

Brief Report: Preliminary Findings from a Pilot Health Care Transition Education Intervention for Adolescents and Young Adults with Special Health Care Needs

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Objective To assess acceptability and feasibility of a school-based health care transition education intervention designed to equip adolescents and young adults (A/YA) who have special health care needs with important health literacy, self-advocacy, and self-determination skills. **Methods** A qualitative research approach was used to assess a 40-hr curriculum implemented with 137 A/YA in 13 high school special education classes. Three focus groups were conducted with 15 students and 7 educators. Participants were questioned about perceived relevance, readability, interest, ease of implementation and completeness of the curriculum. **Results** All focus group participants said the curriculum was highly relevant and valuable. Teachers reported little difficulty with ease of implementation, though the reading level appeared high for some students. **Conclusions** This intervention model shows promise for empowering A/YA with special health care needs to become more independent in managing their health care, and warrants further development and evaluation. The curriculum is available at http://health.usf.edu/medicine/pediatrics/ad_med/resources.htm.

Key words adolescents; chronic illness; developmental disabilities; educational interventions; health behaviour; health education.

Introduction

The 2005/2006 National Survey of Children with Special Health Care Needs reports that only 41% of adolescents with special health care needs ages 12–17 in the United States receive the services they need for transition to adult health care, work, and independence (Child and Adolescent Health Management Initiative [CAHMI], 2008). Despite increasing recognition of the importance of a smooth transition from pediatric to adult health care, numerous and well documented barriers have limited the development of policies and practice that adequately support health care transition for youth and young adults (A/YA) (Scal & Ireland, 2005; Stewart, Stavness, King, Antle & Law, 2006). For the purpose of this report, we use the term A/YA to encompass all adolescents and young

adults with disabilities, chronic health conditions, and/or other special health care needs who are approximately 14 through 22 years old.

Formative Research

In an earlier study funded by the American Academy of Pediatrics (AAP), our multidisciplinary research team used the PRECEDE-PROCEED health planning model (Green & Kreuter, 1999) and a social marketing framework (Kotler, Roberto & Lee, 2002) to examine factors that might influence the development of an effective health care transition intervention. Data from 17 focus groups and interviews with A/YA, families, pediatric and adult primary care providers (PCPs), nurses, education professionals, and social service providers lead us to conclude that the public

education system may provide an effective alternative—or complimentary—venue to the health care system in reaching and educating A/YA about health care transition (Straub, Hess, Millrose, & Barrow, 2005).

First, our data indicated few pediatric PCPs were adequately preparing A/YA and families for transition, despite the AAP's position that pediatricians should take an active role in all aspects of health care transition (American Academy of Pediatrics [AAP], 1996; American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP], and American College of Physicians-American Society of Internal Medicine [ACP], 2003; Society for Adolescent Medicine [SAM], 2003; McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008). Families said they need to be better informed about the financial, emotional, and social impact of leaving childhood systems. Our data, consistent with reports in the literature (McManus et al., 2008; Reiss, Gibson, & Walker, 2005), indicated that many families and providers do not anticipate the importance and complexity of teaching A/YA health care management skills, and may not consider the impact of those skills on a young person's potential to live and work independently. These findings suggest more attention should be given to preparing A/YA, including those with developmental disabilities, for an increased level of responsibility in managing their own health care. Second, special education teachers who participated in focus groups were very responsive to the concept of utilizing the classroom to prepare A/YA for health care transition. Special education classes generally offer a comfortable and safe learning environment in which A/YA up to age 22 can model and practice new skills.

Indeed, federal legislation requires public schools to provide transition services for students with disabilities ages 16 and older in order to prepare them for further education, employment and independent living (Individuals with Disabilities Education Act [IDEA 2004]). Currently, there appears to be little integration of health care transition into educational transition activities offered by school districts, despite studies that show a high level of interest among school personnel, families and other stakeholders (Heller & Tumlin, 2004; Repetto, Gibson, Lubbers, Gritz, & Reiss, 2008). To date, we are not aware of any published reports of school-based interventions that specifically address health care transition. Importantly, there is considerable evidence that schools provide an effective setting for other psychosocial and behavioral interventions such as prevention of drug, alcohol, and tobacco use; human immunodeficiency virus, sexually transmitted diseases; pregnancy; bullying; and

obesity (Botvin & Kantor, 2000; Coyle et al., 2009; Neumark-Sztainer, Story, Hannan, & Rex, 2003).

