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Development of a Group-Based, Peer-Mentor Intervention to Promote Disease Self-Management Skills Among Youth With Chronic Medical Conditions

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ABSTRACT

Study purpose: The purpose of this paper is to describe the development of a group-based peer-mentor intervention to enhance knowledge/skills of transition-age youth (TAY) from three clinical services (gastroenterology, renal or rheumatology) at a large children's hospital in order to facilitate transition from pediatric to adult healthcare.
Design and methods: Using a multi-modal, iterative approach, the structure/content of the intervention was based on peer-reviewed literature; surveys/interviews conducted with TAY, families, and adult and pediatric providers; principles of Self-Determination Theory and motivational interviewing; and guided by a logic model. A TAY community advisory board helped interpret the information and develop the intervention.
Results: The resulting intervention has eight sessions led by peer mentors (young adults who have successfully transitioned to adult healthcare, who are trained to use a motivational interviewing approach) covering topics such as goal setting; understanding my diagnosis; organizing personal, health & insurance information; characteristics of a good provider; filling/refilling prescriptions; and mental well-being. The TAY community advisory board recommended holding two sessions on each of four Saturdays, using interactive group activities to make it fun, and creating a written complimentary manual for caregivers.
Conclusions: A TAY community advisory board was instrumental in developing an innovative peer-mentor intervention to promote the development of specific skills TAY require to manage their disease within adult healthcare.
Practice implications: Although the intervention was developed with extensive stakeholder input, a next step is to evaluate the intervention with respect to how well it fits the broader membership in the target population.

Background

This paper describes the development of a group-based, peer-mentor intervention designed to improve condition self-management skills needed by transition-age youth as they transition from pediatric to adult healthcare. The intervention is innovative as it is based upon principles of Self-Determination Theory and guided by a logic model, includes transition-age youth from multiple subspeciality services, and adolescents with chronic health conditions helped guide its development and implementation.

The need for healthcare transition preparation

Approximately 27% of children in the U.S. have a chronic health condition (Van Cleave, Gortmaker, & Perrin, 2010). Ninety percent of individuals with chronic illness and disability survive childhood and 750,000 young adults with special needs in the U.S. transition to adulthood annually (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Goodman et al., 2011; Scal, Davern, Ireland, & Park, 2008). We address five conditions within three clinical services in this paper – inflammatory bowel disease, kidney disease, hypertension, lupus, and juvenile idiopathic arthritis – which are among

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the most common in the U.S. and/or have had a significant improvement in life expectancy in the past two decades (Quinn, Rogers, McCavit, & Buchanan, 2011). The post-transition period for these conditions is a time of increased morbidity and mortality. Surgery and hospitalization were higher in a group of inflammatory bowel disease patients who had not gone through a transition program, compared to those who did (Cole, Ashok, Razack, Azaz, & Sebastian, 2015). More transplanted kidneys are lost between ages 16–21 years than any other age group (Kreuzer et al., 2014). Similarly, morbidity and mortality are increased for juvenile arthritis patients post-transition (Minden, Nieworth, Zink, & Horneff, 2014). These data indicate that healthcare transition (HCT) represents both a vulnerable period and a clear opportunity to alter the trajectory of health outcomes.

Evidence base for successful healthcare transition programs lacking

Despite a strong agreement on the importance of HCT for transition-age youth (TAY), the evidence base for successful HCT programs is lacking (Lotstein et al., 2009; Quinn et al., 2011; Lebrun-Harris et al., 2018; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; McManus & White, 2017). Few studies have used a comparison group and only four descriptions of existing transition programs used a randomized clinical trial study design (Campbell et al., 2016). One longitudinal study of TAY with chronic conditions evaluated the impact of two transition interventions, an online organizational and goal-setting tool and an online mentor. Both were determined to be insufficient for empowering self-management during transition to adult healthcare (Gorter et al., 2015). Although the transition readiness stage of HCT has been addressed in the literature, little attention has been paid to what factors facilitate the actual successful transition to adult healthcare. Beyond knowing the basics of disease self-management (e.g., able to describe their disease, where to get their medications refilled), TAY need specific skills to both enter into and effectively manage their disease within the adult healthcare system. For example, it is not enough to have the number of a recommended adult healthcare provider; TAY also need the skills to navigate the process of making and keeping appointments.

