

ETHICAL AND EPISTEMOLOGICAL INSIGHTS: A CASE STUDY OF PARTICIPATORY ACTION RESEARCH WITH YOUNG PEOPLE

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ABSTRACT: DEBATES OVER HOW TO DETERMINE AGE of consent for youth to participate in research feature prominently in the practice of researchers, research ethics boards (REBs), and community decision makers working with youth. In particular, tensions can arise over how the ethical principles of beneficence, autonomy, and justice are interpreted and applied in research involving young people. We discuss our experiences obtaining ethical approval to conduct a participatory action research project involving youth and the differences of opinion we encountered regarding underage youth's capability to make informed consent. We suggest that researchers, REBs, and community decision makers all share a responsibility to conduct proactive outreach to youth participants, so that they are adequately informed of their rights related to research.

KEY WORDS: participatory action research, ethics, autonomy, beneficence, justice, adolescent health, sexual health

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THE MEANINGFUL PARTICIPATION OF CHILDREN and young people in research is a much discussed and contested issue in a number of countries, including Canada, the United States, and the United Kingdom (Bruzzese & Fisher, 2003; Cashmore, 2006; Flicker & Guta, 2008; Holder, 2008). For example, debates over how to determine age of consent for youth to participate in research remain contentious and feature prominently in the practice of researchers working with children and youth, as well as the members of research ethics boards (REBs) and community decision makers (e.g., school board and health authority officials who oversee ethics review for local area) (Heath et al., 2007). In particular, sociocultural taboos and fears related to research regarding sexuality and gender identity present complex issues for researchers and ethics review boards

(e.g., privacy rights of minors versus parental control over children's participation in research).

Here, we describe some of the challenges of conducting research with youth when multiple stakeholders (e.g., REBs, school boards), and their particular ethical standards and frameworks, are involved. This paper draws on data from a case study based on our experiences as researchers conducting a participatory action research (PAR) project that included participants aged between 16–24 years living in northern British Columbia, Canada. We begin by summarizing the ethical concepts of autonomy, beneficence, and justice as they relate to children and youth under the age of majority, review the previous research literature that informed our approach to our project, and then identify several ethical and epistemological issues that emerged through our work. Finally, we suggest ways that researchers, REBs, and community-based decision makers can work together to increase young people's meaningful engagement in research.

In this paper, we define personnel who grant researchers permission to conduct a study at their institution (e.g., a school or social services agency) as community decision makers. In much of the literature, these individuals are frequently referred to as "gatekeepers" (e.g., Heath et al., 2007; Homan, 2001). In studies where parental/guardian consent is required, parents and guardians of youth under the age of majority are also sometimes referred to as gatekeepers (e.g., David, Edwards, & Alldred, 2001; Kirk, 2007). We fully recognize that gatekeepers have the power to control access to a potential research population. However, we find this term has negative connotations, implying that researchers have limited or no ability to negotiate how access might be obtained and how participants' consent might be granted. While this does indeed occur sometimes (as in the study we discuss here), we have found in other studies that many so-called "gatekeepers" are willing to negotiate how to ensure that the ethical principle of beneficence is maintained while considering potential youth participants' right to autonomy. Therefore, we have chosen to use the term "community decision makers" instead of "gatekeepers" in this article.

Autonomy, Beneficence, and Justice—Competing Ideals

In many jurisdictions, the principles of autonomy, beneficence, and justice typically inform research ethics guidelines. The principle of autonomy (or self-determination) captures the right of individuals to determine their own interests and participation in research (CIHR, NSERC, & SSHRC, 2010; Spencer, 2000). Beneficence refers to the idea of “doing good,” and research ethics frameworks typically require a thorough assessment of the harms and benefits involved in research (Bessant, 2006; Brooks-Gunn & Rotheram-Borus, 1994; Spencer, 2000). The principle of justice refers to the duty to treat people in a fair and equitable manner (CIHR, NSERC, & SSHRC, 2010). While presenting a framework for ethical decision-making, these principles can prompt contradictory positions and issues for researchers—particularly when research involves children and youth.

Traditionally, in many Western societies, children and youth under the legal age of majority are often denied autonomy rights, as they are not yet regarded as having obtained full personhood (Spencer, 2000). As a result, underage children and youth are regarded as “human becomings” in need of protection as they develop into adults, rather than “human beings” who may be competent to make their own decisions, as long as the information they need to make such decisions is provided to them in ways they understand (James & Prout, 1997). While the assent process—defined as passive agreement or concurrence with the decision of a legal guardian to permit a minor to participate in research—does provide underage children and youth with an opportunity to express whether or not they wish to participate in research, their wishes can be overruled when parental consent is refused (Heath et al., 2007; CIHR, NSERC, & SSHRC, 2010). With reference to research and medical treatment, this means that children and youth are not typically afforded the rights to consent unless their “consent” aligns with the views of parents and other adults. Most parents and guardians, on the other hand, by virtue of their status as adults (with the notable exception of adults who are deemed “incompetent” by state authorities), are regarded by lawmakers and REBs as having the ability and right to consent to important decisions regarding medical treatment or research participation on behalf of minors in their care (Alderson & Morrow, 2011; Leadbeater et al., 2006; Spencer, 2000). The tensions among autonomy, beneficence, and justice revolve on several intertwined points, including conventions regarding the age of majority and determinations of competency; in addition to determining what constitutes a child’s “best interests” or, indeed, whose interests are given primacy when differences emerge (i.e., parent’s or children’s) within decision-making processes.

