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## **Ethical Considerations in Conducting Public Health Nursing Research With Adolescents in the UK: A reflective account.**

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### **Abstract**

The purpose of this paper is to reflect on the ethical complexities to be considered whilst conducting research related to adolescents. In order to facilitate the reflection, John's model is used (John, 2000). This enables structured reflection through analysis of complex decision making to develop learning and understanding which ensures research involving adolescents is ethically sound. Critical evaluation of such ethical considerations helps provide an objective perspective of the process undertaken and the limitations and successes of facilitating children as active agents in research and clarifies the role of the researcher.

### **Introduction**

The purpose of this paper is to reflect on the ethical complexities to be considered whilst conducting research related to adolescents. Reflective writing can aid the development of critical thinking and analytical abilities, contribute to cognitive development, enable creativity, make unique connections between disparate sets of information, and contribute to new perspectives being taken on issues (Jasper, 2005). Within research, reflexivity is the careful consideration of the effect of the research process on who *we* are, where, when, how and why the research is being undertaken (Griffiths, 2009). This is not always an easy process as it can be difficult to assess a person's own preconceptions if they are not aware of what they may be (Parahoo, 2006).

As this is a reflective account there will be instances of using first person narrative where appropriate. In order to facilitate reflection, John's model is used (John, 2000). This enables

structured reflection through analysis of complex decision making which aims to develop learning and understanding to ensure a narrative research project involving adolescents is ethically sound. John's model is structured around a number of stages: A description Of the experience; identifying influencing factors; reflecting on the situation; indicating what has been learned and drawing conclusions from the process, (John, 2000).

### **Description of the experience**

The purpose of the project under scrutiny for this reflective account (undertaken as part of a Professional Doctorate in Nursing), is to elicit narratives from adolescents about their experiences of drinking alcohol. This subject was chosen as my professional background involves working with children and families. Therefore, I have a great interest in the agency of children as expert patients and feel there is an opportunity for them to have a greater say in the way services for them are developed. For the purpose of this project, evidence relevant to the field of public health nursing was gathered. The context was related to supporting adolescents who may have issues with alcohol use.

The issue of underage drinking among adolescents and the consequent outcomes is such that there is a growing recognition that children need to be given the opportunity to share their feelings and wishes about issues affecting and influencing them (Clavierole, 2003). By using a narrative approach, the participating adolescents are allowed to be represented as highly informed experts on their own daily lives (Alderson and Morrow, 2004). This is because they can provide authoritative sources of information about their lives and opinions in relation to drinking alcohol, and how they perceive this behaviour in terms of its short and long term health impact (Morrow & Richards, 1996; Coyne, 1998). Morrow (2001:256) describes this methodology as one which 'incorporates the social concept of place, lay knowledge and lay narratives' to generate theories which can inform public health nursing.

According to Alderson and Morrow (2004), ethical considerations for research are generally based upon the frameworks of duties, rights, harms and benefits. By researching children's experience it demonstrates respect of the child as a person with values and rights (Greene & Hogan, 2005). It was important for me to understand how I could incorporate this sense of rights and values towards children in a research framework, this was a key factor from my

own perspective as I have observed how the concept of underage drinking in the UK has been shaped and formed by adult sensibilities.

There is now a developing body of knowledge conceptualising children as active agents who are social participants to the experience and construction of knowledge about childhood (Uprichard, 2010).

James & Prout (1997) acknowledge childhood to be:

*'a part of society and culture rather than a precursor, and that children should be seen as already social actors, not in the process of becoming such.'*

James & Prout (1997: 4).

So as active agents, consideration must be rigorously given to the process of consent from the eligible adolescents in order for them to engage in the research and to ensure ethical frameworks are adhered to. The UN Convention of Child Rights (1989) (article 12) supports the right for the child who is capable of forming his or her own views to express those views freely in all matters affecting the child, and the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds (article 13).

For some researchers in the UK there are concerns that formal guidelines from the 'National Research Ethics Service' (NRES) for obtaining consent from minors (NRES, 2009a; 2009b), which recommends parental *consent* along with the child's *assent*, has a negative impact on research with adolescents (Diviak et al 2004; Hunter & Pierscionek, 2007; Moreno et al 2008). It is particularly highlighted in areas considered as harmful behaviours, to which parents may have no or little awareness that their children are engaged in. This leads Kelly & Halford (2007) to believe that too much emphasis is placed upon obtaining parental consent to allow adolescents to participate in research.

