



A Patient-centered Model of Substance Use Prevention for Youth with Chronic Medical Conditions



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Background

During adolescence, opportunities to experiment with alcohol and marijuana often emerge. Theories of adolescent substance use decision-making traditionally focus on the salience of social influences. For youth with chronic medical conditions, a group that currently comprises 20-26% of our nations' youth, navigating these decisions is more complex. Substance use presents unique and serious risks of harm for these youth due to the potential for medication interactions, disease exacerbation, and treatment non-adherence.

Objective

To deepen our understanding of youth with chronic medical conditions' experiences and opinions of substance use and specify leverage points for preventive intervention grounded in their personal narratives.

Methods

Qualitative interviews were undertaken with a purposively selected sample of youth ages 16-19 in subspecialty care for a chronic medical condition they had for at least a year. Youth were consented with a waiver of parental consent under the approval of the Boston Children's Hospital IRB. Interviews were conducted in English over the phone using a semi-structured interview guide developed iteratively. Narrative data were audio-recorded, transcribed and thematically analyzed using an iterative inductive process.

Site and Sample

Participants were 25 youth in subspecialty care at a large Northeastern urban teaching hospital of whom: 11 had a rheumatic disease, including 2 with IBD-associated arthritis; 4 had IBD only; 9 had type 1 diabetes; and 1 had chronic persistent asthma. 14 were female.