The age of majority varies considerably across legal jurisdictions (e.g., province, state, or country). It is possible to obtain permission to conduct research involving people under the age of majority without also obtaining parental (or guardian) consent—that is, that they should be treated as emancipated minors—but this varies according to jurisdiction and the nature of the research topic (Flicker & Guta, 2008; Sancit et al., 2004; Santelli, 1997). In the UK, for example, people 16 years of age and over can legally consent to participate in research or medical treatment without parental consent if they are deemed by a researcher or physician to have “sufficient intelligence and understanding to consent” themselves, a status often referred to as “Gillick competent” (Medical Protection Society, 2009, p. 6). In Canada, young people’s legal right to consent to participate in research varies by province. In six of Canada’s provinces and territories parental consent is not required after a youth turns 18 (Leadbeater et al., 2006); in British Columbia (BC), where our research is conducted, the age of majority is 19 (Revised Statutes of British Columbia, 1996). Institutions based in BC typically adhere to the Revised Statutes of British Columbia, which, in general, take precedence over the Tri-Council Policy Statement standard. As a result, people under 19 years of age are legally considered minors, and REBs typically require researchers to obtain both parental consent and youth consent unless the study is considered minimal risk. When research is conducted in school settings, some school districts allow researchers to provide parental notification (followed by student consent). However, in most schools in BC, the student’s consent cannot override parental/guardian refusals—illustrating some of the ways in which young people’s capacity to enact self-determination can be undermined.

Debate surrounds the issue of whether people who are younger than the age of majority are competent to understand the risks and benefits of research participation and their rights regarding confidentiality and anonymity. Traditional developmental psychological theory asserts that a person’s cognitive and psychological development progresses through a series of stages that are connected to age. From this perspective, children and adolescents’ abilities to comprehend the risks and benefits of research and to provide fully informed consent is constructed as being connected to their age, an approach that social scientists have challenged in the past two decades (Danby & Farrell, 2004; Mayall, 2002). This latter group of researchers argue that childhood and adolescence are socially constructed and context bound, suggesting that age is not inextricably linked with cognitive development (Alderson, 2007; James & Prout, 1997; Kirk, 2007; Mayall, 2002). For example, when information about the purpose, risks, and benefits of research is presented to young people in accessible

formats and with adequate time for discussion, they are less likely to be deemed “incompetent” (Bessant, 2006). A number of researchers have found that people as young as eight years of age have the competency to assent to research if details about the benefits and risks of participation, confidentiality, and anonymity are explained clearly and in a supportive, noncoercive environment (Alderson, 1993; Heath et al., 2007; Hurley & Underwood, 2002). Nonetheless, biological age remains an important criterion in the research ethics review process, with most REBs relying on age as a determinant of young people’s competency to consent to participate in a study.

Beneficence—that is, reducing possible harms while maximizing potential benefits to participating in research—is another central concern in conducting ethical research (Brooks-Gunn & Rotheram-Borus, 1994). Parents are frequently constructed as being in the best position to determine their children’s “best interests” and thus, how to protect young people from possible harm in relation to research; hence, many REBs continue to default to a requirement for parental consent as a means of addressing beneficence (Alderson, 2007; Balen et al., 2006). Ironically, in research involving sensitive topics (e.g., sexual behavior; gender identity; and alcohol, tobacco or drug use), defaulting to parental consent may in fact increase potential risks for young people. For example, requiring parental consent in a study about the sexual health needs of sexual minorities could put some of these youth at risk of harm if their parents do not know or approve of their child’s sexual orientation (Miller et al., 2006). In these types of situations, REBs may consider waiving the requirement for parental consent, if it can be argued that this could endanger participants and/or that it could deter youth from participating in research that could be of benefit to them (CIHR, NSERC, & SSHRC, 2010). However, in many instances, parents’ right to know about their underage children’s participation often supersedes considerations related to beneficence as well as young people’s right to confidentiality (Alderson, 2007), an issue we discuss in greater detail later. The complexities facing REBs and community decision makers (e.g., youth agencies, community health services, and schools) in weighing decisions related to autonomy and beneficence are challenging (Heath et al., 2007), potentially outstripping decision makers’ expert capacities and training.