As an aid in deciding whether to override parental consent, researchers in the UK can consider the application of 'Gillick competency' to the participants (Gillick vs West Norfolk and Wisbech Area Health Authority, 1985). Gillick competency is the concept of a child under 16 years of age having the maturity to understand the nature of the research and the

rights, risks and benefits of participation, therefore being able to provide independent consent (Hunter & Pierscionek, 2006). This alleviates the need to gain parental consent, though the researcher must use these guidelines appropriately and they have a responsibility to ensure that they can be legitimately applied. The main issue to be considered is that of assessing the child's competence. There is a need to ensure that the information sheets and the implications of research participation are fully understood if the path chosen is to use adolescent *consent*, (under Gillick competence), rather than adolescent *assent* following parental consent.

When considering the issues of *consent* versus *assent* of child participants, Masson (2004) proposes that where the research purpose, process and outcome is fully explained, (including the impact of participation), then it is appropriate to obtain informed consent from older children. By using this approach, Masson (2004) states that this allows '*maximum opportunity*' for children to express their views and opinions, and avoids potential exclusion due to parents not responding to requests of consent, or wishing to exert control. Heath et al (2007) also recommend that researchers '*respect the rights of agency*' but state that how and where the research is conducted can present challenges to this notion. The methodology of the research can either hinder or promote agency in respect of the environment where the research is undertaken and how the researcher conducts the data collection and analysis. The researcher can also affect the level of agency by their position of perceived power in any interview situation (Kvale and Brinkman, 2009).

My own research project required access to adolescents and utilised the school environment, not only as a site for the study, but also in the role of gatekeeper; or '*in loco parentis*'. Savage and McCarron (2009) define gatekeepers as those who have power and knowledge about the setting in which the research will be undertaken. The role of '*gatekeeper*' is to ensure that participants from the school are protected from any potential harm as a result of the study. They have control over the researcher's access to the participants, but have no legal right to control consent (Masson, 2004). They do, however, have the scope to guard against risk of vested interest of researchers clouding judgement on the competency of participants (Hunter & Pierscionek, 2007).

### **Influencing Factors**

A health related study by John et al (2008) was considered as influential prior to my decision making in my own project. The aim of this study was to establish the appropriateness of asking healthy children to make a decision regarding participation in a research project. The average age of participants was 7.1 years and John et al (2008) concluded that at this age the level of comprehension of the age appropriate information about the purpose of the research, and the role of the child in the research, varied considerably. They concluded that further guidelines about the requirements for informed consent involving children in research are needed. It could be argued that these principles could still apply to older children and in particular adolescents, as to the differing levels of comprehension and ability to safeguard their own interests.

Further to this, Hester (2004) indicated 15 years to be an age for an adolescent at which there are sufficient cognitive and life skills to make autonomous decisions regarding research participation. However, Nightingale and Fischhoff (2003) suggest that by the very nature of the investigation of risky behaviours, such as underage drinking, adolescents do not always act in their own best interests. This highlights that vulnerability is still an issue for those in adolescence and must be considered when providing information about a study and gaining consent to participate.

Under the guidelines from the NRES, researchers using children as participants are required to obtain consent from parents or guardians and assent from the participating child (NRES 2009a). As discussed earlier, investigating social issues for young people can be adversely hindered by obtaining parental consent, with the risk of reduced participation rates and sample bias (Tigges, 2003). As such the implications of accessing active or passive consent from parents needed to be considered. Active consent is where parents give written agreement for their child to partake in an activity. Alternatively passive consent is taken unless parents provide written instruction that their child should not partake in the activity (Tigges, 2003).

Williams (2006) believes it is possible to undertake ethical and methodologically sound research with adolescents without obtaining parental consent. It may be considered that parental permission is not a reasonable requirement in research which includes accessing information about risky behaviours, using a method which involves minimal risk such as questionnaires, or methods constructed to preserve confidentiality such as individual interviews, (Holder, 2008). Difficulties in justifying this to research ethics panels may arise

as research ethics are generally orientated towards medical ethics and little attention is given to the concept of informed consent and the autonomy of adolescents (Kelly & Halford, 2007). The Medical Research Council acknowledges the concept of a child being 'Gillick competent' and in the absence of law dealing with research it is reasonable to apply this principle, whilst considering the level of understanding and the complexity of the research (MRC, 2009).

This presented me with the responsibility to identify the adolescents' capacity to understand the components of the study along with associated risks, benefits and their rights during it (Hester, 2004). Sterling & Walco (2003) suggest the researcher can be guided towards the competency levels by assessing the adolescent's capacity for decision making. This should be based on cognitive function, reasonable judgement and level of personal responsibility. Using well designed information leaflets that clearly communicates these factors to the adolescents in a format which is appropriate and appealing to that age group is important (Dawson & Spencer, 2005; Savage & McCarron, 2009,). It is crucial to do so in order to gain informed consent which is a core principle of research involving human subjects (NRES 2009a).

