, only 40% of youth with SHCN meet national medical transition preparation core outcomes [McManus 2013].

Several families reported successful dental transitions were aided by their medical transition team, and there is some evidence to support that youth with SHCN with a formalized transition plan are more likely to utilize dental care [Chi 2014]. This suggests an opportunity to establish reliable partnerships that integrate dental transition into medical transition programs. Multiple families expressed desire for a robust dental transition process in the comment section of the survey.

Dentists can look to existing evidence-based medical models for guidance in creating a transition program. Abstracting from the success of the AAP's Got Transition® Program, a dental transition program should introduce the concept early in the teen years and work towards the transition at each visit, with periodic assessments of patient/family readiness to transition, and develop a collaborative plan that concludes with a warm handoff to a dentist at an adult-centered dental home. A challenge to designing, implementing, and assessing efficacy of a dental transition program may be the relatively high number of small group practices and solo practitioners in dentistry as compared to larger institutions in medicine. Dentists generally lack ready access to a patient's medical information, medical providers, and laboratory resources.

Barriers

The survey respondents' perceived barriers to transition were consistent with previous studies findings of not being able to find a dentist who understands the individual's special health care needs and difficulty finding a dentist who accepts their insurance [Cruz 2015]. Despite this perception, neither payor status nor accommodation status significantly affected the outcome of having a visit with a new dentist. Our small sample size may explain this difference between perceptions and statistically significant outcome.

Lack of dental education in SHCN has been cited as a barrier to transitioning to adult care when patients with SHCN reach the age of majority and require care beyond the scope of the pediatric dental provider's expertise [McTigue 2007, Bayarsaikhan 2015]. In the Commission of Dental Accreditation (CODA) standards for pediatric dentistry residency programs, 11 sections mention education in the care of patients with SHCN [CODA Pediatric Standards]. By comparison, the CODA predoctoral dental accreditation standards have one section regarding patients with SHCN which states "Graduates must be competent in assessing the treatment needs of patients with special needs." [CODA Predoctoral Standards]. This predoctoral competency was formalized in 2013. A 2004 study of US general dentists found that 1) dentists who reported having hands-on and didactic experiences during dental school were more likely to treat children with SHCN, and 2) there was no difference between those with or without postgraduate training in a General Practice Residency (GPR) or Advanced Education in General Dentistry (AEGD) in their willingness to treat children with SHCN, suggesting that additional education alone may not solve this complex access problem [Casamassimo 2004].

Survey respondents indicated that community clinics may not be ready to accept young adults with SHCN, with comments about provider reluctance related to medical complexity and/or lack of time within the appointment to accommodate patients who are slow to comply with dental team requests. This is a concern, as community clinics are the primary dental venue for patients with Medicaid. Low Medicaid reimbursement rates have been suggested as a factor limiting the number of providers willing to treat patients with SHCN [Casamassimo 2004]. Community clinics which are Federally Qualified Health Centers often have residency programs, presenting an opportunity to incorporate the care of patients with special needs into the clinic operations and educational programs.

In Washington State, the primary provider of dental care for patients with SHCN who have Medicaid insurance and cannot receive care in a community clinic setting is the University of Washington's Dental Education in the Care of Persons with Disabilities Clinic (DECOD), which currently has a two-year wait for a new patient examination. Patients with SHCN who have private dental insurance are eligible for treatment in a practice which includes a hospital-affiliated GPR (Seattle Special Care Dentistry, SSCD).

The six patients who had a dental visit in either the DECOD clinic or at SSCD indicated that the new dental home was a “good fit.”

Although 93% of patients graduated at least 6 months prior to the start of the COVID-19 pandemic, the pandemic was cited by 38% of respondents as a barrier to transitioning care. Surprisingly, regression analysis did not show a significant relationship between time between graduation visit date and survey completion on having a visit with a new dentist. Some patients may have postponed seeking care while others had an appointment scheduled or were on a waitlist. The pandemic may have extended this process, either due to cancellation of appointments by the dental office or patient/family concern for exposure to the virus.

