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ARTICLE

## Tapping the Perspectives of Children

### Emerging Ethical Issues in Qualitative Research

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#### ABSTRACT

The unique ethical issues related to conducting research with children are insufficiently distinguished from issues in working with vulnerable groups, despite a shift to recognizing children as active in the research process. Qualitative researchers are challenged to consider complex ethical issues related to children and are obligated to protect their rights, freedoms, safety, and dignity. While some issues are similar to those in any research context, the nature of the researcher-participant relationship, and the unstructured nature of qualitative research methods, add a dimension of risk. This article examines ethical issues in qualitative research with children: (1) consent and assent; (2) the obligation to protect children from harm while respecting

#### KEY WORDS:

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children's rights; and, (3) the challenges of ensuring that children have fair access to research initiatives and the benefits that ensue. A study conducted by one author illustrates ethical issues that arise. We provide implications for conducting qualitative research with children.

## INTRODUCTION

Qualitative research provides an opportunity to tap into the richness of children's thoughts and feelings about themselves, their environments and the world in which we all live. Through qualitative interviewing we are able to step outside the bounds of adult thinking and discover unexpected differences in the perceptions of adults and children. Yet research with children in general and qualitative research with children in particular has the potential to present unique ethical issues for the researcher. For instance, while issues of capacity to consent and perceived freedom to refuse participation are to be considered in all research with human subjects, cognitive abilities of children and power differentials between adults and children require special consideration. Further, qualitative research carries unique challenges regarding anticipation of risks related to disclosure that may be intensified in research with children. This requires that researchers evaluate the applicability of standard ethical guidelines regarding research with human subjects for conducting qualitative research with children and establish additional guiding principles to ensure the protection of this vulnerable group.

Surprisingly, the rights of children and ethical practice related to children have largely been ignored in the social sciences, professional practice, and research literature. A review of professional codes of ethics for psychology (Antle and Regehr, 2003) and social work within various countries (Australian Association of Social Workers [AASW], 1999; British Association of Social Workers [BASW], 2002; Canadian Association of Social Workers [CASW], 1994; National Association of Social Workers [NASW], 1999) underscores this relative lack of attention to the unique needs of children. Further, examination of social work Codes of Ethics for the United States and Canada (CASW, 1994; NASW, 1999) revealed that children are only mentioned in relation to social workers' duty to protect vulnerable clients from harm (Antle and Regehr, 2003). In contrast, the Codes for both the British and Australian Associations of Social Workers (AASW, 1999; BASW, 2002) refer to the importance of ensuring children's assent to treatment, after appropriate consent has been obtained from parents or guardians. None of these Codes, however, refer to children in the context of research. Moreover, even Butler's (2002) excellent review of distinctive ethical issues in social work research does not examine questions related to studies involving children. Thus, the ethical issues related to social work practice and research with children are underdeveloped and insufficiently distinguished from issues in working with other vulnerable groups (Lindsay, 2000).

Taylor (2000: 32) argues that the intent of the UN Convention on the Rights of the Child is to 'ensure children are given a voice at all levels of decision making, including in the development and implementation of research'. In contrast to the relative paucity of social work-related scholarship in this area, Morrow and Richards (1996), in their review of the literature, report that considerable attention has been given to the ethics of conducting medical and behavioural research with children. Guidelines have been published for non-clinical research involving children, especially covering areas such as consent, confidentiality, and appropriate methodology (Goodenough et al., 2003). These guidelines have focused on the power differential in the relationship between the child participant and the researcher; differences in consent procedures whereby both adult consent and child assent are needed for a child to participate in research; complications regarding confidentiality because adults may expect to be told about what children reveal; and complexities related to protecting children from abuse (Cree et al., 2002; Mahon et al., 1996; Thomas and O'Kane, 1998). However, Morrow and Richards (1996) contend that in everyday life adults do not typically respect children's views and opinions, which they believe increases the challenge of developing research procedures that are fair and respectful to children.

In spite of these challenges, there has been a recent shift from viewing children as passive objects of study unable to directly provide information, to recognizing them as active and competent participants capable of speaking for themselves and of providing reliable information about their situation. Corresponding to this change is an increasing attempt to include children, in varying degrees, as partners in the research (Goodenough et al., 2003; Hill et al., 1996; Hood et al., 1996; Ireland and Holloway, 1996; Mahon et al., 1996; Mauthner, 1997; Morrow and Richards, 1996; Ward, 1997; Woodhead and Faulkner, 2000). This trend underscores that adult 'proxies', such as parents or teachers, are unlikely to be able to accurately represent children's social worlds, no matter how well intentioned or informed the adult (Mahon et al., 1996; Miller, 2000). Further, children's rights are now seen as having priority over the interests of the researcher or research outcomes (Society for Research in Child Development [SRCD], 1990, cited in Woodhead and Faulkner, 2000). This requires, for instance, that researchers must inform children about aspects of the research that might influence their willingness to take part (Woodhead and Faulkner, 2000) as well as consider their interests in research outcomes.

Similarly, there is a growing body of literature that reflects the unique ethical issues that qualitative researchers face (Antle et al., 2004; Brownlow and O'Dell, 2002; Burman, 1997; Denzin, 2002; Hadjistavropoulos and Smythe, 2001; Magolda and Weems, 2002; O'Connor, 2001; Punch, 1994; Van den Hoonaard, 2001). Included in these discussions are issues such as power in the researcher-participant relationship, free and informed consent, protection of

confidentiality regarding personal and highly descriptive information, balancing the roles of the researcher and therapist, ownership of the story, determination of research outcomes, and avenues of dissemination (Antle et al., 2004). In this article we attempt to synthesize these disparate bodies of work by examining ethical issues in conducting qualitative research with children. While some of these issues are similar to those in any research context, we contend that the nature of the relationship between researcher and participant, and the unstructured and thus unpredictable nature of many qualitative research methods, add an extra dimension of risk when conducting qualitative research with children.