Some hospitals have developed disease-specific HCT programs (e.g., Hankins et al., 2012). While these may help in responding to disease-specific needs, such as how to locate a dialysis center, or strategies for multiple medication management/side effects, a substantial number of universal HCT skills exist across specialties. For example, identifying an adult healthcare provider, communicating effectively, and preparedness for a first appointment with an adult provider are common self-management tasks. HCT approaches that are disease-specific face limitations as they exclude patients from multiple subspecialties and therefore have a smaller pool of TAY eligible to participate, resulting in costly interventions in terms of personnel and time to implement. By extending across subspecialties, group interventions have the potential to be less impacted by attrition and remain cost-effective.

The role of peers mentors

Peer mentors have been effectively used in other fields to model skills and behaviors and provide guidance to those navigating new experiences (Callahan & Cooper, 2007; Fraas & Bellerose, 2010; Hughes, Wood, & Smith, 2009; Jerson et al., 2013; Kelly et al., 2014; Wright et al., 2001). Peer-mentoring programs have been successful in improving social, emotional, and academic outcomes in youth (Mackner, Ruff, & Vannatta, 2014). In healthcare, the role of a peer mentor is unique because the foundation of the peer-to-peer relationship is having similar health-related issues, which potentially allows for a deeper understanding (Hughes et al., 2009; Mackner et al., 2014). There is a sharing of experience and knowledge that provides social and emotional support in a mutually-beneficial way. Thus, a peer-mentor program is a promising approach to address the need for evidence-based interventions targeting TAY with chronic health conditions transitioning from pediatric to adult healthcare systems. One study found that participants of a peer-mentor program identified the following benefits: talking to someone 'who's gone through what you're going through', receiving answers to questions and practical information, reassurance, encouragement and increased confidence, support, and hope for the future (Hughes et al., 2009).

Stakeholder engagement and collaboration

Community Advisory Boards provide a mechanism to form partnerships between researchers and stakeholders, allowing research efforts to focus on the concerns voiced by the communities within which they are working (Newman et al., 2011). Numerous studies have reported on the valuable insight and tangible benefits gained from engaging in meaningful partnerships with stakeholders throughout the lifecycle of a project (Likumahuwa-Ackman et al., 2015; Forsythe, Heckert, Margolis, Schrandt, & Frank, 2018; Forsythe et al., 2016; van Bruinessen et al., 2014). For example, stakeholder partnerships have had a demonstrated impact on the patient-centeredness of study processes and outcome selection, as well as the efficiency and acceptability of recruitment, retention and data collection activities (e.g., focus group vs. one-on-one interview vs. survey) (Forsythe et al., 2018; Likumahuwa-Ackman et al., 2015). Additional contributions described in the literature include: improved access to hard-to-reach populations, methods for communicating with participants, culturally-sensitive recruitment methods, interpretation of results, and dissemination activities (Forsythe et al., 2016; Forsythe et al., 2018).

Self-Determination Theory (SDT)

Self-Determination Theory (SDT), an empirically-based theory of human motivation, has proven useful in promoting long-term health behaviors (Deci & R, 1985; Ryan & Deci, 2000). As a model of behavior change, SDT comprises core elements that can be operationalized to address the challenges adolescents with chronic health conditions encounter in attaining self-management competency. SDT suggests that internal motivation and thus behavior performance is driven by three basic psychological needs: competence (i.e., skills, confidence), autonomy (i.e., control, choice), and relatedness (i.e., connection with supportive others) (Ryan & Deci, 2000). Previous empirical work has demonstrated that in adopting any given behavior a person must first be motivated (Ryan & Deci, 2002). SDT has been validated as a model of behavior change and has substantial support from studies of long-term behavior change (Ryan & Deci, 2000; Deci & Ryan, 2012). Studies using SDT as an intervention framework have shown that when people in positions of leadership provide an environment that is supportive of basic psychological needs, attendance in health and exercise settings increases (Edmunds, N., & Duda, 2007; Wilson et al., 2006). Similar support for basic needs has predicted adherence to dietary advice, such as maintaining glycemic control in diabetes, as well as decreasing smoking (Williams, Cox, Kouides, & Deci, 1999; Williams, McGregor, Zeldman, Freedman, & Deci, 2004). Given what we know from SDT, the patient's motivation is a critical first step in being able to master these behavioral skills. Literature suggests that motivational interviewing is a helpful tool to guiding positive health behavior change and working within the participant's internal motivation (Naar-King, 2011). A recent systematic review concluded that motivational interviewing may be a promising intervention for youth with chronic illness in addressing non-adherence and potentially improving quality of life (Schaefer & Kavookjian, 2017).