Guardianship designation for the graduating cohort likely undercounts the number of patients who had parents as guardians. For some, guardianship was in flux at the time of graduation; guardianship status was verified during the consent process for survey participants. The process of establishing legal guardianship can be complicated [Davidson 2017]. Patients with SHCN may face the challenge of a mismatch between their decision-making capacity (legal determination) and competency (functional assessment) as they reach the age of majority, and guardianship status can become yet another barrier.

Suggested enhancements for SCH dental transitions

As neither discussion nor the graduation handout appeared to influence whether the patient had a visit with a new dentist at least one year post graduation, the following enhancements to the current transition process should be considered:

1) Present the clinic transition plan at the time patients establish dental homes with the SCH dental team.

2) Create tools for dental and patient/family assessment of readiness to transition.

3) Begin transition discussion at age 12 visit using the transition tools.

4)Continue discussion of transition concepts at all subsequent periodic recall examination appointments.

5) Identify patients/families who will need support in completing intake documents for adult clinics and provide a hospital resource such a social worker or dental team member to assist as needed.

6) Identify patients best served at the DECOD clinic and ensure completion of application documents two years prior to desired transition.

7) Develop a template to support the dentist-to-dentist handoff which summarizes dental history and necessary accommodations.

8) Obtain signature of patient/guardian on release of health information documents at graduation visit to facilitate transfer of records.

9) Contact of the patient/guardian by the SCH dental team at 3 months post-graduation to follow-up on progress of transition.

Limitations

The survey was limited by including only English-speaking patients. Translation of survey materials was cost-prohibitive for this project. However, multiple survey respondents who had clinical care in English shared during the telephone interview that they did not feel comfortable enough in their English to complete the extensive application required for care at the DECOD clinic, suggesting this factor would benefit from further study.

The length of time between the graduation appointment and survey administration (15 – 28 months) may have adversely impacted ability to recall items such discussion of transition with their dentist or perceived barriers.

The patients graduating from the SCH Dental Clinic are not necessarily reflective of the SHCN population as a whole. SCH provides a dental home only to patients with high acuity medical and/or behavioral conditions, this limits the generalizability of our study.

Future studies

Future studies should include dental homes serving patients with lower acuity SHCN. Including the patient and family perspective in this type of research is essential. In the surveys conducted by telephone interview, many comments from the patients provided potential topics of interest for further research. We

encourage other pediatric hospital-based clinics to assess and report the efficacy of transition for their young adult patients with SHCN.

A study could assess the value of telehealth technology and electronic consultation of both medical and dental specialists in the support of community clinics caring for individuals with SHCN in rural and underserved areas.

A multi-state analysis of Medicaid reimbursement rates could study the effect of enhanced Medicaid reimbursement on successful transition to adult care for individuals with SHCN.

As the predoctoral CODA accreditation standard regarding SHCN has been in place close to a decade, a new survey to assess general dentists' perceptions on access to care for individuals with SHCN would be valuable.

Conclusions

This study confirms that the transition process from a pediatric hospital dental home to adult dental home is complex. Due to the multifactorial nature of the challenges of establishing adult dental homes for patients with SHCN, there must be collaboration between families, pediatric dentists, general dentists, medical providers, payors, and policy makers. The authors encourage a multi-partner demonstration process regarding transition models based upon the AAP medical transition program.

Table 1. Characteristics of patients graduating from a dental home at Seattle Children's Hospital between October 1, 2018 and November 30, 2019

Graduating Patients N = 79	
Age at Last Visit (Years)	
Age range	15-24
Mean	19.45
SD	1.59
Gender	n (%)
Male	51 (65)
Female	28 (35)
Residence	
With parent/family	73 (92)
Group home	5 (6)
Independent	1 (0)
Guardianship	
Self	28 (35)
Parent	51 (65)
Dental Insurance	
Medicaid Only	53 (67)
Private	26 (33)
Type of Accommodation Required	
Medical only	37 (47)
Behavioral only	4 (5)
Medical AND Behavioral	33 (42)
No accommodation beyond routine	5 (6)
History of Dental Home other than SCH	
Yes	51 (65)
No	28 (35)
Number of Visits at SCH Dental	
Range	1 - 47
Mean	15.24
SD	11.47
Years at SCH Dental	
Range	1-23
Mean	10.18
SD	6.15

