

# ETHICAL CONSIDERATIONS IN CONDUCTING PUBLIC HEALTH NURSING RESEARCH WITH ADOLESCENTS IN THE UK: A REFLECTIVE ACCOUNT

Julie Southernwood & Rob Burton\*

*Fellow of The Higher Education Academy, School of Human and Health Sciences, University of Huddersfield, UK.*

*\*Corresponding Author: E mail: r.l.burton@hud.ac.uk*

## ABSTRACT

The purpose of this paper is to reflect on the ethical complexities to be considered whilst conducting research on adolescents. In order to facilitate this study, John's model is used (*John, 2000*). This enables structured reflection through analysis of complex decision making, to develop learning and understanding which judges the ethical values regarding research involving adolescents. Critical evaluation of such ethical considerations helps to provide a perspective of the process undertaken. It also helps us to evaluate the limitations and advantages of using children as active agents in research and clarifies the role of the researcher.

*Key words : Ethical complexities, Public Health, Nursing research, Adolescents*

## INTRODUCTION

The present paper attempts to analyze the ethical complexities involved in carrying out research work concerning adolescents. Reflective writing can aid the development of critical thinking and analytical abilities, contribute to cognitive development, enable creativity, make unique connections between dissimilar sets of information, and contribute to new perspectives on topics (*Jasper, 2005*). Within the parameters of research, reflexivity is the careful consideration of the effect of 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 very difficult to assess a person's own preconceptions if he is unaware of his own thoughts (*Parahoo, 2006*).

As this is a reflective account there will be instances of using first person narrative where it is applicable. In order to facilitate reflection, John's model is used (*John, 2000*) for this study. This allows well thought-out perceptions through examination of intricate decision making which aims to develop

learning and understanding to ensure the ethical perspective of narrative research project involving adolescents. 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 aim of this project (undertaken as part of a Professional Doctorate in Nursing), is to elicit narratives from adolescents about their experiences of drinking alcohol. The present subjects were chosen because the children are expert patients and there should be opportunity for them to have a say in the way services are developed for them. For the purpose of this project, evidence was gathered regarding the field of public health nursing. The context was related to support the adolescents who may have issue regarding alcohol consumption.

The issue of underage drinking among adolescents and the consequent outcomes is such that

there is a growing recognition that children should be given the opportunity to share their feelings and wishes about matters 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 an authoritative source 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 and Richards, 1996; Coyne, 1998). Morrow (2001) describes this methodology as one which 'incorporates the social concept of place, lay knowledge and lay narratives' to generate theories which can enlighten nurses in the public health.

According to Alderson and Morrow (2004), ethical considerations for research are generally based upon the frameworks of duties, rights, harms and benefits. The research on children's experience portrays respect for the child as a person with values and rights (Greene and Hogan, 2005). The incorporation of this sense of rights and values of children in a research framework, helps to analyse the role of adult sensibilities regarding underage drinking in the UK.

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 and Prout (1997) considered 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'.*

So active consideration must be rigorously maintained regarding the consent of the eligible adolescents for their participation in the research and to guarantee adherence to the ethical frameworks. The UN Convention of Child Rights (article 12, 1989) supports the right for the child who is capable of forming his or her own views and should be able to communicate those views freely, and the child shall have the rights for freedom of expression; this right include freedom to seek, receive and impart information and ideas of all kinds (article 13).

Guidelines from the 'National Research

Ethics Service' (NRES) are available for obtaining consent from minors (NRES, 2009a; 2009b). These guidelines recommends parental consent along with the child's assent, may have a negative impact on research with adolescents (Diviak et al., 2004; Hunter and Pierscionek, 2007; Moreno et al., 2008). It is particularly highlighted in areas such as harmful behaviours of children, to which parents may have no or little awareness. As a result Kelly and Halford (2007) believed 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 and Pierscionek, 2006). This alleviates the need to obtain parental consent, though the researcher must use these guidelines appropriately and they have a responsibility to apply them legitimately. 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 researcher is concerned with the consent of the adolescent, (under Gillick competence), rather than adolescent assent following parental consent.

When considering the issues of consent versus assent regarding the participation of the child, 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. Masson (2004) states that this allows 'maximum opportunity' for children to express their views and opinions, and avoids exclusion due to parental 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 to 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 situation of interview (*Kvale and Brinkman, 2009*).

This present 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) defined 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 the participants 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 and Pierscionek, 2007*).

### INFLUENCING FACTORS

The study of John *et al.*, (2008) tried to establish the appropriateness of considering healthy children (average age 7 years) to make a decision regarding participation in a research project. John and his co-workers concluded that this age is appropriate for the comprehension of the 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.

On the other hand, Hester (2004) indicated 15 years is an ideal 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*). The 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 and 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, considering the level of understanding and the complexity of the research (*MRC, 2009*).

