Adolescent Decisional Autonomy Regarding Participation in an Emergency Department Youth Violence Interview

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Much attention has been given to determining whether an adolescent patient has the capacity to consent to research. This study explores the factors that influence adolescents’ decisions to participate in a research study about youth violence and to determine positive or negative feelings elicited by being a research subject. The majority of subjects perceived their decision to participate to be free of coercion, and few felt badly about having participated. However, adolescents who were alone in the room during the assent process were more likely to report that they chose freely to be a research subject. This study may influence the ways physicians communicate with adolescent patients around research assent within a clinical care environment.

INTRODUCTION

Over the past several decades, much attention has been given to determining the extent to which an adolescent patient has the capacity to consent to research or medical treatments (English 2000). Although research may enhance health promotion and disease prevention for adolescent subjects, guidelines state that, with very specific exceptions, research on an adolescent can only be done with parental permission and patient assent (English 1995; Mammel and Kaplan 1995; Sigman et al. 1997). Assent is often unstructured and vague. In this light, it remains unclear to what extent adolescents who participate in research do so of their own volition (Santelli et al. 1995).

Research on youth violence is often based on cross sectional, self-reported data; there are advantages and disadvantages to collecting these data in the Emergency Department (ED) directly after a violent event has occurred. Often, the only point of medical contact for violently injured urban youth is the Emergency Department (Ziv et al. 1998). Their recollection of the event may be more accurate in the hours or days afterward, and it is possible that the “teachable moment” can open doors for future interventions (Ziv et al. 1998). However, it is not known which factors influence an adolescent’s decision to participate in a research endeavor related to youth violence, and to what extent the presence of parents or other authority figures influence this decision while in the ED.

The objectives of this study are to explore the factors that influence adolescents’ decisions to participate in an ED-based research study about youth violence, and to determine the positive or negative feelings elicited by being a research subject. We hypothesized that adolescents would report having participated of their own volition. We further hypothesized that we would be able to identify factors that influenced the adolescent’s perceptions of his or her choice to participate.
METHODS
We enrolled a consecutive sample of ED patients, ages 11–19 years, between January 21, 2000 and April 25, 2000 from a children’s hospital and an adult hospital at an urban academic center. IRB approval was granted at both institutions. Patients were eligible for inclusion in this study if they were injured as a result of a violent event, defined as an altercation between two or more people in which there was some intent to harm. We excluded patients whose injuries were considered accidental, due to child abuse or domestic violence, or if they were too ill to participate in an interview. Social workers were prepared to assist any youth who reported feeling upset or who showed signs or symptoms of distress either from the incident or from participation in the research interview.

A research assistant (RA) first consented the parent or guardian to allow the adolescent to participate in the study. The RA then asked the adolescent to participate in the study using a specific script:

I’d like to ask you a few more questions about what has happened. Everything you tell me is private, unless I think you or someone else is in danger. It will only take a few minutes and you will get the best care we can provide, whether you agree to talk with me or not. Is this OK with you?

The RAs were college or postgraduate students who were enrolled in a course about clinical research, and underwent an initial training session during which they learned to obtain consent and assent. The RAs also underwent periodic monthly retraining during which questions were answered and issues regarding the study were addressed. The RAs administered a violence assessment survey to enrolled subjects using a structured interview. The survey included questions about the details of the event, the patient’s lifestyle, a depression screening measure, and the patient’s emotional response to the event. Upon completion of the survey, subjects answered three questions about their research participation (each requiring a “yes,” “no,” or “maybe” answer):

1. CHOICE: “It was my choice to participate in this interview; I could have said ‘no’ even if others wanted me to say ‘yes.’”
2. GLAD: “I am glad that I agreed to answer these questions.”
3. UPSET: “Answering these questions made me feel bad or upset.”