Table 2. Characteristics of patients graduating from a dental home at Seattle Children's Hospital who did or did not participate in the post-graduation survey

	Graduating Patients who Did Not Participate in the Survey N = 50	**All Survey Respondents N = 29**	**p-value**
Age at Last Visit (Years)			
Age range	15-24	16-24	0.934*
Mean	19.44	19.47	
SD	1.50	1.79	
Gender	n (%)	n (%)	
Male	32 (64)	19 (66)	0.892**
Female	18 (36)	10 (35)	
Residence			
With parent/family	48 (96)	25 (86)	0.214** No difference between any groups in two-by-two comparisons
Group home	2 (4)	3 (10)	
Independent	0 (0)	1 (3)	
Guardianship			
Self	21 (42)	7 (24)	0.110**
Parent	29 (58)	22 (76)	
Dental Insurance			
Medicaid Only	37 (74)	16 (55)	0.086**
Private	13 (26)	13 (45)	
Type of Accommodation Required			
Medical only	21 (42)	16 (55)	0.282** No difference between any groups in two-by-two comparisons
Behavioral only	3 (1)	1 (3)	
Medical AND Behavioral	21 (42)	12 (41)	
No accommodation beyond routine	5 (10)	0 (0)	
History of Dental Home other than SCH			
Yes	31 (62)	20 (69)	0.533**
No	19 (38)	9 (31)	
Number of Visits at SCH Dental			
Range	1-47	1-44	0.174*
Mean	16.58	12.93	
SD	11.61	11.04	
Years at SCH Dental			
Range	1-23	1-19	0.019*
Mean	11.4	8.07	
SD	6.04	5.84	

*t-test **chi-square test

Table 3. Characteristics of patients graduating from a dental home at Seattle Children's Hospital who did or did not have a dental visit after graduation

	Had Dental Visit N = 12	**Did Not Have Dental Visit N = 19**	**p-value**
Age at Last Visit (Years)			
Age range	17-24	16-21	0.259*
Mean	19.93	19.15	
SD	2.19	1.42	
Gender	n (%)	n (%)	
Male	8 (67)	11 (65)	0.913**
Female	4 (33)	6 (35)	
Residence			
With parent/family	11 (92)	14 (82)	0.165** No difference between any groups in two-by-two comparisons
Group home	0 (0)	3 (18)	
Independent	1 (8)	0 (0)	
Guardianship			
Self	3 (25)	4 (24)	0.927**
Parent	9 (75)	13 (77)	
Insurance			
Medicaid Only	5 (42)	11 (65)	0.219**
Private	7 (58)	6 (35)	
Type of Accommodation Required			
Medical only	8 (67)	8 (47)	0.469** No difference between any groups in two-by-two comparisons
Behavioral only	0 (0)	1 (6)	
Medical AND Behavioral	4 (33)	8 (47)	
No accommodation beyond routine	0 (0)	0 (0)	
History of Dental Home other than SCH			
Yes	9 (75)	11 (65)	0.555**
No	3 (25)	6 (35)	
Visits at SCH dental			
Range	1-44	1-27	0.046*
Mean	17.75	9.53	
SD	13.46	7.68	
Years at SCH Dental			
Range	1-19	1-18	0.248*
Mean	9.58	7.0	
SD	6.14	5.56	

*t-test **chi-square test

Table 4. Barriers to transitioning care reported by survey respondents who graduated from a dental home at Seattle Children's Hospital

