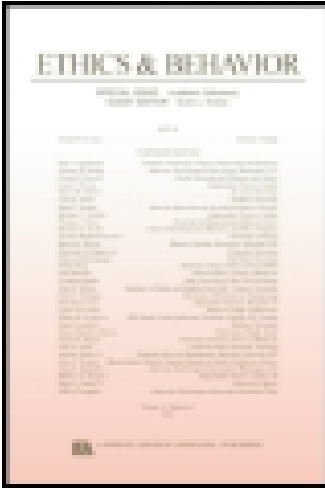


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Consent Challenges for Participation of Young Men Who Have Sex With Men in HIV Prevention Research in Thailand

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Young men who have sex with men (YMSM) younger than 18 years are often excluded from HIV prevention research in Thailand due to cultural attitudes toward youth sexuality, social stigma, and difficulties obtaining guardian permission. Culturally sensitive focus group discussions conducted with parents and YMSM in Bangkok, Thailand, identified barriers and facilitators related to minors' participation in HIV prevention research. Although gender and class differences emerged, mothers and fathers were generally accepting of research to reduce HIV risk but not in favor of waiver. Youth's positive attitude toward parental permission was tempered by concerns about harms posed by disclosing same-sex attraction through permission forms.

Keywords: gay, bisexual, youth, minors, HIV, research, Thailand, guardian consent, IRB

HIV prevention research involving youth younger than 18 years of age is scarce in the Global South (Borek, Allison, & Cáceres, 2010) despite high HIV incidence in this group in countries with generalized and concentrated epidemics (Joint United Nations Programme on HIV/AIDS, 2011). Reasons for this are many. HIV prevention research often deals with socially sensitive topics considered too sensitive or taboo in certain cultures. These include HIV stigma and refusal to recognize youth sexual behavior, drug use, and mental health problems. An additional barrier to HIV research involving youth is Institutional Review Boards (IRB) and local community

standards that often oppose waiving the guardian permission requirement and subsequently investigators' reluctance to engage with minors if guardian permission is required. Together, these factors contribute to the scarcity of sexual health research involving minors in Thailand, other low-resource countries, and the United States (Fisher & Mustanski, 2014; Thokoane, 2015/this issue).

This problem is intensified for research involving young men who have sex with men (YMSM) in Thailand. Gay and bisexual behavior, although legal, is still stigmatized in Thailand, despite Thailand being known as a "gay paradise" (Jackson, 1999, 2011). Because many YMSM have not yet disclosed their sexual orientation to their parents, requesting them to obtain parental permission for what is clearly participation in gay-themed research may be problematic and, in some cases, more harmful than beneficial. Some YMSM who have not yet disclosed their sexual orientation may, for example, be physically or verbally attacked by their parents, or worse, thrown out of their homes (Jackson, 2011). For these cases, it is more harmful than beneficial to ask for parental permission.

THE NEED FOR THE INCLUSION OF YMSM IN HIV PREVENTION RESEARCH IN THAILAND

Worldwide, gay, bisexual, and transgender youth exhibit various health disparities as compared to their heterosexual peers (Beyrer et al., 2012; Beyrer et al., 2010; Guadamuz et al., 2011a; Guadamuz et al., 2011b; Guadamuz et al., 2013; Wolitski, Stall, & Valdiserri, 2008). These disparities include higher prevalence of mental health disorders, childhood sexual abuse, drug and alcohol abuse, intimate partner violence, peer victimization and bullying, and sexually transmitted infections, including HIV. Reasons for this have been postulated to include deep-rooted societal and internalized homophobia, gender and sexual orientation-based discrimination and stigma, and minority stress (Guadamuz et al., 2013; Meyer, 2003; Meyer, Schwartz, & Frost, 2008; Wolitski et al., 2008).