A qualitative study conducted by one of the authors (FM), will be used to illustrate key ethical issues in conducting qualitative research with children. The study we are using as a paradigm case investigates bullying from the perspectives of three of the most important parties in the bullying dynamic: the children who are victims, the children's parents, and the children's teachers, vice principals and principals. The children were drawn from grades four and five in four schools in a large Canadian city. Children were provided information about the study during school time, prior to sending home written invitations to participate. Children, with parental consent, completed a questionnaire to identify whether they were victims of bullying. From the 'pool' of students who identified themselves as bullied during the current school term, we selected four or five children in each school to be interviewed. A letter was sent to the parents of the selected children, informing them that a researcher would telephone them to invite the child and one parent to participate in an individual interview. Children with parental approval were asked for their assent. In-depth interviews were conducted with 19 children, one parent and teacher of each child, and school administrators. Fifty-six in-depth individual interviews were conducted.

## **ETHICAL GUIDELINES FOR CONDUCTING RESEARCH**

There are three primary principles that constitute the requirements for acceptable ethical conduct of research involving human subjects (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; National Institutes of Health, 1995; Tri-Council Working Group, 1996). These principles consist of respect for persons and their right to choice (autonomy), beneficence (and its parallel principle non-maleficence), and justice. In demonstrating respect for these principles researchers must: (1) seek informed consent to participation; (2) minimize discomforts and harm to participants and ensure that on balance the research brings about a good; and, (3) ensure that participants are fairly selected and that the burden and benefit of research is fairly distributed among members of the population (Macklin, 1992; National Institutes of Health, 1995; Tri-Council Working Group, 1996). These principles are consistent with the values represented in social work codes of

ethics in western countries (AASW, 1999; BASW, 2002; CASW, 2004; NASW, 1999), which include respect for the inherent dignity and worth of persons, pursuit of social justice, service to humanity (placing the interest of others first), integrity of professional practice, and competence in professional practice. Moreover, ethical qualitative research involves distinctive approaches to ensuring rigor (Erlandson et al., 1993; Lincoln and Guba, 1985), including an emergent focus on authenticity and expectations that research endeavours will directly benefit participants as well as the wider community. In illuminating the unique ethical dimensions in conducting qualitative research with children, we examine the application of these principles in three ways: (1) the special procedures for consent and assent; (2) the obligation to protect children from harm while also ensuring that children's rights in participation in research are respected; and, (3) the challenges of ensuring that children have fair access to research initiatives and the benefits that come from research endeavours. Our discussions of these issues are linked to the underlying ethical principles represented in professional codes of ethics and research ethics guidelines.

### **Respect for Inherent Dignity and Worth of Persons: Autonomy and Right to Choice**

#### *Informed Consent and Assent*

As research is intended to benefit society through knowledge building rather than benefiting the individual participant, informed consent processes in research are more rigorous than in other contexts, such as treatment. The principal elements of informed consent in research have been outlined in detail elsewhere (Antle and Regehr, 2003; Antle et al., 2004; Council for International Organizations of Medical Sciences [CIOMS], 1993; Tri-Council Working Group, 1996); however, a cornerstone of consent is the capacity to appreciate the decision to be made and the associated risks and benefits of proceeding or not proceeding with the matter under decision, in this instance, participation in research (Tri-Council Working Group, 1996). Federal legislation in the USA provides clear direction for those conducting research with children. Written parental consent is required for children to participate in research, and adolescents 18 years of age and under are not allowed to provide consent (Moolchan and Mermelstein, 2002). Institutional Research Boards (IRBs) may waive these consent criteria, but only under strict conditions such as when there may be a risk to the child or adolescent if parental permission is sought and yet the research is of clear benefit to the participant population, or when clear protection for participant rights are in place and obtaining parental consent is not practical. Similarly, British law requires that parents consent to their child's participation in research (McIntosh, 2002), although medical ethics directs researchers to also seek the assent of the child when research is non-therapeutic

in nature. In contrast, Canadian consent procedures are governed by common law and, with the exception of two jurisdictions, there is no specific legislation governing consent practices with children. Thus, in Canada consent procedures are governed by capacity. Viewed through the lens of capacity, children (similar to adults), can vary greatly in their confidence, competence, and ability to consent or assent to research (Miller, 2000).

Increasingly it is being asserted that children's capability to consent to research has been underestimated (Zwiers and Morrissette, 1999). Ondrusek et al. (1998), for example, found that children who were over nine years of age demonstrated that they understood key elements of consent such as harms and benefits and the right to withdraw, whereas those who were younger did not. Bruzzese and Fisher (2003) demonstrated that children's capacity to consent could be enhanced with exposure to 'The Research Participant's Bill of Rights'; nevertheless, comprehension of research procedures remained higher among the older children in the study. Their data reflect that 4th graders (generally 9 years of age) did not do as well as older participants in a true/false quiz on research rights or in identifying rights violations in hypothetical vignettes of research situations. Importantly, 7th graders (generally age 12 years) appeared to struggle in their appreciation of their right to decline, to be protected from harm and to be informed of research procedures and findings. Lastly, only 10th graders (generally age 15 years) demonstrated insights equivalent to adults.

