



Original article

Parent Perspectives About Sexual Minority Adolescent Participation in Research and Requirements of Parental Permission



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Article history: Received March 31, 2016; Accepted May 20, 2016

Keywords: LGBTQ adolescents; Parents; Research ethics; Informed consent; HIV surveillance

A B S T R A C T

Purpose: Lesbian, gay, bisexual, transgender, and other sexual and gender minority (LGBTQ) adolescents and young adults experience health inequities relative to heterosexuals but may be reluctant to participate in research that requires guardian permission. Institutional review boards are often reluctant to approve studies without parental permission because of concerns about parent reactions. There is little to no data from the parent's perspective on these issues. We aimed to understand parent perspectives on parental permission requirements for minimal risk studies of LGBTQ health inequities.

Methods: We conducted semistructured interviews with 31 parents of LGBTQ individuals. We presented a vignette describing an HIV behavioral surveillance protocol and assessed beliefs about whether parental permission should be required under various conditions (i.e., varying adolescent demographics, study procedures).

Results: Most parents (74.2%) believed that parental permission should not be required, and this percent increased when considering adolescent participants for whom permission would be less feasible or potentially more dangerous (e.g., homeless adolescents). Qualitative analyses revealed that many parents were concerned about research quality and negative consequences for adolescents if permission was required. Others wanted to help support their child in making decisions about research and health care.

Conclusions: Most parents believed that parental permission should not be required for a minimal risk study, and the reasons for their beliefs fell squarely in line with federal regulations regarding adolescent self-consent to research. Studies of LGBTQ adolescent health inequities should receive waivers of parental permission to obtain representative samples and minimize risk of harm to the adolescent.

IMPLICATIONS AND CONTRIBUTION

Little to nothing is known about parent perspectives on sexual minority adolescent participation in research and requirements of parental permission. These analyses provide data from the parent's perspective, demonstrating that most parents of sexual minority adolescents approve of their children participating in minimal risk research without permission.

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Lesbian, gay, bisexual, transgender, and other sexual and gender minority (LGBTQ) adolescents and young adults experience various health inequities relative to heterosexuals [1–7]. LGBTQ adolescents younger than 18 years may be reluctant to participate in studies that require guardian permission, which in turn intensifies problems of recruitment and unbiased sampling

[8,9]. Such reluctance is based in part on not being open about their sexual orientation, lacking support from all or some family members, and too often being victimized by their families after disclosure of sexual orientation [10–14].

Federal regulations for human subjects research state that the assent of the child and the permission of the parent(s) are required for research with minors. However, institutional review boards (IRBs) have two general pathways to approve a research study involving participants younger than 18 years that does not seek to obtain parental permission. First, an IRB may determine that minor participants should not be considered “children” for the purpose of the research study. According to 45 CFR 46.402: “Children are persons who have not attained the legal age for consent to treatments or procedures involved in the research, under the applicable law of the jurisdiction in which the research will be conducted.”

Multiple organizations have provided guidance for interpreting this definition, stating that the definition of “children” varies based on laws in each jurisdiction that describe the legal age of consent for the types of treatments and procedures involved in the research [15,16]. Very few jurisdictions describe the legal age of consent for research, and therefore it becomes necessary to rely on the age of consent for the procedures involved in the research (e.g., HIV testing) in making a determination about whether minors should be considered “children” for the purpose of a research study [8]. According to the Society for Research on Child Development, “... an adolescent who by state law has the right to consent to and obtain reproductive and sexual health medical care without parental permission should also have the right to autonomously consent to epidemiological, observational, interview and survey research exploring the antecedents and sequelae of adolescent sexual health behaviors and to intervention research on the effectiveness of related preventive and intervention strategies” [17].

Second, an IRB may approve a waiver of parental permission even if minors are legally considered to be children. Parent permission may be waived if “...the research protocol is designed for conditions or for a subject population for which parental or guardian permission is not a reasonable requirement to protect the subjects (for example, neglected or abused children)...” (45 CFR 46.408[c]). Requiring parental permission for studies of LGBTQ adolescent health may “out” these young people to their parents before they are ready or before it is safe to do so. For these and related reasons, the Health and Human Services (HHS) Secretary’s Advisory Committee on Human Research Protections recommended that studies involving high-school students who may not have revealed their LGBTQ identity to their parents be accepted as studies which offer “a credible argument that serious physical, social or psychological harm may come to child subjects if parents/guardians are informed about the reason for the study” [18].

Only a handful of studies have examined parent perspectives on requirements of parental permission for minimal risk research with adolescents. These studies used samples of parents of presumably heterosexual adolescents and found that most parents believed that permission should be required for research studies of sexuality and risk behaviors (e.g., substance use), particularly when medical procedures were involved (e.g., HIV testing) [19,20]. However, given that potential added risk of requiring parental permission for LGBTQ adolescents, parent perspectives on requirements of parental permission for LGBTQ adolescents may differ. Very few studies have been published

assessing the practicality of conducting research on LGBTQ adolescent health with parental permission [8,21]. In one exception, Mustanski [8] found that a majority of LGBTQ adolescents and young adults held negative attitudes toward and would not agree to participation in sexual health research if guardian permission was required.

While the studies and policies described previously provide compelling evidence that IRBs should use these avenues for determining that a study of LGBTQ adolescents may be conducted without parental permission (particularly in the context of health inequities that disproportionately affect LGBTQ adolescents), many IRBs are reluctant to do so [22,23]. In our own work, the IRB has asked us to provide data from the parent’s perspective on the acceptability of conducting research with LGBTQ adolescents without parental permission. As such, the purpose of this study was to describe parent’s perspectives to aid researchers, IRBs and policy makers in better understanding the nuances in conducting research with LGBTQ adolescents with and without parent permission. This qualitative study was conducted as formative research for an HIV behavioral surveillance study of adolescent men who have sex with men (MSM). Adolescent MSM are at high and increasing risk for HIV [7], and high-quality research with unbiased samples is needed to understand this elevated risk. We currently know little to nothing about how parents of LGBTQ adolescents feel about their participation in research, and to our knowledge, these analyses provide the first data from this perspective.

Methods

Participants, recruitment, and procedures

Participants were 31 parents of LGBTQ individuals who were recruited locally through multiple sources, including advertisements sent to e-mail listservs relevant to parents of LGBTQ individuals (67.7%), presentations at community groups (6.5%), and participant referral (25.8%). See Table 1 for demographic characteristics of the sample. Advertisements and in-person presentations described a university study that aimed to better understand issues related to LGBTQ adolescent participation in research. All interviews were conducted between February and

Table 1
Demographic characteristics of parent respondents and their children, N = 31

Demographic characteristic	n (%)
Child gender	
Cisgender male	12 (38.7)
Cisgender female	9 (29.0)
Transgender	10 (32.3)
Child current age	
Adult	24 (77.4)
Minor	7 (22.6)
Race	
White	23 (74.2)
Black/African-American	3 (9.7)
Hispanic/Latino	2 (6.5)
Asian	1 (3.2)
Other	2 (6.5)
Parent gender	
Cisgender male	4 (12.9)
Cisgender female	27 (87.1)

“Cisgender” refers to people whose current gender is the same as the gender assigned at birth.

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