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Caregiver Comfort in Adolescents Independently Completing Screening Tablet-Based Questionnaires at Primary Care Visits

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Abstract

Objectives—The objective of this study was to assess caregiver comfort regarding adolescent completion of computerized health screening questionnaires created for adolescents.

Design—We conducted a mixed method, cross-sectional survey of caregivers of adolescent patients (n=104) ages 12–18 years that had a medical visit between June and August of 2017. Topics assessed included who completed the questionnaire, caregiver comfort and concern regarding questionnaire data, and caregiver reasons for involvement in completing the questionnaire. A one-way ANOVA was used to compare age of the adolescent and caregiver involvement in the questionnaire.

Results—The majority of adolescents (64%) reported independent completion of the questionnaire. Thirteen percent of caregivers completed the questionnaire with no involvement of the adolescent and 23% reported that caregivers and adolescents completed the questionnaire in tandem. The majority of caregivers (84%) were comfortable with adolescents completing the questionnaire. A variety of reasons were identified for caregivers completing the questionnaire (time constraints, 22%; adolescent requested caregiver help, 19%; caregiver desired to answer questions, 14%; caregiver did not realize that the questionnaire was intended for the adolescent, 11%; caregiver believed that the adolescent was too young to respond alone, 11%. Caregiver comfort with adolescent completing the questionnaire increase with age.

Conclusion—We found the reason most caregivers gave for completing the questionnaires were related to clinic processes (e.g. time constraints) Caregivers were more likely to complete the questionnaire with younger adolescents. Thus, pediatricians should consider how to best prepare families for initial questionnaires in primary care.

Introduction

Adolescence is a developmental time period characterized by the emergence of a myriad of risk behaviors.¹ These risk behaviors are associated with morbidity and mortality, including suicide, homicide, substance use, and sexually transmitted diseases.²⁻⁵ Although guidelines vary, numerous professional health societies recommend screening and intervention in primary care settings.^{1,6-10} In fact, adolescents have more screening services recommended for them than any other age group.¹¹ These recommendations differ from the guidelines of the US Preventive Services Task Force which assigns an “Insufficient” grade for some risk behavior screening in adolescents, but this is likely due to the lack of research in adolescents that met inclusion criteria for these guidelines.¹²

Despite strong recommendations for routine preventive services in clinical practice, implementation is less than ideal. For example, less than half of surveyed pediatricians report screening adolescents for substance use and less than a quarter report screening for alcohol use associated with driving.¹³⁻¹⁸ Noted clinical barriers to the implementation of preventive care recommendations for adolescents include limited resources and time allotted for visits, a lack of knowledge or self-efficacy by providers to respond to positive screens, necessary triaging of other complaints, and a lack of appropriate and efficient screening tools.^{15,16,19-21} Adolescent-specific barriers include their reluctance to discuss certain risk behaviors, such as smoking and alcohol consumption, having a caregiver (parent or guardian) present, and concerns about confidentiality and privacy.^{5,22} As such, screening for risk behaviors prior to an office visit is one way to streamline services and overcome the above barriers of time, confidentiality and privacy.

Adolescents are interested in communicating with their doctors and one way to do so is through self-screening questionnaires.²³ Utilizing questionnaires prior to a primary care visit can be quite helpful in efficiently guiding primary care visit conversations and improving preventive services.²⁴ Electronic screening tools, which are increasingly used,²⁵ have improved preventive services.^{10,14} For the most part, computerized health questionnaires more effectively elicit adolescent responses regarding high-risk behaviors.²⁶⁻²⁹ Primary care based questionnaires administered should be completed by adolescents. This is due to the nature of the questionnaires as they often ask about a personal experience related to private behavior such as sexual activity, feelings of sadness, and/or substance use. However, caregivers may be the ones who fill out the questionnaires rather than the adolescent. This could be attributed to work flow within the clinical practice and/or due a caregiver’s own interest in participating in completion of the questionnaire. For instance, prior to the age of 12, many primary care clinics have pre-visit screening forms on the child’s behavior that are all completed by the parent. Thus, clinic practice may dictate that parents receive the tablet rather than the youth. This is not ideal with adolescents as parents may well not know the extent of their child’s engagement in risk behavior or their internal mental health thought processes.^{5,30}

Due to the reasons stated above, there is a perceived need for an accurate disclosure of risk behaviors by adolescents, potentially unknown to their caregivers, during their medical visits. As such, the objective of this study was to assess caregiver comfort regarding

adolescent completion of computerized health screening questionnaires created for adolescents to complete on their own behalf at primary care visits. Furthermore, we evaluated whether caregivers aided adolescents in completing the questionnaires and, if so, their self-reported reasons. Prior to commencement of the study, we hypothesized that parents would be most comfortable with older, rather than younger, adolescents completing screening tools on their own.

