



Original article

The Development of Health Self-Management Among Adolescents With Chronic Conditions: An Application of Self-Determination Theory

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A B S T R A C T

Purpose: The purpose of the study was to better understand the progressive development of health self-management among adolescents and emerging adults (AEAs) with chronic medical conditions in order to identify opportunities to prepare AEA for transition to adult-based care.

Methods: Twenty-three AEA aged 17–20 years with renal, inflammatory bowel, or rheumatologic diseases, and their parents, completed individual semistructured interviews describing each AEA's health self-management. Self-Determination Theory was used to frame interview questions, including the constructs of competence, autonomy, and autonomy support. Transcripts were analyzed using directed content analysis.

Results: Four themes emerged: Development of Competence in Self-Management; Autonomy: Motivations to Self-Manage; Ways Important Others Support or Hinder Independence; and Normal Adolescent Development. AEA's competency and autonomy increased as they progressed from lack of knowledge about self-management to having knowledge without doing tasks, and, ultimately, to independent completion of tasks. Motivations to self-manage included avoiding sickness/weakness and wanting to engage in activities. Parents and providers supported AEA's autonomy through teaching and transferring responsibility. Parental fear/lack of trust in AEA's ability to self-manage hindered development of AEA's autonomy, producing anxiety. Normal adolescent development impacted timing of self-management task mastery.

Conclusions: As AEA gain competence in increasingly complex self-management tasks, they assume greater responsibility for managing their health. Competence and autonomy are facilitated by a feedback loop: AEA successful self-management increased parent trust, enabling the parent to transfer responsibility for more complex tasks. Conversely, parents' fear of the AEA doing wrong

IMPLICATIONS AND
CONTRIBUTION

This study used an Self-Determination Theory framework to identify opportunities to better prepare adolescents and emerging adults for the transition to adult-based care. Health-care providers should assess where the adolescents and emerging adults and their family are in their feedback loop of competence and autonomy and help identify ways to reinforce the development of self-management behaviors to promote successful transition.

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hinders transfer of responsibility, limiting competence and autonomy. Health-care providers play an important role in fostering autonomy.

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Approximately 750,000 adolescents and emerging adults (AEAs) with chronic illness transition from pediatric to adult health care annually [1]. The transition process occurs in three overlapping phases: preparation, transfer, and integration [2]. During the preparation phase, AEAs with special health care needs learn necessary health self-management skills before transferring to an adult provider. As the AEA approaches adulthood, they transfer from their pediatric provider to an adult provider. Finally, the AEA becomes integrated into adult care. In order to successfully transfer to and engage with an adult provider, AEA must learn health self-management skills. Self-management is broadly defined as the actions that an individual with a chronic illness takes in order to optimize one's health, such as taking medications [3,4] and preventing complications [4,5]. Self-management skills required to engage in adult healthcare, such as appointment making/keeping; obtaining medication refills; maintaining insurance [5], are critical to successful transition, and the lack of skills is associated with an increased risk of poor long-term health outcomes [6–10]. While research has focused on assessing whether AEA possess these health self-management skills [5], less is known about how these skills are developed during the transition preparation process. Utilizing a health-promoting theory, such as Self-Determination Theory (SDT), may help researchers and clinicians better understand how health self-management skills are developed in order to promote these skills within AEA and enable a successful transfer to and integration into adult-based care.

Self-management and personal responsibility needed to successfully engage in adult-based care can be enhanced in AEA by progressively shifting the management of the chronic illness from the parent to the adolescent during the transition preparation phase [11,12]. Adolescence is a critical period in development, during which independence and personal identity are emerging. The progressive shifting of responsibility for managing a chronic illness to the adolescent not only improves self-management skills and sets up the AEA for successful transition to adult-based care but also enhances a sense of personal control [11–14]. Shifting responsibility for management is a complex adaptive process for the AEA and parent, both of whom need to adjust to their evolving roles to enable a competent young adult to emerge from adolescence. Some parents view this process as being positive and incremental [15], while others describe significant challenges in shifting health self-management responsibility to their AEAs [16,17]. Nevertheless, parents generally recognize the need to gradually transfer self-management responsibilities to their AEAs and often use AEA chronological age to guide developmental expectations for disease self-management [18] while offering support during setbacks or perceived lack of readiness [19]. In fact, it has been posited that supportive relationships across the lifespan (childhood, adolescence, emerging adulthood, adulthood) may be beneficial when they support an individual's sense of autonomy [20] and during the high-risk time of emerging adulthood [21].