Currently, there are only a handful of studies where YMSM younger than 18 years were included in Thailand. Routine epidemiological HIV surveillance assessment among YMSM shows significantly increasing HIV prevalence trends in Bangkok, from 17.3% in 2003 to 28.3% in 2005 to 30.8% in 2007 ($p < .001$) and has since been stabilizing at about 30% (Centers for Disease Control and Prevention, 2013; van Griensven et al., 2009). YMSM ages 15 to 17 years were included in the 2005, 2007, 2009, and 2011 assessments, and whereas YMSM 15 to 17 years of age may have lower HIV prevalence, they have higher and increasing incidence (van Griensven et al., 2009). For example, estimated HIV incidence among YMSM 15 to 22 years of age was 4.08 per 100 person-years in 2003, 6.42 per 100 person-years in 2005, and 7.69 per 100 person-years in 2007 ($p < .02$; van Griensven et al., 2009). A subsequent cohort study confirmed these findings, reporting 8.8 per 100 person-years among 18- to 21-year-olds, 6.4 person-years among 22- to 29-year-olds, and 3.7 person-years among at least 30-year-olds (van Griensven et al., 2013). This suggests that younger-aged MSM have the highest risk of acquiring HIV infection in Thailand. In fact, this is about 4 times higher than incidence found among MSM in the United States (Stall et al., 2009). Moreover, these epidemiological assessments also found significantly increasing trends in substance use, and more specifically, substance use during sex. Emerging qualitative data conducted by our research team over the past 2 years indicate that YMSM are

finding their partners online and are increasingly using “ICE” (a crystallized form of methamphetamine) when engaging in sexual activities, many times in the context of anonymous group sex activities (Guadamuz & Boonmongkon, 2013). These findings point to the urgency of including YMSM in HIV prevention and intervention research in order to prevent new infections in this population.

WAIVER OF PARENTAL PERMISSION FOR RESEARCH INVOLVING YMSM

IRB in Thailand are often modeled after the rules and regulations of the Belmont Report (U.S. Department of Health and Human Services, 2010) and the Declaration of Helsinki (World Health Organization, 2001). According to the U.S. code of federal regulations Title 45 DHHS Part 46 Subpart D §46.408 (c), a waiver of parental/guardian permission is allowed for youth younger than 18 years in the United States to participate in research if parental/guardian permission is not considered a reasonable requirement to protect them (U.S. Department of Health and Human Services, 2010). One example of where this regulation is applied is with neglected or abused youth. However, if such a waiver is granted, an appropriate mechanism to protect minors needs to be put in place such that the waiver is consistent with local laws (Fisher et al., 2013). For YMSM who have not disclosed their sexual orientation to their parents/guardians, requiring them to do so in order to participate in a study could, in fact, increase their risk of abuse, rejection, and neglect from their parents (D’Augelli, Grossman, & Starks, 2008; D’Augelli, Hershberger, & Pilkington, 1998; Fisher & Mustanski, 2014; Savin-Williams, 1994). Moreover, to exclude YMSM from these studies or to wait until they become 18 and then retrospectively report events when they were younger than 18 is not satisfactory due to internal and external validity issues (Mustanski, 2011). And, just including in research, YMSM who have disclosed their sexual orientation or are open about their sexuality to their parents may misrepresent the larger group of YMSM and therefore limit the scientific validity of findings.

In Thailand, there are no specific laws or regulations with regards to minors’ participation in research. Moreover, definition of minors in Thailand, or more specifically minors’ ability to make their own decisions in Thai society, is not consistent. For example, although one must be at least 18 years old in order to vote or to enlist in the army, 15-year-old minors are capable of willing their assets under article 25 of the Civil and Commercial Code (Office of the Council of State, 1992). However, this reasoning does not transfer to current practices by IRBs in Thailand whose members are reluctant to grant waivers of parental permission for research involving minors younger than 18 years when the topic includes sex and sexuality. To our knowledge, there has been only one study that was granted a waiver of parental permission by the Thailand Ministry of Public Health’s (MOPH) IRB. In this study, 260 male and 231 female minors 15 to 17 years of age were recruited in public vocational schools in Northern Thailand where they were asked sexuality-related and substance use-related questions and provided oral fluid and urine specimens (van Griensven et al., 2001). Still, this study was not gay themed. Informal discussions with senior social and behavioral researchers and with IRB members indicate that Thai IRBs assume that YMSM may already be at increased risk from social harms (because they are sexual minorities and are marginalized in Thai society) and so there is even more of a need to require parental permission as well as YMSM’s assent. For example, all research involving YMSM, regardless of the research design (e.g., clinical trial versus anonymous survey), or research in which there may