Methods

Materials

The Child Health Improvement through Computer Automation (CHICA) System is a clinical decision support system (CDSS) that integrates information to generate customized pre-visit screener forms (PSF) and subsequent provider worksheets (PWS). The CHICA system operates within five outpatient medical clinics for the primary public health hospital in an urban, Midwestern city. The PSF is administered on a computer tablet and completed by the patient before they are seen by the provider. The 20-item PSF covers health-related topics, with an emphasis on age-appropriate risk behaviors. The items on the PSF are written at a fifth-grade level with average administration time of 5 minutes.

The PSF contains two alerts related to clinic protocol that patients 12 years of age or older should complete the PSF and for adolescents to complete the PSF themselves. The first alert reminds clinic staff that the adolescent patient should fill out the questionnaire if they are 12 years of age or older: "Please tell the family that <Patient Name> should answer each question." The second alert is displayed when the questionnaire begins: "These questions should be answered by <Patient Name> in private." Further information regarding the CHICA system may be found in previous publications.^{31–34}

Study Design and Screening Process

We conducted a mixed method, cross-sectional survey of caregivers of adolescent patient's ages 12–18 years who had a medical visit between June and August of 2017. We included all well visits and sick-visits where the adolescents were administered the PSF as part of pre-visit screening. IRB approval was obtained from the local university system.

Recruitment and Procedures

The CHICA screening database was queried on a daily basis to generate a list of eligible research participants. Research assistants then contacted caregivers by phone to recruit participation for the study, confirm eligibility, and obtain consent. Eligibility criteria included: (1) the caregiver of the adolescent was 18 years of age or older; (2) the adolescent was between 12 and 18 years of age; (3) the caregiver attended a primary care appointment (either a sick or well-visit) for their adolescent, of whom they are the legal guardian, within the previous 48 hours; (4) 10 or more PSF questions were answered; (5) informant and attendee questions were completed; (6) only one adolescent participant per household and; (7) caregiver participant had not been previously interviewed.

If eligible and interested in participation, research assistants asked caregivers questions about their involvement in completion of the PSF, their comfort with their adolescent completing the PSF, and whether they had any concerns regarding the content of the PSF. If the caregiver was involved with completing the PSF, they were asked a follow-up question as to their reason for involvement. Additionally, caregivers were asked to recall if they remembered receiving verbal instructions or a computer prompt for the adolescent to complete the PSF. After completing the survey, participants were compensated with a twenty-dollar gift certificate.

Analysis

Caregiver responses were transcribed and managed using REDCap electronic data capture tools hosted at the Indiana Clinical and Translational Sciences Institute.³⁵ Two authors (M.A. and S.F.) read the transcripts and grouped caregiver's responses regarding their involvement in completing the PSF into three mutually exclusive categories: adolescent-only informant, adolescent and caregiver, and caregiver-only informant. Codes were also created to describe caregiver comfort (e.g., comfortable or concerned). For caregivers involved in completing the screener (e.g., adolescent and caregiver, and caregiver-only informant groups), responses for the follow-up question regarding the reason for their involvement were coded into seven mutually exclusive categories:

1. Time constraints (i.e. they did not have enough time to complete the questionnaire before being seen by the provider);
2. Adolescent requested help from their caregiver in answering the questions;
3. Caregiver reported that the adolescent required assistance (i.e. the adolescent had a learning disability);
4. Caregiver reported a desire to be involved in the process of completing the screener (i.e. they wanted to know how the adolescent responded);
5. Caregiver was unaware that the adolescent was supposed to complete the questionnaire privately;
6. Caregiver expressed concerns with screener questions due to their child's age (i.e. the caregiver felt certain topics were not age-appropriate for their adolescent); and
7. Other

Transcripts were consecutively reviewed and coded by one author (S.F.) and a research assistant, with discrepancies resolved by consensus between the original coders (M.A. and S.F.). The kappa coefficient among reviewers was good ($k=0.87$). We compared age of the adolescent and caregiver involvement using the non-parametric Kruskal-Wallis test as the sample was skewed towards younger ages.

Results

Upon review of clinic visits to the participating sites, 1,126 possible study participants were identified, 433 of whom met inclusion criteria. Of those who were successfully contacted,

104 caregivers of adolescents agreed to participate. The majority of caregivers were female (93%) and African American (70%), with a mean age of 41.9 years (standard deviation [SD] =9.7 years). Caregivers reported that their adolescent children were primarily male (52%) and African American (74%) with a mean age of 14.5 years (SD=1.8 years). Further participant characteristics are detailed in Table 1.

