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Substance Use among Adolescents and Young Adults with Type 1 Diabetes: Discussions in Routine Diabetes Care

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Abstract

Pediatric health care providers are in a unique position to discuss the health implications of alcohol, tobacco, and drug use with adolescents and young adults (AYAs) with type 1 diabetes (T1D). This study evaluated the frequency of self-reported substance use and associated demographic and clinical characteristics in a sample of AYAs with T1D and patient-provider discussions of substance use in T1D care. Sixty-four AYAs completed questions on the Youth Risk Behavior Survey (YRBS) to report on substance use. Corresponding diabetes clinic visits were audio-recorded, transcribed, and reviewed to examine substance use discussions. 56.3% of AYAs reported ever engaging in substance use; 40.6% reported substance use within the past 30 days. Five patients had discussions about substance use during their most recent diabetes clinic visit. Substance use should be proactively addressed by pediatric health care providers and AYAs should be encouraged to raise questions related to substance use during clinic visits.

Keywords

risky behaviors; substance use; adolescents; young adults; diabetes

Adolescence and young adulthood is characterized by burgeoning independence, autonomy, and exploration.[1] While this developmental progression from dependence toward self-sufficiency is normative, increases in autonomy may be accompanied by greater engagement in risk-taking behaviors, including substance use. For adolescents and young adults (AYAs) with type 1 diabetes (T1D), engaging in relatively common risk-taking behaviors increases the risk of adverse health outcomes and complications related to T1D management.[2,3]

Alcohol, tobacco, and drug use (e.g. substance use) is relatively common among AYAs in the United States, and research suggests that youth with T1D engage in substance use at similar rates as youth without T1D.[4–6] In the general population of high school students, the 2017 Youth Risk Behavior Survey (YRBS) reported approximately 60% of students

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endorsed ever having consumed an alcoholic beverage, 30% had smoked a cigarette, and 36% had tried marijuana.[7] A secondary analysis from a large cohort study examining substance use among AYAs aged 12–26 years with chronic health conditions found that 71.7% endorsed prior alcohol use and 46.8% endorsed prior tobacco use.[5] Substance use increases throughout late adolescence and early young adulthood, particularly around developmental transitions such as entering college and moving away from the family home, suggesting this is a critical period for initiation of substance use.[5,8]

Substance use has significant implications for short- and long-term health outcomes as well as daily management of T1D. Alcohol has a hypoglycemic effect for youth with T1D,[9,10] and substances such as marijuana are associated with behaviors directly related to diabetes self-care, including appetite changes, reduced self-monitoring of physiological cues, and inconsistent blood glucose monitoring and insulin use.[11] Substance use also has been associated with increased risk of diabetic ketoacidosis and higher hemoglobin A1c levels.[8,11,12]

Practice-based standards of care acknowledge the importance of addressing substance use and misuse with AYAs as part of medical care.[9,13] However, current literature suggests that pediatric providers may not routinely discuss substance use concerns with AYA patients. In studies examining patient recall of substance use-related discussions, only 50–60% of adolescents reported discussing substance use with a primary care provider in the past year.[14,15] A recent study of youth aged 14–18 years with chronic conditions found that 70% of youth reported being asked about alcohol use in the past year.[16] Common barriers include lack of time to screen for substance use and the presence of parents during the medical visit.[17]

Diabetes health care providers (HCPs) are in a unique position to discuss substance use with AYAs, particularly as substance use has implications for diabetes management. The American Diabetes Association's Transitions Working Group recommends that HCPs working with AYAs actively discuss risky behaviors and the influence of such behaviors on T1D self-care,[9] yet quantitative and qualitative research suggests substance use is not consistently raised by diabetes HCPs.[16,18,19] Proactive discussions of substance use in routine care are associated with improved decision-making around substance use.[20] However, the absence of discussions may contribute to perceived stigma among AYAs with T1D,[18] and recent research suggests that AYAs do not consistently disclose substance use to HCPs.[16,21] Further, HCP barriers to assessing substance use may be more pronounced for youth with T1D, as specialty care visits cover a number of complex topics related to diabetes management and parents often are active participants.[22]

The current study evaluated self-reports of substance use (e.g., alcohol, tobacco, and drug use) in a sample of AYAs with T1D as well as demographic and clinical characteristics associated with substance use in the past 30 days. In addition, transcripts of diabetes medical clinic visits were examined to quantify and evaluate discussions of substance use during routine diabetes care. It was hypothesized that rates of substance use would be similar to prior published samples of youth with T1D, and that older age and living away from home would be associated with engagement in recent substance use. The examination of clinic

conversations was exploratory; however, it was hypothesized that substance use would be infrequently discussed in pediatric diabetes care, and that youth with recent substance use (within the past 30 days) would have more discussion related to substance use than those without any recent endorsement of substance use.

