



TEENS

AS HEALTH-CARE CONSUMERS

PLANNED TRANSITION & EMPOWERMENT

BY EMILY PAJEVIC AND KRIS ENGLISH

TRANSITION PLANNING PREPARES TEENS FOR ADULT HEALTH CARE; HOWEVER, THERE IS ALSO AN ADDITIONAL BENEFIT FOR AUDIOLOGISTS. TRANSITION PLANNING IS THE EPITOME OF PATIENT-CENTERED CONVERSATION, AND IS A NATURAL PROGRESSION IN CARE FOR PEDIATRIC AUDIOLOGISTS.

Teen-aged patients with hearing loss present several challenges to audiologists, not the least of which is our limited understanding of their unique experiences and needs (Neria, 2009). We are well aware that, in general, adolescence is a time of change, instability, and insecurity (Park et al, 2011; Robins et al, 2002), and yet we can still be caught off guard when previously friendly relationships become strained. Teens may withdraw during appointment interactions, convey disinterest in discussions, and choose not to adhere to our recommendations (Pajevic, 2013). Such lack of engagement may not be merely a transitory phase. Pai and Ostendorf (2011) found that appointment attendance in younger teens (i.e., when parents handle scheduling and transportation) was 98 percent, but dropped to 61 percent two years following transition to adult care.

Even if apparently uninterested, when directly asked what they would like to occur during health appointments, teens have expressed some clear preferences, listed in TABLE 1 (Britto et al, 2004; van Staa et al, 2011a, b), and parents indicate parallel interests (TABLE 2) (van Staa et al, 2011a). These reports indicate that both teens and families see the need for a planned transition from pediatric to adult health care, and many health-care professions have already developed these kinds of plans in the management of diabetes, cystic fibrosis, juvenile rheumatoid arthritis, and other chronic health conditions (Manganello, 2008; National Alliance to Advance Adolescent Health, 2014).

Teens on Individualized Education Plans (IEPs) receive support as they transition from high school to college or work settings, but, by definition, an IEP does not typically include the life skills required of a health-care consumer. Additionally, many teens with hearing loss are not on an IEP at all. Rather than leave the transition from pediatric to adult care to chance, we propose that

audiology adopt health-care transition planning as a standard of care for pediatric patients.

Planning with the Destination in Mind

Teens and their families may not be aware of the changes that take place once patients are discharged from pediatric services. Compared to child- and family-centered appointments, adult-level audiologic care includes shorter appointments that involve higher levels of language and terminology. Some of the advanced skills expected of adult patients include being able to:

- provide accurate and complete information for a case history;
- manage insurance forms and appointments, prescription dosages and refills; and
- communicate effectively with the health-care provider (i.e., explain symptoms clearly, ask relevant questions, understand explanations and instructions).

A transition plan develops these skills over time, “starting early” as both teens and their parents recommend. Transition planning appears to be an efficacious practice. Health-care professionals in the Netherlands, for example, found that, when they consistently used transition plans, their pediatric patients were more likely to adhere to recommendations, understand the patient-professional relationship, and take a more active role in their health as consumers in the adult-care system (van Staa et. al., 2011a). The time and effort involved were deemed a positive “return on investment.”

A Proposed Transition Plan

We have adapted a transition model developed by the Royal College of Nursing (2004). Our model (FIGURE 1)

Teens as Health-Care Consumers: Planned Transition and Empowerment

includes three stages, each one fully respecting the goals and values of every family. It is duly noted that many families value interdependence more than the Western-based value of independence depicted here (L. Wiley, personal communication, March 2014).

The following is a “walk-through” depicting transition planning. The goals mentioned in this example are drawn from TABLE 3, and would be individualized for every patient.

Stage 1, or the Early Stage, would begin around age 13–14. During this beginning phase, we introduce the concept of transition, describe the rationale and general goals, and provide written support materials for home reading (TABLE 4). We emphasize the collaborative nature of a transition plan, wherein the family and teen take the lead and the audiologist provides support. If the patient and family agree, we draft an initial plan, subject to revision at each appointment.

TABLE 1. What Do Teen Patients Want from Health-Care Providers?

Honesty	Confidentiality
Co-decision making	Answer my questions
Use language I understand	Focus on me, rather than parents
Take interest in me as whole person	Treat me like an adult, most times
Start transitioning me earlier	Allow more time, more choices
Explain differences in pediatric, adult care	Help with smooth, organized transition

Britto et al, 2004; van Staa et al, 2011a, b.