While there is a great deal of complexity and diversity with respect to a child's capacity to consent, there is growing pressure to demonstrate respect for children through consulting them about their interest or willingness to participate (assent) in research, once their parent or guardian has provided consent. Thus, while a child who does not have the capacity to consent cannot in the first instance agree to participate without the consent of a responsible caregiver, when such consent is given, the child can still refuse to participate through the assenting process. Seeking a child's assent, therefore, recognizes children's rights (Ireland and Holloway, 1996; Morrow and Richards, 1996; Stanley and Sieber, 1992) and further requires researchers to provide sufficient information to ensure that children understand the purpose of the research, what they are being asked to do, what they can expect, and that they are not obligated to participate (Ireland and Holloway, 1996; Mahon et al., 1996; Ondrusek et al., 1998)

### **Potential Barriers to Informed Consent and Assent in Qualitative Studies**

#### *Unstructured Nature of Qualitative Data Collection*

One of the unique ethical challenges in reference to qualitative research is the unpredictable and often unstructured nature of the data collection process, for example, open-ended interviews (Van den Hoonaard, 2001). In the consent

process, researchers are expected to disclose potential risks, including such issues as loss of social status, embarrassment or anxiety (Tri-Council Working Group, 1996), yet the range of potential risks may be difficult to assess in any research context. This is perhaps even more problematic for young participants in a qualitative study. Children and young adolescents may have difficulty anticipating the range of personal experiences that will be addressed in a qualitative interview, and their potential reactions to the kind of in-depth discussion inherent in qualitative interviewing. Thus, even if cognitively capable of appreciating the nature of the study, children's relative lack of life experience may make it more difficult for them to project into the future and anticipate the potential pitfalls for them in participating in a qualitative study. Further, safeguards identified for qualitative research with adults, such as warning about the unstructured nature of the research and risks of over disclosure (Antle and Regehr, 2003; Larossa et al., 1981), may not be sufficient to adequately inform children. Discerning how to adequately prepare children for consenting or assenting to qualitative research is further complicated by emerging evidence that suggests that children and adults may have different frames of reference with respect to what might cause discomfort or harm (Woodhead and Faulkner, 2000). For example, in a study on children's ability to consent to research, the aspect of the clinical trials for a nutrition study identified by the children as among the worst aspects of the study was not even listed as a potential harm in the information form because medical staff considered it so benign (Ondrusek et al., 1998).

### **Distinctive Concerns about Voluntariness**

Another important dimension of informed consent and assent is appreciation of the voluntariness of the participation process. Scholars suggest that children may also find it more difficult to act on their right to withdraw from a study by not knowing the practicalities of how to withdraw should they wish to, by being more likely to view the researcher as an expert and authority (Mahon et al., 1996), and by being concerned that they will suffer negative consequences if they withdraw (Bruzzeze and Fisher, 2003; Zwiers and Morrisette, 1999). This latter concern is underscored by the work of Ondrusek et al. (1998), who found that most children believed that the researcher would be unhappy if they withdrew after the study had begun. This concern was offset by the researcher's reassurance that he or she would not be upset if the child withdrew, however it is noteworthy that such reassurance by parents was not as effective. Further, children may communicate discomfort or desire to withdraw from the research in indirect ways. Kay et al. (2002) consequently suggest that interviewers need to be aware of more subtle signs that the child may wish to no longer discuss a particular issue in an interview, such as suddenly falling silent or moving to another part of the room, and treat these as signals to the researcher.

Although there is considerable variation among qualitative research methods, a cornerstone of the method is the distinct nature of the relationship between the researcher and participant, which aims to lessen the power imbalance between participant and researcher. Rather than observing from a dispassionate distance, researchers using qualitative methods engage with participants in order to gain an insider's perspective on the phenomenon of interest. The aim is often to illuminate the experiences of vulnerable groups such as children, and/or sensitive issues, such as sexual abuse or bullying (Antle et al., 2004; Eder and Corsaro, 1999). However, despite attempts to equalize the power between the researcher and those affected by the issue, there remains an inherent power imbalance in which the researcher has a distinct 'advantage' in the relationship (Antle et al., 2004). This imbalance is heightened in research with children and indeed, Morrow and Richards (1996) maintain that the biggest ethical challenge for researchers working with children is created by the inequality in power and status between adults and children. Further, research conducted within the confines of a school or hospital or under the auspices of a university or government agency imbues the researcher with status and power that a child may feel unable to challenge.

In our view, these pressures are more greatly felt in a qualitative method where there is an increased likelihood of direct interaction between researcher and child. It may be easier for a child to simply stop filling out a questionnaire or object to a procedure, than to stop an adult interviewer, particularly if the interviewer has successfully engaged the child in telling his or her story. Elsewhere, the disarming effect of a therapeutic alliance has been discussed (Regehr and Antle, 1997) and we believe that many aspects of in-depth interviewing mirror key conditions for the development of a therapeutic alliance. The effectiveness of the research interviewer in placing a child at ease may indeed affect the child's capacity to protect themselves from disclosing information they might otherwise not have intended to share. While participant observation and focus group methods of data collection each are affected by these risks, in our view, greatest care by the researcher must be taken in the context of one-on-one interviews.