be minimal risk (e.g., no sensitive information, data that are anonymous/stripped of all identifiers), require full board review. To our knowledge, the same MOPH IRB has been the only IRB in Thailand to grant a waiver of parental permission for YMSM 15 to 17 years of age for HIV surveillance assessments conducted in 2005, 2007, 2009, and 2011 (Centers for Disease Control and Prevention, 2006, 2013). The reason may be that these assessments are considered public health surveillance activities, and not research. These phenomena suggest that although Thailand does not have clear laws and regulations regarding participation of minors in research activities, IRBs often follow the U.S. code of federal regulations, which itself has been criticized for containing ambiguous language that has posed problems for legitimate waiver of guardian permission in studies involving youth sexuality (Fisher et al., 2013; Mustanski, 2011).

The goal of this exploratory study was to gather empirical data to inform investigators and IRB members about the consent challenges for minors' participation in HIV prevention research in Thailand. This qualitative study drew on parent and YMSM perspectives to (a) illuminate barriers and facilitators related to minors' participation in HIV prevention research, and (b) explore concerns and solutions related to obtaining parental permission and waiver of parental permission.

METHOD

This community-engaged study was conducted in Bangkok between May 2013 and March 2014. To guide the study, a 12-member community advisory board (CAB) was created that consisted of current Chairs and members of several major research university IRBs throughout Thailand, parents with sons 15 to 17 years of age, and YMSMs age 18 years who were still in high school. The objective of the CAB was to give feedback on the working study protocol by providing comments and recommendations regarding the study design, participant recruitment and incentives, data analysis, and dissemination of study findings. After meeting with the CAB, the study protocol was revised and submitted to the Mahidol University IRB, where it was reviewed and approved.

Participants

For YMSM participants, the inclusion criteria were that they were biologically male, 18 years old, identifying [to research staff] as YMSM, currently studying at a high school level or similar (e.g., technical school, vocational school) and residing in Bangkok for at least 1 year when 15 to 17 years of age. For parents, the inclusion criteria were that they were current parents/guardians of sons 15 to 17 years of age and had resided in Bangkok for at least 1 year. After consulting with the CAB, we decided that the parent participants should not be restricted to those who were aware that their sons were gay, as this would better represent most Thai parents who do not discuss sex or sexuality issues with their teens (Boonmongkon & Jackson, 2012). The exclusion criterion for both YMSM and parents was being unable to verbally communicate in Thai.

Fathers and mothers were specifically suggested by the CAB, as opposed to any guardian, because CAB members felt that in Bangkok, they are considered more protective of their sons than foster parents or other relatives serving as guardians. We also decided to conduct separate focus group discussions (FGDs) based on parent gender and social class, as these factors are particularly important in Thai society as documented by previous sexuality studies conducted by our research team. Two categories of class were designated based on occupation: whether parents

were (a) professionals (e.g., civil servants, teachers, nurses, business owners) or (b) nonprofessionals (e.g., laborers, taxi drivers, market vendors). In total, six focus FGDs were conducted: (a) nonprofessional fathers of sons 15 to 17 years of age; (b) nonprofessional mothers of sons 15 to 17 years of age; (c) professional fathers of sons 15 to 17 years of age; (d) professional mothers of sons 15 to 17 years of age; (e) YMSM 18 years of age, still in high school, who live with their parents; and (6) YMSM 18 years of age, still in high school, who live in dormitories and are not living with parents. Drawn from these FGDs were three in-depth interviews (IDI) that included a father from the nonprofessional FGD group, a YMSM from the living with parents group and a YMSM from the living in dormitories group. IDIs were used to triangulate FGDs by exploring more in-depth issues that were brought up that may be more sensitive and thus require more time and one-on-one interaction (see Figure 1 for details).

Materials

Parents and YMSM were given a participant information sheet and a parent permission form that needed to be signed. The participant information sheet contained details about the research study.