Methods

Participants

Participants in the current sample were enrolled in a longitudinal study evaluating AYA-HCP communication in routine pediatric diabetes care. Inclusion criteria included being between the age of 16 and 20 at study enrollment, having a preexisting diagnosis of T1D for at least one year, receiving T1D care from a pediatric HCP, having no other significant chronic medical conditions, and being fluent in English.

As part of the larger project, 211 recruitment letters were sent to potential participants. Of these, 133 AYAs were reached and deemed eligible to participate, and 75 AYAs enrolled in the study. The protocol was changed after the first 11 participants to include a modified version of the Youth Risk Behavior Survey (YRBS) to assess lifetime and recent substance use. Thus, the current study sample of 64 participants represents a subset of the larger sample with a completed YRBS survey at baseline. Clinic visit transcripts were available for 59 of the 64 participants.

Study Design

For the larger study, AYAs with T1D completed self-report measures at four consecutive diabetes outpatient visits (typically 4–5 months between each visit) in an outpatient pediatric diabetes clinic at a children's hospital in the Mid-Atlantic United States. Each visit was audio-recorded to evaluate interactions between AYAs with T1D and their HCPs. Recordings were transcribed by an independent third party. Approximately 10% of transcripts were compared to audio-recordings to ensure accuracy.

Measures

Substance Use.—The Youth Risk Behavior Survey (YRBS) is a self-report measure of engagement in various risk behaviors over the past month, year, and lifetime as well as the frequency and age of onset of such behaviors. The YRBS was created by the Centers for Disease Control and Prevention (CDC) and has been well-validated in nationally representative samples of high school youth in the United States.[23] For the purpose of this study, items from the YRBS were selected to assess the prevalence of risk behaviors that may be directly relevant to diabetes care (i.e., alcohol use, tobacco use, and marijuana/other drug use). AYA responses to YRBS items were collected confidentially for the purpose of this study and not shared with HCPs.

Diabetes-related health indicators.—Biometric data were collected from patients' electronic health records from the diabetes clinic visit date that corresponded to their completion of study measures. Relevant data collected included HbA1c and frequency of

blood glucose (BG) monitoring from glucometer data downloaded at the clinic visit (as available) as indicators of glycemic control and diabetes self-management, respectively.

Medical Clinic Transcript Data.—The content of outpatient diabetes clinic visits was audio-recorded with AYA, HCP, and parent consent. Audio-recordings of visits were evaluated by a third-party service using the Roter Interaction Analysis System (RIAS), a coding system used to quantify and evaluate medical interactions between patients and their HCPs.[24] This system analyzes the content of medical discussions and overall emotional tone of the medical visit (e.g., anger, relatedness). As part of RIAS coding, key content areas of interest were tagged by independent coders. For the current study, content areas related to alcohol, tobacco, and drug use were tagged to identify any conversation related to these topics. In addition, clinic visit recordings were transcribed by an independent transcription company and reviewed by the study team to ensure that all discussions of substance use were identified. Of note, HCPs were given no instructions to change their behavior during the medical visit and were not aware of specific content being coded.

Procedure

AYA participants consented to participate in the study in accordance with IRB protocol at the recruitment site and completed all baseline measures, including the YRBS. Participants then were seen for a standard diabetes outpatient medical visit with audio-recording. Participants received a modest incentive ($25 gift card) for completion of the baseline visit procedures.

Data Analytic Plan

Data were analyzed in SPSS version 24[25] to determine frequency of substance use endorsement over the lifetime and within the past 30 days, mean differences by group, and relation of substance use endorsement to demographic and diabetes characteristics. The study team completed a content review of transcribed medical visits based on the categories identified in the RIAS coding process to identify any discussions of substance use and evaluate how substance use was raised and discussed in the context of pediatric diabetes care.