SDT, an empirically based theory of human motivation, has proven useful to explain long-term health behaviors [22,23]. It describes the internalization of human motivation, which is fundamental to the development of competence and autonomy, as being on a continuum from non-self-determined to self-determined [23,24]. Individuals are considered amotivational when they are non-self-determined and are considered intrinsically motivated when they are self-determined. Individuals between these two stages of self-determination may progress through four stages of being extrinsically motivated (external regulation, introjected regulation, identified regulation, integrated regulation) until they reach intrinsic motivation [23]. As individuals move along the spectrum to becoming self-determined, they become more intrinsically motivated to perform a behavior. In the case of an AEA, this manifests as improved self-management knowledge and skills. It is postulated that individuals will be more intrinsically motivated to perform a behavior if the three needs—competence, autonomy, and relatedness—are fulfilled. Competence, feeling effective in performing the behavior; autonomy, feeling volitional (in control of one's actions); and relatedness, being supported by and connected to others, collectively drive motivation and subsequent behavior/action [23]. SDT has been supported as a model of behavioral change, and previous studies indicate the need for motivation in order for behavioral change to take place [25].

Although SDT is a promising theory for understanding the development of medical self-management among AEAs with chronic health conditions, it has not been adequately investigated with respect to acquiring the skills needed to successfully engage in adult care. SDT constructs have been found to be positively associated with disease self-management in youth and young adolescents with diabetes [21,26–32]. However, these studies focused on disease self-management tasks that are more immediate or intrapersonal, such as monitoring blood glucose, administering insulin, and tracking carbohydrates. SDT has not been utilized to determine how AEA develop broader or more interpersonal self-management tasks, such as communicating with physicians or understanding their insurance. Additionally, SDT has not been utilized to understand the development of these self-management tasks in AEA who are in the process of preparing to transition from pediatric to adult-based care—a period in which AEA experience increased health risks. Exploring how transition-age AEA develop health self-management skills using an SDT framework would expand upon the work conducted in diabetes and demonstrate ways in which this theory may be useful in helping AEA from a variety of chronic conditions develop self-management skills necessary for successful transition. Furthermore, few studies have utilized a developmental perspective among AEA with these types of chronic conditions to understand how health self-management skills develop [19]. Therefore, the purpose of this qualitative study was to use an SDT theoretical framework and interviews with AEA and parents to better understand the progressive development of health self-management among AEA with chronic medical conditions in

order to identify opportunities to prepare AEA for the transition to adult-based care.

Methods

Recruitment and sampling

A sample of AEA aged 17–20 years and their parents were recruited from the gastroenterology, renal, or rheumatology services of a large children's hospital. These services were chosen because adolescents from these departments tend to have increased morbidity and mortality following poorly planned transition. Providers from each subspecialty service provided a list of eligible participants. Research staff contacted potential participants by letter or phone call and described the purpose of the study.

Inclusion criteria. All genders and racial/ethnic groups were included. Eligibility included the AEA's ability to read and speak English; however, AEA 17 years of age whose parents spoke only Spanish were able to participate due to having a bilingual research staff member who was able to secure informed consent and interview the parents in Spanish.

Exclusion criteria. AEA were excluded if they had conditions that limited participation (e.g., cognitive disability).

A purposeful sample of AEA was recruited to achieve maximum variations in age, sex, and diagnoses. For example, participants with different conditions from each service (e.g., within the renal service, AEA with hypertension, chronic kidney disease, or kidney transplants) were asked to participate.

Written consent and adolescent assent were obtained with approval from the Institutional Review Board for Human Subjects Research. Participants who agreed to participate received an interview date and time, with all interviews conducted at the same children's hospital.

Data collection

One-to-one, in-depth qualitative interviews with AEA and parents were performed separately by members of the research team. Open-ended, semistructured questions were used to elicit opinions from AEA and parents regarding the AEA's transition to adult health care based on the main constructs from SDT (see Table 1). Each participant also completed a demographic questionnaire that included age (AEA's age only), education, gender, race, and ethnicity of the AEA and parent, the patient's service, and perceived severity of difficulties caused by the AEA's health condition. Interviews were conducted until thematic saturation was reached. Participants received cash compensation for parking and completing the interview. All interviews were audio-taped with participants' permission, and a professional transcription service transcribed the audio verbatim. The transcriptions were verified for accuracy using the recordings by members of the research team.

