

Purpose

Use emic perspectives of transition-age youth (TAY) with chronic conditions to develop recommendations, which complement position statements for engaging TAY in meaningful interventions

Background

TAY, comprising the ages of 16-26 years old, experience a multitude of health risks, including higher rates of serious psychological distress and suicidal thoughts, increased participation in risky behaviors, and the beginning of chronic conditions that continue for the lifespan [1]. The need to intervene at this time period has been recognized nationally, spurring medical position statements that provide recommendations for how to provide effective healthcare for this population [2-5]. While position statements provide a strong starting point to guide healthcare for TAY, patient input provides an essential perspective to tailor developmentally-appropriate care.

Methods

This research is derived from a composite of data from three active studies. These projects focus on the needs, experiences, and preferences of TAY who primarily represent low-income, ethnic minorities. Combined data for this analysis includes:

1. narrative data focusing on real-world experiences and delivery of personalized care for TAY with spinal cord injury;
2. survey data and field notes recorded from clinical conversations at an existing community-based mental health OT setting; and
3. follow-up interviews after participating in a pilot study of a novel diabetes OT intervention.

Early, independent analysis has been conducted by each research team to identify times when emic voices directly or indirectly inform health care practices for TAY. Both convergent and divergent findings have been discussed to understand similarities and differences between practice settings.

Universal recommendations for TAY are presented here in the framework of doing, being, and becoming [6] to represent a holistic view of individuals living dynamic lives.

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Results and Implications

	Doing	Being	Becoming	Recommendation	
	<ul style="list-style-type: none"> • Activity participation, including daily experiences that encompass “wants,” “needs,” and “have tos” • Integration of illness work into everyday routines • Situated in dynamic contexts 	<ul style="list-style-type: none"> • Focus on present state of self and experiences • Desired autonomy at odds with impacts of illness/disability • Challenge of reconciling chronic condition with exploration of identity, body image • Importance of social roles within family, peer relationships, and larger social structures 	<ul style="list-style-type: none"> • The biographical narrative • Future possibilities extending beyond young adulthood • Impacted by layers of context, including illness/disability 	<ul style="list-style-type: none"> • “What [my friends and I] do isn't the same, like there's a friend that I see him every day at school, and I don't think we're together half as much because we were pretty much always on bikes... And then I'm probably closer to the friend with the RC cars because I do that with him now.” • “I would like to discuss more obvious teen needs like safe sex and things like this.” • “[My OT would] ask me... like how much longer do you have in school and what are you going to do after school... I want to move soon, so [she] helped me find information on getting health insurances and what I need to look at.” 	<ul style="list-style-type: none"> • Facilitate self-efficacy for health management through activity-based treatments. • Anticipate and attend to changes in context. • Consider role of peers and address social participation. • Discuss gender and sexuality. • Determine individual communication preferences and learning styles. • Facilitate transition of self-management and health advocacy responsibilities from parent to TAY. • Advocate for role of OT in supporting TAY with chronic conditions. • Talk about future expectations and trajectory. • Meet TAY where they are in regards to understanding and accepting their diagnosis.
	<ul style="list-style-type: none"> • “Having another college kid [as a caregiver] around is easier, and I prefer it more just because it's more of a college life than being here, knowing you need help. You do, but just avoiding the obvious scenario of I have a caretaker around me. That person is disguised as someone else who's in class.” • “My mom wants me to stop having an attitude but she also needs to play her part.” • “I'm barely entering adulthood so many are expecting me to have my life together, and I'm just not ready.” • “[The OT] never forced me to do anything that I didn't want to and he made that very clear, every time that it came down to him asking me or thinking that something will be good. [If he was more like you need to do this], maybe I would have not appreciated how he was talking to me...probably I wouldn't want to participate anymore.” 	<ul style="list-style-type: none"> • “Yeah, I like cooking. I used to say I wanted to be a chef. [Not anymore], I don't know too many chefs in a wheelchair.” • “I was like, ‘Drive?’ When I'm thinking of driving, I'm thinking put your foot on the pedal and gas, you know. But when I learned all about the hand controls and all that different thing, I was like wow, like nothing could stop you. You can do whatever you want to do really.” • “The things I need work on and the services here is helping do better and be better as a person.” • “So much time goes by where it's like, it's stuck on the back burner, but it can't be, since you live with it, you have to put it in front of everything. Because if you don't take care of yourself, at the end of the day that's what's going to burn you. Like, you're going to end up with no sight. You're going to end up with no foot... all that shit is going to happen... This is your priority. You need to take care of yourself. Because a lot of people [forget] that without taking care of yourself, there's not going to be a future.” 			