Results

Participants were between 16 – 20 years old (mean age =17.76 years, *SD* = 1.22), with 50.8% of the sample identifying as female and 53.8% identifying as non-Hispanic white. Participants were diagnosed with T1D for an average of 8.18 years (*SD* = 4.32), with a mean HbA1c of 8.89% (*SD* = 2.41%). Nearly one-third of the sample (35.9%) was enrolled in a 2-year or 4-year college/university, and 20.3% of the sample reported living away from home. HCPs included six licensed endocrinologists/diabetologists and two licensed nurse practitioners; 88% of HCPs were female. Table 1 describes total sample demographics; the sample also was split to compare participants who did not endorse substance use within the past 30 days of their clinic visit (i.e., non-risk sample) as compared to participants who did endorse substance use within the past 30 days (i.e., risk sample).

Differences in Engagement in Substance Use by Demographic Data.

Across the sample, 56.3% of AYAs (n = 36) endorsed engaging in a risky behavior (i.e., alcohol, tobacco, and/or drug use) in their lifetime. Of those, 47.2% (n = 17) reported alcohol use only, 22.2% both alcohol and drug use (n = 8), and 13.9% (n = 5) alcohol, tobacco, and drug use. Less frequent endorsements included both tobacco and alcohol use (8.3%, n = 3), both tobacco and drug use (2.8%, n = 1), drug use only (2.8%, n = 1), and tobacco use only (2.8%, n =1). Modal age at first alcohol, drug, and tobacco (i.e., age of first trying a whole cigarette) use ranged from 15 to 16 years old. Participants also reported substance use within the last 30 days prior to their clinic visit. Out of the total sample, 40.6% (n = 26) endorsed substance use within the past 30 days. Among this subgroup, 65.4% (n = 17) reported alcohol use only in the past 30 days. An additional 15.4% (n = 4) reported both tobacco and alcohol use, 11.5% (n = 3) reported both alcohol and drug use, and 7.7% (n = 2) reported drug use only within the past 30 days. A detailed description of substance use endorsement by the non-risk sample as compared to the risk sample is presented in Table 2.

Chi-square and independent samples t-tests revealed no significant differences between patients who endorsed substance use within the past 30 days versus those who did not with respect to age, gender, race/ethnicity, disease duration, HbA1c, or frequency of blood glucose checks (all ps > .05). Significant differences were found between groups based on living situation and education level, with the non-risk sample being composed of significantly more participants living at home (89.5%, χ^2 (1) = 5.53, p = .019) and in high school (76.3%, χ^2 (1) = 6.10, p = .014) than the risk sample.

Medical Clinic Transcript Review.

Across the full sample, five clinic visits (8.5%) included discussions of substance use. All five visits were with participants who endorsed a past history of substance use (alcohol use only, n = 3; alcohol and drug use, n = 2); 3 of these 5 participants also endorsed alcohol use only within the past 30 days. All five participants were non-Hispanic white females with a mean age of 18.76 (SD = 0.95) and mean HbA1c of 8.2% (SD = 0.74%). Length of the diabetes medical visit ranged from 6.42 minutes to 49.0 minutes (M = 23.78 minutes; SD = 9.56 minutes). There was no significant difference in visit length between those that included a discussion of substance use (M = 29.57 minutes) and those that did not (M = 23.25 minutes, P > .05).

Four of the five participants with substance use discussions saw their HCP alone, with one participant accompanied by her mother. A review of discussion content revealed that HCPs initiated a conversation about substance use in three diabetes clinic visits by directly asking about substance use. The patient initiated a conversation about substance use in two visits, either in response to discussions of glycemic control (e.g., “My blood sugar might be a little high because when I do drink alcohol, I usually drink it with something that has sugar in it”) or in response to a question about any recent hospitalizations (e.g., HCP asked, “Any other hospitalizations, ER trips, surgeries, anything else since your last visit?”). All five substance use discussions included information about alcohol use. One patient was explicitly asked about drug use (e.g., “Any issues about recreational drug use?”) and no patients were

explicitly asked about tobacco use. See Table 3 for excerpts from clinic visit transcripts detailing patient-HCP discussions of substance use.

