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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.

Methods: We share our institutional review board 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 who are at high risk for negative health outcomes or may potentially put them at risk because of 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 encourage research informed by SMY, parental consent waivers may be necessary.

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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/sexually transmitted infection (STI) prevention. However, the perception that they are at high risk and are a vulnerable population also implies that more protection 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

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psychological harm stemming from research participation (Fisher & Mustanski, 2014), particularly when it comes to sexuality-based research (Miller, Forte, Wilson, & Greene, 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, Williamson, & Kent, 2003; Balen et al., 2006; Hunter & Pierscionek, 2007; Scott, 2013; Taylor, 2008; Zuch, Mason-Jones, Mathews, & Henley, 2012).

Compared with 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 with 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 National Institutes of Health-funded studies were related to LGBTQ health (Coulter, Kenst, Bowen, & Scout, 2014). Furthermore, 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 et al., 2006; Savin-Williams, 2008).

Background

In general, nursing research on broad LGBTQ health issues has been inconsistent, whereas focus on their civil and human rights has been largely overlooked (Keepnews, 2011). Although 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 et al., 2015), the discipline's researchers are strongly encouraged to pursue robust knowledge generation to inform practitioners, advocates, and policymakers 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 used to address the anticipated concerns of institutional review board (IRB), 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 (GBQ) 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.

U.S. 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:

a. The research involves only minimal risk.
b. The rights and welfare of the participants will not be adversely affected.
c. The research cannot be practically carried out without the waiver.
d. 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