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Obtaining Waivers of Parental Consent: A Strategy Endorsed by Gay, Bisexual, and Queer Adolescent Males for Health Prevention Research

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Abstract

Background—Requiring parental consent in studies with sexual minority youth (SMY) can sometimes be problematic as participants may have yet to disclose their sexual orientation, may not feel comfortable asking parents' permission, and may promote a self-selection bias.

Purpose—We discuss rationale for waiving parental consent, strategies to secure waivers from review boards, and present participants' feedback on research without parents' permission.

Method—We share our IRB proposal in which we made a case that excluding SMY from research violates ethical research principles, does not recognize their autonomy, and limits collection of sexuality data.

Discussion—Standard consent policies may inadvertently exclude youth that are at high risk for negative health outcomes, or may potentially put them at risk due to forced disclosure of sexual orientation. Securing a waiver addresses these concerns and allows for rich data, which is critical for providers to have a deeper understanding of their unique sexual health needs.

Conclusion—To properly safeguard and to encourage research informed by SMY, parental consent waivers may be necessary.

Keywords

LGBTQ health; nursing research; waiver of parental consent; research ethics; gay, bisexual, or queer males

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Introduction

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) youth are in need of research to help us better understand their health issues, especially in terms of HIV/STI prevention. However, the perception that they are high risk and are a vulnerable population also implies that more protections must be formulated to safeguard them from research harm (Elze, 2009). In an effort to protect them from research-related harm, varying interpretations by regulatory boards of minimal or acceptable levels of risk have led to overestimation of potential psychological harm stemming from research participation (Fisher & Mustanski, 2014), particularly when it comes to sexuality-based research (Miller, 2006). Despite the Declaration of Helsinki's statement that calls for research involving disadvantaged populations that is responsive to their health needs and priorities (World Medical Association, 2004), regulatory boards inadvertently limit the participation of LGBTQ youth in studies, which systematically ensures that they remain an obscured and marginalized population (Schelbe, et al., 2015). Across the world, requiring parental permission during adolescent sexual health research, including LGBTQ youth, is viewed as problematic when they otherwise have full capacity to make informed choices (Ashcroft, Goodenough et al, 2003; Balen, et al., 2006; Hunter & Piersionek, 2007; Scott, 2013; Taylor, 2008, Zuch et al., 2012).

Compared to their heterosexual counterparts, LGBTQ youth more frequently engage in risky sexual behaviors that increase their lifetime chances of acquiring HIV. In a U.S. survey on health behavior risks, LGBTQ youth had a pronounced difference in HIV-related risks compared to heterosexual individuals, including earlier age of sexual initiation, having had sex before the age of 13 and having more than four sexual partners (Eaton et al., 2012). Despite the elevated risky sexual behaviors of these LGBTQ youth, limited research has been conducted that directly gathers data from their points of view (Allison et al., 2012; Mustanski, 2011). Very few publicly funded population-based data systems use or ask standard questions about sexual orientation or gender identity (Institute of Medicine [IOM], 2011; Meyer & Wilson, 2009). Since 1989, only 0.5% of NIH-funded studies were related to LGBTQ health (Coulter, Kenst, Bowen, & Scout, 2014). Further, studies on topics of a sensitive nature, such as LGBTQ sexual attraction and behavior, are challenging to conduct and fraught with methodological limitations (D'Augelli & Grossman, 2006; Fisher, 2012; Grov, 2012; IOM, 2011; Miller, Forte, Wilson, & Greene, 2006; Savin-Williams, 2008).

Background

In general, nursing research on broad LGBTQ health issues has been inconsistent while focus on their civil and human rights have been largely overlooked (Keepnews, 2011). While there has been an increase in nursing research about LGBTQ adult health (e.g., 2016 special issue on LGBTQ health by the Journal of Research in Nursing), attention to young LGBTQ people's health remains on the margins. With nursing's slow integration of LGBTQ-related content to its curricula (Carabez, Pellegrini, et al., 2015), the discipline's researchers are strongly encouraged to pursue robust knowledge generation to inform practitioners, advocates and policy makers about this young population's health (Culley & Haigh, 2016).