Data analysis

Demographic characteristics were described using descriptive statistics (frequencies, means). Responses to open-ended questions were examined using directed content analysis [33], a type of qualitative analysis that is appropriate when using an a priori conceptual framework or theory to guide data collection

Table 1

Self-management interview questions

Asked of adolescents and emerging adults (AEA) and parents
What is it like for someone with your/your child's condition to take care of themselves?
How hard is it for someone with your/your child's condition to take care of their health?
What motivates you/your child to stay healthy? Why is it important to stay healthy?
Tell us about your/your child's experience preparing to transition from pediatric to adult-based care (i.e. accomplishments, difficulties, things that are missing)
If you/your child has a problem or question about your/their health, who would you go to for help? How important is it for you/your child to get support from others in regards to health?
What was the last self-management task your parents praised you for/you praised your child for being able to do?
Do you and your parents/you and your child ever disagree about how to take care of your health?
Asked of AEA only
How important is it for someone with your condition to follow their care plan?
What is the hardest part of managing your health condition?
In what ways do you wish your peers/family/others would provide more support?
Asked of parents only
If you have a problem or question about your child's health, who would you turn to for help?
What have you seen your child struggle with in taking care of their health?
What does your child do to overcome these struggles?
How important is it for your child's friends to know about his/her condition? Does your child lean on his/her friends for support?

and analysis [34]. Initial coding categories included constructs from SDT: competence, autonomy, and support for autonomy. A subset of the transcripts were reviewed by all authors, who were from diverse disciplines (medicine, developmental and clinical psychology, public health), in order to become familiar with the data and generate initial codes for often repeated phrases and ideas [35]. These codes were then applied to several transcripts in order to evaluate completeness. This process was repeated until no new codes were identified. Transcripts were read independently by pairs of coders, who coded responses to specific questions using the previously generated codes. Discrepant codes were discussed until consensus was reached. Using Atlas.ti, the codes were indexed and sorted into larger subthemes and final themes. All coded quotes were reviewed by the six coders, and overarching themes were agreed upon. An audit trail was maintained throughout the process to ensure that the analysis could be replicated if necessary.

Results

Sample description

Twenty-three AEAs and 23 parents were enrolled in the study. The interviews averaged 35 minutes (range: 18–45). Demographic information is reported in Table 2. There were nearly equal numbers of participants recruited across the three services. Specific diagnoses were Chron's disease (n = 5); ulcerative colitis (n = 4); systemic lupus erythematosus (n = 6); kidney transplant (n = 6); and chronic kidney disease (n = 2).

Themes

An initial 69 discrete codes were combined into 25 subthemes that fit within four overarching themes: Development of

Table 2

Participant demographic characteristics

	Adolescents/emerging adults (N = 23)	Parent (N = 23)
Mean age, years ^a (range)	18.13 (17–20)	-
Gender, female, n (%)	13 (57)	19 (83)
Race, n (%)		
Caucasian/white	11 (48)	12 (52)
African American	5 (22)	5 (22)
American Indian/Alaska Native	1 (4)	0
Asian	2 (9)	2 (9)
Biracial/2 racial groups	2 (9)	1 (4)
Multiracial/3 or more racial groups	0	1 (4)
Missing	2 (9)	2 (9)
Ethnicity, n (%)		
Hispanic or Latino	8 (35)	7 (30)
Subspecialty service, n (%)		
Renal	8 (35)	-
Rheumatology	6 (26)	-
Gastroenterology	9 (39)	-
Education level, n (%)		
< High school graduate	9 (39)	5 (22)
High school graduate/some college	14 (61)	9 (39)
Associate's/bachelor's degree	-	5 (22)
Master's/doctoral degree	-	4 (17)
"Moderate" or "severe" difficulties caused to youth by diagnosis, n (%)	10 (43)	14 (61)

Due to rounding, percentages may not total 100%.

^a Parent age is not available.

Competence in Self-Management; Motivation to Self-Manage; Ways Important Others Support or Hinder Independence; and Normal Adolescent Development. Table 3 contains a description of each theme, the subthemes, and illustrative quotes. In the following section, quoted text is followed by parenthetical identification of the specific AEA or parent (P) transcript from which it came.