Caregiver Recall

Figure 1 presents the findings related to caregiver recall of questionnaire instructions. When asked if they remember receiving verbal instructions from clinic staff that the PSF was to be completed privately by the adolescent, 45% of caregivers could recall receiving instructions. When asked if they remembered receiving an alert from the computer tablet prompting the adolescent to answer privately, 24% of caregivers recalled seeing the alert. Overall, 60% of caregivers recalled receiving either the verbal instructions, computer alert, or both.

Caregiver Involvement

According to the caregivers, adolescents completed the PSF independently 64% of the time. Caregivers reported completing the PSF without involvement of their adolescent 13% of the time. Adolescents who completed the PSF with assistance from or participation by the caregiver occurred 23% of the time.

Caregiver Comfort and Concerns

A majority of caregivers (84%) reported being comfortable with the PSF, a minority (10%) expressed concerns with their adolescent completing the PSF independently, and the remainder (6%) did not respond. Among those who reported that adolescents completed the PSF alone, caregivers predominantly reported being comfortable rather than having concerns with the questionnaire (comfortable=97%; concerns=2%; missing=1%). In comparison, when a caregiver was involved in completion of the screener, whether by assisting the adolescent or being the sole respondent, the caregiver expressed less comfort and more concerns (comfortable=69%; concerns=25%; missing=6%).

Caregiver Reasons for Involvement

The most common reason caregivers cited for involvement in completing the PSF was time constraints during the clinic visit (22%). Other reasons for caregiver involvement were: the adolescent asked for their caregiver's help (19%); the adolescent required assistance due to disability (14%); the caregiver desired to be involved with answering questions (14%); the caregiver did not realize that the PSF was intended for the adolescent to complete independently (11%); and the caregiver believed that the teen was too young to respond alone (11%). The remaining responses provided by the caregiver that could not be coded were placed into a miscellaneous category (9%). See Figure 2 for reasons provided by caregiver for completing questionnaires and Table 2 for example responses.

Mean Ages of Adolescents and Screener Completion

The mean ages of adolescent who completed the questionnaires independently, those who had caregiver involvement, and those for whom the caregiver completed the questionnaire

were compared. There was a significant association between whether the adolescent answered the PSF independently and their age, such that caregivers of younger adolescents were more likely to be involved in completing the questionnaire. Age differences between reporters was significantly different (Chi square = 10.20, $p=0.006$, $df = 2$). The mean age of adolescents who completed the screener independently was 14.9. For the group where both the adolescent and caregiver answered the questionnaire, the mean age was 13.9 and in the group where only the caregiver completed the screener, the mean age was 13.5.

Discussion

Screening questionnaires are often used in primary care practice to encourage comprehensive content coverage in adolescent preventive clinical care. These questionnaires have been shown to improve identification and discussion about risky behaviors and the delivery of preventive services.^{1,24,36} Integrating such questionnaires into the clinical workflow, however, can be difficult. Historically, self-screening questionnaires have been on paper, but with the movement towards electronic medical records, they are also transitioning to electronic platforms.³⁷ This increased use of electronic screening tools (including tablet-based platforms such as the one used in our study) can be given to the adolescent to complete prior to the clinical encounter in an effort to assist the provider in identifying risk factors. Given that adolescents report concerns regarding confidentiality and privacy during primary care visits, it is also important to maintain confidentiality and privacy when adolescents report on sensitive behavior via computer-based screening tools.^{5,30} Despite these concerns, most adolescents express a desire to discuss risk behaviors with their clinician.²³

The use of such screening tools in combination with organizational level changes such as clinician training and use of customized questionnaires and charting forms has resulted in higher delivery of preventive services for high-risk behaviors in adolescents.^{10,14} Adolescents themselves seem to enjoy the use of computerized self-screeners and surveys; moreover, some studies have shown computerized health questionnaires more effectively elicit adolescent responses regarding high-risk behaviors, although reports are conflicting.^{26–28,36} Below we highlight important issues discovered through this project.

Screening questionnaires administered in pediatric settings are typically designed for completion by adolescents on their own behalf to ensure validity. However, for a variety of reasons, caregivers may fill out the surveys themselves or be involved in the process of completing them. This is problematic as adolescents are more likely to disclose sensitive information when screening is confidential^{5,30}. From our study we found that the electronic screening questionnaire was mostly completed independently by adolescents (64%). When adolescents complete screening tools independently, it increases the potential for valid responses and is therefore useful in providing preventive services. If a majority of the questionnaires had been completed by caregivers or in tandem with caregivers, there would have been more concerns about the validity of the answers. Parents' perceptions of the correct response, or false responses provided by adolescents who feel they cannot answer accurately without privacy, would be of little use to providers trying to ascertain what risk factors may be present during a limited clinical visit.