RESULTS
Of the 94 eligible patients who were approached in the ED, 70 (74%) completed the entire survey, including the corresponding questions related to study participation. No participants who completed the violence assessment portion of the questionnaire refused to answer the three research participation questions. The 24 non-participating patients did not significantly differ from the 70 enrolled patients in terms of their gender, age, race, or nature of the violent event. The 70 enrolled participants ranged from 11–19 years of age with a mean age of 13.7 years (SD = 2.1). Forty-eight (67%) of the participants were male. Sixty patients (86%) were Black, 1 was White, and 2 were of another race. In 7 (10%) the patient’s race was unknown. Forty-three (61%) of the participants reported being injured in a fight/argument and 24 (34%) reported an assault (uninitiated by the participants); for 3 patients (4%) this information was not known.

Fifty-four participants (77%) stated that it was their own choice to take part in the interview (CHOICE). Fifty-nine participants (84%) reported that they were glad they agreed to answer the survey (GLAD). Three participants (4%) stated that answering the interview questions made them feel upset (UPSET), and 7 more stated that they may have been upset (see Table 1). These ten patients were mixed with regard to whether or not they were glad to answer the interview (GLAD): six answered “yes,”
Table 1. Number (Percent; 95% CI) of Participant Responses to Survey Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Maybe</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>It was my choice to participate; I could have said no even if others</td>
<td>54 (77%; CI)</td>
<td>9 (13%; CI)</td>
<td>7 (10%; CI)</td>
</tr>
<tr>
<td>wanted me to say yes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am glad that I agreed to answer questions.</td>
<td>59 (84%; CI)</td>
<td>9 (13%; CI)</td>
<td>2 (3%; CI)</td>
</tr>
<tr>
<td>Answering questions made me feel bad or upset.</td>
<td>3 (4%; CI)</td>
<td>7 (10%; CI)</td>
<td>60 (86%; CI)</td>
</tr>
</tbody>
</table>

three answered “maybe,” and one answered “no.” All 16 (23%) participants who suggested that it may not have been their choice to partake in the interview (responded “maybe” or “no” to CHOICE) still felt positively about the experience: 14 answered “yes” to GLAD, and two answered “maybe.” Only two of these 16 patients reported that the questions may have made them feel upset (1 “yes” and 1 “maybe”).

Potential Influences on Patients’ View of Research Participation

No significant differences were found in responses to the three survey questions based on gender, age category, or whether the injury was sustained in an assault versus a fight.

For 54 of the 70 participants (77%), the research associate documented whether or not the subject was alone in the room at the time of the consent process. Of these 54 participants, those who had someone else present with them in the room at the time that they gave assent were more likely to give an answer of “maybe” or “no” when asked about CHOICE ($p < 0.03$; Table 2).

DISCUSSION

This study provides support for adolescents’ participation in research interviews, even in the midst of a stressful situation such as an ED visit for violent injury. The majority of our participants reported having made their own choice about taking part in a research and were glad they participated. Very few (only four percent) reported being upset by the experience. Feeling upset was not necessarily tied to regret about participation (most who reported being upset were still glad to have participated). A patient’s perception of whether or not he made a fully autonomous choice was not associated with regretting participation or feeling upset by participation. These findings are reassuring for researchers interviewing adolescent patients, indicating that the overall experience may be a neutral or positive one for adolescent participants, even when the consent/choice process is not perfect, or when the adolescent experiences some discomfort during an interview.

The issue of an adolescent’s decision-making capacity (and his or her perception of the consent process) is central to both research and clinical practice with this age group (Hartman 2001). Legal views of child and adolescent capacity for consent for clinical treatment are evolving. As recently as 1971, patients under twenty-one years of age were not allowed to provide consent for their own medical treatment (Schlam and Wood 2000). A 1987 Tennessee Supreme Court ruling serves as an example of the evolution of minor consent laws. By adopting the “Rule of Sevens,” the Court held that it is rarely reasonable for a physician to treat a patient under the age of seven without parental consent, that patients age seven to fourteen are presumed incapable to consent, and that over the age of fourteen, minors should be presumed capable of consenting to medical care (Glantz 1998). Currently, in many jurisdictions, adolescents are given legal authorization to consent to their own medical care in specific situations (such as emergency medical services, substance abuse, or sexually transmitted disease) or with special legal status (e.g., emancipated minors; English 2000).