Purpose

The purpose of this paper is to describe the development of a group-based peer-mentor intervention to enhance knowledge and skills of TAY from gastroenterology, renal or rheumatology clinical services at

a large children's hospital in order to facilitate transition from pediatric to adult healthcare. This paper describes the intervention *development* only; a companion paper in this special issue reports results of evaluating the proposed intervention's relevancy and fit to the broader target population of TAY and their caregivers (parents) from these three subspecialty services (Wiemann et al., 2019).

Design and methods

We conducted a needs assessment using a multi-modal, iterative approach, including reviews of published literature and interviews or surveys with multiple stakeholder groups. Stakeholders were adolescents and young adults with special health care needs (AYASHCN) who had or had not transitioned to adult healthcare (n = 95) and family members (n = 49), as well as a range of pediatric (n = 81) and adult (n = 17) providers. The initial literature review provided the basis for in-depth interviews with AYASHCN and family members that explored individual experiences with the process of transitioning to adult healthcare, including what went well and what was missing in their preparation. The results of the interviews helped us craft survey questions to implement with a larger sample of TAY, including those recruited into a longitudinal study of TAY as they prepared to transition to adult care (Hergenroeder et al., 2018; Wiemann et al., 2016). Questions on these surveys assessed whether TAY had the specific skills needed to transition. Surveys were also developed to administer to AYASHCN, families and, both pediatric and adult providers who attended an annual transition conference held locally. These anonymous surveys elicited perceived needs for TAY and families to prepare to transition and what would make it easier to do so. Findings from interviews and surveys were brought to a transition-age youth community advisory board that included TAY from Gastroenterology, Renal and Rheumatology subspecialty patient populations, among others, to help interpret the information and provide additional insights, and develop the content and structure of the resulting intervention. A logic model, discussed in greater detail in a later section of this paper, was developed based on the needs assessment.

Findings from the needs assessment

Five specific needs were identified, described more fully below.

AYASHCN are not prepared for HCT

In 2009, Lotstein et al. used the core transition outcome consisting of four components of HCT planning: (1) discussions with their provider about future adult needs; (2) finding an adult provider; (3) securing health insurance; and (4) encouraging young adult patients to take more responsibility for their care (Lotstein et al., 2009). Only 40% of parents of children and youth with special healthcare needs reported that this core process outcome was occurring (McManus et al., 2013). This percentage has not improved in subsequent surveys. Impoverished and ethnic minority youth were less likely to report receiving HCT preparation (McManus et al., 2013; Lebrun-Harris et al., 2018). Barriers to HCT identified by youth who have actually transitioned to adult healthcare from our clinics included not having: 1) a list of potential adult healthcare providers who would be willing to take them as patients, and who have the knowledge and skill to treat their condition; 2) someone to help them navigate the transition process (supporting the need for peer mentoring); 3) adequate knowledge of their own condition and its management; and 4) pediatric medical records in the adult healthcare provider's office at the time of their first visit.

Barriers identified by local adult healthcare providers who care for AYASHCN include TAY's lack of: 1) knowledge about how to navigate the adult healthcare system; 2) health literacy about systems in general, and specifically about their own disease; 3) self-efficacy in managing the disease; 4) health insurance familiarity; and 5) parental involvement in case managing and preventive and routine care.

Most families interviewed/surveyed reported not being taught, encouraged, or supported to transfer knowledge and skills, first as a teacher, then as a mentor, and later as a consultant coach to the young adult. The range of supports required by TAY will depend upon their health status and cognitive level. At age 18, the decision maker can range from the patient alone, the parent/caregiver as temporary health surrogate/power of attorney with partial support on specific health areas, or full-time support via guardianship. Consistent with family- and patient-centered care, it is important to understand what constitutes transition readiness from the patient's perspective. For example, before transfer, patients desired to be more responsible by gaining a sense of control over their health (Lugasi, Achille, & Stevenson, 2011) including: scheduling appointments, talking to their doctor alone, and wanting to be taken more seriously by their physicians. Patients also wanted information about their condition.

Pediatric healthcare providers are not prepared to assist in transition readiness for AYASHCN and their families (Okumura et al., 2008)

Many pediatric and adult healthcare physicians, nurses, dietitians, social workers, dentists, psychologists, and other professionals who are involved in the lives of AYASHCN are ill-prepared to partner with youth or their families to implement transition from pediatric to adult healthcare (American Academy of Pediatrics et al., 2002; Scal, Horvath, & Garwick, 2009). Internists and pediatricians local to our institution also report lack of time and reimbursement as major impediments to providing primary care to transitioning patients.