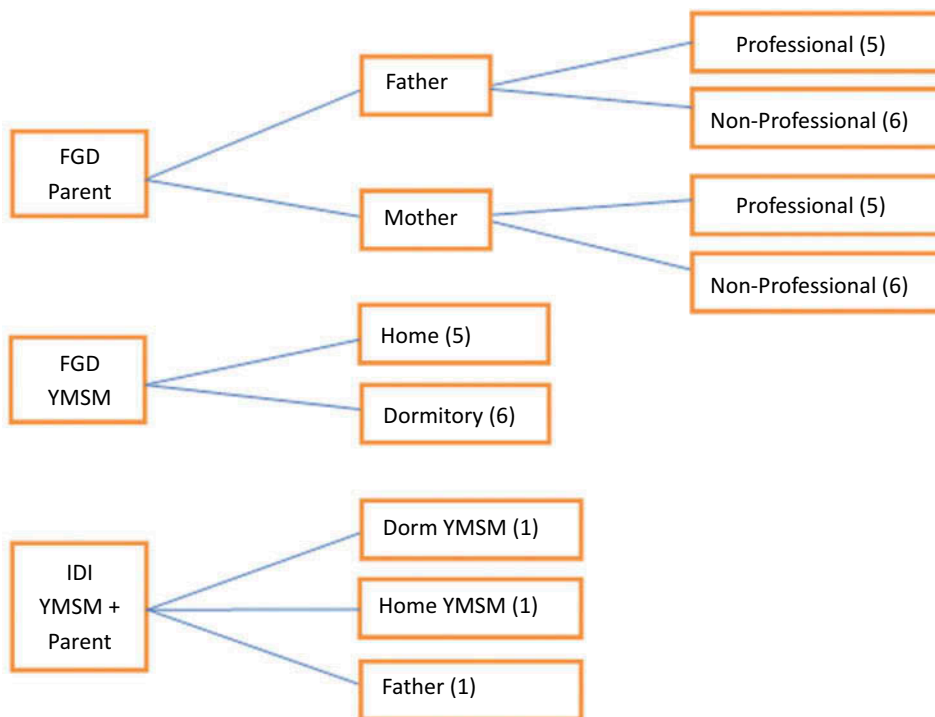


FIGURE 1 Allocation of research participants to various FGDs and IDIs.
 Note. FGD = focus group discussion; IDI = in-depth interview; YMSM = young men who have sex with men.
 (n) indicates the number of participants.

This included background information/rationale, research objectives, and research methodology. Moreover, it also contained information on the benefits and potential harms associated with the study including additional protections provided by the investigators (e.g., FGDs conducted in a safe setting, all data will be kept confidential, etc.). For this study, participants discussed four mock research studies described in separate information sheets including studies of youth physical activity, school-based violence, substance use, and HIV risk behaviors among YMSM.

A standard model parent permission form accompanied each of the four types of studies to enable parents to understand the nature of the materials other parents would receive if any of the four studies were actually implemented. The parent permission form was a standard form provided by the university IRB that clearly states that parents permit their children to participate in the study having understood related benefits and potential harms, including additional protections provided by the investigators if such harms were to occur, and that they had a chance to ask investigators about any reservations or concerns related to study participation. Moreover, the form describes study participation as voluntary, that participants may stop or leave the study at any time, and that their discontinuation will not affect them in any way. Finally, the form states that data from the study will be used for research purposes only and if, for any reason, their children were mistreated or were asked to do something outside what was stated in the participant information sheet, parents have the right to contact the Chair of the IRB (address and telephone numbers provided).

Procedures

All FGDs and IDIs took place at safe locations throughout Bangkok, usually at places/locations that were easily accessible by public transportation and that were considered to be safe spaces for YMSM (i.e., places where YMSM will not be labeled as gay) such as karaokes and restaurants with private rooms. YMSM were given \$10 U.S. dollars (USD) to compensate for their time and travel. YMSM participants were offered more if their travel cost more than \$10 USD. Parents were given \$40 USD to compensate for their work time and travel. This level of compensation was recommended by the CAB. The first author facilitated all FGDs and conducted all IDIs in Thai. The purpose of the study and participant research rights were explained to parents and youth and oral consent was obtained. All participants were also provided with a participant information sheet to take home that contained detailed information about the study, as well as the names and contact information for both the study PI and the Chair of the Mahidol University Social Sciences IRB.