Development of competence in self-management

AEA and parents described self-management tasks ranging from those considered more immediate to AEA, which we call intrapersonal, such as taking daily medications, to tasks that were considered more distal or interpersonal, occurring less often, such as arranging insurance after they age out of their pediatric insurance coverage. Most AEAs (22 of 23, 96%) described being able to perform at least one immediate task, such as taking their medications or managing their diet, and more than half (14 of 23, 61%) were able to make appointments or refill their prescriptions. No AEA reported that they understand their insurance or know how to pay for their medical care. AEA and parents described how illnesses and flare-ups temporarily limit the AEA's ability to perform certain self-management tasks: "I have memory loss, so [taking my medicine] gets hard" (AEA #6) and therefore parents stepped in to help.

AEA and parents expressed a range of competency, from AEA not knowing how to perform self-management tasks, to knowing how to perform these tasks without necessarily doing them, and finally to completing these tasks independently. Aligning with the theory's competence definition of feeling effective in performing tasks, AEA felt that moving from not knowing how to perform self-management tasks to completing the tasks independently was facilitated by their level of comfort with the specific self-management task, co-management with their parents, and their acceptance of responsibility for their illnesses.

AEA expressed how acceptance of responsibility for their illnesses influenced their perspectives of self-management, with one AEA stating, "It took time for me to realize that I'm gonna have to take care of myself more now than I did before I had a transplant." (AEA #26). AEAs and parents described how the AEA became more knowledgeable and progressively performed more tasks independently as parents became more trustful and transferred self-management responsibilities.

Autonomy: motivations to self-manage

AEA expressed several motivations to perform health self-management tasks that reflected the spectrum of self-determination. The most common motivation to engage in self-management behaviors described by both AEA and parents (11 of 23 AEA, 48%; 13 of 23 parents, 57%) was to be "normal" and experience daily activities that "normal" adolescents experience. They included attending school and enjoying fun activities, such as going to the movies. One parent stated that her adolescent's motivation to stay healthy was to "...participate and do everything that everybody else is doing, like a normal, healthy person is doing" (P #12). The second most common (10 of 23 AEA, 44%; nine of 23 parents, 39%) motivation to self-manage was to feel good or avoid negative health-related consequences, such as being hospitalized or returning to dialysis. As one parent replied to questions about whether her son takes his antirejection medications on his own, "He does it completely on his own. I have not reminded him a day since he got out of the hospital. I don't have to" (P #9). Several AEA were motivated to self-manage either to please others, primarily family members, or to avoid upsetting, disappointing, or burdening them (4 of 23 AEA, 17%; four of 23 parents, 17%).

Ways important others support or hinder independence

Parents described supporting their AEA's independence by teaching them self-management skills or connecting them to supportive others. AEA mentioned how friends and family provided helpful reminders to take medications or avoid certain foods. AEA expressed how important it was to receive support from family and friends. Many parents (16 of 23, 70%) and AEA (13 of 23, 52%) also recounted how they gave and received praise, respectively, for performing self-management tasks, which AEA felt reinforced their health-related autonomy. A majority of parents (13 of 23, 57%) noted that by supporting AEA's independence, they gained more trust in the AEA's ability to self-manage, resulting in handing off responsibility for additional self-management tasks. AEA also noted that as they performed more self-management tasks, their parents became more trustful.

AEA and parents also discussed parental actions that hindered the development of autonomy. Half of the parents (11 of 23, 48%) expressed difficulty in letting go, with some parents stating that they preferred to perform tasks that the AEA could do, due to fear that the AEA would incorrectly self-manage or that the AEA could not handle the responsibility. Several AEA confirmed this, expressing their ability to perform self-management tasks that parents insisted on doing for them. Some parents described not trusting that the AEA was correctly self-managing their health, especially in terms of medication adherence. For example, some parents texted their AEA both before and after their scheduled

Table 3

Themes identified through qualitative analysis of adolescents/emerging adults (AEAs) and caregiver interviews