### **Research Example: Addressing Informed Consent and Assent**

In our paradigm research example, the team decided to obtain consent for participation from parents, based on current policies prevailing in the settings where children were recruited and the sensitive nature of bullying, the subject under study. However, in order facilitate the children's ability to assent (Ireland and Holloway, 1996; Mahon et al., 1996; Morrow and Richards, 1996; Ondrusek et al., 1998; Stanley and Sieber, 1992), we met with them as a group in school prior to sending home the invitation to participate. We recruited children in grades four and five in part because children of this age can reliably reflect on

their own and others' behaviours and reactions (Damon and Hart, 1982). Selection of this particular age group was also consistent with the research of Ondrusek and colleagues (1998), which suggests that children in this age group have the capacity to understand research protocols and their rights in research and thus can meaningfully participate. The children were informed of risks, for instance, the possibility of becoming upset because we would be asking about hurtful matters. Children were assured that if they felt upset, they should tell a research assistant, who would talk with them and make sure that they received help. Further risks identified related to the children's privacy and confidentiality. In both the children's information letter and the oral classroom presentation, the limits to confidentiality and circumstances in which confidentiality would not be kept were clearly stated. Children were informed that indications of abuse require reporting to child welfare services. In addition, they were informed that if during the course of their participation in the research, they disclosed that they had been bullied at school, we would tell their parents and teacher, although we stressed that we would not share the details of what they said.

Importantly, during the consenting process, the researchers also repeatedly emphasized that the children were not obligated to participate and that it was okay if they changed their mind at any time in the study. As indicated earlier, findings that reassurance by the researchers influenced the children confirms the need for such clear guarantees, as a way of addressing the power imbalance and threats to voluntariness children may experience (Ondrusek et al., 1998).

### **Balancing Right to Confidentiality and Non-maleficence in Qualitative Studies**

An important advantage that comes with conducting qualitative research is that participants often reveal private experiences to the researcher who is outside of the participant's community (Eder and Corsaro, 1999). Through these insights research can help to not only provide greater appreciation of participants' perspectives, but also break down barriers to understanding complex social phenomena and/or experiences, especially those that are surrounded by misunderstanding and stigma. Given that in qualitative research one is frequently investigating sensitive matters such as bullying, the potential exists for children to disclose hurtful events through a sense of alliance with the researcher. The disarming nature of such an entry into the private world of children and youth may result in greater disclosure than anticipated by either the child or the researcher. One of the ethical tensions in conducting research with children is that although parental consent is often needed for participation in research, there is increasing pressure to afford children the right to have control over information revealed during the research process and to specifically keep information confidential from their parents (Macklin, 1992). Yet the disclosures of a child in qualitative research may result in dilemmas about whether one can maintain

confidentiality. For instance, parents may well have a legitimate interest in knowing about a child's level of unhappiness or victimization, even if these events do not constitute abuse (thus an obligation to break confidentiality). This is a difficult predicament to resolve, because while one wishes to respect the child by upholding confidentiality, social workers are also responsible for appreciating the social justice dimensions of their work, which calls for an expectation of advocacy for disadvantaged and marginalized people. Eder and Corsaro (1999: 527) capture this tension well: '... every intervention increases the separation between the adult researchers and youth. At the same time, every nonintervention potentially decreases young people's perceptions of adults as responsible advocates on their behalf'. We also direct the reader to an excellent chapter of the unique concerns for conducting research (not necessarily qualitative research) with children who have been exposed to domestic violence for an outline of ethical issues in the context of potential abuse (Peled, 2001). Qualitative researchers need to work to anticipate some of the potential harms in their research with children and to clearly present their intentions with respect to sharing any information with a parent, and the process they will follow with the child and the parent to ensure both the child and parent understand this process in advance. Wherever possible, in keeping with Morrows and Richards (1996), we encourage involvement of the child in a discussion on the strategy to pursue when these situations arise and recommend responding to a child's disclosure of being harmed by supporting the child to tell someone who could do something about the situation (Thomas and O'Kane, 1998).

### **Research Example: Balancing the Right to Confidentiality and Non-maleficence**

An ethical dilemma that arose during the course of our research consisted of children disclosing or implying that they experienced hurt, but in a way that clearly did not fit within the legal definition of abuse or with our additional point of agreed upon disclosure, bullying at school. In this instance some participants were being bullied by siblings. The researcher in this case did not have the legal obligation or indeed the right to follow-up if a child does not indicate a desire for such intervention. Rather, the researcher is obligated to maintain the child's confidentiality and autonomy as much as possible (Jokinen et al., 2002). However, by not acting on information that a child is being hurt means that adults – in this instance the researchers – are not protecting the children, which raises ethical concerns about non-maleficence and beneficence. Since one parent of each child was interviewed and the topic was clearly related to the child being hurt, the principles of non-maleficence and beneficence direct us to weigh the child's right to confidentiality with the parents' right to know so that they may take steps to further help or protect their child. In particular a question that arises is whether the researcher is then giving the message that

adults are interested in the child's story for his or her purposes (research and knowledge-building) but not for the child's welfare (Eder and Corsaro, 1999; Morrow and Richards, 1996).

As Eder and Corsaro (1999) recommend, we attempted to address each situation separately. Thus, if the 'bully' was a sibling the researcher asked his or her age. If the sibling was not 'significantly' older, it was felt that we did not have the obligation or the right to intervene if a child did not desire help. Even returning to inquire about the age could be construed as outside the bounds of research or as paternalistic. However, we believed that the obligation to protect children necessitated gathering more information about the perpetrator. This dilemma was particularly significant in this research because our preliminary analysis suggested that an adult intervening when children do not wish them to do so was a worry for children in the study. Indeed, many of the children reported that one of the prime reasons that they do not tell their parents or teachers about being bullied is precisely because of their fear and/or past experiences with not having their wishes respected and their fear that their parents or teachers will in fact intervene. Thus, in this instance we struggled with whether breaching confidentiality to protect children from assault and abuse was warranted if the intervention itself would be viewed by children as a potential harm associated with research participation. In our experience, each case required judgment and expert consultation.