Procedures for Parents

At the start of each FGD, after confidentiality procedures and ground rules had been reviewed, parents were informed that the FGD was part of a study on parents' attitudes toward their children's participation in research and that they would be reviewing mock participant information sheets and permission forms, followed by a discussion of their attitudes toward their sons' participation in a range of different health-related research studies. After the purpose of the study was explained and informed consent was obtained, participants completed a brief demographics survey prior to the start of the FGD.

Each parent in the FGD was given mock parent permission forms and participant information sheets. For each mock study, the facilitator assessed parents' perceptions by asking questions adapted from Fisher's qualitative and quantitative studies on parent and youth research ethics perspectives (Fisher, 2002, 2003). Questions covered parents' initial response to the parent permission form, perceived risks and benefits of their child's participation, whether they would provide permission for their child's participation, protections that investigators might include to alleviate concerns, and their attitudes toward waiver of parental permission for this type of research. Depending on the conversations of the FGDs, sometimes the facilitator would brighten up the mood/"shake things up" through culturally appropriate jokes about parenting and allowing discussion to move to research on other high-risk adolescent behaviors (e.g., teenage pregnancy, suicide/suicidal ideation or depression).

Procedures for YMSM

Similar to FGDs with parents, YMSM who were 18 years old were briefed on confidentiality procedures and ground rules, told about the overall aims of the project, and then given a short demographics survey to complete before the start of the FGD. Participants were then presented with the same mock parental permission form and participant information sheets given to parents. For each mock study, the facilitator assessed YMSM's perceptions by asking questions similar to those described for parents with a few additional questions tapping attitudes toward obtaining parental permission, waiver of parental permission, and suggested protections that might be put in place if parental permission was waived.

RESULTS

Data collection and analysis was an iterative process. All FGDs and IDIs were digitally recorded and transcribed. The PI, coinvestigator, and two research assistants went through the transcribed text for the first FGD and independently developed preliminary codebooks. These were then compared and revised to develop one codebook (Miles & Huberman, 1994). Nvivo 10 was used to store, organize, code, and annotate findings.

Demographics

Tables 1 and 2 present the demographic characteristics of research participants. The mean age of parents was 44.8 years. Parents were from various regions of Thailand, with a third from Bangkok. Almost all parents were employed, had their sons in public schools, and were living with them at home. Only one parent had previously participated in a research study. Among YMSM, about one third had part-time jobs, almost all attended public schools, and none had ever participated in research studies.

Parental Perspectives

In general, parents want their children to participate in research studies because they believe that their children will benefit from them. This belief does not seem to differ even when the study

TABLE 1
Demographic Characteristics of Parents

	n	%
Gender		
Male	11	50.0%
Female	11	50.0%
Birthplace		
Bangkok	8	36.4%
Central	5	22.7%
North	3	13.6%
Northeast	3	13.6%
South	1	4.5%
Did not answer	2	9.1%
Employment		
Unemployed	1	4.5%
Business owner	5	22.7%
Teacher	1	4.5%
Nurse/Dental	2	9.1%
Laborer	3	13.6%
Factory worker	1	4.5%
Housewife	1	4.5%
Sales	6	27.3%
Security guard	1	4.5%
Did not answer	1	4.5%
Highest education		
Primary	3	13.6%
Secondary	7	31.8%
Vocational	1	4.5%
Bachelor's degree or higher	11	50.0%
Monthly income ^a		
Under 5,000	1	4.5%
5,001–15,000	7	31.8%
15,001–20,000	2	9.1%
Over 20,000	12	54.5%
Experience as research participant		
Yes	1	4.6%
No	21	95.5%
Demographics of their sons		
Living		
Home	19	86.4%
Dormitory	2	9.1%
Did not answer	1	4.5%
Type of school		
Private school	4	18.2%
Public school	17	77.3%
Did not answer	1	4.5%
Grade		
9	1	4.5%
10	3	13.6%
11	8	36.4%
12	9	40.9%
Did not answer	1	4.5%

Note. $N = 22$. Age $M = 44.81$.

^aIn THB, 1 USD = 30 THB.