HCP discussion primarily provided education about the impact of substance use on blood glucose levels. In the majority of conversations ($n = 4$), providers gave recommendations for substance use and T1D management, including practicing moderation, consuming both a carbohydrate and protein if one is experiencing a low BG following alcohol consumption, and continuing to consistently check BG levels and treat high and low BG levels accordingly. In one interaction where the patient denied any alcohol use and no recommendations were given, the provider encouraged the patient to inform them if they were thinking about using substances in the future. Of note, this patient did endorse alcohol use within the past 30 days on the YRBS (confidential and completed for research purposes only). The clinic letters from these five medical visits also were reviewed; none of the letters sent to primary care providers contained information or recommendations about substance use.

Discussion

The present study examined substance use endorsement among AYAs with T1D, demographic and clinical characteristics associated with recent endorsement of substance use, and the frequency and content of discussions of substance use between AYAs and their HCPs during routine diabetes care visits. Over half of the AYAs with T1D in the current sample endorsed a past history of substance use, and nearly 40% endorsed substance use within the past 30 days. Despite this high rate of endorsement, substance use was not consistently discussed in routine diabetes care; only 8.5% of clinic visit transcripts included a discussion about substance use.

In the current sample of AYAs aged 16–20 years, over half of participants endorsed any past use of substances, with alcohol being the most commonly endorsed substance. Rates of reported substance use were similar to other samples of U.S. youth with diabetes, and these findings add to the literature demonstrating that youth with diabetes engage in substance use at comparable rates to youth without chronic conditions.[4,5,26] Substance use varied by education and living situation, with patients in college and those living away from the family home more likely to endorse recent substance use. This is similar to other studies of youth with T1D finding that alcohol use increases post-high school,[5,8] and supports the need for preventive education about substance use and T1D management prior to experiencing some of the seminal transitions of emerging adulthood.

In this cross-sectional sample, substance use was not regularly assessed or addressed as a part of routine diabetes care for AYAs. It is important to note that all participants in the current study were below the legal age for alcohol use or marijuana possession (in the states where marijuana had been decriminalized) and the mean sample age was below the legal age for purchasing tobacco. Specialty care providers may perceive substance use as a sensitive topic of discussion, and previously identified barriers of time and parental presence in clinic visits may influence how substance use is discussed. Specialty care providers must address complex medical needs while gathering comprehensive information from their patients

during a very limited amount of time. Parent presence during medical visits is also common and poses several potential challenges to HCPs, particularly when parental visit participation is high or when AYAs are not able to see providers alone for part of the visit.

Other potential barriers to discussion of substance use in diabetes care include insufficient training to manage endorsements of substance use, limited availability of treatment resources, or unfamiliarity with appropriate substance use screening measures.[17] A lack of discussion with HCPs may lead to inadequate information about the effects of substances and impacts on diabetes self-care. Studies of youth with chronic conditions have demonstrated that misinformation about alcohol and its interactions with medication is associated with significantly increased odds of engaging in alcohol use.[27] Thus, routine discussion of substance use and related education in diabetes care may be a critical factor in reducing risk behaviors among AYAs with T1D.

Qualitative research on AYAs with T1D indicates that HCPs are the most trusted source of information about substance use and diabetes-related risks. However, there may be stigma related to endorsement of substance use and substance use education may be perceived as conservative and inadequate.[18] Of the five medical visits with a discussion of substance use, only two discussions were initiated by the patient raising specific questions or disclosing information about substance use. Further, one patient who endorsed alcohol use within the past 30 days via confidential self-report denied alcohol use with the HCP and therefore, did not receive additional information about alcohol and diabetes management. Taken together, these findings add to the literature supporting the diabetes HCP's primary role in screening for substance use and providing education regarding risky behaviors.[28]

Results from the current study have a number of important clinical implications. Questions about substance use should be integrated into the electronic medical record or clinic-based screening measures for all AYAs with T1D. After the conclusion of this study, providers in the participating clinic included questions regarding substance use as part of a standard "adolescent risk assessment" administered during routine diabetes care visits. Proactive discussions about substance use initiated by diabetes HCPs can serve to encourage and empower AYAs to be responsible for their own health and diminish any associated stigma, and universal education with all AYAs with T1D is recommended.[21] Substance use education should be evaluated to ensure that information is current and appropriate for young adults, and these resources may benefit from review by young adults or other key stakeholders for input. Best practices in diabetes care recommend that AYAs have time alone with their diabetes HCPs to discuss sensitive topics.[9] While this was not evaluated statistically, four of the five visits which included a discussion of substance use did not have a parent present. Finally, diabetes HCPs need to address a number of critical topics in their medical visits, and time may be a barrier to addressing substance use.[17] Other diabetes team members, including nurse educators, dieticians, or behavioral health providers, are an integral part of comprehensive diabetes care and are well suited to discuss substance use and related risks with AYAs with T1D.