It has been recommended that both pediatric primary care and subspecialty providers should improve in specific knowledge and skills, such as their ability to: (1) emphasize transition as a normative event; (2) ask patients about their expectations of transition and address and attempt to adjust their expectations as necessary; (3) give the patient a copy of their medical record; (4) provide the name and number of a person who can help them with questions during the transition period; and (5) if possible, arrange a visit where the pediatric and adult healthcare providers are present jointly (Lugasi et al., 2011). A young adult peer mentor could help address all five items by helping TAY become self-sufficient advocates for these items with their pediatric and adult healthcare providers.

AYASHCN and their families need to be prepared for differences between pediatric and adult healthcare systems (Reiss & Gibson, 2002)

Patients with juvenile idiopathic arthritis have described child-centered care experienced in pediatric settings as patronizing yet adult healthcare as alienating (Shaw, Southwood, & McDonagh, 2004). Patients preferred knowing about the cultural differences between child- and adult-centered healthcare prior to transition (Lugasi et al., 2011). Specifically, patients reported liking the efficiency of the adult staff, feeling more in control of their decisions, and feeling more responsible for their health, yet did not like being with older, sicker patients, and receiving care that is not holistic. There is a reciprocal responsibility between pediatricians, pediatric providers and families to (1) prepare for these differences, to delineate the roles of the youth, the family and providers; and (2) encourage youth who can, and youth with supports who may be able, to act as informed decision makers and co-managers of their health. Youth specifically have identified the need for increased continuity of care, assistance with logistics, improved communication between providers and caregivers, and individualized management of their transition process (Wiener, Kohrt, Battles, & Pao, 2011). These needs all require behavior change on the part of TAY. Needs assessments of pediatric providers at our institution revealed that there are elements in pediatric hospitals that facilitate returning to the pediatric hospital after transfer to the adult healthcare system. For example, there have been several cases reported by the hematologists in our hospital of young adults with sickle cell disease who returned to their pediatric hospital in medical crisis, either by entering the pediatric emergency room or being transferred back to the pediatric

service from an adult hospital for inability to care for the patient in life-threatening circumstances. This may undermine the transfer and engagement processes and could endanger long-term adult health.

The adult healthcare system is not adequately prepared to receive AYASHCN

Even if AYASHCN are ideally prepared to transition into an adult healthcare system, there is a perceived lack of availability of appropriate treatment services in the community. Families and youth report "not being able to find providers who were willing to treat their special needs" (Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Patients and providers report a lack of adult primary care and specialist providers to whom AYASHCN can be referred (Lugasi et al., 2011; Scal, Evans, Blozis, Okinow, & Blum, 1999). Excluding systems issues such as lack of insurance and difficulties that heathcare providers have in getting reimbursed for providing transition services to AYASHCN, Scal identified the four most significant barriers to transition encountered by providers in interdisciplinary transition programs (Scal, 2002). These include: (1) difficulty identifying adult primary care providers; (2) adolescent resistance; (3) family resistance; and (4) lack of institutional support. These issues could be addressed in a peer-mentoring program.

Communication between pediatric and adult healthcare providers is inadequate (Peter, Forke, Ginsburg, & Schwarz, 2009)

Consistent with the feedback from pediatric providers interviewed for this needs assessment, a 2008 survey in New Hampshire found that fewer than half of adult healthcare providers communicated with previous providers of young adults; however, 90% wanted written summaries and/or conversations with them (http://www.nhps.org/default.htm). TAY providing their oral medical history, especially without an adult present, can lead to inaccuracies with obvious implications for reduced quality of care (Wiener et al., 2011). The chronic condition for many TAY is diagnosed early in life, which should allow providers, families and patients years to plan, prepare for, and facilitate HCT discussions between pediatric and adult healthcare providers. A well-informed TAY, armed with their medical summary and having self-advocacy skills through mentoring, could fill this important information gap (American Academy of Pediatrics et al., 2002).

Taken together, these barriers portray multiple needs for successful HCT from the patients', families' and providers' perspectives as well as systems of care that are inadequate, including being culturally incompetent in planning for and carrying out the successful HCT to adult healthcare. They also describe families and youth who are unprepared to navigate the adult healthcare system. In this context, a young adult who has successfully navigated the transition could help broker these barriers – the culture of the adult healthcare system and the language of the specific disease and its manifestations – for another AYASHCN. This logic provides the basis for the proposed peer-mentoring intervention.