Participatory Approaches and Research Ethics Conventions

Participatory research (hereafter referred to as PAR) is a broad research methodology rather than a method

(Pain & Francis, 2003; Shore, 2007). Known by a variety of names (e.g., action research, participatory action research, community-based participatory research), PAR is a social process that seeks to engage people who typically have limited power and influence in decisions made regarding a particular issue (Miskovic & Hoop, 2006). PAR “is a collaborative approach in which those typically ‘studied’ are involved as decision makers and co-researchers in some or all stages of the research” (Cahill, 2007, p. 268). Because PAR engages community members as co-researchers and decision makers, the design of most participatory studies is iterative and informed by a “learning by doing” approach that provides academic researchers and community members with frequent opportunities to share the knowledge and strengths acquired from their unique standpoints and experience (Fernández, 2002). Ultimately, the goal of PAR is to make concrete improvements in the lives of participants and their communities (Schensul, Berg, & Williamson, 2008).

PAR with young people also is based on collaboration and is premised on the understanding that sociocultural and structural forces have a profound effect on the lives of youth (Ginwright & James, 2002). For example, PAR approaches facilitate greater opportunities for youth to provide input about what issues are important to study and how such studies should be conducted. However, the social dynamics of conventional research and policy-making approaches make it difficult to deploy fully the principles of autonomy whereby youth are situated as power brokers who are to be taken as seriously as adult policy makers (Grover, 2004). Differences in social positions between youth and researchers also can make it difficult to build trusting research relationships. Power differentials between young people and adults are particularly pronounced when the substantive research topic is deemed by decision makers (and society in general) to be controversial (e.g., related to sexuality).

Research teams that attempt to engage in PAR need to work carefully to ensure they do not reinforce or exacerbate the negative effects of existing social hierarchies whereby academic researchers are regarded as “experts” and co-researchers simply as “informants” (Pain & Francis, 2003). For example, academic researchers typically have greater access to resources than co-researchers, as well as several years of research training and experience. As a result, these researchers “can never stop being authorities or having authority” (Kelly, 1993, p. 21), although power differentials can be minimized if team members recognize and respect the different types of knowledge and experience everyone brings to the project. To date, most PAR approaches in the area of

youth health research have applied the concept of participation to only a limited degree, focusing on consulting with and informing youth about their perspectives and experiences (Hagey, 1997; Pain, 2004). This type of participation in research typically involves conducting surveys or focus groups with youth to solicit their comments on research results (Hart, 1997). While practical and expedient, such research practices have been described by some researchers as “tokenism and decoration” (Hart, 1992, p. 9).

One way to move forward is to develop study teams, wherein decision making is shared between youth and adults, and where youth lead or initiate decisions and actions that affect the research process (Checkoway, Dobbie, & Richards-Schuster, 2003; Hart, 1992). This strategy attempts to realize more fully PAR approaches by adopting a co-researcher model, whereby members of a study’s “target population” (e.g., young people) help to conduct the study (e.g., interview participants and/or analyze data). Successfully engaging youth in PAR requires power-sharing in research relationships and demands high levels of mutual trust, which require time and resource investments to develop (Cahill, 2004, 2007).

Within our own field (youth sexual health research), there is a paucity of research emphasizing PAR approaches (Flicker et al., 2008 and Flicker & Guta, 2008 are notable exceptions). Despite the fact that a majority of young people are either currently sexually active or have previously had sex by the time they reach early adulthood (Bibby, 2001; Statistics Canada, 2005), researchers typically choose to employ conventional research approaches that are rooted in a positivist paradigm (e.g., using a survey to assess quantifiable, individual risks and/or deficiencies), while avoiding approaches rooted in other epistemological traditions (e.g., social constructivism) that focus more on how context and structure affect young people’s sexual lives (e.g., youth co-researchers who conduct fieldwork to develop detailed descriptions of how sociocultural and structural factors can influence young people’s sexual health). Because risk factor surveys tend to concentrate on individual-level explanations for sexual health (Shoveller & Johnson, 2006), and whereas more constructivist approaches tend to facilitate the uncovering of evidence that situates the individual in context, we undertook a study that adopted a constructivist epistemology and a corresponding set of methodological techniques that we hoped would dovetail effectively with the tenets of PAR. What follows is a case study description and analysis of the ethical and epistemological issues that arose through our collective experiences and reflections on stage one of the project.

Methods

This study was conducted in two stages. In stage one, we sought to understand how existing policies regarding research with youth affect young people’s experiences in participating in research within one northern British Columbian community. In stage two, we used the knowledge we gained in stage one to collaboratively develop a small PAR project that examined local youth’s experiences with sexual health education. Our project was conducted in a mid-sized city (population 75,000) located in northern British Columbia, Canada. The research team included four young people (aged 19 to 22 years—three women; one man) who were employed as Youth Co-Researchers (YCRs) as well as three academic health researchers and two research coordinators.