Thus it is our responsibility to identify the adolescents' capacity to understand the study along with associated risks, benefits and their rights (*Hester, 2004*). Sterling and 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. It is important to use well designed information leaflets for clear communication of these factors to the adolescents in a format which is appropriate and appealing to that age group (*Dawson and Spencer, 2005; Savage and McCarron, 2009*). Thus this task is crucial 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 and Pierscionek (2007) state that the majority of research does not warrant the application of Gillick competency as they fail to think about the benefit of those participants. But it must be acknowledged that benefit can be measured at different levels. A research

work may not directly do well to the participant, but it may benefit the wider population of young people.

A further consideration when deciding to apply consent or assent of a study was the concept of confidentiality. This risk factor can affect the recruitment of 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 and Halford, 2007*).

According to Williams (*2006*), studies have identified that gaining parental consent for adolescent research can lead to biasness. 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 interventions. They should be considered competent as they have the cognitive ability and life skills to make responsible decisions based on rational reasons (*Beauchamp and Childress, 2001; Hester, 2004*).

In spite of considering the vulnerability of this group regarding 'risky behaviour' among adolescents and the consequent outcomes, we must highlight 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, in the present study Gillick competency was appropriately applied to prospective participants in order to gain consent rather than assent when researching risky behaviour amongst adolescents (*Hewitt, 2007*). Moreover it was considered appropriate to offer information to parents about the research project taking place within the school. This would be a purely informative process and therefore allow prospective participants to be treated as wholly autonomous during the study period.

The present study even considered to inform the parents of the sixteen years old participants who were eager to take part. There are ongoing debate about the best procedure for the facilitation of 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 they in fact have autonomy over the level to which they decide to participate (*Morrow, 2008*).

## OUTCOME OF THE STUDY

The use of age appropriate information sheets was fundamental for 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'. This kind of passive consent was made from the perspective of a parent as well as a researcher (*Langhinrichsen-Rohling et al., 2004*).

As a result there was 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 should have the right for 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 (Lewis and Lindsay, 2000). 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 adolescents in research creates an awareness of the process undertaken and helps to understand 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 the involvement of adolescents was made more active in this project. As a result this project could contribute 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.

## References.

- Alderson, P & Morrow, V (2004). Ethics, social research and consulting with children and young people. Essex: Barnados.
- Arber, A (2006). Reflexivity: a challenge for the researcher as practitioner? *Journal of Research in Nursing*. 11(2), pp 147-157.
- Beauchamp, TL & Childress, JF (2001). Principles of biomedical ethics. 5th Ed. Oxford: Oxford University Press.
- Clavierole, A (2003). Listening to young voices: Challenge of research with adolescent mental health service users. *Journal of Psychiatric and Mental Health Nursing*. 11, pp 253-260.
- Coyne, I (1998). Researching children: some methodological and ethical considerations. *Journal of Clinical Nursing*. 7, pp 409-416.
- Dawson, A & Spencer, S (2005). Informing children and parents about research. *Archives of Disease in Childhood*. 90(3), pp 233-235.
- Diviak, KR, Curry, SJ, Emery, SL & Mermelstein, RJ (2004). Human participants challenges in youth tobacco cessation research: Researchers' perspectives. *Ethics & Behaviour*. 14(4), pp 321-334.
- Finlay, L (2002). "Outing" the researcher: The provenance, process and practice of reflexivity' *Qualitative Health Research*. 12(4), pp 531-545.
- Gillick v West Norfolk & Wisbech Area Health Authority [1985] UKHL 7 (17 October 1985) from the British and Irish Legal Information Institute (BAILII) website.
- Greene, S & Hogan, D (2005). (eds) *Researching children's experience. Methods and approaches*. London: Sage Publications.
- Griffiths, M (2009). Re: process addictions. Email communication with author. April 29, 2009.
- Heath, S, Charles, V, Crow, G & Wiles, R (2007). Informed consent, gatekeepers and go-betweens: negotiating consent in child- and youth-orientated institutions. *British Educational Research Journal*. 33(3), pp 403 - 417.
- Hester, CJ (2004). Adolescent consent: Choosing the right path. *Issues in Comprehensive Pediatric Nursing*. 27, pp 27-37.
- Hewitt, J (2007). Ethical components of researcher researched relationships in qualitative interviewing. *Qualitative Health Research*. 17, pp 1149-1159.