Research designed to be sensitive to children's unique circumstances can result in the accurate collection of their experiences and views (Docherty & Sandelowski, 1999). However, requiring parental consent may select for adolescents who are at lower risk and may exclude teens who do not feel comfortable openly discussing their life experiences for fear of disclosure to their parents. Obtaining waivers of parental consent is an underused strategy that allows for the inclusion of LGBTQ minors in research without obligating youth to request permission from their parents.

This article will discuss our experiences in securing such a waiver, detail the strategies we employed to address the Institutional Review Board's (IRB) anticipated concerns, explain responses to stipulations required for our study, and enumerate study design features that researchers can incorporate in their research proposals to successfully allow LGBTQ minors to participate in research without parental consent. The article includes the perspectives of self-identifying gay, bisexual and queer males, ages 15 to 17 years old, regarding participating in our study without their parents' permission. Their thoughts about waiving parental consent will assist in clarifying issues about realistic measures for research protection.

United States Federal Guidelines on Adolescent Research

When it comes to research involving children and adolescents, most IRBs follow the Common Rule (45.CFR.46 Subpart A) (U.S. Department of Health and Human Services [DHHS], 1991) that requires assurances that research institutions will conduct studies that protect the rights and welfare of all individuals. The Additional Protections for Children Involved as Subjects in Research (45.CFR.46 Subpart D), (U.S. DHHS, 2015) serve as guidelines regarding required parental consent and child assent in research. Porter (1999) explained that pursuant to 45.CFR.46.116 (d), an alteration of the consent requirement may be made if it meets the following criteria:

1. The research involves only minimal risk;
2. The rights and welfare of the participants will not be adversely affected;
3. The research cannot be practically carried out without the waiver;
4. When appropriate, the participants are provided with additional pertinent information after participation, such as when a study generates new information about medical interventions that were used on the subjects.

Making the case to regulatory boards that participation in a study only entails minimal risk is a critical gateway to the approval of research involving minors (Fisher & Mustanski, 2014). To meet the minimal risk criteria, researchers have to make the case that participation will not present any greater risk to the subject than they already face in daily life or during the performance of routine or psychological examinations or tests (English, 1995). For the risk to be considered minimal, only one standard of the two (daily life or routine examinations) must be met (Nelson, Lewis, Struble, & Wood, 2010).

Data Sources

Our original study involved an examination of communication patterns between parents and their gay, bisexual, or queer (GBQ) sons. Studies on parent-child sex communication that have mostly sampled heterosexual adolescents show these conversations can lead to effective HIV prevention interventions. Forty years of sex communication research has provided strong evidence that effective communication about sex can delay sexual initiation (Sneed, 2008), promote greater efficacy with condom use (Buzi, Smith, & Weinman, 2009; Miller & Whitaker, 2001), enhance resistance when pressured to have sex (Hutchinson & Montgomery, 2007), and result in a higher tendency among LGB adolescents to access and use reproductive and sexual health services (Crosby et al., 2009; Hall et al., 2012; Hutchinson & Cederbaum, 2011; Kapungu, Baptiste, Holmbeck, et al., 2010). Data about sexuality-specific sex education provided by parents to GBQ sons in the home, however, have only begun to be published and with mixed results.

Since research on the perceptions of GBQ sons regarding sex communication has been underexplored, a qualitative study with semi-structured interviews was proposed to ascertain the descriptions and meanings participants attribute to the communication process. Participants included 15- to 20-year-old individuals who self-identified as GBQ and who could recall at least one conversation with their parents about sex. Participants included GBQ sons who may have already disclosed their sexual orientation (those who have “come out”) and those who have not disclosed their sexual orientation (those who are “in the closet”) to their parents at the time of the interview, allowing the exploration of how parents' knowledge of a child's sexual orientation affected sex communication in the household.

Since this study was designed to include GBQ sons who had not disclosed their sexual orientation to their parents, or whose parents may know but are not supportive, a waiver of parental consent was requested from the IRB. In recent years, waivers of parental consent have been used effectively to advance health research for LGBTQ adolescents and young adults (Bruce, et al., 2011; Outlaw et al., 2011) and thus, we proposed that the knowledge we generate may ultimately help curb the HIV infection rates of this high-risk population, who are soon to be beyond the influence of direct parental supervision.