The present study is limited by a relatively small sample that includes participants from one pediatric medical center. Substance use was assessed via self-report from AYAs as part of

baseline questionnaire completion for a longitudinal study. Although the self-report responses were solely collected for research and thus kept confidential, it is possible that AYAs chose not to disclose substance use on self-report questionnaires. Clinic visit transcripts reflected only one diabetes medical visit per participant and as such, substance use may have been discussed in more detail at a prior or future diabetes clinic visit, which was not captured in the study. Outpatient diabetes clinic visits did not routinely include meetings with nurse educators or other HCPs. However, it is possible that AYAs discussed substance use with dieticians, diabetes educators, or other providers during their visits.

Relatively few studies have examined substance use in AYAs with T1D, and no prior studies have linked self-reports of substance use to actual content discussed in routine diabetes care visits. The current study adds to extant knowledge about rates of substance use among AYAs with T1D and highlights a key area for clinical improvement in routinely addressing substance use with AYAs with T1D. The use of clinic visit transcripts provided an objective look at how the topic of substance use is approached in vivo by HCPs. Future studies should examine substance use discussions over a longer period of time and with other diabetes team members to provide a more comprehensive assessment of education related to substance use and T1D management.

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Table 1.

Sample Demographics

	Overall Sample (*n* = 64)	**Non-risk Sample (*n* = 38)**	**Risk Sample (*n* = 26)**	***t*-test/χ^2**
Age, *M* (*SD*)	17.79 (1.21)	17.62 (1.13)	18.03 (1.31)	−1.34 (*p* = .186)
Gender, *n* (%)				.659 (*p* = .417)
Female	33 (51.6)	18 (47.4)	15 (57.7)	
Male	31 (48.4)	20 (52.6)	11 (42.3)	
Race/Ethnicity, *n* (%)				8.52 (*p* = .074)
Non-Hispanic White	32 (50.0)	17 (44.7)	15 (57.7)	
Hispanic	6 (9.4)	3 (7.9)	3 (11.5)	
Black or African American	23 (35.9)	18 (47.4)	5 (19.2)	
Asian	1 (1.6)	0	1 (3.9)	
Other	2 (3.1)	0	2 (7.7)	
Education, *n* (%)				6.10 (*p* = .014)
High School	41 (64.1)	29 (76.3)	12 (46.2)	
College	23 (35.9)	9 (23.7)	14 (53.8)	
Living Situation, *n* (%)				5.53 (*p* = .019)
At home	51 (79.7)	34 (89.5)	17 (65.4)	
Away from home	13 (20.3)	4 (10.5)	9 (34.6)	
HbA1c, *M* (*SD*)	8.89 (2.41)	8.83 (2.56)	8.97 (2.20)	−.229 (*p* = .820)
Frequency of Blood Glucose Checks, *M* (*SD*)	3.54 (2.35)	3.71 (2.26)	3.30 (2.51)	.616 (*p* = .541)
Disease Duration, years *M* (*SD*)	8.18 (4.32)	8.01 (4.72)	8.42 (3.76)	−.360 (*p* = .720)
Regimen, *n* (%)				1.08 (*p* = .583)
Pump	22 (34.4)	12 (31.6)	10 (38.5)	
Basal/Bolus	20 (31.3)	11 (28.9)	9 (34.6)	
Fixed Injections	22 (34.4)	15 (39.5)	7 (26.9)	

Note. Risk sample is comprised of participants endorsing substance use within the past 30 days of their clinic visit.

Table 2.