Intervention development

The TAY community advisory board met monthly with an intervention development specialist for two hours to review the needs assessment findings, reflect on their own transition-related experiences, and develop the intervention. The intervention specialist presented a summary of the needs assessment findings from the perspective of each of the stakeholder groups (AYASHCN, family member, and pediatric and adult healthcare providers). Specifically, advisory board members helped prioritize the topics identified through the needs assessment to be included in the intervention. They were instrumental in the development, testing and modifying of activities designed to teach TAY self-management skills related to these topics. Advisory board members also helped delineate the role of the mentor, including the amount and form of contact between proposed intervention sessions. Lunch was provided and each board member was compensated $25 per meeting. Our TAY community advisory board told us finding a good doctor, understanding their medical condition and limitations, communicating records and medical information to a new doctor, knowing how to handle insurance by themselves, scheduling doctor's appointments alone, figuring out transportation and parking for doctor's appointments, and being an assertive patient so doctors take you seriously are all important tasks and skills involved in transitioning to adult healthcare. This feedback drove the final content of the proposed intervention. The TAY community advisory board developed, tested, and reviewed the entire planned intervention curriculum and pilot-tested session activities. Board members told us they would prefer a transition intervention to be delivered over a series of weekend workshops versus weekday nights, and led by a former patient who is slightly older and has already gone through the transition process. They also suggested some sessions be led by a mix of providers, a psychologist or therapist, and other topic experts. Thus, through these activities, advisory board members helped craft the Program Activities portion of the logic model, described below.

Self-Determination Theory and healthcare transition framework

Fig. 1 presents the conceptual framework guiding the intervention, and illustrates theoretical relationships among participant and environmental characteristics, components of the intervention, SDT factors (Ryan & Deci, 2000) and HCT behaviors and health outcomes. The intervention is designed to impact autonomy, competence and relatedness. These three factors interact to promote transition readiness and engagement in HCT behaviors, thereby facilitating successful transition to adult healthcare, and ultimately leading to positive health outcomes.

Motivational interviewing approach

The behavioral skills described in the proposed intervention are crucial towards achieving the desired health behaviors and health outcomes. The intervention will integrate motivational interviewing techniques into the first session of the intervention and then weave, when appropriate, motivational interviewing language into the skills teaching (Markland, Ryan, Tobin, & Rollnick, 2005; Rollnick, Miller, & Butler, 2008; Vansteenkiste & Sheldon, 2006). From the first session, the peer mentors will focus on the participants' desired outcomes and potential personal reasons for transitioning to adult healthcare. From a motivational interviewing perspective, the peer mentors will use skills such as open-ended questions, affirmations, and reflective statements and match the processes of motivational interviewing, such as engagement in the process of transition, focusing on the desired change, evoking comments from group discussions in the direction of change, and planning towards the behavioral skills. Also, information gained in the first session will be utilized in future conversations related to the behavioral skills to personalize and individualize these skills for each participant's situation.

Logic model

A logic model is a theory or conceptual framework about the proposed causal linkages among the components of a program and is often used to design interventions (Buzi et al., 2014). The logic model framework identifies targeted behaviors to be changed, determinants predisposing individuals to those behaviors, and program activities that can address those determinants and behaviors (Kirby, 2004). Through this process, it is possible to set clear goals and make a plan in order to reach the targeted health goals (Hulton, 2007). A logic model based on the needs assessment above guided the development of the intervention described in this paper.