Rationale for Requesting a Waiver of Parental Consent

Our team presented our request to the IRB Chairperson for a waiver of parental consent, which described the need to conduct research in order to understand, prevent, or alleviate a serious problem affecting the health or welfare of children. We proposed that 15- to 17-year-old adolescents have unique psychosocial issues and are in a cognitive and developmental stage that distinguishes them from younger or older GBQ males. The following section details our rationale for requesting from the IRB a waiver of parental consent.

Undisclosed sexual orientation to parents—Our team proposed that many of our target GBQ participants may not have disclosed their sexual orientation to their parents, or may have already disclosed but may have parents who are not accepting of their sexual orientation. Parental reactions upon learning of a child's non-heterosexual identity range from unconditional support and acceptance to hostility, rejection or even expulsion from the

home (D'Augelli et al., 2005; D'Augelli, Grossman, Starks, & Sinclair, 2010). Within the family, the immobilizing fear of an anticipated negative reaction from parents (Pearson & Wilkinson, 2012; Savin-Williams, 2001b) often keeps GBQ sons from disclosing their sexual orientation and inhibits open and honest dialogue about sex-related concerns. We argued that a waiver of parental consent would safeguard participants from risks associated with forced disclosure (D'Augelli & Grossman, 2006; Mustanski, 2011), especially about a sensitive topic where deferring to parents' permission can actually place participants at a higher risk (Chabot, Shoveller, Spencer, & Johnson, 2012; Ruiz-Canela et al, 2013; Martin and Meezan, 2003).

High-risk versus competent minors—Adolescents, including LGBTQ youth, are capable of adult-level decision making because they begin to engage in more abstract thought, develop competence and become future oriented (Kim, 2004; Lindeke, Hauck, & Tanner, 2000; Piko & Gibbons, 2008), and have the same decision-making capacity as adults regarding their medical care and research participation (Fisher, Arbeit, et al, 2016; Kives, 2008; Steinberg, 2013), with many beginning to show decision-making competency at age 14 (Santelli et al., 2003; Susman, Dorm & Fletcher, 1992). Being GBQ also does not predispose them to risk of coercion or undue influence to participate in research (Mustanski, 2011). The Society for Adolescent Health and Medicine (Reitman et al., 2013) has in fact advocated for future health research to be inclusive of and focused on LGBTQ individuals.

Our team proposed that the target population has the ability to reason as adults and to perceive the possibility of the negative consequences of their actions (Piko & Gibbons, 2008). A distinction had to be made between older adolescents who are able to make competent decisions about research participation and younger children who truly require protection (Santelli et al., 2003). We added that the criteria for competence have moved from biological age towards individual children's experiences and understanding (Alderson, 2007; Ashcroft, Goodenough, Williamson, & Kent, 2003; Horn, Kosciw, & Russell, 2009). Further, we argued, requiring written permission from parents would decrease participation because adolescents most at risk for HIV because of their risky sexual behavior are more likely to decline participation (Santelli, 1997; Rew, 2000).

Existing state laws that allow mature minors to seek medical care without parental consent—An adolescent's capacity to provide informed consent about certain health aspects of their lives is the reason behind state laws known as Minor's Consent Laws. These laws allow adolescents to avail themselves of sexual and reproductive health services such as access to contraception, pregnancy care, and STI and HIV testing without parental permission (Goodwin et al., 2012; Lerand, Ireland, & Boutelle, 2007). As recommended by the Society for Research in Child Development (2013), their classification as mature or emancipated minors as guaranteed by existing state laws that allow autonomous consent for sexual health services should be extended to their ability to consent without parental permission to participate in research about sexual health.