For instance, at the end of her interview in which one mother felt that her child's situation was being dealt with, but was concerned that her child did not tell her about all of the bullying incidents, the mother asked whether she was on the right track about her child and whether the child was OK. Clearly, she was concerned that there may be other worrisome information regarding her daughter. The interviewer responded, 'If there were concerns which came out of my interview with your child I would have discussed this with your child and with you. So there really wasn't anything for which I felt she needed support.' Here the researcher adjudicated that while the child was experiencing some difficult things they were not of the magnitude to require either a breach of confidentiality or a negotiation with the child to disclose the issues to her mother.

In another situation, a girl described being bullied by her sibling who was two years older. Our dilemma was heightened because the bullying behaviour sounded quite concerning, and yet the age and size difference between this girl and her brother was not significant. Further, this girl was adamant that she could manage without help and told the research assistant (a school social worker) that she planned to tell her parents that very evening. Because of her discomfort, the research assistant indicated to the girl that she would consult with the principal investigator about the situation and told her that she would get back to her. The girl accepted this. After much deliberation, the researchers decided that although they had no legal obligation with respect to child abuse,

they were concerned that the girl had not been able to ask for help and thus felt obligated to intervene, in accordance with the principles of beneficence and non-maleficence, which underlie the need to engage in a risk/benefit analysis and to minimize risks. When the research assistant returned the next day, the girl informed her that she had told her parents about the bullying. The research assistant was supportive but encouraged the girl to accept school social work help because of the difficult situation. The girl agreed and a referral was made.

As highlighted earlier, parents may consent to participation, but children can refuse to offer assent. This is highlighted in a study by Miller (2000) whereby parents were required to consent on behalf of their child and at the same time children were given the opportunity to refuse to participate even if their parents had consented. While there is no literature on this position, we wonder if parents may be more reluctant for their child to participate in qualitative research where the nature of the child's participation is more open-ended and thus cannot be predicted ahead of time. If so, would parents be more comfortable knowing the planned methods of data collection, for example, questions and probes to be used in a focus group?

### **Justice, Authenticity, and the Sharing of Burden and Benefit**

Research ethics guidelines have recently expanded the definition of justice to include a consideration of the scientific validity of the research. Research, in order to be ethical must address a question of sufficient value to justify the risk posed to participants, it must follow the approved protocol, and findings must be reported accurately and promptly (Tri-Council Working Group, 1996). While notions of scientific rigor remain contested in qualitative research (Van den Hoonaard, 2002) more recent representations surrounding authenticity (Erlandson et al., 1993; Lincoln and Guba, 1985) point to opportunities to ensure a good for society (beneficence) and to also ensure that participants themselves benefit directly from the research endeavour (Peled and Leichtenritt, 2003).

This direction is consistent with a more empowered consumer voice and the perspective of a number of communities who have argued persuasively that participants should be afforded greater control over the research process. (The disability community has been particularly vocal on this matter; see L'Institut Roehrer Institute, 1994; Longmore, 1995; Woodill, 1992) A body of literature that highlights authenticity-related dimensions of qualitative rigor supports this view. Specifically, guidelines suggest that all stakeholders should have equal access to the research process (fairness) and that through the research process, all participants should have an enhanced understanding of their own experience (ontological), an enhanced appreciation of the phenomenon under study (educative), and encouragement to act on this expanded understanding (catalytic). Ultimately if others are empowered to act, the research contributes to change (tactical) (Erlandson et al., 1993; Lincoln and Guba, 2000). This direction in

qualitative research parallels developments in participatory action research methods (Heaney, 1993; Hick, 1997; Park, 1993), although such research does not always rely on qualitative methods. Similarly, Thomas and O’Kane (1998) argue that when children are involved in a participatory fashion in research, the overall rigor of the research is enhanced.

### **Potential Barriers to Authenticity in Qualitative Research with Children**

Significant involvement of stakeholders in research and individually benefiting from research is perhaps the area most underdeveloped in research with children (Goodenough et al., 2003). However, consistent with our thrust in this article that children’s competencies have traditionally been greatly underestimated, it may also be that the potential for children to contribute to the development of research as well as become a part of the process of change has been underrated. Ward (1997) for example, has detailed her successful approaches to involving children in all stages of research from planning, to interviewing, to analysis. While, clearly greater effort is needed in involving children as key stakeholders, in conducting research, we have concerns about the degree to which children could conduct in-depth interviews, adequately probe sensitive matters, and evaluate the impact of the interviewing process on participants. However, other qualitative methods might be lower risk and better suited to child participants, such as focus groups or focused participant observation.

Authenticity requirements (Erlandson et al., 1993; Lincoln and Guba, 1985) also promote education and empowerment of research participants. Another area requiring improvement is the development of more child-friendly mechanisms for communication of research results. Typically, qualitative researchers rely on text-heavy documents and face-to-face meetings; however, using video and internet media may be more effective ways in meaningfully connecting with children about research findings. The emerging field of knowledge transfer may indeed be an important source for qualitative researchers interested in more effective ways to communicate research results, particularly with children (Broner et al., 2001; Canadian Health Services Research Foundation, 2001). Lastly, involvement of children in social change as a result of participation in qualitative research is another dimension of authenticity that demands creativity. Future opportunities might involve more child-friendly forms of communication, such as plays, comics, or the internet. The degree to which parents need to be a part of these processes along with and on behalf of their children who have participated in research will also require further consideration.

### **Research Example: Justice and Research Authenticity**

We also believe that researchers could do a better job at the end of studies to meet expectations of rigor in qualitative research, with respect to research contributing to the development and well-being of participants. In our own study

we are mindful that our analysis of study results involves developing ways of using the information in a way that influences practice (Eder and Corsaro, 1999). It is critical to apply knowledge obtained and disseminate results of the study in ways that are practical and that benefit children who are victims of bullying. It is also vital to ensure that final feedback is provided to the children and school staff who participated in this research (Mauthner, 1997).