Consequently, by positioning health care transition as an expansion of current educational transition practices, we formulated an intervention approach that leverages the infrastructure and capacity of the public education system to reach a large and diverse group of A/YA. Rather than addressing clinical aspects of health care transition, it is designed to equip A/YA, including those who have developmental disabilities, with critical health literacy, self-advocacy, and self-determination skills adults need in order to become successful health care consumers.

We describe here the development and components of a pilot school-based health care transition education program implemented in 2005 in a large urban county in central Florida. We then present data on program acceptability (report of relevance and satisfaction) and feasibility (ease of implementation, integration, and expansion). Finally, we provide recommendations for future execution of the program, research, and practice.

Program Description

Partners in the pilot intervention were the local school district and the University of South Florida College of Medicine (USF COM). A project director had primary responsibility for coordinating program development, implementation and assessment.

Student Curriculum

A seven-member interdisciplinary advisory committee comprised of professionals in special education, social work, and health care guided development of a health care transition curriculum. Committee members reviewed existing materials, such as those developed through MCHB's Healthy & Ready to Work National Center, and developed original content based on key health care transition concepts. The curriculum was reviewed for content validity by several field experts, including physician faculty members from USF COM, an adolescent medicine physician, a school district nurse/prevention specialist, and an advisor from the Transition Center at the University of Florida (UF). Importantly, the curriculum was developed in collaboration with experienced special education teachers who were knowledgeable about practicalities and limitations within the classroom, text formats teachers and students generally prefer, and state education standards.

Classroom instruction provided A/YA in 13 special education classes with critical health-related information and skills they may not learn at home or in the community.

The eight-unit module consisted of approximately 40 hrs of instruction, and was implemented over 8 weeks in spring 2005 as part of a required science, health, or life management course (varied by school and class). In 10 of the 13 classes, the curriculum was implemented 1 hr per day, 5 days per week. In the remaining three classes, it was implemented 1.5 hrs per day, 5 days per week, which provided more time to cover the material. Each unit was designed to take approximately 1 week to complete, and included the following topics: *Moving toward adulthood: What do I need to know? What do I need to do?* (importance of self-advocacy); *I'm an adult. So now what?* (rights and responsibilities at age 18); *Which doctor is for me?* (finding and communicating with adult providers, completing medical forms); *Do I need insurance?* (understanding health insurance); *What do I need to know about medications?* (reading prescription labels, managing medication needs); *What is sexual health and why is it important?* (reproductive system, sexually transmitted diseases); *How can I avoid getting hurt or injured?* (basic safety, bullying, abuse); and *Wrap it up!* (constructing a Health Journal and Medical Summary to keep and use after completing the class).

The text was written at a seventh grade reading level. Each chapter had standard components, including vocabulary lists, crossword puzzles, skill-building activities, Health Journal forms, and unit quizzes. Personal health information was not discussed in class; rather, students practiced completing sample Journal forms in school, and were encouraged to complete their personal Journal forms at home with their parents. The curriculum was accompanied by a teacher's guide that included recommended guidelines for instruction, additional skill-building exercises, and an answer key.

Educator Training

Training materials were developed by the research team to introduce health care transition concepts and strategies to educators participating in the pilot intervention, and were reviewed by the advisory committee. Twelve teachers and eight support staff (school nurses, social workers, and transition specialists) attended a 6-hr training session prior to the start of the curriculum. In addition to an in-depth review of the teacher's guide and eight-unit module, participants learned how to identify health-related factors to be addressed in students' Transition Individual Education Program (IEP). The Transition IEP, a legally required document for all high school students who receive special education services, identifies the student's desired post-school goals as well as courses and services that are needed to fulfill those goals. Educators also met with an

adolescent medicine physician who talked to them about the clinical aspects of health care transition.

Methods

A/YA Participants

The curriculum was piloted in five geographically and demographically diverse high schools from March through May 2005. Thirteen classrooms were selected from the recommendation of school district administrators, who took into account interest level of teachers and functional level of students. Classes varied in size from 6 to 20 students. Students ranged in age from 14 to 22 years, with a mean age of 16.3 years. They were enrolled in Grades 9 to 12, and ranged in reading ability from fifth to eighth grade levels. Twelve teachers implemented the curriculum (one teacher had two classes).

Of the 137 students who participated in the pilot, 31% received services from the Educable Mentally Handicapped (EMH) program, 28% from Physically Impaired (PI), 26% from Specific Learning Disabilities (SLD), and 15% from other programs such as Language Impaired (LI), Traumatic Brain Injury (TBI), Emotionally Handicapped (EH), and Other Health Impaired (OHI). Students in the sample represented a wide range of abilities, though all had some degree of cognitive limitation. While the majority of students were considered "high functioning" special education students, all expected to earn a special diploma rather than standard diploma upon graduation (i.e., would be unable to meet testing or coursework requirements for a standard diploma). Demographic breakdown of the student sample, which was similar in composition to the total population of special education students in the school district, was 57% male, 43% female; 43% White/Caucasian, 29% Black, 23% Hispanic or Latino.