TABLE 2
Demographic Characteristics of Young Men Who Have Sex With Men

	n	%
Birthplace		
Bangkok	3	27.3%
Central	3	27.3%
North	1	9.0%
Northeast	2	18.2%
South	2	18.2%
Living		
Home	5	45.5%
Dormitory	6	54.5%
• Alone	2	33.3%
• With friend(s)	2	33.3%
• Other	2	33.3%
Part-time employment		
Yes	4	36.4%
No	7	63.6%
Monthly income ^a		
Under 100	1	9.1%
100–200	7	63.6%
201–300	3	27.3%
Type of school		
Private school	1	9.1%
Public school	10	90.9%
Experience as research participant		
Yes	—	—
No	11	100%

Note. N = 11.

^aIn THB, 1 USD = 30 THB.

deals with sensitive topics like drug abuse, violence, and sexuality. Parents feel that having their children participate in research studies is by far a better use of time than being in front of the television monitor:

“I want my son to have other activities than just being in front of the monitor [TV and computer] . . . at least open the world/society to my son.” — Father professional FGD

Furthermore, parents feel that their children should have equal access to research like anyone else so that their children can learn and benefit directly from the research study:

Mother non-pro FGD 1: “I think that all parents feel the same way.”

Mother non-pro FGD 2: “Yes, it is a good thing and I want my child to be a part of it.”

Mother non-pro FGD 3: “It’s like [my child] needs to also want to do it, but for me I want my child to learn everything there is.”

Mother non-pro FGD 4: “Yes, all the Moms give permission, these are good studies.”

Parents indicated that the academic institution where the research is based, and the fact that the researcher is an *ajarn* (faculty member), gives credence and assurance to parents. For example, parents felt that studies that have been screened by educational institutions like the university are beneficial, safe, and do not have potential adverse consequence for their children.

“Then I am ok [with consenting] since there is a guarantee from the university.” — Mother non-pro FGD

“Since the *ajarn* is requesting to take my son here and there, I feel rest assured because there is an *ajarn*, as long as there is an *ajarn*.” — Mother non-pro FGD

Nevertheless, professional parents were more cautious and not as trusting of academic institutions or researchers, as compared to nonprofessional parents. They asked many more questions about the study and stated that they will call the phone numbers listed on the permission form to inquire more details about the study. Further, professional parents commented that the information sheet and the permission form did not provide enough information. For example, they want to know when and where the study will take place, and who and how many adults will be there. They were also concerned with the legitimacy of the studies, of the permission form, and of the investigators themselves.

“Is this really a Mahidol University’s study? Is this a legit form?” — Father professional FGD

Gender also played a role in parents’ perceptions. Fathers, more than mothers, seemed hesitant in granting permission for their sons’ participation in gay-oriented studies. Some fear that their sons may be exposed to gay topics, meet with gay students and then become gay themselves.

“I can’t condone it [homosexuality]. . . . If we let them pay much attention to it [homosexuality], it may be the same as being suggestive to them. I mean if we let them to get to know about this topic [gay-themed issues], it may be as if we lead them to think that we do not prohibit it, not reprimand it. So for children between 15–18 years, their decision making skill is still not ok. . . . If they listen to this topic when they are too young, it may spark an idea.” — Father nonprofessional IDI

However, most fathers were generally fine with having their sons participate in gay-oriented studies.

“I will sign allowing him to go. I want him to learn more, not to prevent him if he wants to know. In the future, he will decide which way he wants to walk, it is his business. So for now, it’s like we give him all the information, and he will go in his own direction. We can make him follow our direction, but let them choose, let them learn everything so they see what the world outside is like. Where you will stand in society that is your choice. I just ask only that he is a good citizen in society, that’s all.” — Father nonprofessional FGD

In summary, parents want their children to participate in research studies because they feel that their children will benefit from it. Professional parents were more cautious of the study’s details and the study investigators than nonprofessional parents. Research topics did not seem to matter, however; fathers were more hesitant in granting permission on gay-oriented studies than mothers.

Youth Perspectives

In general, YMSM want to be engaged in research studies as a way of contributing to society. For example, if they feel that their participation will help improve the livelihoods of other youth, then they are willing to participate. In addition, they feel that research participation will increase their own knowledge on the issue/topic.