At the outset of the project, we advertised job opportunities for the YCR positions at local secondary and post-secondary schools, and at community organizations frequented by youth. Two members of the research team interviewed all applicants. The YCRs engaged in in-depth training in qualitative research methods, including semi-structured interviewing techniques. The YCRs also received specialized training on the principles of ethical research, and each YCR completed the *Interagency Advisory Panel on Research Ethics’ Introductory Tutorial for the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (CIHR, NSERC, & SSHRC, 2005). This document, frequently referred to as the TCPS, is the governing framework for Canada’s three main research funding agencies: the Canadian Institutes of Health Research (CIHR), the National Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC). The TCPS is the principal document that informs Canadian university, as well as many non-academic, REB policies. It is similar to the Belmont Report, which describes key ethical principles for conducting biomedical and behavioral research involving human subjects in the United States (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Data Collection and Analysis

Our project began with YCRs and other team members conducting in-depth, semi-structured interviews with community decision makers (e.g., health authority and school board officials) who vet proposed research projects in their jurisdictions. Community decision makers

were asked to describe their research ethics review and approval procedures, their experiences with PAR projects, how PAR fits with the existing procedures that they currently use for vetting research applications, and how their experiences with those procedures might vary depending on the research topic (e.g., a youth sexual health survey compared with a dental health project). We also interviewed youth (ages 16 to 24) who had previously participated in health-related research. These participants were recruited through advertisements at bus shelters, community organizations frequented by youth, post-secondary campuses, and the city's youth health clinic. We also attempted to recruit youth through posters and presentations conducted by YCRs at some secondary schools. However, no 16- to 18-year-olds enrolled in school district programs at the time of the study responded to our recruitment efforts in the schools. When we asked the youth who did participate in our project to explain what they perceived to be the problem with our recruitment efforts at schools, they replied that it was too time-consuming to get parents' consent and a few told us that most of their peers think they should have the right to make independent decisions about whether to participate in research.

Youth were selected for an interview if they had completed a school-based survey, attended a focus group, or participated in a phone survey about any health-related issue during the previous three years. The interviews with young people included open-ended questions about youth's experiences with the consent process, their reasons for participating, data collection procedures (e.g., how long it took to complete the study; how often they had to provide data), and knowledge transfer and translation efforts (e.g., did they receive a report; how did the results make them feel; what actions were taken as a result of the research). A YCR and a research coordinator conducted all interviews jointly.

Data analysis was conducted jointly by the YCRs, Shoveller, Chabot (authors) and the second research coordinator, with contributions from Johnson (author).¹ After transcribing the interviews verbatim and removing unique identifiers, we began coding during the data collection period in order to identify preliminary themes and categories in the interviews (Dey, 1999). We initially coded the first few interviews and field notes to develop a preliminary set of open codes that represented abstract ideas we identified in the interviews (Strauss and Corbin, 1998). After creating our initial codebook, the research team analyzed data from subsequent interviews and field notes, using constant comparative techniques to identify new codes and modify initial ones in order to better reflect the themes we identified in the data. The

qualitative analysis software QSR NVivo (version 2) was used to code and manage the data. Notes about analytical decisions, changes to the codebook, connections between themes, and key findings were recorded in an audit trail.

Ethical Considerations of Conducting PAR with Young People

At the outset of our project, we learned that a number of previous studies conducted by other researchers in the local area had been implemented without parental consent. Thus, we anticipated that some of the youth who volunteered to participate in our study regarding their experiences of being a "study subject" might not have disclosed to their parents their participation in previous health research. We were concerned that having to seek parental consent for *our* study might inadvertently contravene youth's privacy and confidentiality as it pertained to their participation in previous studies where parental consent had not been sought. As well, we learned that youth who were estranged from their parents and/or living "in care" of the State were often unwilling or unable to obtain their parents' or social workers' consent to participate in research. We were concerned that requiring parental consent for these otherwise "emancipated minors" could unfairly preclude them from making important contributions to our project and that their exclusion could ultimately limit the applicability of our findings to their situations and further marginalize their perspectives. Therefore, in our project, we sought approval to invite youth ages 15 to 18 to consent on their own behalf. Since our project was about young people's experiences with previous health-related studies (and did not have any questions about sexual health issues), we anticipated that this request would be granted.

To proceed with our project, we were required to obtain approval from two university REBs (because our research team included faculty members from two universities), as well as from the local health authority and the school district where our project was conducted. One university's REB approved our request to treat all potential study participants (ages 15 to 18) as emancipated minors, while the other university's REB insisted that only youth 16 and older were capable of consenting on their own behalf. Despite repeated discussions with the second university's REB about the arbitrariness of determining competence by age, we eventually opted to increase the age of eligibility for our project from 15 to 16 years in order to obtain REB approval from that university. Next, the local health authority's research review committee approved our request related to emancipated minors, but the school district's Parent Advisory Council

(DPAC) did not. We were surprised by this decision, since this school district does not usually require researchers to obtain parental consent for students under 19 years of age to participate in research, provided that students' identities are kept anonymous and that the research topic is considered to be not "intrusive" (e.g., questions about sex or family issues, such as whether or not a student lives with her or his biological parents). We explained during an information session with the DPAC that our research was not "intrusive" according to the school district's operational definition (since we were only interviewing youth about their experiences with previous health-related research and we were not asking any questions about sex or family issues). In response, we were told by one school district official that sometimes the DPAC has to "make a judgment about whether parents would find [the research questions] intrusive or not" (personal communication). Furthermore, the DPAC was concerned about the roles of YCRs, particularly the idea that they would co-conduct interviews with community decision makers and young study participants. Despite assurances that the YCRs would *always* conduct interviews in tandem with a university-based researcher, the DPAC denied our request to allow young people to participate in our study without parental consent, based on two concerns: (1) parents should *always* have the right to know what research projects their children are being asked to participate in; and (2) YCRs interviewing other similar-age youth was perceived to be inherently "risky" because of their age and because they were not "professional" researchers.