Theme/subthemes	Description	Data sample ^a
Core Theme #1: Developing Competence in Self-Management <ul style="list-style-type: none"> Self-management pathway Not knowing → knowing → doing Becoming comfortable self-managing Parent-AEA co-management Conditions of illness, regimen, or emotional response make it difficult to self-manage 	<ul style="list-style-type: none"> Self-management tasks vary in level of complexity, with AEA mastery of simpler, more immediate intrapersonal tasks occurring first. The AEA begins by not knowing how to self-manage and moves to knowing but perhaps not doing, then finally taking over the doing. A sense of comfort develops around self-management activities as AEA become more knowledgeable and feel more competent. Illness- and regimen-related factors can hinder AEA ability to self-manage. During the process of developing competence, collaborative co-management may occur, which involves the AEA and parent working together as a team to carry out self-management tasks. 	<ul style="list-style-type: none"> "I feel like he's in the middle of where I want him to be. I think he's doing a really good job of taking his medication, but he has a lot to go with as far as making sure he has medication, his doctor's appointments, his labs. He's not totally independent. He's about midway." (P #5) "...I can make my own phone calls, and I can make my own appointments, but I don't know much about how my insurance policy works...." (AEA #23) "I am learning to speak up for myself and speak my thoughts because two years ago, I was so uncomfortable and shy that my parents were the ones speaking for me all the time. But now I go into my doctors and I talk to them. I tell them what I want and what I need and what I think, so I think that makes me pretty independent from two years ago." (AEA #10) <p>Interviewer: What have you seen Y5 struggle with specifically?</p> <ul style="list-style-type: none"> "The anxiety around taking the medication has been very difficult on him. He has focused a lot on if I don't take it, something's gonna happen to me, something really bad. It's not like the fear of unexpected. It's more of the fear of what he's already been through. That's a huge thing for him." (P #5)
Core Theme #2: Motivation to Self-Manage <ul style="list-style-type: none"> Avoidance of illness symptoms Engaging in daily activities For the sake of others 	<ul style="list-style-type: none"> Some AEA are motivated to self-manage in order to avoid experiencing sickness or weakness that would prevent AEA from engaging in daily activities. AEA also want to stay healthy in order to do fun things, such as traveling, going to school, learning things, hanging out with friends and family. AEA also can be motivated to self-manage to please others, primarily family members, or to avoid being a burden on them. 	<ul style="list-style-type: none"> "Every time I come to the doctor's office, my doctor tells me your levels are a little bit off. You keep this up, eventually you're gonna be back on dialysis. I think I don't want to go back there, so maybe I need to start doing what I need to do in order to improve my levels. Thinking that I can go back on dialysis motivates me to take more care of myself." (AEA #26) Interviewer: What kind of motivates you to stay healthy? Interviewee: "Just to take care of my dog and go outside, listen to music, maybe read a book and hang out with friends and go to the movies, shopping, do fun stuff." (AEA #19) Interviewer: What motivates you to stay healthy? "My parents 'cause I seen them cry and worry about me like they did. It's not something good." (AEA #11) Interviewer: What's involved with setting up your dialysis? "I get bags out. I take weight and blood pressure. Using that information, I can deduce which exact solutions to use for my dialysis and how long it should be, what the treatment during dialysis should be, stuff like that. We had to go through training. ...They teach it upstairs, at [the children's hospital]. My nurse taught me." (AEA #4) "One time I went to Cici's Pizza with my friends. I forgot the medicine in the car. I started eating, and they were like hey, where's your medicine? I was like oh, yeah, so I went back to the car and grabbed my medicine and took it." (AEA #13) "He can always Mommy, what is such and such? That can be a phone call. I'm slowly weaning myself out of the process. As I see that he's able to do something, I kind of pull back in that area, and I'll pull back in another area, so pretty much, he's left on his own two legs to stand. He's getting there." (P #9) "About two hours ago, I, on my own, got my medicine out and took it, and my mom told me good job." (AEA #4) "I have a friend that is a lupus advocate. If I have any questions to something about her going through certain things...and then she'll talk to my daughter. They kind of have their little talk 'cause it's different from somebody that's going through what you're doing. She's a big help." (P #6) "We just said you've gotta go get the refill. My wife looked up the closest Walgreen's and said you need to go here, and here's how you handle it, and he did. He went to a bike kiosk, rented a bike, drove it down through downtown Minneapolis, from the university into town, picked his medicine up, and then drove back. He took care of it." (P #20) "Once she turned eighteen, her doctor gave her an assignment and that I have to be quiet when I come in the room, and she has to answer her own questions, because before, I was answering the questions. And she was like, okay, so now that you're eighteen, I need to know how you feel. Mom can't tell me how you feel." (P #15) "As far as actually the procedure, she can do the whole procedure herself, and she wants to do it herself. I still prefer to do it, just to make sure that no steps are missed. 'Cause when she has done it in the past, there'll be little things where it's a little different from the way I do it." (P #4) "my mom...babies me...her being like did you take your medicine, or her to reminding me to. I have to remember on my own. Or her being like did you drink some water today, something like that. I probably could be able to remember on my own" (AEA #6)
Core Theme #3: Ways Important Others Support or Hinder Independence <p>Supportive:</p> <ul style="list-style-type: none"> Teaching/modeling Helpful reminders/technical support Parental trust Handing off responsibility to carry out self-management Praise for self-management Connecting to supportive others Treatment that supports autonomy Health-care team reinforces parent letting AEA self-manage Teaching and providing AEA resources to drive <p>Hinder:</p> <ul style="list-style-type: none"> Parent not letting AEA self-manage Parental lack of trust 	<ul style="list-style-type: none"> Parents and health-care providers (doctors, nurses, transplant coordinators, pharmacists) support AEA autonomy through various methods, such as teaching, modeling, helpful reminders, providing resources, and transferring responsibility to carry out self-management. Parents also reinforce autonomy through praising AEA for their medical self-management. Health-care providers also support autonomy by shifting treatment regimen to support AEA independence in self-management. Parents do not allow AEA to self-manage out of fear of the AEA doing wrong. Lack of trust in AEA's ability to self-manage leads to nagging and produces anxiety in AEA. 	