“It [research participation] is a good thing, not something *rai sara* [insignificant], since this is dealing with society and youth.” — YMSM home FGD

“I feel that [research] will give me more knowledge/information” — YMSM dorm FGD

In terms of acquiring parental permission, YMSM want to involve their parents in the decision-making process. However, they also realize that their parents are busy and may not have the time to read permission forms or that they need to know the details of the study. Thus, several YMSM end up signing these permission forms for their parents.

“Just like the first study, my parents will know of the study and I will sign. My parents don’t have time to sign anything, they have to work and so I just sign and let them know about it [later].” — YMSM home FGD

“Sign it first and then give my mom the details later. Mostly my mom likes to leave it up to me.” — YMSM home FGD

This “culture” of signing for their parents is even more pronounced among YMSM who do not live with their parents. In the FGD, YMSM who live in dormitories laughed when asked whether they usually sign permission forms for their parents. YMSM said that they are used to deciding their own fate when things are about them. They feel that they have the power, the right to decide whether they can participate. So signing permission forms is a common practice among students who live in dormitories. However, there are some caveats where parental involvement is expected, including activities that cost money/require financial support (e.g., tuition payment) and field trips to faraway places, like in other provinces that require an overnight stay.

“In reality, I will usually sign for my parents because for all activities that I am involved in, I am the one that signs [give permission for myself]” — YMSM dorm FGD

“When is not important, I will sign the forms. These [unimportant activities] include school-sponsored sport events/competitions, merit-making at the temple, and other activities that take place at school, then I will sign.” — YMSM dorm FGD

At the same time, there are some YMSM who have not disclosed their sexual orientation. For them, bringing the permission form to their parents may affect them, thus they worry about bringing these forms and subsequently will just sign them.

“Because this is the only issue I cannot tell my Mom . . . my family does not know that I am gay . . . yes there will be questions . . . lots of questions, I don’t want to have any problems with Mom. If I participate in this study, I will not let my family know. Being gay will destroy my parent’s expectations.” — YMSM home FGD

It is interesting to note that of all the mock studies presented to them, they feel most connected and want to participate in the sexuality/YMSM study, despite having to navigate the potential risks/harms of their parents and others knowing about their sexual orientation.

Still, there are some YMSM who are not open to their family about their sexuality but are happy to be part of the research study. They will therefore sign for their parents and will participate in the study without telling their family.

“I have to sign myself . . . so that I know how to protect myself [be beneficial to me and people like me] like about sex. . . . My family do not want me to be like this [gay], they cannot accept it.” — YMSM home IDI

Among YMSM who have disclosed their sexual orientation to their family, they stated that their parents will be happy to give permission to participate because they will see the importance of the research, especially when it deals with YMSM.

On another note, there were a few YMSM who refused to sign the permission forms for their parents. One YMSM who has not disclosed his sexual orientation to his father and is living in a dormitory stated that he had a conflict with his father when he lied about a school-related activity, and his father stopped giving him any financial support and did not talk to him for a month. However, he said that he still would want to be in our mock study on sexuality:

“[I will] try to find a reason related to just HIV by itself and not disclose about the study involving YMSM or about [gay] sexuality. If he ends up reading the permission form and don’t like the study, then I [will listen to him and] will not participate.” — YMSM dorm IDI

Here he chooses to tell his father but intentionally leaves out certain information so as to protect himself from potential harm.

Waiver of Parental Permission

Most parents do not agree to having a waiver of parental permission and thus losing their power to permit their children to participate in research. However, when explained to them in detail the rationale behind the waiver, how it will actually protect minors from potential harms (e.g., parents were told that some parents may react negatively when learning that their children are gay; therefore it may be potentially harmful to obtain parental permission for a gay-themed study because that itself may disclose the children’s sexual orientation), they were more sympathetic but still affirmed their position of disagreeing with the waiver.

“Mahidol [university] backup but how does this help if the society outside cannot be trusted.” — Father nonprofessional FGD

“They are still our sons and under our care. They are still minors, still our son and we want to know [where they are] and to protect them. We don’t know if we let them go if this will be good for them or that there may be negative consequences.” — Mother professional FGD

When probed more about this, parents seemed to be afraid for their sons’ safety and not knowing where they are and who they are with, not necessarily the research topic itself. This concern is most pronounced among professional parents. Because several professional parents pick up/drop off their sons at schools, they were concerned about their sons’ safety. But parents did make some recommendations on additional protections for their children, while ensuring privacy and confidentiality of sensitive issues. Almost unanimously parents suggested that the only way research can be conducted without their permission, or their knowledge of it, is when it is conducted at school, on school property.