Having the right to participate in research about their health—As outlined in the Belmont Report (U.S. DHHS, 1979), the principle of justice suggests that all individuals be provided reasonable opportunities to participate in research. In keeping with the recent

strides made in LGBTQ inclusivity in the U.S., our team proposed that GBQ adolescents also be afforded the chance to take part in sexuality research and that barring their inclusion may impede the creation of knowledge on their behalf (Elze, 2009) or the development of protocols for sexuality-sensitive care (Rew, 2000). Our team argued that for a complete understanding of the potential for sexuality-specific, home-based HIV prevention, we must include the thoughts and opinions of young individuals who have previously been excluded from research (Eliason, Dibble, & DeJoseph, 2010; Grossman et al., 2011; Harper & Riplinger, 2013; IOM, 2011). Although research has been conducted on adolescents' risk behaviors that directly or indirectly lead to HIV infection (i.e., substance use, sexual behaviors, depression), there is sparse literature focused on these same behaviors in young men who have sex with men (YMSM) under the age of 18, particularly YMSM from minority backgrounds (Phillips, Morrisseau-Beck, & Patsdaughter, 2012). Additionally, the lack of avenues for research participation keeps this group from experiencing the positive feelings derived from such activities (Kuyper, Wijsen, & de Wit, 2014), including having a therapeutic outlet on a topic they might not have previously discussed (Lakeman, McAndrew, MacGabhann, & Warne, 2013).

Limitations of retrospective studies and sampling bias—The norm when studying LGBTQ adolescent behaviors is to conduct research involving the retrospective recall of young adult LGBTQ individuals (Mustanski, 2011). These recollections are subject to recall bias (Richards & Morse, 2012). Particularly when dealing with sensitive topics, there is a tendency among participants to minimize the negative aspects of their past and present a more optimistic picture of their childhood (D'Augelli & Grossman, 2006; Savin-Williams, 2001a). Our team also contended that retrospective studies, even by 18-year-old GBQ young adults, may not be reflective of the rapid social changes that define this population's current home and social milieu. Further, developmental changes in the context of one's life around age 18 in the United States implies that research about them may not generalize to individuals even just a few years younger (Mustanski, 2011). Moving out of the home, going away to college or getting a job are examples of life events that alter one's perspective compared to previous assumptions held when they were still living with their parents. Additionally, sampling bias related to mandatory parental consent has been well-documented (Anderman, Cheadle et al, 1995; Braun-Courville, et al, 2014; Stablein & Jacobs, 2011). We argued that requiring parental consent in our study would have resulted in the oversampling of GBQ youth who have disclosed sexual orientation to parents at the time of the interviews or those who had supportive guardians. With these two points underscored, we explained in the letter to the IRB Chairperson that allowing GBQ youth between the ages of 15 to 17 years old to share their perspective will allow us the opportunity to collect current data that is more representative of all GBQ males recent experiences.

Reluctance to seek parental permission regarding a sensitive topic—In general, fewer adolescents enroll in studies about STIs when parental permission is obligatory compared to when parental permission is waived (Reed & Huppert, 2008). In the case of our target population, even in the best type of parent-child relationships where a GBQ son may be fully accepted by his family, the routine and full disclosure of sex-related issues to parents is an unrealistic expectation. Most adolescents are protective of their privacy and

would prefer not sharing their sexual status with their parents (Anderson & Branstetter, 2012; Huebner & Howell, 2003; Reed & Huppert, 2008).

Strategies for Gaining Approval of Waiver of Parental Consent

Prior to submitting the study proposal, we set out to gauge leadership support for the waiver of parental consent through consultation with IRB Section Chair, provision of supporting literature, securing expert endorsement, and other additional measures. The goal of these steps (Table 1) were to strategically address potential arguments against granting our request. By preemptively consulting with the IRB, we felt we were minimizing the chances of the IRB's rejection of our request for the waiver of parental consent through identification and mitigation of problematic areas (Gilbert et al, 2015).

Perceived Risks in Not Seeking Parental Consent

Based on the feedback of our IRB Section Chair, the protocol we submitted to the main IRB addressed the major issues associated with conducting sexuality research with underage participants. Table 2 provides a list of potential risks when working with adolescents in research that were identified in our discussions with study consultants and the methods we proposed to address these concerns.

IRB Stipulations and Study Team's Response

After submitting the full protocol for review, we received a deferral notice that contained a request for additional information. The main concerns raised involved the IRB's perception that our study narrowly labeled potential participants as GBQ, the lack of a third-person observer during interviews, concerns for the safety and mental health of potentially at-risk participants, the traceable paper trail, and incentives involved when GBQ adolescents participate in our study.

