

## **Older adolescents participating in sensitive research: the voices we can't hear**

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Research with young people is essential for identifying and addressing current and future health issues of our youth. Health research with adolescents often involves topics considered sensitive, and can include issues around body image, health care practices, sexuality and substance use. Some areas are more sensitive than others and Lee and Renzetti (1990) argue that the degree of sensitivity is directly related to perceived level of risk to participants. Adolescence is also a crucial developmental period, in which young people become increasingly independent and the responsibility for health care and other aspects of life transition from parents to the young person themselves. Adolescence is a time of learning and experimentation; therefore, some potentially high-risk behaviours (such as drug and alcohol use, sexual activities) are commonly associated with the age group.

Researching sensitive topics has always presented challenges due to ethical and moral concerns that for researchers and communities (Hayter 2010). Preventing harm to research participants is a main concern for researchers and regulatory bodies. In sensitive research, drawing on past traumatic experiences can cause distress. Therefore, it is understandable that ethics committees and other regulatory bodies have responded

cautiously by, for example, requiring the consent of the parent or guardian in addition to the young person himself or herself.

However, in order to get a good understanding of issues pertaining to adolescent health, the participation of as many young people as possible in research is paramount. Over cautious safeguarding might in fact diminish the potential benefits of the research. For instance, advances in cervical cancer screening would have not been possible without studies involving adolescents (Moscicki *et al*, 2000) and in order to maximise these advances, inclusive involvement of young people in research is required. There is a concern that inclusivity might be reduced by parental gate keeping of the young person's participation in research. In many countries, the need for parental permission reduces in accordance with the capacity of young people to make decisions. This means that many adolescents can consent to treatments once they understand what they entail (Wheeler, 2006). However, many authorities set additional requirements around consent to research and hence it is not unusual for parental permission to be sought prior to research, when this would not be required prior to treatment.

Parental permission refers to the situation where an additional consent from the parent or guardian is required before the young person enters a study. This gives the parent or guardian the right to veto the participation of the young person, or indeed might put off the young person expressing interest in the study in the first place. Parental permission assumes that parents assess the risks and benefits and ultimately act as safeguard by making a decision which is in the best interest of the young person (Ott *et al*, 2009). We argue that the need for parental consent in research could be waived for those aged 16 to 18 years old.

Exploring a sample of the existing research undertaken in sexual health involving adolescents, the requirement for parental permission is common in under 18's (Blacke *et al*, 2012; MacPhail *et al*, 2013). One French study stated researchers deliberately opted to not recruit people under 18 years to avoid the need for parental permission (Fernandez-Gerlinger *et al*, 2013). It is often unclear in published research whether parental consent has been required; a recent literature review examining the consent procedures and risk behaviours in adolescence identified that in around 90% of the studies published, no details about consent procedures were given. Furthermore, no studies stating waiver for parental consent were found (Liu *et al*, 2014).

In spite of a clear position regarding treatment decisions for those over 16 including sexual health related conditions in many countries, researchers are often restricted by dissonant and unclear guidelines stemming from tensions between protecting participants and the need to develop research-based knowledge and ensure relevance of research findings. The rationale for requiring parental consent prior to a young person's involvement in research is linked to the concept of autonomy, which refers to the participants' ability for self-determination, in this case the informed decision whether to participate in research (Biggs, 2009). It is often argued that a higher level of autonomy is required before participation in research; hence the requirement of parental permission.

The pillar of exercising autonomy in medical ethics is the ability to decide whether one wants to take part in research or therapeutic interventions in full cognisance of the facts; therefore, being able to provide an informed consent. Consent is not required just for clinicians' protection from legal liability but for promoting and respecting individual autonomy (Mutcherson, 2005). Those who advocate parental consent for young people

taking part in research might argue that whilst this group might be autonomous enough to consent to therapeutic interventions, consent to research is a different concept, and a higher level of understanding is required since the research involvement might not represent direct benefit for those who participate. The evidence on whether 16 and 17 year olds are sufficiently autonomous to participate in nursing research on sensitive topics is scarce.