To add to this debate of consent over assent, Hunter & Pierscionek (2007) state that the majority of research does not warrant the application of Gillick competency to participants as there is no primary aim to benefit those participants, as would be the case in this research project. It must be acknowledged however, that benefit can be measured on different levels and whilst not directly benefitting the participant, it may benefit the wider population of young people.

A further consideration when deciding to apply consent or assent for the study was the concept of confidentiality. It is generally this risk factor that can affect recruitment to such studies where surveys relating to adolescent behaviour involve parental consent, as many adolescents may not wish to make their parents aware of such behaviours. Therefore parental consent may be seen as a breach of their confidentiality (Kelly & Halford, 2007).

According to Williams (2006), studies have identified that gaining parental consent for adolescent research can lead to bias. As long as meaningful consent is obtained and the limits of confidentiality are clear, adolescents should be encouraged to share their own perspectives on social issues without parental consent. They should be considered competent

as they have the cognitive ability and life skills to make responsible decisions based on rational reasons (Beauchamp & Childress, 2001; Hester, 2004,).

The issue of 'risky behaviour' among adolescents and the consequent outcomes, whilst demonstrating the vulnerability of this group, also highlights the growing recognition that children need to be given the opportunity to share their feelings and wishes about issues affecting them (Clavierole, 2003). In doing so policy makers should be able to develop strategies which can influence these young people and contribute to minimisation of harm.

## **Reflection**

Following the review of literature I considered it appropriate to apply Gillick competency to prospective participants in order to gain consent rather than assent when researching risky behaviour amongst adolescents. I also felt it would be considered appropriate to offer information to parents about the research project taking place within their child's school. This would be a purely informative process and therefore allow prospective participants to be treated as wholly autonomous during the study period.

On reflection, if I had known that those that were mainly sixteen years of age would come forward as participants I would still have sent information to parents. It would appear that there is still ongoing debate as how to best facilitate research with adolescents which aims to gather information about their lives and behaviour (Singer, 2011). The importance of the process of gaining consent or assent relies on the appropriate provision of information and making it clear to those who are to be involved that their consent or assent can be withdrawn at anytime. This can ensure that the researcher does not have complete power over the participants, but that they in fact have autonomy over the level to which they decide to participate, (Morrow, 2008).

## **What did I learn from the experience?**

The use of engaging and age appropriate information sheets was fundamental to informing the students and parents. The school played a key role as gatekeepers in ensuring that the children were fully informed of the project and that the study took place in a safe and

appropriate environment which also enabled confidentiality. It demonstrated the importance of having a good relationship with those who are *'in loco parentis'*. The decision to apply passive consent was made from my perspective as a parent as well as a researcher; in that I would want to be made aware of activities that my own child had the opportunity to be involved in whilst at school.

As a result there was no response from the eligible 205 pupils' parents who received the letters and information sheets. This may demonstrate that providing information to parents is not a hindrance to undertaking health related research with adolescents. The adolescents who agreed to be part of the study were articulate, well informed young people, and therefore represented minimal risk in respect of assessing cognitive ability to understand the consequences of taking part. This is a positive aspect of allowing adolescents the opportunity to make informed choice. However, it could also be seen as a limitation where other, perhaps less articulate and well informed adolescents who could have made a valuable contribution to the study did not come forward. The majority had turned or were almost turning sixteen years of age which again negated the need for assent over consent.

## **Conclusion**

The UN (1989) states that children shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds (article 13). The review of literature purports that children can be considered as active agents in research when ethical considerations are fully explored. If children are to be active in research, the researcher has an ethical and moral responsibility to ensure that the participants are fully comprehensive of the aims and their roles within the research. This can be achieved by using professional knowledge and experience to clarify the need for active or passive consent and to be confident in evaluating children's capabilities by understanding the rule of Gillick competency. However, researchers must also acknowledge the importance of involving gatekeepers or parents to ensure the safeguarding of children.

Reflexivity demonstrates the capacity to evaluate your own actions, values and beliefs whilst participating in the research process. It necessitates the recognition of the influence of the interaction between the researcher and participants on the research outcome (Finlay, 2002; Arber, 2006.). By undertaking a critical analysis of the ethical issues relating to involving

adolescents in research I have been able to demonstrate an awareness of the process undertaken and the limitations and successes derived from this phase of the project.

By utilising the concept of passive parental consent and having the support of gatekeepers I have enabled adolescents to be involved as active agents in my project and be contributors to the social world, by allowing an exploration of their perspectives of drinking alcohol which can then be used to inform the field of public health nursing.

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