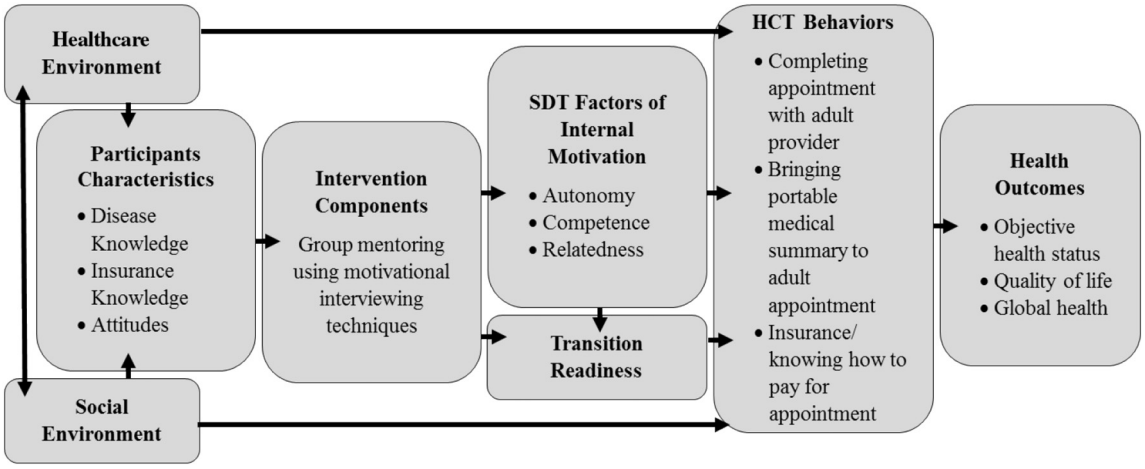

Fig. 1. The conceptual framework guiding the intervention, illustrating relationships among participant and environmental characteristics, components of the intervention, Self-Determination Theory SDT factors, and healthcare transition (HCT) behaviors and health outcomes.

Results

A Logic Model for the group-based peer-mentor program was developed based on the multimodal needs assessment, TAY community advisory board feedback, and principles of SDT and Motivational Interviewing (see Logic Model, Fig. 2). **Assumptions** include circumstances and resources outside of the program implementation itself that are necessary for program success. **Program activities** are the actions or products that will be taken to implement the program (i.e., what will happen as part of the program). The **determinants** are the factors thought to influence the **behaviors** that need to change in order to achieve the health goals. The **health goals** are the outcomes we hope to see improve as a result of the program.

Intervention content and structure

Based on the principles of SDT, and using a motivational interviewing approach, the intervention was designed to promote internal motivation among TAY for transferring to and engaging in adult healthcare. TAY will be paired with young adult peer mentors to guide them through motivational, skill-building activities. Over the course of three months, TAY will complete eight group-based intervention sessions held across four Saturdays, with each Saturday including approximately three hours of content. Table 1 contains the Intervention Curriculum Outline, including Major Objectives and the evidence of the need for each objective, based on our formative research with families and youth and both pediatric and adult healthcare providers, as

Logic model for group-based, peer mentor intervention to promote knowledge and skills needed to transition to adult healthcare

Assumptions	Program Activities	Determinants	Behaviors	Health Goals

• Use of Transition Planning Tool (TPT)
• Patient expected to transition
• Facilities: meeting space; parking; food
• Staff
• Trained young adult peer mentors
• TAY Community Advisory Board
• Funding to conduct intervention
• Self-Determination Theoretical Framework
	• Regular pediatric subspecialty service meetings to promote TPT use and transition planning activities
	• Intervention Content and Structure
	  • Group sessions:
	  ○ Connection to other AYA
	  ○ Adult provider panel
	  ○ Insurance talk/guest speaker
	  ○ Self-management/ self-advocacy
	  • TAY transition manual
	  • Caregiver session and transition manual
	  • Mentoring/phone calls
	  • Motivational interviewing training
		• Pediatric providers:
		  ○ Lack training to prepare AYA
		  ○ Difficulty letting go
		  ○ Support autonomy
		  ○ Attitudes: adult healthcare; readiness
		• Youth:
		  ○ Medical self-management
		  ○ Self-advocacy
		  ○ Self-efficacy
		  ○ Transfer readiness
		  ○ Transfer satisfaction
		  ○ Satisfaction with adult provider
		  ○ Social support
		  ○ Connectedness to family
		  ○ Attitudes: HCT; adult healthcare
		• Caregivers:
		  ○ Involvement
		  ○ Support autonomy
		  ○ Attitudes: adult healthcare; readiness
		• Adult providers:
		  ○ Training to work with AYA
		  ○ Attitudes: expectations of AYA knowledge and skills in self-management
		  ○ Comfort with AYA
		  ○ Quality care
		• System:
		  ○ Inadequate communication between pediatrics and adult care
		  ○ Undermining transition
			• Condition self-management
			• Engaging in adult care
			• Having a portable medical summary
			• Minimal gap between pediatric and adult care
			• Having insurance/knowing how to pay for healthcare
				• Health-related quality of life
				• Global health

Fig. 2. Logic model for group-based, peer mentor intervention to promote knowledge and skills needed to transition to adult healthcare.

Table 1
Intervention curriculum outline, including major session objectives and evidence of the need for each session.