Finally, through the process it became evident that in some cases the research study had a significant impact, although it clearly was not an intervention study. Because of the limitations of contact, we cannot know for sure whether the impact was positive or negative in some instances. For example some children and adults disclosed, for the first time, that they experienced victimization by their peers. In other examples, it was clearer that the impact was positive. In several instances, hearing the definition of bullying which was provided and which included non-physical and indirect forms as well as physical and direct forms, led to some children and adult participants changing their views of bullying. Thus, one girl recognized that the ways some peers treated her constituted bullying, which seemed to 'empower' her. In contrast to her previous sense that she had to tolerate this treatment, she said she learned that this behaviour was unacceptable. In another instance, a teacher stated that hearing the definition made her realize that behaviours she had up to that time considered 'minor' could in fact have a significant negative impact on a child. Moreover, some teachers and parents became aware of a particular child being a victim of the damage caused by bullying. These parents became more active in contacting the school and informing them clearly of the issues and the teachers became more observant and more likely to intervene. Again, because of the limitations, we do not know if this impact was sustained. However, it highlights the need to be aware of the potential impact of research on the lives of the children who are participants.

## **IMPLICATIONS FOR QUALITATIVE RESEARCH WITH CHILDREN**

Recognizing the ethical dilemmas that emerge when conducting qualitative research with children and adolescents allows the researcher to more successfully prepare processes that will support effective responses in the context of complex and uncertain research. First and foremost researchers must expect that unanticipated issues may arise at any stage and thus assess their ethical obligations on an ongoing basis. Suggestions to increase children's ability to be able to truly assent to the research include providing them with detailed and comprehensive information in order to help and allow them to make decisions. This includes presenting any intention or possibility of sharing information with a parent and under what circumstances this would occur. It is necessary to be specific and explicit in listing the potential harms or risks involved in participation. For

instance, breaching confidentiality to protect a child from abuse would be considered a potential risk. Moreover, in informing the child of this risk, it is recommended that researchers specify exactly what is meant by abuse. Similarly, it is necessary to recognize the need to be specific when informing children of their rights. Thus, children must be told not only that they can choose not to participate or to withdraw at any time in the research process, but they also need to be told what to do in order to withdraw, for example if they are in the middle of an interview they can say they changed their mind. Further, children must be clearly reassured that if they withdraw this would be OK (Ondrusek et al., 1998). Suggestions to minimize the power imbalance between the child and the researcher include co-determining the data with the children and using multiple data collection methods (Morrow and Richards, 1996) and, if possible, first reviewing the study with the children before sending home the information and consent forms (National Institutes of Health, 1995; Penslar, 1993). Despite the need to implement procedures to minimize the power difference between the researcher and child participant, these clearly cannot equalize the power. Nevertheless, we contend that it is beneficial to implement as many strategies as possible to minimize the power imbalance and maximize the child's power, and to be mindful of the imbalance and associated implications, especially since some cannot be anticipated. Recognizing that there might be negative effects of participating in research, some researchers check with child participants after the interview is over to determine how the children felt and whether they desired help (Mahon et al., 1996).

O'Connor (2001) recommends that qualitative researchers acknowledge that study results are co-created by the researcher and participant(s) and, although they ideally represent participants' experiences, are represented through the lens of the researcher and influenced by his or her theoretical orientation and worldview. While the intent of qualitative research interviews is to obtain the perspectives and experiences of child participants, paradoxically the very fact of the interview has an influencing and mediating effect upon the child's 'voice'. It is critical that researchers be aware of the tremendous amount of influence and power adults have over children, who typically are compliant with adults. Moreover, the interactive context of the interview between researcher and child influences just which experiences will be privileged and how the child will articulate these (Orange et al., 1997). Indeed, the experiences as they are presented are filtered through the particular dialogue (verbal and nonverbal) between the participant and the interviewer. The process of coding and interpreting then filters how these experiences are understood.

Finally, it is important to recognize and inform others who are involved with the child participants, for instance their parents, that participation may pose risks to these other individuals (Peled and Leichtentritt, 2003). For example, in our study some parents and teachers were surprised to hear that a child identified

him or herself as a victim of bullying, which could cause emotional distress and there were other parents or teachers who in their interview disclosed painful information for the first time.

## CONCLUSIONS

Children's experiences of the world are often under-represented in our models for understanding social phenomena. Qualitative research represents an excellent venue for enhancing their participation in knowledge building and in theory development. However, as qualitative researchers, we are challenged to consider complex ethical issues when applying our methodology in the context of work with children. We are obligated to ensure that their rights, freedoms, safety, and dignity are protected and that the search for understanding does not overshadow concern for the vulnerable.