Subsequent to our communicating the DPAC's decision to the two university REBs, both these agencies reassessed our application and modified their decisions by requiring us to obtain parental consent from youth under the age of 19 who were enrolled in school district programs. Youth ages 16–18 who were *not* enrolled in school during our study period were permitted to consent on their own behalf because the two REBs agreed with our original argument that these underage youth had the competence to understand the risks and benefits to study participation. This decision demonstrated how REBs and researchers can work together to facilitate research that balances the protectionist concerns of the DPAC with our request that participants aged 16–18 years be considered autonomous individuals when possible. Our research team also shared the DPAC's decision with the health authority's research review committee, which stood by their original decision to consider all youth ages 16–18, regardless of whether they were enrolled as students in the school district, as emancipated minors for the purposes of our study.

Results

After spending five months under review and/or reconsideration at the four review boards, data collection began. Nine community decision makers were interviewed to gather data about their experiences reviewing study protocols that involve youth. Six of these worked at community health care and social service agencies and were not familiar with PAR. This was not surprising because their primary job is to provide health care or social services, not to conduct or review research. Two other community decision makers worked for research review boards and one worked in education; these three decision makers said that our project was the first PAR project they had encountered in their work. Five of the nine research decision makers reported that neither they nor their colleagues on their research review committees had any formal training in conducting or evaluating research projects (including PAR projects). Several community decision makers indicated that they did not need any formal training in this area because they refer to the researchers' track record or the outcomes of previously approved projects when making decisions during the ethical review process. We also interviewed 20 young people aged 16 to 24 years (9 women and 11 men) about their previous experiences participating in research. Four participants under 19 years of age were recruited outside of the school system.

During our thematic analysis of the interview data (Strauss & Corbin, 1998), we discovered that nearly half of the 20 youth reported that they did not fully understand the purpose of the previous studies in which they had participated—raising concerns about the notion of informed consent in research with young people. Seven reported that they were not asked to provide informed consent or assent during previous studies, some of which had been administered in public schools. When asked if it is important to them to be asked to provide informed consent or assent, 10 youth replied that this is more important for interview-based studies than for survey-based research. Ten youth reported believing their previous participation in school-based surveys was compulsory and that there would be negative consequences to not participating. Of the 16 youth who participated in survey-based studies, 10 reported never interacting with the researchers conducting the study. They could not recall ever being told about how the data was used or where it would be stored. None of the 16 young people who participated in survey-based studies were given the option to provide feedback to the researchers, or told how to access the study findings. The

majority of youth said it was important to them to have an opportunity to meet the researchers conducting a study so they could ask questions about the research, provide feedback, and feel that researchers were truly interested in their experiences.

These findings suggest that research about young people is frequently conducted “on” them, rather than “with” them. That seven of the 20 youth participants could not recall being asked to provide informed consent (or assent) when they participated in previous studies also suggests that the concerns of adults were possibly prioritized over those of youth (e.g., the desire of researchers or teachers to have the research conducted as quickly as possible). We could not ask the school personnel to identify what studies these students may have participated in because the sheer volume of research that is carried out in this school district would have likely required us to disclose details about what our participants told us (e.g., school name, grade level, year of participation, and type of study) and could have breached their confidentiality. However, we know from our interviews that some youth completed school-based surveys designed by the provincial Ministry of Education. The DPAC does not require parental consent because research conducted by the Ministry of Education in schools is considered to be “internal” and of minimal risk. We also know that some youth were asked to complete a province-wide survey where the DPAC only required the researchers to conduct parental notification and student assent. Unfortunately, it seems that many of the youth we interviewed did not fully understand the concept of assent. This could be because it was poorly explained, or because students assumed their participation was compulsory given these studies were conducted during class time. These findings represent a violation of youth’s rights to personhood on which the ethical principle of autonomy is founded. In response to these findings, the YCRs spearheaded the development of the two-page “Know Your Rights with Research” handout (see Figures 1 and 2). This resource explains some common research terms in nonacademic language and young people’s rights as research participants.

