

Transition of Patients with Special Health Care Needs from Pediatric Dentistry to Adult-Centered Care

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Introduction

Moving from pediatric to adult-centered care can be a stressful process for adolescents with special health care needs (SHCNs) as they transition into adulthood. Pediatric dentistry has within its scope the treatment of children with SHCNs, and at times pediatric dentists maintain health care relationships with their patients with SHCNs as they age. However, the majority of adolescents in pediatric practice will eventually need to seek care elsewhere as they “age out” of their dental homes. Patients with developmental disabilities list dental care among their highest unmet needs. There are often significant changes in state insurance coverage and number of providers trained to treat these patients as they transition from adolescent to adult care. Medicine and education are universally recognized as essential services for people with SHCN. These essential services have clear policies, procedures and protocols to help people transition from adolescence to adulthood while maintaining continuity of care. Resources such as gottransition.org reinforce the medical timeline of transitioning patients from adolescent to adult care. The purpose of this project is to examine how patients with SHCNs are transitioned from pediatric to adult care in dentistry, and the barriers they face, in order to improve access to appropriate dental care for this population.

Methods

Qualitative analysis was conducted following interviews with individuals involved in the care of patients with special needs and the transfer of their health care. The participants primarily reside and practice in Washington state; however, practitioners from across the US were consulted. The following categories of professionals were interviewed:

- Special Care Dentist (4)
- Pediatric Dentist (3)
- Developmental Pediatric Fellow (1)
- Family Medicine Practitioner (1)
- Social Worker (2)
- Nurse Care Coordinator for Medical Transitions Program (1)

The interviewees were asked questions based on the topics of:

- Skills believed to be helpful as patients move away from pediatric to adult dental care and ways to help patients acquire those skills
- Surrogate decision making
- Expectations of care families and patients bring to the adult special care dental practice and how those expectations are addressed.

Results were organized by themes and subthemes

Results

Skills to be developed during pediatric care

Provider expectations related to skill development

- Some providers (pediatric and special care) expected development of skills prior to entering adult care
- Some providers (pediatric and special care) were not concerned about development of skills prior to entering adult care: planning that they would have general anesthesia only
- Some providers (pediatric and special care) noted general anesthesia inhibits skill-building

Goals/expectations of specific skills to be developed

- Some special care dental providers requested that pediatric providers worked on skill building prior to entering adult practice
- Some pediatric providers worked on skill building prior to entering adult practice
- Some providers were not concerned about skill building (when transition was with same provider, when general anesthesia was planned)
- Desired skills related to body positioning in dental setting:
 - Lying back/sitting in dental chair
 - Opening mouth when requested
- Desired skills related to completing procedures
 - Minor operative procedures, radiographs, prophylaxis, oral hygiene instructions, examinations

Sharing information on skill-building

- Some providers noted it would be helpful to share information between pediatric and adult practice on what procedures/facilitation techniques were previously tried, what worked and what failed

Surrogate Decision Making

Who needs a surrogate decision maker?

- Several providers noted that patients not able to understand their options need a surrogate decision maker.
- There were different ways of determining if a patient needed a surrogate decision maker.
 - Examples: Clinical judgement of dental provider, use of medical-legal resource at hospital facility, status as secondary dependent, referral to psychiatrist, surrogacy court

Type of surrogate decision makers

- Providers emphasized different options for surrogate decision making:
 - Guardianship, Power of Attorney, next of kin, supported decision making, secondary dependency

When to start the process for obtaining a surrogate decision maker

- There was considerable variation in provider’s views on when to start the process, or whether to be involved in the process at all

Resources for surrogate decision making

- Some providers noted they had resources to help facilitate patient’s ability to obtain a surrogate decision maker when needed
 - Medical-legal team
 - Surrogacy court
 - Dedicated staff member
 - Paperwork/pamphlets to give patients
 - State regulations that outlined options

Family and Patient Expectations

Family and patient expectations

Satisfying expectations of patients, families and caregivers

- Some providers noted that patients/families/caregivers were frustrated with transition process

Discussing expectations prior to referral

- Some special care providers felt discussing expectations prior to referral to adult care would facilitate transitions

Area of discussion that could facilitate transition per special care providers

- Medicaid/insurance coverage may change for adults
- Awareness of facilitation techniques if needed
 - Access issues
 - General anesthesia
 - Medical immobilization
 - Desensitization
- Treatment expectations
 - Time needed may be longer
 - How much work is done
 - Types of procedures possible

Barriers to discussing adult care expectations by pediatric providers

- Some did not feel comfortable discussing what to expect
- Some feared there would be questions that they would not be able to answer
- Some noted they did not want to speak for other practitioners
- Some did not feel knowledgeable about what to expect in adult settings
- Some did not feel knowledgeable about adult Medicaid coverage

Conclusion

The transition to adult-centered care can be overwhelming for many patients with SHCNs and their families. Issues such as insurance coverage, consent, guardianship, finding an appropriate provider and the transfer of records are important concerns. A strong workforce of providers with special care dentistry training is essential to meet the needs of this population.

Recommendations:

- Share information amongst providers
 - Sharing information about adult practice with pediatric providers
 - Sharing information about pediatric experiences with special care providers
- Start transition process early
 - Medical providers start at age 12, education transitions start at age 14
 - Transitions take time
- Discuss transition process with patients and families
 - Transition process and barriers
 - Transition of care policy
 - Develop a packet of information to give to patients
- Seek out and advocate for resources in your state related to common transition concerns
 - Adult Medicaid benefits
 - Surrogacy, if appropriate