Interestingly, we found a significant minority of youth completed the screening tool with their caregiver (23%). A large number of factors were identified as reasons for caregivers to aid an adolescent with completion of the screening tool (see Table 3). The most common reason provided was related to clinic processes (i.e. time constraints). Clinic processes can be amended to improve the possibility that adolescents can complete the screening tool in a timely manner.

We found that most caregivers were comfortable with their adolescent completing an electronic health screener prior to the clinical visit, regardless of whether the caregiver was involved in answering the questions. However, a significant proportion of caregivers expressed concern about their adolescent completing the screener. Reasons for concern included feeling that the adolescent was too young to answer sensitive questions, such as sexual activity. Caregiver concern was higher among young adolescents. Thus, clinic should be aware that for young adolescent patients, some parents may raise these concerns. One solution to this concern could be to begin building the case at a young age that questions regarding sexual behavior and substance use will be asked when a child turns a certain age. This still may not assuage caregiver concerns, but it does begin to place the sensitive screening questions in a developmental context.

Limitations and Future Areas of Research

One limitation of this study is the potential for recall bias on the part of the caregiver, although efforts were taken to minimize this by recruiting participants within 48 hours of the clinic visit. Another limitation is related to generalizability of study findings, as a majority of both caregivers and adolescents were non-Hispanic, non-Latino African Americans, and the caregivers were overwhelmingly female. Whether caregiver involvement varies based upon the sex of the caregiver is an area for future research. Other potential limitations include response bias from the caregivers on what they believe the desired response to the survey question may be, as well as selection bias of those caregivers who agreed to participate in the survey.

An area of potential future interest is the adolescent perspective on autonomous screening for risk behaviors. Previous research has shown that parental involvement can encourage adolescents to receive care for sensitive issues.^{5,38,39} In one study, the parent-adolescent relationship (including supervision, support of the teen's autonomy, and the teen's desire for involvement by the parent) impacted the adolescent's health, with the parents often being a "third person" in the adolescent-physician partnership.⁴⁰ In light of this previous study, and the results described herein, areas for future research may be to determine whether adolescents report completing the questionnaire on their own, whether they are comfortable completing the questionnaire on their own, and how they perceived caregiver involvement may have affected their response.

Conclusion

When reviewing the reasons provided for caregiver involvement, in adolescent health risk screener completion, we discovered that the reasons were generally not related to concerns about the questionnaire content being too explicit or mature. The response of the adolescent

being “too young”, which can be used as a marker for concerns about the level of perceived appropriateness for the maturity level of the adolescent, was a small percentage of reasons given for caregiver involvement. Rather, external factors such as time constraints, the adolescent having disabilities that required the caregiver’s involvement, or the caregiver simply wishing to be involved were more common reasons for the caregiver participating in completion of the screener. Moreover, the “concern” expressed by parents changed with youth age. Thus, most parents expressed no concerns regarding computer-based screening for adolescents and this concern was reduced with increased age of adolescents.

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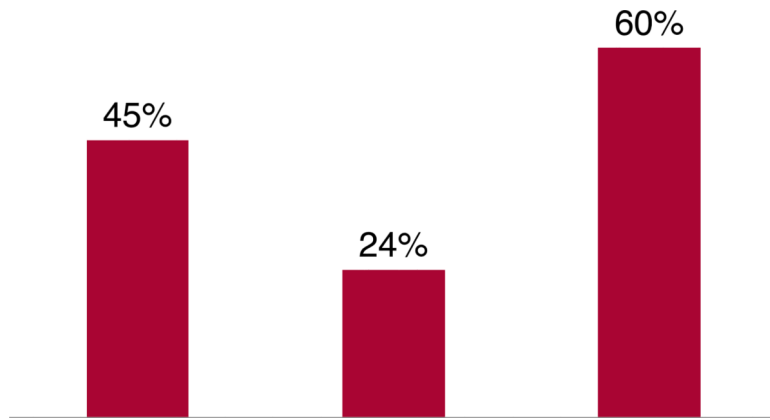


Figure 1:
Caregiver recall of screening instructions.