Research regarding adolescent decision-making suggests that adolescents are capable of adequate decision making in a range of situations (Glantz 1998; Hartman 2001; Schlam and Wood 2000). This research indicates that, even in emotionally challenging situations, older adolescents are capable of similar levels of volition and cognitive competence as
legal adults (Hartman 2001). A survey of physicians who care for adolescents found that the majority reported that adolescent patients are capable of understanding medical treatment and conditions, engage in rational decision-making, and clearly convey their choices and concerns (Hartman 2001).

In the present study, more than three fourths of subjects aged 11 to 19, who had agreed to participate in an interview during their ED treatment, reported having made their own choice regarding that participation. When a parent or other family member was in the room at the time the patient was asked for consent, fewer adolescents reported having made their own choice about participating. This may indicate that adolescents perceive their decisions about research or treatment to be more autonomous, and under less influence from others, when made alone with the person requesting consent. This interesting finding can guide both researchers and clinicians as they seek to establish the optimum environment for adolescents to make honest and independent decisions. To adequately care for the adolescent patient, whether he or she is a victim of violence seen in the Emergency Department or a healthy patient presenting to a clinic for routine care, a physician must strive to create an atmosphere that protects the patient’s autonomy, as well as privacy. Health care providers should be cognizant of factors in the clinical encounter that may influence the adolescent’s perception of decision-making, including the presence of family members or misconceptions about the clinician’s promise of confidentiality. For example, adolescent concerns about privacy can decrease their willingness to seek health care for sensitive health problems and impinge upon their open communication with physicians (Ford et al. 1997). Published recommendations for physicians who care for adolescents guide them in assuring confidential care for their patients (Ford et al. 2001). A position paper by The Society for Adolescent Medicine has endorsed this viewpoint (Sigman et al. 1997). Most adolescent practitioners subscribe to the notion that, although privacy of information is paramount in forming a therapeutic relationship with these patients, it is also important to include parents or family in appropriate ways that support the adolescent’s health and welfare. The present study does not dispute this approach; rather it suggests that we must be mindful of the relationship between privacy and an adolescent’s perception of autonomy when requesting assent for research participation.

Less conventional methods of communicating with adolescents might present viable options for the future, to facilitate the sense of privacy and active decision making from adolescents. For example, computer-based questionnaires have been developed that ask adolescents about issues relevant to their personal health and lifestyles. One study found that a computerized self-assessment led to a two- to three-fold increase in adolescents’ intentions to discuss lifestyle questions with their physician (Cross 1994). Another established the ability of computer-assisted interviews to obtain stable test-retest responses to questions on sensitive topics when used on adolescents (Stanton et al. 1996).

This study possesses several limitations. First, we explore the issue of consent and assent but are not able to examine the reasons for refusal among patients who opted not to participate in the study at all. Though non-participants did not differ from participants in their sociodemographic profile or injury status, they may have differed from our subjects in relevant ways, such as level of frustration with their experience in the ED, or impatience with the length of time needed for their care. More relevant to the area of this study’s interest, non-participants may have been influenced not to consent to the study by the adults accompanying them. It would have been useful to know more about the non-participants, and of the factors that influenced them to refuse participation. Moreover, since our study demonstrated a significant difference between those who had parents in the room and those that did not, data recording the presence or absence of adults for non-participants would have been helpful but was not collected. Next, regarding the question concerning choice, the wording “even if others wanted me to say yes,” could have been interpreted as referring to anyone involved in the consent process including the study personnel. Since study personnel were present for all subjects, any difference between groups appears to be attributable to the presence of family or friends during the consent procedure. Finally, our sample size precluded us from exploring differing consent/assent needs by developmental stage. Because individuals pass through several moral and cognitive developmental stages during adolescence it would be a mistake to assume that the 11-year-old patient has the same needs as the 19-year-old.

CONCLUSION
This study revealed that, in the context of a research protocol within a clinical care environment,
the majority of violently injured adolescent participants believed that their decision to take part in the study was autonomous and free of coercion, and few felt badly after answering very personal questions about themselves and the event. However, adolescents were more likely to perceive that they chose freely to be in the study if they were alone in the room when assent was obtained. Future studies with larger samples may be helpful to investigate further how these findings relate to the evolving decisional development of adolescents in different developmental stages, and in varied cultures. ■

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REFERENCES