During stage two of our project, the YCRs and the rest of the team used the findings from our interviews with community decision makers and youth to inform a set of interviews with young people about their experiences with sexual health education (both within and outside the school-based curriculum). We again obtained permission from both university-based REBs to interview youth ages 16 to 18 without parental consent. However, because we anticipated difficulties in obtaining permission from the local school board to recruit “underage youth” via the schools without parental consent, we

collectively decided to recruit youth only through public venues and community agencies. As per our ethics protocol, before any interview was conducted, a YCR and another member of our research team jointly spoke with potential participants about the study’s purpose, its potential risks and benefits, confidentiality, and assured each youth that their participation was entirely voluntary. We also provided all interview participants with a copy of the “Know Your Rights with Research” handout and encouraged them to ask us questions at any time during the interview. In total, we interviewed 22 youth ages 16–21 (14 women and 8 men) about their sexual health education experiences. Several young people who completed interviews spontaneously indicated that the “Know Your Rights with Research” handout (and the pre-interview discussion with the YCRs and adult interviewer) represented the first time they had been meaningfully engaged in informed consent and that they now had a greater understanding of the meaning of confidentiality and anonymity (and the distinctions between these terms). The majority of participants also said that they were pleased to be interviewed by the YCRs, as it helped them feel more relaxed and comfortable.

Discussion

We recognize that conducting research with people under the age of majority raises special considerations and that requiring parental or guardian consent can help to ensure that young people, especially children, are not exposed to potential physical, psychological, or social harms in research. However, as has been noted by other researchers, requiring parental consent in some studies can reduce participation in research by adolescents and young adults up to the age of majority. Not only does such non-participation prompt concerns about the study’s reliability and applicability of findings (Cashmore, 2006; Johnson et al., 1999); but the potential exclusionary processes that emerge from insisting on parental consent may inadvertently cause greater harm, as the perspectives of those youth prevented from participating in research are increasingly marginalized. While often defended on the principle of beneficence and “protecting” young people’s “best interests,” such actions not only deny young people’s autonomy and agency within research, but potentially skew research findings as the perspectives of some young people are effectively excluded in the name of beneficence—without acknowledging the social gradient that is often implicated in such “beneficence.” For instance, denying the participation of some young people may serve to contribute to silencing processes that effectively marginalize the differing perspectives and

Know Your Rights with Research

As a study participant it is important that you understand the full details of participating in a research study. The better you and the researcher understand each other and the details of the study, the more likely it is that you might have a positive research experience. Here are some things you should know before you participate in a research study.

You are allowed at any time to:

- Refuse a question.** Whether it's an interview question or one in a background questionnaire.
- Withdraw from the study.** With most studies you can stop participating at any time during the study and all of your information will be withdrawn as well. Make sure you check with the researcher, because some studies have a limited withdrawal period.
- Speak with the researcher at any point during the study.** Make sure you are able to speak with them before, during, and after the study, if you wish.
- Ask the researcher questions about anything in the study that you don't understand or you are unsure of.**

Has the researcher told you:

- The benefits and risks of the study?** If not, ask.
- The purpose of the study?** If you don't understand it, ask questions.
- The study procedures and methods?** (For example, how the study will be conducted, the length of time it will take to complete the study.) If you think they left something out, ask them questions.
- Where and how your information is going to be used?** Make sure this is clear to you.
- That your participation is entirely voluntary?** You do not have to participate if you don't want to.
- That you have time to decide whether or not you want to participate?** Make sure you have the time to think about participating.
- The details of the incentive/honorarium?** (For example, how and when you will receive it.) Be sure you know beforehand when and how you will be recognized for your participation.
- That you have the right to remain anonymous?** If they don't give you the option of using a fake name or ID number, tell them you want to. Make sure that when you receive your honorarium your identity is still kept confidential.
- Who they work for and who is conducting the actual study?** It's important to know if the person distributing the study is the actual researcher conducting the study.
- Where you can contact them if you have further questions?** If not, ask them for their contact information.

FIG. 1.

Research Vocabulary

Here are some common words that are often used by researchers that might help you better understand how a research study is being conducted.

Analyze: to examine something carefully and in detail so you can identify causes, key factors, or possible results of an event, behaviour, issue, or experience.

Anonymity: the personal identity of a research participant is not known to the researchers.

Confidentiality: researchers do not share any of the information provided during the study with anyone, except those working on the research project who need to know. Researchers also don't share the identities of people they may have met, seen or spoken with, with anyone outside of the project.

Ethics: the principles that describe how a research project should be conducted. Universities, health authorities, and school districts typically have a strict set of guidelines that a researcher must follow to make sure research is done in ways that do not harm participants. Universities also have ethics boards that review a researcher's project and must approve it before the researcher can begin their study.

Findings: information (or data) that is discovered because of research.

Focus Group: a small group of people specially chosen to represent a wider population who are asked to talk about and share their opinions about a particular subject.

Honorarium: money or a gift in kind (for example, gift certificate) given to research participants as a way to compensate them for sharing their time, knowledge, and opinions with the researchers.

Informed Consent: when a person agrees to participate in a study after having been told about and understood the risks and benefits of participating.

Interview: a meeting where a researcher asks questions in order to find out a study participant's views or experiences. Sometimes, interviews are audio or video recorded. Other times, only written notes are taken. The researcher should tell you about how the interview will be conducted before you agree to participate.

Pseudonym: a false name used by a participant instead of their real name to keep their identity a secret.