Narrow labeling versus fluidity of adolescent sexual orientation—In recognition of young males' fluid sexual orientation during adolescence, the IRB requested that recruitment materials, consent forms and demographic data forms refrain from addressing our participants solely as gay. The initial proposal broadly defined *gay* as any individual who self-identified as having same-sex attraction that also included queer and bisexual individuals. The IRB noted that broadly referring to potential participants as gay “may be upsetting to subjects who otherwise meet entry criteria but are not yet willing to identify with that term.” Our team agreed with their concern, and verbiage in all study documents was amended to reflect all of the categories the IRB suggested be included. In the end, we defined our target population to include self-identifying gay, bisexual or queer adolescent males.

Third-person observer—The IRB requested that we revise our interview procedure to have more than one adult present at all interviews. We were initially concerned that a third-party observer would limit the interviewer's ability to establish rapport with the participants and would deter adolescents from fully sharing their honest thoughts about sensitive topics. Although these restrictions appeared to undermine the strengths of conducting a qualitative inquiry, having a third person in the room does not reduce interview rapport (Driskell,

Blickensderfer, & Salas, 2013) and has some benefits. From our perspective, these benefits included the observers being able to remind the interviewers of protocol fidelity, to identify areas of improvement as the study progressed, to serve as a partner during peer debriefing, and even to serve as a witness in case questions of unethical conduct arose. To ensure that qualified individuals would serve as our observers, we formulated criteria that only graduate students and university staff who received training in the responsible conduct of research and the protection of human subjects would serve in this capacity. These observers were added as Key Personnel in the IRB proposal.

Safety and mental health of at-risk participants—The principle of beneficence requires that measures be taken to ensure the well-being of study participants, as is the case for formulating protocols for mental health referrals when conducting research about sensitive topics (Elze, 2009). To identify depressed participants, the 9-item self-administered Patient Health Questionnaire-Adolescents (PHQ-A) (Johnson, Harris, Spitzer, & Williams, 2002; Spitzer, Kroenke, & Williams, 1999) was administered after the participant signed the consent form. This screening tool has been validated for use to measure depressive symptoms with adolescents. In addition, two other indicators to measure current suicidality (within the past two weeks) were used (Hightow-Weidman et al., 2011). Youth were asked about current suicidal ideation (“Have you ever made a plan for committing suicide? Have you ever figured out a specific way of ending your life?”) and prior suicide attempts (“Have you ever tried to take your own life?”). Both items could be answered “yes” or “no.” Similar screening questions have been used for multiple studies about sexual orientation and suicidality among young men who have sex with men (Herrell et al., 1999; Kessler, Borges, & Walters, 1999).

Those participants who did not meet criteria for depressive disorders or suicidality were included in the study. Youth who scored for moderate depressive disorder or episode (a PHQ-A score of 10 and above) and who answered affirmatively to any of the suicidal ideation questions were assessed for current engagement with a mental health professional and the availability of any personal safety plans. Adolescents who were not engaged in care and did not want to form a personal safety plan would have been referred to our on-call mental health professionals. A decision tree of the anticipated scenarios during participant screening — including rules for providing help to participants, contact information for experts to provide guidance and emergency procedures for dealing with life-threatening situations or adverse incidents (Bauman, Sclafane, LoIacono, Wilson, & Macklin, 2008; McDermott & Roen, 2012) — was devised.

Traceable paper trail and incentives—To minimize the risk that an adolescent's participation in our study would be discovered by parents who may react negatively, the IRB suggested that the paper trail associated with the research be minimized. We received guidance on seeking an additional waiver of documentation of the minor's informed consent. Given that the only record that normally links participants to research are consent documents and incentives, the IRB recommended eliminating both as proof of research participation. The appropriate form was filed that would forego providing copies of signed consent documents and incentives to participants to safeguard against parental discovery and

association with research about their sexual orientation. Because prior consultations with officers of Gay-Straight Alliances in area high schools and staff at non-profit LGBTQ recruitment sites revealed optimism about their members' openness to discuss issues pertinent to their concern, our team agreed to forego study incentives. Literature and our prior experience working with young men who have sex with men also showed us that altruistic reasons motivate youth to participate in research (Flicker & Guta, 2008; Flores, Blake & Sowell, 2011; McDermott & Roen, 2012).