Focus Groups

Three focus groups were conducted by a moderator and co-moderator following completion of the curriculum. Two student focus groups were held in participating SLD classes; the groups were comprised of six students (four boys, two girls) and nine students (five boys, four girls), respectively, for a total of 15 A/YA. All student participants were under age 18. Scheduling conflicts prevented the participation of students receiving EMH and PI services. An educator focus group was comprised of five teachers and two support staff. While 7 of the 12 teachers who implemented the curriculum could not attend the focus group, five completed a paper questionnaire covering focus group topics. Their responses are included in our analyses.

Participants were asked to assess the curriculum in terms of value, relevance, likes and dislikes, interest, readability, and completeness. For example, students were asked about parts of the curriculum that were most and least important to them, and how they might use the information and skills covered. Educators were asked about content, structure of the module, ease of implementation and changes they would make for future execution. The groups lasted from 1 to 2 hrs each and were audio taped.

Analyses

Focus group data were organized and analyzed by the research team using a priori codes and a content analysis framework. A priori codes were developed within the context of program acceptability (e.g., value, satisfaction) and feasibility (e.g., ease of implementation.). The lead investigator then grouped the data by common themes and reviewed for commonalities in responses, differences, degree of emotion, degree of specificity (detailed explanation), frequency (number of similar responses), and extensiveness (number of different people who had similar responses). Descriptive summaries were developed for each theme, and participant quotes provided further evidence for interpretation and recommendations by the research team.

The study was approved by the USF Institutional Review Board for the Protection of Human Subjects (IRB). Parents/guardians were given the opportunity to decline their child's participation in the study if the student was less than 18 years old.

Results

Study results are summarized around three major themes: perceived relevance of the curriculum, readability, and degree of interest and completeness.

Perceived Relevance of the Curriculum

All educators and A/YA said the curriculum was highly relevant and important for students. Educators felt the course should be required for all special education students, particularly for those who expect to graduate with a special diploma or do not plan to continue with post-secondary education. Almost half (48%) of students and educators felt it should also be offered to the general population of high school students. All students said the curriculum provided information they did not receive elsewhere; 75% of students said it was important to receive the information in a classroom setting (as opposed to simply reading a book) because it provided them with the opportunity to ask their

teachers questions and discuss items they did not understand. Approximately one-third (33%) of educators felt students receiving PI services (vs. other types of special education services) likely received the most immediate benefit from the curriculum due to their complex health issues.

While comments from focus group participants reflected a high degree of satisfaction with the module, they also highlighted systemic deficiencies in preparing A/YA for transition to the adult health care system, such as lack of knowledge among parents and inadequate guidance from pediatric PCPs:

Students

- “(We) don’t get that much (information) in the doctor’s office.”
- “It’s a good course. Parents don’t tell you everything. It helps you get prepared.”

Educators

- “The entire curriculum was fantastic because all of my students have health-related issues.”
- “My kids loved being able to take the curriculum home and follow up with their parents, especially because many parents don’t know this information.”
- “This curriculum gives students real-world information to guide them with decisions they will be faced with.”
- “I know I will continue to use this curriculum when I teach Health next year. Thank you for allowing me to participate.”

Readability

Both A/YA and educators said the reading level was too high for some students. The majority (90%) of teachers said they read portions of the text aloud or had students take turns reading the text aloud as a class activity. While all teachers felt the vocabulary words were very challenging for their students, they all acknowledged that it was important for students to become familiar with medical terms they will encounter as adults. They suggested that, given more time to cover each unit, students should be able to better understand and retain the information. Teachers with class periods that lasted 1.5 hrs per day (totaling close to 60 hrs of instruction) rather than 1 hr per day had less difficulty with time constraints. In the words of educators and students:

Students

- “Our teacher explained vocabulary words we didn’t know.”
- “My mother helped me fill out the forms.”

Educators

- “I felt rushed. I didn’t have enough time for vocabulary words.”
- “I didn’t have enough time because my students wanted to share their stories!”
- “The Journal pages were wonderful, though difficult for some students to fill out. It was great to have pages with personally relevant content.”