Substance Use Data (per YRBS) Comparison (N = 64)

	Overall Sample (*n* = 64)	Non-risk Sample (*n* = 38)	Risk Sample (*n* = 26)
Alcohol use			
Ever having at least 1 drink of alcohol	33 (51.6)	8 (21.0)	25 (96.2)
Consumed at least 1 alcoholic beverage in past 30 days	24 (37.5)	0	24 (92.3)
Tobacco use			
Ever tried cigarette smoking	10 (15.6)	4 (10.5)	6 (23.1)
Used at least 1 tobacco product in the past 30 days	4 (6.3)	0	4 (15.4)
Drug use			
Ever having used drugs at least once	15 (23.4)	4 (10.5)	11 (42.3)
Used drugs at least once in the past 30 days	5 (7.8)	0	5 (19.2)

Note. Risk sample is comprised of participants endorsing substance use within the past 30 days of their clinic visit

Table 3.

Selected Excerpts from Provider-Patient Conversations with Substance Use-Related Content

		Substance Use Endorsement (past 30 days)		
	Age (years)	**Alcohol Use**	**Tobacco Use**	**Drug Use**
Participant 1	17.8	Denied	Denied	Denied
Excerpt	**Provider:** Ok. Before I look at you, do you have any questions? Anything you want to ask? Do you know what alcohol does to blood sugars? **Patient:** Lowers them. **Provider:** Right. Why is that? **Patient:** Because it takes longer for you to digest the alcohol. **Provider:** Well, not really, but the answer to your question is correct. The answer is that it can, you're at risk for lows because what happens is the alcohol gets metabolized by the liver and the same pathway that the liver uses to break up stored glucose if you go low, you can't do it so because it's busy breaking down the alcohol, so if you don't have carbohydrates when you drink, you can go low and can pass out. So I caution you, even though I should say that drinking is illegal under 21, I have to say that, if you do drink, you need to have carbs with it… **Patient:** No.			
Participant 2	17.7	Denied	Denied	Denied
Excerpt	**Provider:** …So next question, any exposure to alcohol? **Patient:** No. **Provider:** Are you interested in trying? Not that I'm encouraging you. **Patient:** I mean, I want to know what it would do. **Provider:** Right. That's the real question. So do you have any thoughts? **Patient:** I mean [name] told me that it lowers her blood sugar but I'm don't -- **Provider:** Yes. It does. What it does, if you don't have carbs with it, the alcohol uses the same pathway as glycogen to break down glucose. So if you go low and drink alcohol, it doesn't get your blood sugar up because it's too busy metabolizing the alcohol. So if you drink, and it is illegal under 21 -- **Patient:** I know. **Provider:** Actually under -- yeah, under 21, you're putting yourself at risk for hypoglycemia. So what we tell our patients is that make sure you eat something if you're going to drink. Well, I don't recommend it.			
Participant 3	19.6	Endorsed	Denied	Denied
Excerpt	**Patient:** I think that usually, because 12:00 AM, especially on the nights when I go out, that all comes back. My blood sugar might be a little high because when I do drink alcohol, I usually drink it with something that has sugar in it. Just because I'm still sort of trying to figure out the whole alcohol with my blood sugars. **… Provider:** So you can be in total control over this. So the way -- you could say it's, okay, I need to be careful of the alcohol carbs and other carbs.			
Participant 4	19.3	Endorsed	Denied	Denied
Excerpt	**Provider:** Well, so remember what happened -- did we talk about alcohol before you went to school? **Patient:** Yeah. **Provider:** So it's hard to say exactly what happened. And alcohol, I know we talked about this last July, is tough. I mean what I would love to say to you is don't drink. But you're human, you know, so I don't expect that you are going to not drink anything when you go to college… **…Provider:** …So I think, for you, the message or the takeaway is, are you going to drink? Probably. Do I love it? No. But am I realistic? Yes. You have to practice moderation.			
Participant 5	19.4	Endorsed	Denied	Denied
Excerpt	**Provider:** And do you drink alcohol? **Patient:** No. **Provider:** Okay.			

Substance Use Endorsement (past 30 days)			
Age (years)	**Alcohol Use**	**Tobacco Use**	**Drug Use**
Patient: I'd be too scared to have diabetes. I don't want to mess with it. **Provider:** Well, that's okay. If there ever comes a time when you feel like you're ready to make that decision, let us know so we can teach you how to do it safely, okay? **Patient:** Yeah. **Provider:** Because you can do it safely. There's a safe way to do it.			