TABLE 2. What Do Parents Want from Their Teens’ Health-Care Providers?

Start earlier	Involve parents
Provide more information	Include other life transitions
Appoint someone to coordinate transition	Help teens become responsible, accountable

van Staa et al, 2011a.

At this stage, we should determine our patients’ knowledge of their hearing loss and their ability to describe it to others. Does the teen need practice, information, clarification? We can also inquire about the patient’s participation in school, friendships, sports, and other activities. Throughout, we listen for any concerns that would warrant a referral to counseling or social work.

TABLE 3. Sample Health Goals (Knowledge and Skills)

- Explain degree and nature of hearing loss
- Explain functional impact of hearing loss
- Describe and apply assistive technologies and communication repair strategies
- Case history information:
 - Etiology of hearing loss
 - Family history (hearing loss and other health concerns)
 - Blood type
 - History of injuries, illnesses, surgeries, and additional health concerns
 - Current and past medications
 - Names, contact information of health-care providers, insurance, emergency contact information
- Fill out intake, self-assessments
- Maintain health records
- Keep health information and other private data (Social Security number, etc.) secure
- Know basic health terminology (diagnosis, nausea, prescription, antibiotic, etc.)(see Davis et al, 2006)
- Schedule and keep track of appointments
- Explain legal rights and accommodations relative to health care
- Explain confidentiality and the patient–health care provider relationship
- Describe patient autonomy and patient rights
- Explain location, intensity, frequency of pain, and other symptoms
- Understand explanations, instructions, options, and recommendations

Finally, we ask families to consider *gradually* withdrawing from future appointments. Our role during this stage is to “plant the transition seed,” help the family consider some initial goals, and provide educational materials and other resources.

Stage 2, the Middle Stage, may begin around age 14–15. During this stage, we address any new concerns and developments (general health, school, friendships, part-time work, etc.). We may start describing how the adult health-care system differs from pediatric care and, depending on patient maturity, we may ask the patient to start keeping track of appointments. We should evaluate the patient’s level of responsibility in managing hearing aids or implants. When families are willing, they could yield five minutes at the end of the appointment for one-on-one conversations with the patient. During these five minutes, we can clarify the concept of confidentiality and give the teen an opportunity to ask questions.

Stage 3, the Late Stage, begins around age 16–18. As before, the plan and goals are adjusted as the patient continues to mature. We may now encourage the patient to demonstrate expertise in addressing communication

needs and self-advocacy. Developing a personal health file could be an age-appropriate goal (e.g., family and medical history, inoculation records, emergency and other contacts, insurance information). The topic of health records gives us the opportunity to address the importance of keeping health and personal information secure. The patient might practice conveying case-history information, completing intake forms, and scheduling appointments. We continue to provide relevant educational materials, discuss rights and accommodations, and share advanced information on communication strategies and support groups. The one-on-one consultation could be expanded to 10–15 minutes, continuing to encourage participation and communication skill development.

Preliminary Endorsement of Transition Planning

Recently, the topic of transition planning in health care was shared at a conference attended by parents and teachers (English, 2014). Attendees were asked to review TABLE 1 and share their thoughts and concerns. The following comments were conveyed:

From parents:

- This (transition plan concept) would be useful for ALL my children, not just my child with hearing loss. No one has mentioned this life skill before.
- Families see their audiologists as trusted advisors, and if we had this conversation, I would trust the situation and work with it.
- I just happened to ask our audiologist if she also served college students, and that opened up a whole new world of information for us. She might have brought up the future eventually, maybe she was waiting for the right time. (Q: How old is your child? She’s a sophomore in high school; it’s not like we have lots of time ahead.)
- The overall idea is brilliant and I like how it is gradual.

From a teacher:

- The list of words [from health-literacy screening tool] (Davis et al, 2006) would be very useful for language development in the context of self-advocacy as a patient. No one has ever talked about building up this particular vocabulary set, but the need is obvious. I am looking forward to using this.