Interest and Completeness

While all participants said the content of the material was interesting to students, degree of interest varied by topic. Both students and teachers reported that students were most interested in the unit on sexual health—one PI teacher said her students had never been exposed to the information—and least interested in the unit on insurance. Recommendations were to add more color pictures and hands-on activities (e.g., field trips into the community, guest speakers, more role playing exercises, using actual prescription bottles and insurance cards in the classroom); add more material concerning the impact of alcohol and drug use; put more emphasis on what young people need to do to be mentally healthy; and offer a parent training module concurrently with the student curriculum (e.g., online or evening classes).

Other than the challenges associated with difficult vocabulary words and time limitations, teachers had few problems implementing the curriculum. Several (80%) commented that they especially appreciated the module’s thoroughness, organization, and standard unit components. Participants said:

Students.

- “I’d like more information on the consequences of major drugs, and doing them over and over.”
- “I’d like a doctor or pharmacist to come (to class).”

Educators.

- “The insurance unit was great because many of my students will probably live in supported situations, but they think everything is free.”
- “They (students) need to know (more) about emotional health and self-esteem, and where to go for mental health services.”

Discussion

Given the rise in the number of children with complex health conditions who survive to adulthood, it is increasingly important to examine ways to prepare A/YA for entry to the adult health care system. Rather than addressing

clinical aspects of transition, this pilot health care transition education intervention adopts a framework that can help equip A/YA with critical health literacy, self-advocacy, and self-determination skills. It builds on federally mandated educational transition planning by integrating health care transition into school-based transition practice.

Study data on program acceptability and feasibility show both strengths and areas for improvement. First, the curriculum was perceived by both students and educators as highly relevant and valuable. The data indicate many A/YA are not receiving critical information or learning health care management skills in their homes or community. While some educators felt students receiving PI services benefited most from the curriculum due to their complex health issues—a consideration for prioritizing expansion plans—the consensus among educators was that it should be required for all students who receive special education services. Moreover, almost half of students and educators recommended expanding instruction to reach general education students.

All educators felt the reading level and complexity of vocabulary words presented the greatest challenges to implementation. Recommendations from both students and educators included allowing more time to implement the module and creating another version for students at lower reading levels. Beyond these constraints, teachers reported little difficulty in implementing the module as it was designed. It was easily integrated into required health, science and life management courses; materials were well organized and thorough; and units could be adapted to further engage students, such as adding more hands-on activities and scheduling field trips.

Among study limitations to be considered are the number and composition of focus group participants. The groups were scheduled upon completion of the instructional module at the end of the school year, and time limitations made it difficult to coordinate the availability of both students and educators before summer break. As a result, we were not able to include any students who receive EMH or PI services, and several teachers could not attend the focus group. Future research efforts should consider alternative implementation schedules that allow adequate time for post-intervention assessment, minimize competing school activities, and maximize participation of study subjects.

Another consideration is that our findings may be influenced by the interest level of individual teachers (e.g., teachers were recruited, in part, based on their interest in the topic). Teachers who are not familiar with the importance of health care transition may respond less enthusiastically to the curriculum. Privacy policies limited

our ability to specify medical conditions or diagnoses among students; we could only identify types of special education services provided. It should also be noted that many A/YA with chronic health conditions such as asthma and diabetes do not receive special education services under IDEA yet have significant health care transition needs. Some of these students may qualify for accommodations and supports under Section 504 of the Rehabilitation Act (1973 as amended, 29 U.S.C. 794) if their condition limits one or more major life activities (e.g., breathing, speaking, walking, or working). In addition, school nurses and social workers can provide a critical link to health care transition information and resources for all A/YA.

While our experiences demonstrate a number of challenges associated with intervention studies in school settings, we believe this pilot shows promise for empowering A/YA to become more independent in managing their health care and warrants further development and evaluation. Clearly, further research is needed for a more thorough understanding of the intervention. Comprehensive assessment of the curriculum's impact on student knowledge and skills is a critical next step, and should include an analysis of variables such as gender, age, ethnicity/race, and special education program. Because health literacy, self-advocacy, and self-determination skills are important for youth of all ages, researchers might consider developing and evaluating outcomes from a sequential series of modules that begin for students in middle school and continue through high school, with a particular focus on accommodating low reading levels.

Finally, this project raises some provocative questions about whether traditional school health education programs are effectively preparing young people—with and without special health care needs—to manage the complexities of our current health care system. Indeed, teachers in our study reported many parents themselves do not understand how to fill out medical and insurance forms, and had difficulty assisting their child in completing Health Journal activities at home. While it is important to teach young people about the benefits of good nutrition and physical activity, health education programs arguably could be designed to better prepare all A/YA to be informed health care consumers. Individuals or groups interested in replicating this intervention may access program materials at http://health.usf.edu/medicine/pediatrics/ad_med/resources.htm.

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