“There is one way [to not let us know/waive our permission] . . . use the [research] time in school”
 — Father nonprofessional FGD
 “When they [our sons] are at school they are safe, we are concerned with their safety” — Father
 non-professional FGD

Parents also feel that the school and their children’s teachers will have already screened the study and the researchers associated with the study. This is the only way they do not need to know the details of the research study or require a permission form.

DISCUSSION

Overall, parents were generally receptive to granting permission for their children to participate in studies that would provide their children fair access to information and knowledge, irrespective of the socially sensitive nature related to the studies. However, as we had anticipated, there were some differences by class and gender. For example, fathers were more hesitant than mothers to permit their children’s participation in gay-themed studies. The concerns of fathers may speak to issues surrounding masculinity (Courtenay, 2000) rather than outright homophobia. However, our findings also show that parents generally were tolerant of their children participating in gay-themed studies. This may be due to the transitional modernity in Thai society that is becoming more tolerant of multiculturalism and gender and sexual fluidity (Jackson, 2011). Similarly, professional parents were more cautious than nonprofessional parents. This is not surprising, as almost all professional parents in our study had bachelor degrees (see Table 1), which suggests that they have been trained to be critical, to question the information given to them.

YMSM in general want to be a part of research studies, particularly when they concern issues they care about like gay-themed studies, violence, and drug abuse. This is remarkable, as studies have already shown that studying these HIV vulnerabilities are urgently needed to understand their interacting effects that ultimately contribute to increased risk for HIV infection among MSM (Guadamuz et al., 2013; Guadamuz et al., 2014). YMSM also expressed positive aspects of involving their parents in decisions, tempered by concerns about harms posed by disclosing same-sex attraction through permission. For other YMSM, they had already developed a strategy to bypass their parents knowing specific school-related information, including that they are gay or bisexual, by just signing the permission forms themselves, a practice that is already common among many youth in our study, particularly youth that live in dormitories.

Finally, most parents did not favor the waiver of parental permission; they responded positively to waivers when cast as a means of ensuring that their children had fair access to research that could improve their health—as long as some adult proxy mechanism was put in place to protect their children’s rights. One suggestion from parents was to conduct the research study at schools, on school property, and under the supervision of teachers. In this way, they would feel secure that their children are safe and being watched by schoolteachers, and therefore would not require a permission form or research study details.

Limitations

There were some limitations in the study. First, there may be some socially desirable answering by both parents and YMSM participants in the FGDs. The facilitator and research assistants were

prepared for this and therefore conducted additional activities like spending a significant amount of time developing rapport with each parent and YMSM before the actual FGD and answering questions and providing additional details about the study through telephone calls; online chats; and, for some participants, in-person visits. In addition, the FGDs took place in a private room of restaurants, and before each FGD, the facilitator, research assistants, and participants ate lunch/dinner together. This was useful because participants were able to informally introduce themselves to others, and an informal social gathering then followed. This energy and rapport were then carried over into the FGDs. We therefore feel that social desirability answering may be minimal.

CONCLUSION

The findings have potential to influence current IRB practices in Thailand. The fact that parents expressed faith in schools as proxy protectors of their sons suggests that collaborating with schools in Thailand may be an ethical approach to the waiver of parental permission and a means of involving YMSM in critical HIV-related prevention research. Specifically, drawing on recommendations by Fisher (Fisher, 1999, 2004, 2015/this issue) we suggest that investigators conducting research on youth in Thailand and other developing countries (a) serve on the IRB and bring expertise about youth's developing consent capacity to board discussions, (b) convene and draw on the wisdom of community advisory boards to guide culturally sensitive and ethically appropriate human subjects procedures, (c) become familiar with local laws and regulations regarding minors and age of consent, (d) pilot ethical procedures by conducting small-group discussions with prospective participants to better understand the risks and benefits of study participation, and (e) incorporate into publications data reflecting participant attitudes or responses to ethical procedures to contribute to an empirical data base to inform future human subjects protections.

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