(continued on next page)

Table 3
Continued

Theme/subthemes	Description	Data sample ^a
Normal Adolescent Development <ul style="list-style-type: none"> • Concrete versus abstract thinking • Family dynamics (parent/AEA disagreements) • Problem solving • Importance of peer belonging/normalcy • Staying in school • Not being able to drive 	<ul style="list-style-type: none"> • Adolescent development impacts timing of mastering self-management tasks, perceiving importance and consequences of doing so, family dynamics, and problem-solving ability. AEA's desire to engage with peers and achieve (e.g., attend school) provides important motivation to take care of themselves, while feeling different from others creates enormous stress until AEA are able to adapt to illness as a way of life. 	<ul style="list-style-type: none"> • “If I go out with friends maybe I don't do anything the week before, so I can have that fried whatever with them. But when I go out, I just have to make sure when I get back I do take my medicine because that's important.” (AEA #22) • “It's hard because you feel different than your friends growing up. Because they can all do normal stuff. All my friends are going to the beach this summer, and I can't because I'm not allowed to swim. I can't get wet. Even going to the kidney camp this weekend, I can't swim. I can't do canoeing.” (AEA #4) <p>Interviewer: What makes it harder to follow your care plan?</p> <ul style="list-style-type: none"> • “Wanting to be normal. You can't. You have to worry about your medicines. You've gotta be checking up on your time. If I go out, I'll go out with my friends, and I have to be back at a certain time 'cause I probably didn't take my medicines with me so I take them over there.” (AEA #11) • “It was my idea to try and get to where I didn't have to get these infusions nearly as often. [Mom is] a creature of habit, so she wants me to do the same thing for eternity...That was the one disagreement that we had was I was ready to try and alter it a little bit to be more manageable, and she was like no, we should stick with how things are 'cause if it ain't broke, don't fix it.” (AEA #27) • “We just know that when we eat too much of certain things, that's gonna cause your body to feel the inflammation. [My daughter], in her weakness, will disagree with me. She still wants to eat certain things, and then I'm gonna go it's gonna cost you.” (P #28) • “Yeah, so I skip a lot. I skip doses, and they get mad at me for doing it, but then they don't understand how hard it is to take that many...I just stop taking stuff” (AEA #4) • “After he came home from transplant, he had a slew of medicines because he had some complications while he was in there...He had to really stay on top of those meds and keep up with the appointments and try to get back into normal life and deal with home responsibilities and his brothers and school. He was able to prioritize, manage everything, and still graduate on time.” (P #9) • “Right now, she doesn't get herself to be in doctor appointment because I have to drive her up here all the time” (P #14)

^a The quoted text is followed by parenthetical identification of the specific adolescent/emerging adult (AEA) or parent (P) transcript from which it came.

medications to confirm compliance. AEA reported these constant reminders felt like nagging and induced anxiety.

AEA (10 of 23, 44%) and parents (9 of 23, 39%) described ways in which health-care providers supported AEA's autonomy. These included providing them with phone numbers to call with questions or if feeling sick, encouraging direct AEA-provider communication during clinic visits, encouraging AEA to take more responsibility for their health, adjusting medication regimens to allow greater independence, or teaching or modeling self-management behaviors.