Thematic Network

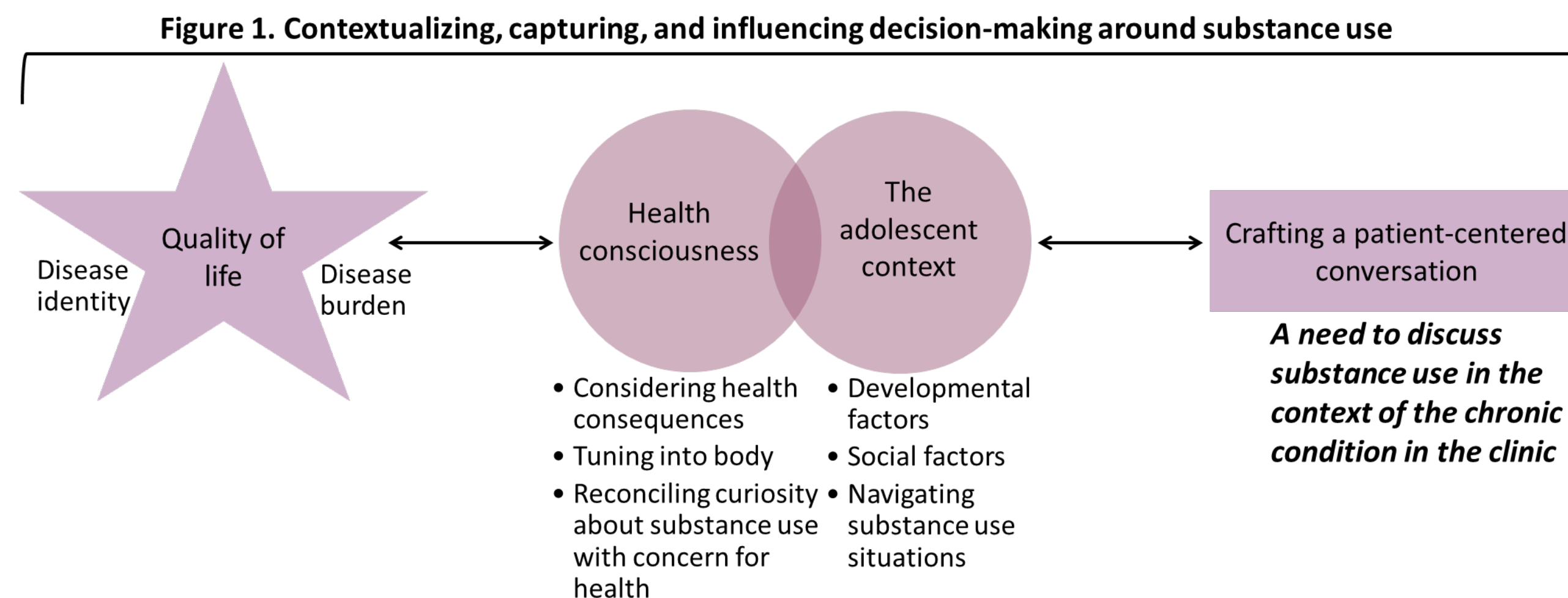


Table 1. Theme of Health Consciousness: Youth with chronic medical conditions' acute focus on health plays a central role in their decision-making around substance use.

Subtheme	Concept	Illustrative Quote
Considering health consequences	Chronic condition	I kind of just have to pay more attention to what I do during my daily life. I've had to like adjust my life according to what aggravates the arthritis and what doesn't...I think because it consumes so much of my life that I wouldn't want to just throw it away in one night [of drinking]. (Female, age 19, juvenile idiopathic arthritis)
	Alcohol & medication interactions	...Part of [my motivation for not drinking] would be one of the medications I'm taking...I cannot have alcohol because it'll have adverse effects on my liver and I would get like really, really sick. (Female, age 19, IBD-associated arthritis)
Tuning into body	Prioritizing physical cues	...I'm just hyper aware. Like if one day I'm planning on going out with my friends and my stomach hurts or something like that and I won't drink. Like that's it...I do that with everything, not even just alcohol. Like I always listen to my body. (Female, age 19, Crohn's disease)
	Valuing mental clarity	It's just all about like feeling if you're high or low, and you can lose that if you get too drunk; you don't have those same feelings anymore. (Male, age 18, type 1 diabetes)
	Using substances for symptomatic relief	I was in a lot of pain and I smoked [marijuana] and I was high and [my friend] was like "Oh, how do you feel?" and I was like "I can actually like move my leg more"...there was less of a soreness and stiffness, like I could move my leg more to a higher degree. (Male, age 16, juvenile idiopathic arthritis)
Reconciling curiosity about substance use with concern for health	Minimization of risk	...I keep [my drinking] under control pretty good. I'm not an alcoholic or anything so it doesn't affect[my diabetes] much. (Male, age 17, type 1 diabetes)
	Adjusting treatment regimen	I try really hard to take my methotrexate on the day that's like the furthest from the day that I would be drinking. (Female, age 18, juvenile idiopathic arthritis)
	Obtaining information about substance use and chronic condition	I Googled if there were any super adverse side effects [of drinking on my medication] because I remember my doctor -- he told me one or two drinks should be fine...obviously I am not looking to mess anything up I Googled it...just to make sure there were no, "you're gonna die if you do this"... (Female #2, age 19, Crohn's disease)

Findings

Four themes emerged around the topic of contextualizing, capturing, and influencing decision-making around substance use (Fig. 1).

Quality of life: Having a chronic condition shapes how these youth approach and experience life, which provides a backdrop for decision-making.

Health consciousness: For many youth with chronic conditions, their acute focus on health plays a central role in their decision-making around substance use (Table 1).

The adolescent context: Additionally, social and developmental factors that characterize adolescence play into their motivations to use or not use substances.

Crafting a patient-centered conversation: Youth are eager to have factual, nonjudgmental clinical conversations about how substance use affects their condition.

Conclusions

For youth with chronic medical conditions, their condition is a significant aspect of their life and identity that is considered when making decisions in all domains of life. For many, decisions around substance use are no exception. Youth in our sample report that health factors, in addition to the social, environmental and developmental factors that are common to all teens, weigh heavily in their substance use decisions. The close tie between the chronic condition and the decision to use substances speaks to the potential value of integrating the two topics in clinical conversations with these teens. The desire to be healthy and complication-free is a salient motivator for youth with chronic medical conditions, providing a point on which to anchor substance use prevention messages.

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