Discussion

After two months of deliberation, our amended proposal received IRB approval. Thirty gay, bisexual, and queer youth were interviewed; five of them were under the age of 18 years. Towards the end of each interview session, we solicited all underage participants' thoughts about participating in sexuality research without parental consent. We also explored with the larger sample their perspectives on some of the aforementioned issues associated with adolescent GBQ research.

Four of the five underage participants informed their parents of their decision to participate in the study before sitting for the interviews. These youths attributed their willingness to share this information to open and honest relationships they have with parents. According to them, factors that reassured parents about their research participation included parents' confidence in sons' maturity level and ability to make sound judgments, parents' generally supportive attitude of sons' participation in LGBTQ-related advocacy, and knowledge that their son's friend had previously participated in the study. These findings are in accord with parents' belief that research participation should be allowed due to educational benefits, acknowledges adolescent autonomy, and is permissible when family or friends have already participated (Ott, Rosenberger & Fortenberry, 2010).

Despite the supportive relationships with parents that our participants reported, they acknowledged that the majority of their peers with undisclosed sexual orientation would most likely not be able to participate if parental consent was required. According to them, many of their GBQ peers do not have the same level of closeness that they have with their parents. This belief supports recent work that establishes how mandatory parental consent is a barrier to participating in GBQ-inclusive HIV prevention research (Fisher et al, 2016; Macapagal, Coventry et al, 2016).

Participants under the age of 18 and some over 18 years provided rationales for parental reluctance to allow sons to participate in sexuality-related research. First, parental objection may be due to concerns that participation in research may incite further sex-related questions to which parents would not have answers. This supports sex communication literature that identified parents' hesitation to discuss sexual health due to their own knowledge gaps (Flores & Barroso, 2017). Second, even in situations when a participant has already shared their GBQ identity with parents, there is variation in parental reactions to disclosure. For youth, even the most accepting parents may have qualms about the confidentiality of data sons share during the study. Furthermore, GBQ males may have non-accepting parents or parents who are still actively dealing with a recent disclosure. For this group of parents,

concerns about sons' information that they think should not be shared may take primacy over the perceived benefits of participating in scientific research.

When asked about their views on the importance of engaging GBQ youth under 18 in studies about sexuality and sexual health, participants stated that it is relevant to establish information from young GBQ sons as many parents are not comfortable with the process of talking about same-sex behaviors and identities. All of them shared their satisfaction with how the study was conducted, were grateful for the chance to share their insights on the topic, and felt good about contributing to research that would help their community. These reports are consistent with the positive effects associated with research participation (Arrington-Sanders, et al, 2016). For the youth under 18 who also had close relationships with their parents, this study was their first chance to reflect on the nature of their relationship. None of the youth exhibited distress during the interviews or contacted the study team to report negative outcomes as a result of study participation. The favorable response they reported plus the lack of any negative outcomes shows that participating in this study did not present any greater risk than they would ordinarily face in everyday life or during the performance of routine examinations or tests – the two considerations for waiving parental consent. In fact, two underage participants subsequently referred friends for research participation.

Implications for Nursing

There are several implications that pertain to research and nursing practice. As this and other studies have demonstrated, requiring studies to have parental consent for participation may promote a self-selection bias. This self-selection may inadvertently exclude youth that are at high risk for negative health outcomes, or may potentially put an adolescent at risk after forced disclosure of their sexuality. Having a waiver of parental consent is one way to address these concerns, and allows for richer data, which is critical for health care providers to have a deeper understanding of adolescent development.

As nurses, we are expected to provide anticipatory guidance to both our adolescent patients and their parents to identify high-risk behaviors and prevent negative health outcomes (Kyle & Carman, 2012). However, if nurses are not up-to-date with their knowledge about LGBTQ adolescent development, they will be ill-prepared to provide such guidance to patients and their families (Sirota, 2013). This is important to consider as much of the research and information we have is based on the development of adolescents from studies that required parental consent. Considering research that includes LGBTQ participants under 18 will expand the current base of knowledge we have on this population's unique health needs.