Normal adolescent development

During interviews, the AEA and parents described normative aspects of adolescent development as well as the unique social, developmental, and environmental challenges that impacted the timing of mastering self-management tasks, and the perceived importance and consequences of doing so. Concrete thinking was illustrated by AEA who did not at times take their medication as prescribed because they “felt fine” and, therefore, did not think they needed it. In contrast, AEA with more advanced abstract problem-solving skills were able to plan for future contingencies, such as avoiding high-fat foods for several days before eating pizza when out with friends. Feeling different from peers and not being able to do normal teen activities were described by AEA (6 of 23, 26%) and parents (12 of 23, 52%). For some AEAs, the desire to spend time with friends, attend/remain in school, participate in sleepovers, or do other fun activities, became strong motivators to adhere to treatment regimens.

As expected during normal adolescent development in which conflict can result from AEA pushing for greater independence while parents constrain that push over safety concerns, AEA (13 of 18, 72%) and parents (14 of 20, 70%) reported having disagreements over managing the illness. Examples of disagreements included conflict regarding adherence, as well as differing opinions of dietary choices and what AEA feel they can do on their own, and when the AEA should take their medication. For example, one parent stated “I tell her, ‘You need more rest. You don’t need to eat that. You need to eat better, don’t drink the milk’” (P #18). An AEA noted, “She’s like even if you don’t tell me that you’re not taking your medicine, test scores will show it.” (AEA #26).

Discussion

This study used an SDT framework and interviews with AEA and parents to better understand the development of self-management of health among AEA with chronic medical conditions. Our findings illustrate a continuum of increasing personal responsibility and self-determination for self-management wherein as the AEA gains competence in progressively more complex self-management tasks, he or she becomes more autonomous in managing his/her health. This increasing competence was facilitated by a feedback loop: as AEA successfully performed self-management tasks, the parent’s trust increased, enabling the parent to provide more autonomy support and transfer responsibility for more complex tasks, thereby supporting AEA’s competence and autonomy. Parental praise for the AEA’s self-management, which was reported by AEA and parents, positively reinforced self-management behaviors. Interviews of AEA and parents also suggest a reciprocity between developing knowledge and becoming more comfortable with

managing illness. These findings are consistent with other studies that have demonstrated the importance of the key tenants of SDT of autonomy [29], relatedness [31,32], and competence [30]. Satisfying these basic needs promotes the development of more self-determined motivation, which is critical for long-term behavioral change [23,24] toward greater health-related self-management.

AEA offered several perspectives of the self-management tasks that exist on the continuum of Not Knowing, Knowing, and Doing. Viewed through a developmental lens, immediate tasks may seem more immediate or concrete, whereas more distal tasks seem more abstract and the effects or repercussions less tangible. For example, AEA generally expressed competence with and understood the implications of taking medications, but none reported the ability to navigate billing or understood health insurance. Support received from others, comfort, and adjustment to illness seemed to impact the movement from knowing to actually acting upon self-management knowledge. Furthermore, a directional relationship emerged among comfort, adjustment to illness, and movement from knowledge to action. As AEA performed and repeated self-management tasks, they reported feelings of acceptance, comfort, and confidence with their care regimen. Both parents and health-care providers play important roles in teaching and modeling, which facilitate the acquisition of knowledge concerning how to perform self-management tasks, such as administering shots and ordering medications.

Although parents supported greater self-management by the AEA through methods such as teaching, helpful reminders, and praise, they also described having feelings and engaging in behaviors that hinder the development of competence and autonomy. Consistent with research on various illness populations noting parent-child disagreements, such as inflammatory bowel disease [36], lupus [37], and diabetes [38], more than 70% of AEA and parents in our study reported having disagreements over managing the illness. Parents acknowledged the difficulties in releasing and transferring responsibility to AEA, particularly in light of illness set-backs and potential negative consequences of AEA failing to follow-through with tasks. This lack of parental trust resulted in nagging or worrying, which produced anxiety in AEA and discouraged autonomy. Such behavioral outcomes are consistent with the process of miscarried helping, wherein the misplaced but well-meaning behaviors of parents can yield a negative cycle of adverse health outcomes and impede development of desired behaviors in their children with chronic illnesses [26]. In order to prevent this problematic cycle, it is important to address parents’ fears as well as behaviors that hinder autonomy. Health-care providers may want to provide parents with a map or guide describing the changing expectations in health self-management between the parent and the AEA as the AEA ages. It may be helpful for health-care providers to communicate with parents one-to-one to set realistic expectations that progressively move the AEA toward autonomous self-management and provide reassurance with regard to the AEA’s self-management skills and health [26]. This finding is consistent with the SDT model, in that patients with autonomy-supportive physicians are more likely to have higher levels of autonomy and competence [39]. Future research should examine the utility of sharing SDT with parents to enable them to see their AEA’s self-management more objectively and foster autonomy-supportive communication and behaviors. Future research is also needed to determine whether autonomy support provided

by physicians to parents helps in shifting responsibility for health self-management tasks from the parent to the AEA.