	All Survey Respondents N = 29	**Had Visit N = 12**	**No Visit N = 17**
Perceived Barriers		n (%)	
Other (not COVID)	2 (7)	0 (0)	2 (12)
Does not understand SHCN	19 (66)	7 (58)	12 (71)
Insurance	10 (34)	5 (42)	5 (29)
Transportation	3 (10)	2 (17)	1 (6)
No Problems	6 (21)	5 (42)	1 (6)
COVID	11 (38)	2 (17)	9 (53)

Table 5. Documentation and patient recall of transition process for patients graduating from a dental home at Seattle Children's Hospital who did or did not have a dental visit after graduation

	All Survey Respondents N = 29	Had Visit N = 12	No Visit N = 17
Discussion of Transition		n (%)	
Documented in electronic health record	25 (86)	11 (92)	14 (82)
Remembered by patient	15 (52)	8 (67)	7 (41)
Graduation Document Given			
Documented in electronic health record	12 (41)	6 (50)	6 (35)
Remembered by patient	11 (38)	5 (42)	6 (35)

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Appendix A: Graduation Document

Seattle Children's HOSPITAL • RESEARCH • FOUNDATION | Department of Dentistry

CONGRATULATIONS!

You are now graduating from pediatric dentistry care in the Dental Clinic at Seattle Children's Hospital. We have enjoyed watching you grow and being your "dental home" over the past years.

As we have discussed at your most recent pediatric dentistry appointments, we have identified some highly capable adult dentistry community resources. These practices offer comprehensive dental care as described below.

Clinics:

UW DECOD Clinic - Dental Education in the Care of Persons with Disabilities (DECOD) is a dedicated program of the University of Washington School of Dentistry that treats persons with severe disabilities and prepares dental professionals to meet their special oral health needs. Information on becoming a patient is available at:

www.dental.washington.edu/departments/oral-medicine/decod-clinic.html
University of Washington Health Sciences Building
Room B-239
Phone: 206.543.4619

Seattle Special Care Dentistry (SSCD) - Provides dental care for patients with complex medical, mental and physical challenges of all varieties. Sedation and General Anesthesia care are available in the office and also at Swedish Hospital. SSCD's facility was specifically designed for mobility-impaired patients. Information on becoming a patient is available at:

www.seattlespecialcaredentistry.com
Northcut Landing, West Building, Suite 205
4915 25th Avenue NE, Seattle, WA 98105
Phone: 206.524.1600 | Fax: 206.524.1603

Resource:

Washington State Dental Association, website- This searchable website provides a directory of Dentists who provide dental care for patients with special needs.

www.wsda.org/special-needs-directory/

For information on how to become a patient of any of these clinics, please use the links above.

Please let our staff know if we can be of further assistance to you in recommending other providers in the community in which you live. Thank you for allowing us to play a part in your oral health care needs.

The Dentists & Staff of Seattle Children's Hospital | Department of Dentistry

4800 Sand Point Way NE
M/S CD PO Box 5371
Seattle, WA 98145-5005

TEL 206-987-2243
FAX 206-987-3891

www.seattlechildrens.org

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Appendix B: Survey

Survey about moving from Seattle Children's Hospital Dental Clinic to a dentist who cares for adult patients

Survey Instructions:

- If you are a previous patient at Seattle Children's Hospital Dental Clinic, you may complete this survey yourself or you may choose to have a parent or guardian help you complete this survey.
- If you are a parent or guardian, please complete this survey on behalf of your child.

1. **Who is completing this survey?** [SELECT ONE]
   - ☐ Patient – I am completing this survey for myself
   - ☐ Patient – I am completing this survey for myself with help from a parent or guardian
   - ☐ Parent or guardian – I am completing this survey on behalf of my child

2. **What information did you receive from the Seattle Children's Hospital Dental Clinic about moving from a pediatric dentist to a dentist who cares for adult patients?** [SELECT ALL THAT APPLY]
   - ☐ Graduation handout with information about other clinics
   - ☐ My dentist discussed it with me
   - ☐ No information was given
   - ☐ I don't remember