Conclusion

Research with GBQ youth that includes waivers of parental consent is crucial to address their risks for HIV/STI infection. A waiver of parental consent is endorsed by GBQ youth and must be sought when attempting to engage them in prevention research, especially since many may have not disclosed their sexual orientation to their parents. Appropriate safety measures included in the study design ensured human subject protection. Future HIV/STI

prevention research for GBQ youth will benefit tremendously with the inclusion of youth between the ages of 15 to 17, and perhaps even those who are younger.

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Highlights

- Requiring parental consent can be a barrier to research with sexual minority youth.
- Review Boards are amendable to waivers of consent when protections are guaranteed.
- Waivers of consent allows inclusion of sexual minority youth in nursing studies.

Table 1
Strategies for Engaging with the IRB and Securing Approval

Strategies	Rationale	Action Taken
IRB consultation	To identify potential issues against granting our request for a waiver of parental consent.	Met with IRB section chairperson to explain the study aims, described the design, provided the rationale for the waiver request and solicit feedback about the IRB's potential concerns.
Supporting literature	To provide resources and examples of studies that used waivers of parental consent	Memo sent to IRB Chairperson that included: <ul style="list-style-type: none"> • Introduction of the study and its significance • Limitations of retrospective study designs • A table of recently published studies and institutions that successfully used waivers of parental consent • A list of professional organizations that endorsed waivers of parental consent
Expert Endorsement	To provide an endorsement of our study's design and significance from a university expert who had extensive experience with adolescent research	Consulted with university expert who helped us identify ways to bolster our arguments and provided suggestions to ensure human subjects protection. He wrote a letter of support which stated that the benefits of using direct adolescent informed consent without seeking parental permission far exceeded the risks for this population.
Additional measures	Additional measures to reassure IRB members of the study's commitment to human subject protection were included.	Obtained a federal Certificate of Confidentiality (CoC) from the National Institutes of Health to protect against data from being subpoenaed in court. Provided laminated referral cards for local LGBT resources and national crisis hotlines to each participant at the conclusion of each interview.

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Table 2
Methods to Address IRB Concerns for Waiver of Parental Consent

Potential Risks	Concerns	Methods to address potential risks
Study coercion	Minors would not be competent enough to consent and be coerced to participate in the study	<p>Included questions during the consent process that ascertained participants understanding of the study. For example, “<i>Tell me in your own words what this study is all about</i>” or “<i>What options do you have if you decide you don’t want to be in this study?</i>”</p> <p>Participants were also given the opportunity to skip any questions they were uncomfortable with. We also emphasized that they can withdraw from the study at any point (Lamb, Puskar, & Tusaie-Mumford, 2001).</p>
Inciting parental anger	Foregoing parental permission to discuss sex-related topics with young individuals will undermine parental authority and incite parental anger (Elliott, 2012)	<p>Provided evidence of ways youth already seek support and discuss sexuality (i.e., high school Gay-Straight Alliances, online forums) without parental consent (Schelbe, et al, 2014).</p> <p>(See Newcombe, Clifford, Greene & Mustanski, 2016 for parental support of LGBTQ children participating in minimal risk research without their permission).</p>
Emotional distress	Concern that research questions or their responses to questions might trigger emotional discomfort	Provided participants opportunities to pause, reschedule or stop the interview when they report or exhibit distress. Also emphasized that participants’ decisions to stop an interview would not impact their standing with the organization or any other entity from which they have been recruited.
Encouraging sexual activity	By participating in the study, participants would be exposed to, and/or be influenced by topics about sexuality and ‘act out’ sexually.	<p>Assured the IRB there is no evidence that supports the fear that discussing or providing information related to sex encourages sexual behavior (Holder, 2008). In fact, adolescents who rate their general communication with parents more positively are less likely to be sexually active (Karofsky, Zeng & Kosorok, 2000). Further, research participation in one longitudinal study about microbicides showed no significant differences between two adolescent age groups for health and behavioral risk outcomes (Schenk et al 2014).</p> <p>Informed the IRB about North Carolina’s sexual health education policy in the classroom related to HIV transmission, testing and treatment, risk reduction strategies, and healthy relationships starting in grade seven (“Healthy Youth Act,” 2009). Compared to our asking questions, this state law mandates the provision of information about sex.</p>