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## References

- AASW (1999) *AASW Code of Ethics*. Kingston: Australian Association of Social Workers.
- Antle, B. J. and Regehr, C. (2003) 'Beyond Individual Rights and Freedoms: Metaethics in Social Work Research', *Social Work* 48(1): 135–44.
- Antle, B. J., Regehr, C. and Mishna, F. (2004) 'Qualitative Research Ethics: Thriving within Tensions', in A. R. Roberts and K. Yeager (eds) *Handbook of Practice-focused Research and Evaluation*, pp. 126–36. New York: Oxford University Press.
- BASW (2002) 'BASW: A Code of Ethics for Social Workers', <http://www.basw.co.uk/articles.php?articleId=2> (consulted Nov. 2002).
- Broner, N., Franczak, M., Dye, C. and McAllister, W. (2001) 'Knowledge Transfer, Policymaking and Community Empowerment: A Consensus Model Approach for Providing Public Mental Health and Substance Abuse Services', *Psychiatric Quarterly* 72(1): 79–102.
- Brownlow, C. and O'Dell, L. (2002) 'Ethical Issues for Qualitative Research in On-line Communities', *Disability & Society* 17(6): 685–94.
- Bruzzese, J. M. and Fisher, C. B. (2003) 'Assessing and Enhancing the Research Consent Capacity of Children and Youth', *Applied Developmental Science* 7(1): 13–26.
- Burman, E. (1997) 'Minding the Gap: Positivism, Psychology, and the Politics of Qualitative Methods', *Journal of Social Issues* 53(4): 785–801.
- Butler, I. (2002) 'A Code of Ethics for Social Work and Social Care Research', *British Journal of Social Work* 32(2): 239–48.

- CASW (1994) *Social Work Code of Ethics*. Ottawa: Canadian Association of Social Workers.
- CASW (2004) *Social Work Code of Ethics: Revised Draft for Approval*. Ottawa: Canadian Association of Social Workers.
- Canadian Health Services Research Foundation (2001) *Knowledge Transfer: Looking Beyond Health*. Toronto: Canadian Health Services Research Foundation.
- CIOMS (1993) *International Ethical Guidelines for Biomedical Research involving Human Subjects*. Geneva: Council for International Organizations of Medical Sciences.
- Cree, V. E., Kay, H. and Tisdall, K. (2002) 'Research with Children: Sharing the Dilemmas', *Child and Family Social Work* 7(1): 47–56.
- Damon, W. and Hart, D. (1982) 'The Development of Self-understanding from Infancy through Adolescence', *Child Development* 53(4): 841–64.
- Denzin, N. K. (2002) 'Social Work in the Seventh Moment', *Qualitative Social Work* 1(1): 25–38.
- Eder, D. and Corsaro, W. (1999) 'Ethnographic Studies of Children and Youth: Theoretical and Ethical Issues', *Ethnographic Studies of Children and Youth* 28(5): 520–31.
- Erlanson, D. A., Harris, E. L., Skipper, B. L. and Allen, S. D. (1993) *Doing Naturalistic Inquiry: A Guide to Methods*. London: Sage.
- Goodenough, T., Williamson, E., Kent, J. and Ashcroft, R. (2003) "'What Did You Think about That?': Researching Children's Perceptions of Participation in a Longitudinal Genetic Epidemiological Study', *Children & Society* 17(2): 113–25.
- Hadjistavropoulos, T. and Smythe, W. E. (2001) 'Elements of Risk in Qualitative Research', *Ethics & Behavior* 11(2): 163–74.
- Heaney, T. (1993) 'If You Can't Beat 'em Join 'em: The Professionalization of Participatory Research', in M. P. Park Brydon-Miller, B. Hall and T. Jackson (eds) *Voices of Change*, pp. 41–6. Toronto: OISE Press.
- Hick, S. (1997) 'Participatory Research: An Approach for Structural Social Workers', *Journal of Progressive Human Services* 8(2): 63–78.
- Hill, M., Laybourn, A. and Borland, M. (1996) 'Engaging with Primary-aged Children about their Emotions and Well-being: Methodological Considerations', *Children & Society* 10(2): 129–44.
- Hood, S., Kelley, P. and Mayall, B. (1996) 'Children as Research Subjects: A Risky Enterprise', *Children & Society* 10(2): 117–28.
- Ireland, L. and Holloway, I. (1996) 'Qualitative Health Research with Children', *Children & Society* 10: 155–64.
- Jokinen, P., Lappalainen, M., Meriläinen, P. and Pelkonen, M. (2002) 'Ethical Issues in Ethnographic Nursing Research with Children and Elderly People', *Scandinavian Journal of Caring Sciences* 16(2): 165–70.
- Kay, H., Cree, V. E., Tisdall, K. and Wallace, J. (2002) 'At the Edge: Negotiating Boundaries in Research with Children and Young People', *Online Journal: Forum: Qualitative Social Research* 4(2), <http://qualitative-research.net/fqs-texte/2/03/203kayetal-e.htm> (consulted Sept. 2003).
- Larossa, R., Bennett, L. A. and Gelles, R. J. (1981) 'Ethical Dilemmas in Qualitative Family Research', *Journal of Marriage & the Family* 43(2): 303–13.
- Lincoln, Y. and Guba, E. (1985) *Naturalistic Inquiry*. Thousand Oaks, CA: Sage.