3. **What steps have you taken towards establishing care with a new dentist?** [SELECT ALL THAT APPLY]
   - ☐ Contacted a dental clinic to set up appointment
   - ☐ Reviewed websites listed on graduation information sheet
   - ☐ Completed an internet search for dentists
   - ☐ Reached out to parental or other groups for resources
   - ☐ Called an agency such as Washington State Dental Association for recommendations
   - ☐ I have not taken any steps towards getting a new dentist

4. **Have you established medical care with a medical clinic for adults?** [SELECT ONE]
   - ☐ Yes, I have moved all of my medical care to adult medical providers
   - ☐ I have moved some of my medical care to adult medical providers, but I am still seeing some of my pediatric medical providers
   - ☐ No, I am still seeing only pediatric medical providers

Study ID Number: _____

5. **Where have you gone, or where do you plan to go, for future dental care?** [SELECT ONE]
   - ☐ University of Washington DECOD Dental Clinic for adults with disabilities
   - ☐ Seattle Special Care Dentistry Clinic
   - ☐ Swedish Medical Center Dental Clinic
   - ☐ A dental clinic in my community
   - ☐ Other, please write in: _____
   - ☐ I don't know

6. **Have you seen a dentist who cares for adult patients since your last visit at Seattle Children's Hospital Dental Clinic?** [SELECT ONE]
   - ☐ Yes, I have had a dental appointment
   - ☐ No, but I have a dental appointment scheduled
   - ☐ No, but I am on a wait list for an appointment
   - ☐ No, I have not yet found a new dentist

7. **Have you experienced any of the following problems moving to a dentist who cares for adult patients?** [SELECT ALL THAT APPLY]
   - ☐ I can't find a dentist who understands my special health care needs
   - ☐ I can't find a dentist who will take my insurance
   - ☐ I can't find transportation to a new dentist
   - ☐ Other: _____
   - ☐ I had no problems moving to a new dentist

8. **What type of dental insurance do you currently have?** [SELECT ONE]
   - ☐ No dental insurance
   - ☐ Apple Health (Medicaid) insurance
   - ☐ Private insurance (example: Delta Dental, Cigna, Humana, etc.)
   - ☐ Both Apple Health (Medicaid) and private insurance
   - ☐ Other, please write in: _____

9. **Is there anything else you would like us to know about your experience moving to a dentist who cares for adult patients?**
   - ☐ No
   - ☐ Yes:_____
     _____
     _____
     _____

Study ID Number: _____

Appendix C: Invitation Letter

Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Date
Name
Address

Dear <Patient>,

We are writing to invite you to fill out a short survey about your progress in finding a new dentist who cares for adult patients with special health care needs.

We are a team of dentists from Seattle Children's Hospital. We are doing research on moving dental care from a pediatric dentist at Seattle Children's Hospital to a new dentist who cares for adult patients with special health care needs. We want to learn how this is going for you so we can improve the process for future patients.

The survey has nine questions and will take 5-10 minutes to complete. It asks questions about your dental care since your last visit in the Seattle Children's Hospital dental clinic. We will compare your answers to information from your medical chart. This will help us find common challenges in finding a new dentist who cares for adult patients with special health care needs.

All your information collected in this study will be kept private, and will not be added to your medical or dental record. Your answers will be viewed only by members of the research team listed below. Being in this study is voluntary. Your future medical or dental care will not change if you decide to complete the survey or not.

We will be calling you in about two weeks to ask if you are interested in taking the survey and answer any questions you may have about the research study. If you do not want to be contacted about this research study, please send an email or call the phone number below.

We can provide the survey in **paper form**, in **electronic form**, or **over the phone**. You may complete the survey yourself. You can also have a parent or guardian help you complete the survey.

Thank you very much for your time and help with this important research. If you have any questions about this research project, please contact Dr. Audrey Mikkelson by email at Audrey.Mikkelson@SeattleChildrens.org or by phone at 206-987-1299.

Sincerely,

Barbara Sheller, DDS, MSD
Chief of Pediatric Dentistry
Department of Dentistry
Seattle Children's Hospital

Bryan Williams, DDS, MSD, MEd
Pediatric Dentist
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