- Holder, AR (2008). Research with adolescents: Parental involvement required? *Journal of Adolescent Health*. 42, pp 1-2.
- Hunter, D & Pierscionek, BK (2007). Children, Gillick competency and consent for involvement in research. *Journal of Medical Ethics*. 33, pp 659-662.
- James, A & Prout, A (eds) (1997). *Constructing and reconstructing childhood*. 2nd Ed. Basingstoke: Falmer Press.
- Jasper, M (2005). Using reflective writing within research. *Journal of Research in Nursing*. 10(3), pp 247-260.
- Johns C (2000). *Becoming a Reflective Practitioner: a Reflective and Holistic Approach to Clinical Nursing, Practice Development and Clinical Supervision*. Oxford: Blackwell Science.
- John, T, Hope, T, Savulescu, J, Stein, A & Pollard, AJ (2008). Children's consent and paediatric research: is it appropriate for healthy children to be the decision-makers in clinical research? *Archives of Disease in Child*. 93, pp 379-383.
- Kelly, AB & Halford, WK (2007). Responses to ethical challenges in conducting research with Australian adolescents. *Australian Journal of Psychology*. 59(1), pp 24-33.
- Kvale, S & Brinkman, S (2009). *Interviews. Learning the craft of qualitative research interviewing* 2nd Ed. London: Sage.
- Langhinrichsen-Rohling, J, Arata, C, Bowers, D, O'Brien, N & Kilbert, J (2004). Sensitive research with adolescents: Just how upsetting are self report surveys anyway. Cited in: Kelly, AB., Halford, WK. (2007) Responses to ethical challenges in conducting research with Australian adolescents. *Australian Journal of Psychology*. 59(1), pp 24-33.
- Lewis, A & Lindsay, G (2000). *Researching Children's Perspectives*. London: Yaylor Francis Publishing.
- Masson, J (2004). The legal context. In: Fraser, S., Lewis, V., ding, S., Kellett, M., Robinson, C. (2004) (eds) *Doing research with children and young people*. London: Sage publications.
- Medical Research Council (2009) Consent arrangements: Children. [Online] Available at: [www.dt-toolkit.ac.uk](http://www.dt-toolkit.ac.uk). Accessed 16th September 2010.
- Moreno, MA, Fost, NC & Christakis, DA (2008). Research ethics in the MySpace era. *Pediatrics*. 121(1), pp 157-161.
- Morrow V & Richards M (1996). The ethics of social research with children: an overview. *Children and Society*. 10, pp 90-105.
- Morrow, V (2001). Using qualitative methods to elicit young people's perspectives on their environment: some ideas for community health initiatives' *Health Education Research*. 16(3), pp 255-268.
- Morrow, V (2007). Challenges for social research and action with working children' In Hungerland B, Leibel M, Milne, B, Wihstutz A (eds), *Working to be Someone: Child focused research and practice with working children*. Jessica Kingsley: London.
- Morrow, V (2008). Ethical dilemmas in research with children and young people about their social environments. *Children's Geographies*. 6(1), pp 49-61
- National Research Ethics Service (2009a) Information Page. [Online] Available at: [www.nres.npsa.nhs.uk](http://www.nres.npsa.nhs.uk). Accessed 16th September 2009.
- National Research Ethics Service (2009b) Explaining Research. [Online] Available at: [www.nres.npsa.nhs.uk/application/guidance/#InformedConsent](http://www.nres.npsa.nhs.uk/application/guidance/#InformedConsent). Accessed 16th September 2009.
- Nightingale, E & Fischhoff, B (2003). Adolescent risk and vulnerability. Overview. *Journal of Adolescent Health*. 31(1), pp 3-9.
- Parahoo K (2006). *Nursing Research: Principles, Process and Issues*, 2nd edn. Palgrave Macmillan, Basingstoke.
- Royal College of Paediatrics and Child Health: Ethics Advisory Committee (2000). Guidelines for the ethical conduct of medical research involving children. *Archives of Disease in Child*. 82, pp 177-182.

- Savage, E & McCarron, S (2009). Research access to adolescents and young adults. *Applied Nursing Research*. 22, pp 63-67.
- Singer, P (2011). When is research on children ethical? *The Lancet*. 377(9760), pp 115-116.
- Sterling, C & Walco, G (2003). Protection of children's rights to self determination in research. *Ethics and Behaviour*. 13(3), pp 237-247.
- Tigges, B (2003). Parental consent and adolescent risk behaviour research. *Journal of Nursing Scholarship*. 35(3), pp 283-290.
- United Nations (1989). United Nations Convention on the rights of the Child. [online] Available at: [http://www.unicef.org.uk/publications/pub\\_detail.asp?pub\\_id=210](http://www.unicef.org.uk/publications/pub_detail.asp?pub_id=210). Accessed 16th September 2010.
- Uprichard, E (2010). Questioning research with children: Discrepancy between theory and practice? *Children & Society*. 24, pp 3-13.
- William, B (2006). Meaningful consent to participate in social research on the part of people under the age of eighteen. *Research Ethics Review*. 2(1), pp 19-24.