Research:

Academic: research done for educational purposes that is completed by schools, universities, colleges, health authorities, or government agencies.

Market Research: the work of collecting information about what people buy and why.

Study Methods: the way that the study is being done. Common study methods include surveys, interviews and focus groups.

Survey: using questionnaires to investigate the opinions or behaviour of a particular group of people.

Transcript: a written word-for-word copy of what was said during an interview.

INSERT STUDY CONTACT
INFORMATION HERE

FIG. 2.

experiences of different groups of young people. In this way, this protectionist discourse can undermine the ethical principle of justice and its emphasis on treating all potential participants in a fair and equitable manner. The epistemological tensions emerging from these processes are discussed later in this section.

For the most part, we have found that REBs we have worked with interpret Canada's Tri-Council Policy Statement guidelines regarding minimal risk and age of consent in a balanced manner that seeks to ensure that researchers protect youth from harm, while at the same time advancing knowledge. However, if youth in schools are to be included in more research studies, further dialogue with school officials is required in order to understand more fully the decision-making process involved in weighing the best interests of youth and parents so that the potential (negative) effects of youth *non*-participation in research can be duly regarded.

The establishment of research ethics guidelines, particularly over the past decade, provides a necessary, but insufficient, condition upon which to protect young people's rights regarding research (Leadbeater & Glass, 2006), as potential harms are not entirely avoided. We argue that age should not be the primary consideration of a participant's competence to understand the risks and benefits involved in research participation (Alderson & Morrow, 2011; Bruzese & Fisher, 2003; Cashmore, 2006). For example, under BC law (Statutes and Regulations of British Columbia, 1996), children under 19 can be considered mature minors who can legally consent to medical treatment without parental consent if they are deemed by a health professional to understand its risks and benefits and treatment is believed to be in the child's best interests. Similarly, REBs in Canada and the UK will consider waiving the requirement for parental consent for youth under the legal age of majority, if researchers can demonstrate that eligible participants are emancipated minors who comprehend the risks and benefits of the study in which they are being asked to participate. Waiving the requirement for parental consent can show respect for their autonomy and ability to make decisions according to their own interests (Geluda et al., 2005). Moreover, allowing young people to consent on their own behalf can encourage greater participation from marginalized youth (e.g., LGBT youth, homeless youth) and allows researchers to obtain a more diverse sample. It can provide researchers with a more nuanced understanding of the experiences and needs of marginalized youth. Finally, it can also help reinforce researchers' duty to treat all potential participants in a just and equitable manner.

Our study participants reported that they perceived their participation in school-based surveys as compulsory and suggested that there could be negative consequences

for refusing to participate. Other researchers have found that students often fear they will be singled out as "uncooperative" or sanctioned if they do not participate in a classroom-administered survey (Edwards & Alldred, 1999; Heath et al., 2007). Students may not be able to differentiate between a voluntary survey conducted in the school and other classroom work, or they may feel "coerced" into participation by teachers and peers (David, Edwards, & Alldred, 2001; Denscombe & Aubrook, 1997). Within the school context, a student's right to refuse to participate in research also must be considered if their rights to autonomy are to be fully regarded and respected. Arguably, in such a (formal) context, it is more difficult for youth to exercise their autonomy and refuse their consent. As Heath and colleagues (2007) observe: "Completion of a questionnaire might, for example, form the centrepiece of a classroom activity, and might be indistinguishable from other routine classroom assignments" (p. 413). Of particular concern is that when youth are not informed that they are participating in voluntary research, rather than a required school activity, adult researchers and educational decision makers are denying them, at a minimum, their right to assent to participate, let alone provide fully informed consent, if and when it is sought. The partial or selective types of information conveyed to young people involved in research not only support developmental assumptions about their inability to understand the purpose and scope of the research, but also deny those young people the right to adequate and appropriate information to make decisions for themselves. These issues also have bearing on the development of an "evidence base" related to young people's health and social concerns (e.g., youth who are highly marginalized may be systematically excluded from having their voices included as evidence if they face barriers to obtaining consent to participate in research). What then emerges as "facts" within this realm may suffer from an incomplete set of data points. At the least, we need to consider how this may relate to the epistemological underpinnings of knowledge in this area.

Limitations

There are some limitations to the generalizability of our study findings. First, this study was conducted according to Canadian REB policies regarding academic research in community-based settings; hence, some of our recommendations may not be applicable in other jurisdictions (e.g., countries with a lower age of majority). We also had a small sample size and our study was only conducted in one community. Third, our recruitment efforts were likely affected by the DPAC's requirement that young people aged 16–18 who were recruited through school district programs had to obtain parental consent. This

requirement may very well have discouraged students from volunteering for our study and limited the diversity of our sample, yet it also highlights the effect that age-based ethical policies can have on sampling.