Hester (2004) argues that complexities surrounding parental permission in adolescent research makes researchers hesitant to undertake such projects. When research is attempted, English *et al* (1995) identified parental permission as being the greatest barrier to non-participation in research involving adolescents. Researching a sensitive topic added to the complexities of gaining parental permission were identified as significant barriers to participation and recruitment (Moilanen, 2015). Mustanski (2011) also stated that researchers avoid conducting research with adolescents who identify as gay and lesbian due to difficulties on gaining ethical approval.

The scant evidence in existence suggests few researchers doing adolescent research have been successful in waiving parental permission. Waiver was previously justified in social studies (Piercy and Hargate, 2004) psychology (Kelly and Halford, 2007) and observational studies (Ruiz-Canella *et al*, 2013). Newcomb *et al* (2016) argue that parents raised concerns of the negative consequences of requesting parental permission for adolescent research participation. As nurse researchers we advocate to waive the parental permission for 16-17 years old taking part in sensitive research. Here are some persuasive arguments supporting the waiver of parental permission for consent:

- The need for parental consent can then introduce systematic bias in research (Liu et al, 2017; Ruiz-Canella *et al*, 2013). When participants who are unable or unwilling to seek parental permission are excluded, bias is introduced. We will never know how the data from those whose parents did not consent would differ from those who did take part.
- The need for parental consent infringes the concept of justice. A recent definition of ethical justice includes authenticity as one major component (Mishna *et al*, 2004). Therefore, accepting the biased results from projects requiring parental permission is not just questioning the validity of the results, but the principle of justice. The same principle is infringed if young people are excluded from research that may help improve knowledge about their health (Flicker and Guta, 2008) and their voices are unheard (Poole and Peyton, 2013).
- The need for parental consent may lead parents to assume that the adolescent is admitting to being sexually active or being involved in risky behaviour, which it is in fact a loss of confidentiality (Flores *et al*, 2017; Risjord and Greenberg, 2002).
- Some adolescents may feel pressured by parents to participate in research against their will, leaving them without a voice (Grady *et al*, 2014)

There is some evidence that the benefits from taking part in research outweigh the risks associated to it. Hasking *et al* (2015) undertook a study to explore the reactions of those who took part in sensitive research. They found that more than half of the adolescents involved in their study had positive reactions and emphasise that the fear of loss of confidentiality as being more important to participants, which supports our argument that

parental permission in such cases could breach the adolescent confidentiality and privacy.

Parental permission requirement without regard to the topic of research can be more

harmful than beneficial (Ruiz- Canella *et al*, 2013).

We are witnessing an ethical paradox and the protection of young people now at risk of contributing to silencing and injustice. This may be due to the paternalistic tendencies of some guidelines from research councils or professional bodies that still advise on obtaining parental permission prior to enrolment in research (Biggs, 2009), or misinterpretation of parental involvement by some regulatory bodies. Protectionist guidelines can diminish adolescent autonomy and '*reflects the dilemma of a nation that is at once afraid of and afraid for its young people*' (Mutcherson, 2005, pg. 243). The reality is not fully grasped as there are various situations in which parental/guardian figures are not present, such as is the case of young people who are runaways, refugees or orphaned, for example. We have a moral duty to include these groups as they are already vulnerable and marginalised.

We argue that the need for parental permission, in addition to the consent of the young person, is often unnecessary and can limit the participation of our young people in research.

Researchers report that their study designs are changed as a result of regulatory bodies' intervention, and in adolescent sexuality research, personal values of those in the ethics committee/ review board could threaten the academic quality of the project (Mustanski, 2011). At present, we are in danger of promoting research with a unilateral perspective in the absence of an inclusive input from the adolescents in terms of contribution and review. This not only silences adolescents but puts researchers at risk of generating findings that may not meet the needs of the target population.

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