- Lincoln, Y. and Guba, E. (2000) 'Paradigmatic Controversies, Contradictions, and Emerging Confluences', in N. Y. Denzin and Y. S. Lincoln (eds) *Handbook of Qualitative Research*, 2 edn, pp. 163–88. Thousand Oaks, CA: Sage.
- Lindsay, G. (2000) 'Researching Children's Perspectives: Ethical Issues', in G. L. A. Lewis (ed.) *Researching Children's Perspectives*, pp. 3–19. Philadelphia, PA: Open University Press.
- L'Institut Roehrer Institute (1994) *Disability is not Measles: New Research Paradigms in Disability*. Toronto: L'Institut Roehrer Institute.
- Longmore, P. K. (1995) 'The Second Phase: From Disability Rights to Disability Culture', *The Disability Rag & Resource* 16(September–October): 3–11.
- McIntosh, N. (2002) 'Ethical Principles in Paediatric Research', *Current Paediatrics* 12(6): 508–12.
- Macklin, R. (1992) 'Autonomy, Beneficence, and Child Development', in B. Stanley and J. E. Sieber (eds) *Social Research on Children and Adolescents: Ethical Issues*, pp. 88–105. Newbury Park, CA: Sage.
- Magolda, P. and Weems, L. (2002) 'Doing Harm: An Unintended Consequence of Qualitative Inquiry?', *Journal of College Student Development* 43(4): 490–507.
- Mahon, A., Glendinning, C., Clarke, K. and Craig, G. (1996) 'Researching Children: Methods and Ethics', *Children & Society* 10(2): 145–54.
- Mauthner, M. (1997) 'Methodological Aspects of Collecting Data from Children: Lessons from Three Research Projects', *Children & Society* 11: 16–28.
- Miller, S. (2000) 'Researching Children: Issues Arising from a Phenomenological Study with Children who Have Diabetes Mellitus', *Journal of Advanced Nursing* 31(5): 1228–34.
- Moolchan, E. and Mermelstein, R. (2002) 'Research on Tobacco Use among Teenagers: Ethical Challenges', *Journal of Adolescent Health* 30(6): 409–17.
- Morrow, V. and Richards, M. (1996) 'The Ethics of Social Research with Children: An Overview', *Children & Society* 10(2): 90–105.
- NASW (1999) *Code of Ethics*. Washington, DC: National Association of Social Workers.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979) *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Washington, DC: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.
- National Institutes of Health (1995) *Guidelines for the Conduct of Research Involving Human Subjects at the National Institutes of Health*. Washington, DC: National Institutes of Health.
- O'Connor, D. (2001) 'Journeying the Quagmire: Exploring the Discourses that Shape the Qualitative Research Process', *Affilia* 16(2): 138–58.
- Ondrusek, N., Abramovitch, R., Pencharz, P. and Koren, G. (1998) 'Empirical Examination of the Ability of Children to Consent to Clinical Research', *Journal of Medical Ethics* 24(3): 158–65.
- Orange, D. M., Atwood, G. E. and Stolorow, R. D. (1997) *Working Intersubjectively: Contextualism in Psychoanalytic Practice*. Hillsdale, NJ: The Analytic Press.
- Park, P. (1993) 'What is Participatory Research? A Theoretical and Methodological Perspective', in P. Park, M. Brydon-Miller, B. Hall and T. Jackson (eds) *Voices of*

- Change: Participatory Research in the United States and Canada*, pp. 1–19. Toronto: OISE Press.
- Peled, E. (2001) 'Ethically Sound Research on Children's Exposure to Domestic Violence: A Proposal', in S. A. Graham-Bermann and J. L. Edleson (eds) *Domestic Violence in the Lives of Children: The Future Research, Intervention and Social Policy*, pp. 111–32. Washington, DC: American Psychological Association.
- Peled, E. and Leichtentritt, R. (2003) 'The Ethics of Qualitative Social Work Research', *Qualitative Social Work* 1(2): 145–69.
- Penslar, R. L. (1993) *Protecting Human Research Subjects: Institutional Review Board Guidebook*, [http://ohrp.osophs.dhhs.gov/irb/irb\\_guidebook.htm](http://ohrp.osophs.dhhs.gov/irb/irb_guidebook.htm) (consulted Mar. 2004).
- Punch, M. (1994) 'Politics and Ethics in Qualitative Research', in N. Denzin and Y. Lincoln (eds) *Handbook of Qualitative Research*, pp. 83–97. Thousand Oaks, CA: Sage.
- Regehr, C. and Antle, B. J. (1997) 'Coercive Influences: Informed Consent and Court-mandated Social Work Practice', *Social Work* 42(3): 300–6.
- Stanley, B. and Sieber, J. E. (1992) 'Introduction: The Ethics of Social Research on Children and Adolescents', in B. Stanley and J. E. Sieber (eds) *Social Research on Children and Adolescents: Ethical Issues*, pp. 1–6. Newbury Park, CA: Sage.
- Taylor, A. S. (2000) 'The UN Convention on the Rights of the Child: Giving Children a Voice', in G. L. A. Lewis (ed.) *Researching Children's Perspectives*, pp. 19–33. Philadelphia, PA: Open University Press.
- Thomas, N. and O'Kane, C. (1998) 'The Ethics of Participatory Research with Children', *Children & Society* 12(5): 336–48.
- Tri-Council Working Group (1996) *Code of Conduct for Research Involving Human Subjects*. Ottawa: Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada.
- Van den Hoonaard, W. C. (2001) 'Is Research-ethics Review a Moral Panic?', *Canadian Review of Sociology & Anthropology* 38(1): 19–36.
- Van den Hoonaard, W. C. (2002) 'Introduction: Ethical Norming and Qualitative Research', in W. C. van den Hoonaard (ed.) *Walking the Tightrope: Ethical Issues for Qualitative Researchers*, pp. 3–16. Toronto: University of Toronto Press.
- Ward, L. (1997) *Seen and Heard: Involving Disabled Children and Young People in Research and Development Projects*. Layerthorpe, York: York Publishing Services, for Joseph Roundtree Foundation.
- Woodhead, M. and Faulkner, D. (2000) 'Subjects, Objects or Participants? Dilemmas of Psychological Research with Children', in P. Christensen and A. James (eds) *Research with Children: Perspectives and Practices*. New York: Falmer Press.
- Woodill, G. (1992) *Independent Living and Participatory Research: A Critical Analysis*. Toronto: Centre for Independent Living in Toronto.
- Zwiers, M. L. and Morrisette, P. J. (1999) *Effective Interviewing of Children*. Ann Arbor, MI: Edwards Brothers.

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