Best Practices

Employing participatory action research methods in youth sexual health research can help promote new insights that could be used to identify novel interventions to promote sexual health, and more meaningfully engage adolescents and young adults in the research process. Working collaboratively with youth to examine structures and policies affecting their sexual health (e.g., access to youth sexual health services) can, ideally, help to promote changes to policies and services that are informed and promoted by youth themselves (Fernández, 2002; Flicker & Guta, 2008). Furthermore, when possible, the use of research funds to employ YCRs can provide them with valuable research skills and gainful employment. However, to be successful, the value of youth's participation in PAR must be recognized by ethics review committees in both the university and community/school contexts. To enable that, researchers must engage in further dialogue with REBs and community decision makers about the benefits and risks of having youth in participatory research, particularly when it involves sensitive issues such as the waiving of parental consent and/or sexual health topics.

REBs should also ensure that researchers take the time to adequately explain the principles of informed consent and assent, as well as participants' rights in ways that young people can understand. We recognize that this is a standard requirement in most REB policies; however, our findings suggest that this policy is often not adequately put into practice. For example, whenever feasible, researchers should be strongly encouraged to speak directly with participants and use layperson's language when explaining participants' rights and the meaning of informed consent forms.

Research Agenda

This study highlights a number of issues that would benefit from additional research and discussion. For instance, further research is required in order to better understand how young people from a variety of different backgrounds and ages experience the research ethics process. Attention should be paid to the extent to which young people understand their rights as research participants, particularly in institutional contexts (e.g., schools, health care facilities) where they may be more

likely to think that research participation is required as part of the work they do or care they receive. Researchers, REBs, and community decision makers would also benefit from an analysis of the epistemological differences that influence ethical policies regarding underage youth in research. For example, in our experience, we have found that community-based research review policies regarding youth tend to emphasize age-based protectionist discourses rather than allowing consent to be determined by competency alone. Last, but not least, researchers working with children and youth under the age of majority in a variety of jurisdictions should be encouraged to publish articles about their experiences obtaining research ethics approval from REBs and community decision makers.

Educational Implications

REBs, researchers, and community decision makers who vet research projects involving youth should increase their efforts to educate young people about the informed consent process and other issues regarding their rights as potential research participants. Doing so can make up for the lack of parental consent and can mitigate risk sufficiently to protect youth. The information researchers provide to youth must be presented in such a way that they can fully comprehend the implications of their participation. Researchers and community decision makers should be mindful of the potential ways in which information conveyed to younger participants may be partial or selective, reflecting dominant (developmental) assumptions about the ability of youth to understand "complex" information and the risks and benefits of participation. Such assumptions can be countered, in part, through the use of participatory research methods, when appropriate. For example, youth who are employed and trained in studies that use PAR can help to educate young people regarding their rights as research subjects. Using a tool such as the "Know Your Rights with Research" handout (Figures 1 and 2) can be an effective means with which researchers can educate young people about their rights, and could be adapted to meet the needs of other study populations.

REBs and community-based review boards should consider recruiting young people to be active representatives on their committees, particularly when vetting research proposals that involve children and adolescents. Youth representatives who have experience in conducting participatory research and/or who have been educated about research ethics can make valuable contributions to the review process, alongside other groups of young people who bring important insights and perspectives regarding how any proposed research may be perceived and experienced by young people

themselves. For example, youth representatives could propose ways to improve the consent process with children and youth, or to inform young people of their rights as research participants.

Finally, researchers and REBs should also reach out to community decision makers who oversee ethics review for studies that are conducted in their jurisdiction and encourage in-depth discussions about ethical issues involving young people. In our study, we found that the majority of community decision makers we interviewed lacked formal training in evaluating or conducting research. By sharing knowledge, resources, and experiences regarding the ethics review process, REBs and researchers can promote a mutually beneficial exchange of information with community decision makers that seeks to advance research reflecting the ethical principles of beneficence, autonomy, and justice.

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Grace Spencer is a registered nurse and Lecturer in Adult Nursing at the School of Nursing, Midwifery, and Physiotherapy at the University of Nottingham (UK). She has extensive experience in research and practice related to adolescent sexual health. In particular, Spencer has experience in working directly with young people to gather their input on research and research processes and has been a member of a research ethics board in the UK for over seven years. Spencer's work focuses on empowerment, sexual health, and young people. She provided substantive contributions and feedback on drafts of this manuscript.

Joy L. Johnson is Professor in the School of Nursing at the University of British Columbia and Scientific Director of the Canadian Institutes of Health Research's Institute of Gender and Health. Her research interests focus on health promotion and health behavior change. Drawing on a broad array of theoretical perspectives, her work explores the social, structural, and individual factors that influence the health behavior of individuals. Johnson was a Co-Investigator on this study, contributed to the development of the research methodology, conducted data analysis, and provided substantive contributions and feedback on drafts of this manuscript.

Note

1. Two of the YCRs, Stephenie Berlinger and Jesse Ogen, contributed to the oral presentation given to the Canadian Association for the Study of Women and Education's 2008 Conference, upon which this manuscript is based. Grant funding for this study ended shortly thereafter and the YCRs moved on to other work. Neither of them chose to contribute to the development of this manuscript. We gratefully acknowledge the contributions they made to the project and the ideas behind this paper.

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