Session	Major objectives	Evidence of need
Session 1a	• Orientation to the program-both TAY & caregiver • Personal goals and expectations • Knowing my diagnosis	• Adult and pediatric provider voices[a] • Family and youth voices[a] • Peer-reviewed literature: (Applebaum et al., 2013; Bell et al., 2011; Fair et al., 2011; Huang et al., 2014; S. Young et al., 2011)
Session 1b	• Organizing personal, health, & insurance information • Paying for health services/-using insurance coverage	• Adult and pediatric provider voices • Family and youth voices • Peer-reviewed literature: (Hankins et al., 2012; Applebaum et al., 2013; Bell and Sawyer, 2010; Rehmet al., 2012; Sawicki et al, 2014; Singh et al., 2010)
Session 2a	• Considering characteristics of a good provider • Evaluating potential adult providers • Choosing adult provider	• Adult and pediatric provider voices • Family and youth voices • Peer-reviewed literature: (Hankins et al., 2012; Huang et al., 2014; Dimitropoulos et al., 2013; Tuchman et al, 2008)
Session 2b	• Choosing appointment date and time • Scheduling an appointment • Remembering appointment date and time • What to bring to appointment • Questions/concerns to talk about during appointment • Transportation plans for getting to appointment	• Adult provider voices • Family and youth voices • Peer-reviewed literature: (Applebaum et al., 2013; Fair et al., 2011; Singh et al., 2010; Gilmer et al., 2012)
Session 3a	• Managing medications • Remembering to take medications • Filling/refilling prescription	• Adult and pediatric provider voices • Family voices • Peer-reviewed literature: (Applebaum et al., 2013; Bell et al., 2011; Fair et al., 2011; Rehm et al., 2012; Sawicki et al., 2014; Tuchman et al., 2008)
Session 3b	• Questions/concerns to talk about during appointment • Being an assertive patient • Taking notes & keeping track of information during/after appointment	• Adult provider voices • Family and youth voices • Peer-reviewed literature: (Fair et al., 2011; Dimitropoulos et al., 2013; Tuchman et al., 2008; Gilmer et al., 2012; Betz et al., 2013; Jedeloo et al., 2010)
Session 4a	• Emotional wellness/self--assessment • Red flags for getting help • How to talk about mental health concerns • Relaxation skills, coping strategies for stress • Destigmatizing seeing a therapist	• Adult provider voices • Family and youth voices • Peer-reviewed literature: (Young and Calloway, 2015)
Session 4b	• Identifying barriers to completing first adult appointment/troubleshoot • Evaluating appointment and new adult provider • Scheduling follow-up appointment(s) • Identifying barriers to follow-up/troubleshoot • Review of the program	• Adult and pediatric provider voices • Family voices • Peer-reviewed literature: (Fair et al., 2011)

[a] Perspectives of various stakeholders as described in the needs assessment.

well as the peer-reviewed literature. Sessions will focus on the following skills: knowing my diagnosis, identifying an adult healthcare provider, paying for my healthcare, organizing health information, scheduling and preparing for my appointment, managing prescriptions, being an assertive patient, getting to my appointment, evaluating my new adult healthcare provider, and emotional/mental wellness. In addition, content will be provided in other formats outside of traditional didactic, such as modeling, group discussion, and activity-based. The intervention sessions will promote the development of complex skills needed to transition to adult healthcare among TAY of all race/ethnicities who complete the peer-mentor intervention. Peer mentors will communicate with TAY at regular intervals between and after group sessions to reinforce concepts, address additional needs, and build on the mentoring relationship, largely through electronic media, such as phone calls, text messaging and email. These communications will be scripted to ensure consistency across TAY. Communication initiated with peer mentors by TAY will be logged to better understand the needs of transitioning TAY.

Although caregivers will not be included in all intervention sessions, they will be invited to a separate orientation during the TAY's first session, in which they receive an overview of the program. As recommended during formative caregiver interviews, caregivers will be invited to attend an adult healthcare provider panel and a guest speaker on health insurance coverage. Caregiver collaboration with youth with a chronic condition has been associated with favorable disease management/outcomes (Vesco et al., 2010; Wysocki et al., 2009). Caregivers will be provided with a transition manual to work through on their own, based on Texas Parent to Parent's Transition Inventory. At the recommendation of caregivers, this transition manual will include discussion prompts for use with TAY to reinforce skills addressed in the group-based intervention sessions.