TABLE 4. Online Resources on Health-Care Transition

Adolescent Health Transition Project
<https://depts.washington.edu/healthtr>

Centers for Disease Control and Prevention National Health Education Standards
www.cdc.gov/healthyyouth/sher/standards

GAP/Guide to Access Planning
www.phonakpro.com/us/b2b/en/pediatric/gap.html

Got Transition? Center for Health-Care Transition Improvement
www.gottransition.org

Stepping Up Transition Information
<http://steppingup.ie>

Transition Health-Care Checklist: Preparing for Life as an Adult
www.waisman.wisc.edu/cedd/pdfs/products/health/thcl.pdf

Transition to Adult Health Care: A Training Guide in Three Parts
www.waisman.wisc.edu/cedd/pdfs/products/health/tahc.pdf

Teens as Health-Care Consumers: Planned Transition and Empowerment

Implementing a Transition Plan

As with every aspect of pediatric audiology, transition planning is a team effort. Our role is to help the family look ahead, identify age-appropriate goals, and provide education and materials relevant to audiology and general health care. Ongoing support to families could include a list of health-related life skills (TABLE 3) and transition Web sites (TABLE 4). The initial conversation would take a few minutes, and once a plan has been initiated, subsequent conversations also would require only a few extra minutes each visit in order to check on progress and address new concerns.

Everyone Wins

Transition planning prepares teens for adult health care; however, there is also an additional benefit for audiologists. Anecdotally, many audiologists report often feeling uncomfortable trying to talk with uncommunicative teen patients (“How are things going, Joni?” “Fine”), and resort to directing the conversation to their parents instead. We can work through this awkward stage by using transition planning as a conversational springboard. By focusing on meaningful life skills, and providing support to acquire those skills, we now have much to talk about: what the teen knows, doesn’t know, wants to learn, wants to do, worries about, is ready for. Transition planning is the epitome of patient-centered conversation, and is a natural progression in care for pediatric audiologists. 🗣️

Emily Pajevic is an AuD student at the University of Akron/NOAC and is completing her fourth-year externship at Cleveland Clinic. Kris English, PhD, is a professor and interim school director at the University of Akron.

References

Britto MT, DeVellis RF, Hornung RW, DeFries GH, Atherton HD, Slap GB. (2004) Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics* 114(5):1272–1280.

Davis T, Wolf MS, Arnold CL, Byrd RS, Long SW, Springer T, Kennen E, Bocchini JA. (2006) Development and validation of the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen): A tool to screen adolescents for below-grade reading in health care settings. *Pediatrics* 118:1707–1714.

English K. (2014, June) Health literacy: Asking the right questions. Presentation at campUS program for teens with hearing loss, Columbus, Ohio State University.

Manganello JA. (2008) Health literacy and adolescents: A framework and agenda for future research. *Health Education Research* 23(5):840–847.

National Alliance to Advance Adolescent Health. (2014) “Got Transition?” Six core elements of health-care transition 2.0. Transitioning youth to an adult health-care provider. Available: GotTransition.org.

Neria C. (2009) Where are the voices of adolescents? An examination of adolescent cochlear implant users’ socio-emotional development. *Perspectives on School-Based Issues* 10:123–126.

Pai ALH, Ostendorf HM. (2011) Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: A literature review. *Children’s Health Care* 40(1):16–33.

Pajevic E. (2013, April 15) Counseling adolescents: How to manage the transition from child to young adult? Available: <http://advancingaudcounseling.com/?p=287>.

Park MJ, Adams SH, Charles CE. (2011) Health care services and the transition to adulthood: Challenges and opportunities. *Academic Pediatrics* 11(2):115–122.

Robins RW, Trzesniewski KH, Tracy JL, Gosling SD, Potter J. (2002) Global self-esteem across the life span. *Psychology and Aging* 17(3):423–434.

Royal College of Nursing. (2004) *Adolescent transition care: Guidance for nursing staff*. Available: <https://www.rcn.org.uk/DocStore/FileLibrary/PDFs/RCNGuidanceAdolescentTransitionalCare.pdf>

van Staa A, Jedeloo S, van der Stege H. (2011a) “What we want”: Chronically ill adolescents’ preferences and priorities for improving health care. *Patient Preference and Adherence* 5:291–305.

van Staa A, Jedeloo S, van Meeteren J, Latour JM. (2011b) Crossing the transition chasm: Experiences and recommendations for improving transitional care of young adults, parents, and providers. *Child: Care, Health, and Development* 37(6):821–832.