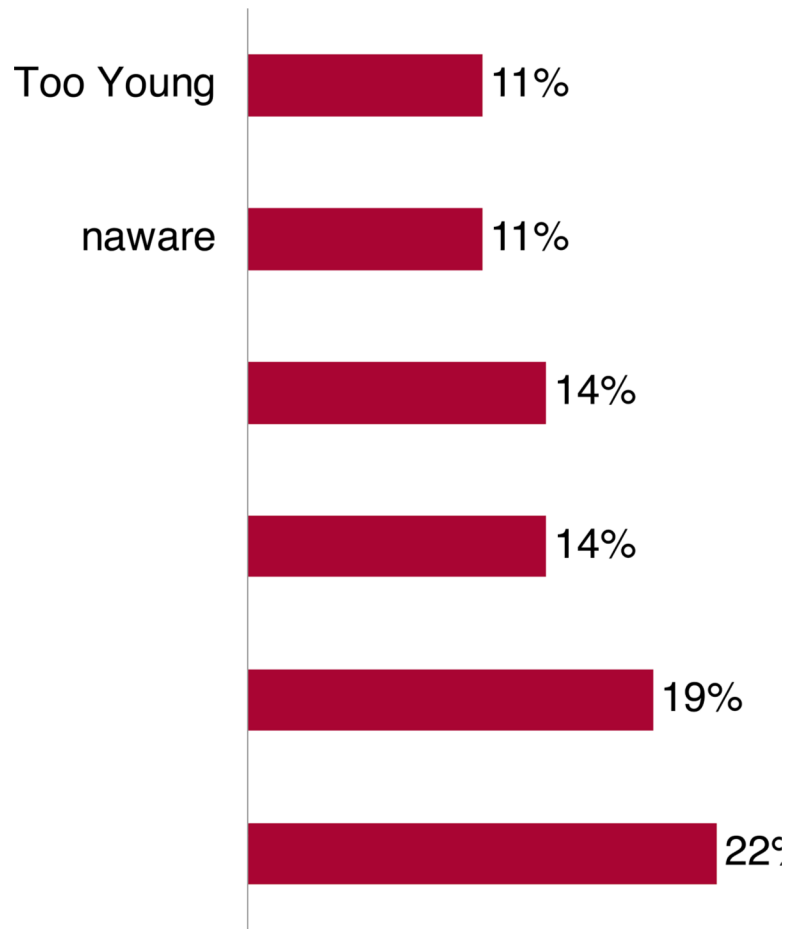


Figure 2:
Reasons provided for caregiver completing questionnaire.

Table 1.

Sample characteristics.

VARIABLES	Parent n (%)	Adolescent n (%)
Sociodemographic		
Gender:		
Male	7 (6.7)	54 (51.9)
Female	97 (93.3)	50 (48.1)
Race/ethnicity:		
Black/African American	73 (70.2)	77 (74.0)
Hispanic/Latino	17 (16.3)	18 (17.3)
White	11 (10.6)	9 (8.7)
More Than One Race	7 (6.7)	--
Unknown/Unreported	13 (12.5)	18 (17.3)
Age:		
Mean	41.91	14.52
Range	28–76	12–18
Caregiver's Relationship to Adolescent:		
Biological Mother	88 (84.6)	--
Step-mother	1 (1.0)	--
Foster or Adoptive Mother	3 (2.9)	--
Other Female Guardian	5 (4.8)	--
Biological Father	6 (5.8)	--
Other Male Guardian	1 (1.0)	--

Table 2:

Caregiver responses regarding involvement in adolescent screening.

Time Constraints	“Because we got called to the back and [they were] busy with weighing and height. If we had more time [it] would have been okay.”
	“It seemed faster for me to get it done.”
Adolescent Requested Assistance	“She just had a couple questions about them; she was just reading them out loud.”
	“She asked for help.”
Adolescent had Disability	“Because she has special needs. She answered the questions to the best of her ability and I was beside her to help answer anything she couldn’t understand.”
	“[My] son is disabled. He has a hard time reading.”
Caregiver Desired to be Involved	“I was right there in the room with her, watching over her and helping.”
	“He’s never filled one out [before]. It asked a lot of questions, I wanted to show him the questions.”
Caregiver Unaware	“Because I honestly thought it was forms for me to fill out.”
	“I thought they wanted me to do it. They didn’t say that she was supposed to do it.”
Adolescent Too Young	“Felt like questions were deep; shocked by the question regarding sexual activity mostly because [he] is so young.”
	“[I] almost couldn’t believe asking some of these questions [to] a 12-year-old.”
Miscellaneous/Could Not Code	“I didn’t feel anything because [I] wasn’t sure what the questions were.”
	“Because she was taking care of another child.”