Discussion and practice implications

We propose a model for improving HCT for TAY and their caregivers that focuses on the mastery of specific skills needed to successfully engage in adult healthcare. These skills are based on our needs assessment of adult and pediatric healthcare providers, TAY and caregivers, and published research, and the insights of a TAY community advisory board. The use of an SDT conceptual framework and a motivational interviewing-informed approach to develop skills needed to manage adult healthcare among TAY is innovative. SDT is relevant to adolescent behavioral motivation given that competence, autonomy, and relatedness undergo significant developmental changes during this period (Springer, 2013). Despite its proven efficacy in promoting long-term health behaviors (Deci & R, 1985; Ryan & Deci, 2000), few studies on HCT have utilized SDT as a theoretical framework (Stevens et al., 2018). Motivational interviewing allows a personalized approach that takes into consideration what is important to the individual and is, therefore, consistent with the concept of taking responsibility for the management of one's own health. SDT and motivational interviewing are particularly relevant to our target population given that adolescence is a time of increasing autonomy and developing sense of competencies and expanding social connections.

The proposed project is also innovative in its inclusion of TAY from multiple subspecialty care services. The majority of HCT intervention studies address TAY receiving care from a single clinic or service (e.g., diabetes, sickle cell disease) (Hankins et al., 2012). If this intervention is ultimately proven effective, it could have an impact for a larger population of TAY and potentially be adapted to many clinical services serving TAY. Smaller subspecialties may struggle with the manpower to run a group and/or retention in a small number of eligible TAY. Having a group intervention that can function across specialties may allow for increased economic benefit and feasibility.

Engaging and training young adults with lived experience in managing chronic illness to serve as paid mentors adds an essential youth voice to all facets of the project. It also provides an important segment of the population with skills and a work record that may enable them to be competitive for future jobs, which is an important component of the broader transition to adulthood (e.g., vocation, education, housing, mental well-being) (Dresser, Clark, & Deschenes, 2015). For some young adults, this could be their first formal work experience. Moreover, as we experience mentor turnover, AYASHCN who have successfully transitioned out of the target services can be recruited to serve as

peer mentors themselves, a phenomenon that will ultimately enhance program sustainability and a broader reach. This project will also allow us to evaluate the extent to which young adults who are not clinicians can be trained to use a motivational interviewing-informed approach, which has implications for a whole host of potential interventions to promote health behavior change for the thousands of TAY who are unprepared to transition to adult healthcare.

This project utilizes a unique stakeholder collaboration that includes a TAY community advisory board, and TAY/family and pediatric and adult healthcare provider voices in developing and testing a peer-mentor intervention to promote management in adult healthcare. This is consistent with Triple Aim recommendations for improved quality of care and improved health of populations at a lower cost per capita (Berwick, Nolan, & Whittington, 2008) and our own observation that successful HCT planning is not a pediatric physician-driven phenomenon.

There is a need for evidence-based programs that address the specific skills TAY require to enter into and effectively manage their disease within the adult healthcare system. The program described in this paper, that utilizes young adults with chronic conditions who have successfully made the transition to adult healthcare as peer mentors, is one promising approach for teaching the needed skills. Evidence and outcomes, in the form of determinants, behaviors and health goals (see Logic Model), will be critical to further understand required supports for HCT in general, and also important milestones along the way to help providers, TAY and families monitor progress towards transition readiness and recognize opportunities to help TAY develop competence and autonomy.

Next steps: intervention validation

Although the intervention was developed with extensive stakeholder input, a next step is to evaluate the intervention with respect to how well it fits the broader membership in the target population. We intend to evaluate the relevancy and fit of the proposed intervention using in-depth interviews with TAY and caregivers from the three services (see Wiemann et al., 2019). Findings from the interviews will be brought back to the TAY community advisory board to interpret and apply to the final intervention, which will be evaluated for feasibility, acceptability and preliminary efficacy using a pilot randomized clinical trial design.

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Declaration of interest

None.

CRediT authorship contribution statement

Constance M. Wiemann: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Writing - original draft, Writing - review & editing. **Sarah C. Graham:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - original draft. **Beth H. Garland:** Conceptualization, Formal analysis, Investigation, Methodology, Writing - original draft, Writing - review & editing. **Albert C. Hergenroeder:** Conceptualization, Formal analysis, Investigation, Methodology, Writing - original draft, Writing - review & editing. **Jean L. Raphael:** Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Writing - review & editing. **Blanca E. Sanchez-Fournier:** Conceptualization, Data curation, Project administration, Writing - review & editing. **Jacqueline M. Benavides:** Conceptualization, Writing - original draft, Writing - review & editing. **Laura J. Warren:** Conceptualization, Resources, Writing - review & editing.

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