Our findings demonstrate that AEA motivations to self-manage are reflective of several stages in the SDT's process of becoming more self-determined, as the motivations to stay healthy helps to drive the AEA's self-management. For example, some AEA reported their motivation to stay healthy as pleasing or keeping a parent from worrying which aligns with external regulation [23], whereas others reported a desire to avoid sickness in order to go about their daily lives which aligns with introjected regulation. The varying levels of self-determination demonstrate the wide range in development on the part of the AEA. There was a common desire among parents for AEA to take charge and make their own decisions, which applies to chronic illness and other tasks of independence. Present understanding of SDT states that motivation must first be present for a person to undergo behavioral change [23]. Higher levels of autonomous motivation are related to better health outcomes and adherence in numerous health-care settings [39,40]. These results suggest the need for autonomous motivation in order to sustain behavioral change [24].

The need for a developmental perspective when working with AEA with chronic illnesses was recognized in this and prior studies [13,19,26]. The importance of recognizing that AEA undergo maturational steps and may differ in their openness to behavioral change has been noted in AEA with diabetes [14,26]. A finding of our study also suggests that health-care providers need to understand and identify the extent to which motivation is internalized in the AEA when encouraging and teaching self-management skills. This may include an ongoing, brief assessment aligned with the Transtheoretical Model [41] to better understand an AEA's stage of change. Health-care providers can then utilize motivational interviewing to address the self-management skills aligned with the current stage of motivation or to increase internal motivation by fostering change talk. Motivational interviewing has been recognized as a technique "to guide positive health behavior change and work within a participant's internal motivation" [42,43]. Findings from a systematic review suggest motivational interviewing may be useful in reducing nonadherence in AEA with chronic illness [44]. In addition to motivation, health-care providers and parents should be aware of the AEA's stage of development in order to prevent premature transfer of responsibility from parent to AEA, thereby avoiding parental distrust and the cycle of miscarried helping. However, parents will always remain as key roles of support in the AEA's life, likely even through adulthood [20]. These findings enhance the understanding that a parent's role will change in support over time as different moments in adulthood emerge.

This study had several strengths and limitations. Other studies utilizing SDT have found that similar constructs, such as autonomy-supportive environments and patient-centered communication, improved health outcomes for individuals with diabetes [30,45]; however, this was the first published study of which we are aware to use SDT as a framework to understand the progressive development of health-related self-management among AEA with chronic conditions as they prepare to transition to adult-based health care. Interviewing AEA with a variety of chronic conditions from diverse cultural backgrounds helped provide a wide range of self-management experiences and perspectives. Our research team was multidisciplinary, adding breadth to our data analysis and interpretation. Despite these strengths, selection from a single

tertiary hospital limits our ability to generalize study findings to other hospital systems or regions of the country. Interview questions did not specifically probe for the ways in which health-care providers supported AEA's autonomy; however, AEA and parents were asked about their preparation for transition to adult-based care and any support AEA received from nonfamily members. AEA may express feeling competent and autonomous in their self-management and readiness to transition, but we do not know if this perspective is associated with successful transition to adult-based care. Next steps should include more formal testing of the utility of SDT in improving health-related self-management and success of transition for AEA with chronic conditions. Future studies should also assess whether increased self-determination is associated with successful health-care transition.

This study supports the utility of SDT in understanding the development of health-related self-management among AEA with chronic medical conditions and their parents. Support for autonomy from families and health-care providers was important in developing AEA's autonomy and competence. AEA who indicated receiving higher levels of support and felt more autonomous and competent expressed greater comfort and ability to perform health-related self-management tasks. Ultimately, these findings may have important implications for clinicians in helping AEA successfully self-manage their health and increase their motivation and comfort with transition from pediatric to adult-based care. Health-care providers can help guide families on ways to provide support for autonomy through fostering the development of their AEA's competence. They can also assess the AEA's motivations for self-management and move them in incremental steps towards values and ideas that are increasingly self-determined. From there, health-care providers can work with AEA to develop the autonomy and competence needed for successful self-management and transition.

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