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‘Living’ ethical dilemmas for researchers when researching with children

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This article will explore some of the ethical dilemmas that confront researchers when they seek to invite children’s participation in research. It firstly tracks the historical landscape of ethical research and will examine the influence of the United Nations Convention on the Rights of the Child (UNCRC) on participatory research with children. Drawing on this background, the article will explore three main themes relating to the ethical participation of children: ethics as protection, the ethics of justice and the ethics of care. We look to contemporary literature in order to ask whether ethical guidelines specifically narrate ethical dilemmas in participatory research. The following are also explored: What is examined and explained as being ethical dilemmas when engaging with children? How does the literature explicate ethics as an explicit consideration in conducting research with children? Where is the ethical sensitivity in participatory practice? The article will conclude by identifying some of the ‘hidden’ dilemmas that need to be openly debated in the literature in order for participatory efforts to move forward.

Keywords: ethical dilemmas; ethical sensitivity; ethics; participatory research with children

Introduction

The focus of this discussion is to identify the casuistry of ethical problems and dilemmas, examining them and thereby making this article descriptive and critical in nature. The aim is not to find a solution for ethical dilemmas; this is an impossible task. Rather, the aim is to begin to nourish a thoughtful discourse about an ethical posture in research, one which promotes a more sensitive approach to the problematic issues implict in research with children. In raising a thoughtful reflection about ethical questions, this discourse does not aim to establish guidelines or protocols. It does, however, outline what Plato, in the Phaedrus (Hamilton and Cairns 1961), described as the land of thinking where a researcher can explore suggestions in order to ensure their decisions are grounded in rigourous considerations. What is relevant in the field of ethics is the exercise of reason and critical inquiry in order to better give voice to the complexity of ethical questions. No argument can resolve in any definitive way, ethical problems, since they are an arduous and endless enterprise. Rather, a position will be offered where ‘there are narratives that make better sense of things’ (Gregory 2003, 3).

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The historical reframing ethics

Ethics refers to a focus on that which is deemed right and good. To adopt an ethical stance is to be concerned/solicitous in order to make that which is good. Since humans are relational beings, that is, beings who live and grow through relationships with the others, the good is relational in its essence. Throughout life, and in each context of life, the human being searches for the good: what the ancient Greeks defined as eudaimonia (Aristotle, *Nicomachean Ethics* 1999). Consequently, even in the context of research, the question of good is inescapable.

In the field of research, a codified regulation of ethical conduct has acquired an important, one could say even reverential, status in recent times. The codified approach to ethics can be traced back to the Nuremberg Code (1949), the Declaration of Helsinki (1964) and the Belmont Report (1979). These early ethical codes were formulated as a response to seriously unethical actions and behaviours in medical research (Dodds, Albury, and Thomson 1994), particulalry in relation to Germany's conduct in the Second World War. Subsequently, a clinical approach has emerged that makes it possible to address the many challenges in biomedical research. However, these codes appear to remain silent on questions that may be specific to other contexts of research, becoming particulalry apparent when related to research with children.

In recent times, the social disciplines that engage with children have begun to elaborate on the foundational ethical codes of conduct mentioned above. The Code of Ethics and Conduct (British Psychological Society 2011) has developed some reflections on the ethics of research with children. The Ethical Standards for Research with Children (SRCD Governing Council 2007) integrates the ethical codes established in Ethical Principles of Psychologists and Code of Conduct (American Psychological Asssociation 2010). More concisely, the National Health and Medical Research Council (NHMRC 2007) identifies four critical considerations for research specifically with children, being: (1) the research must be important for the health and well-being of children; (2) the participation of children is indispensable because when the information is filtered by others it is not reliable; (3) the methods of inquiry must be suitable/right for children; and (4) the inquiry must be developed to guarantee the physical, emotional and psychological safety.

This codified approach to ethics provides a framework for the important work undertaken by human research ethics committees who are charged with monitoring the research proposals and outputs of their particular insitutions. However, one of the inherent risks in the application of a codified approach is the growth of a formalistic system and bureaucratic regulation to ethical questions in research, which consists of filling out forms and obtaining ethical clearance from an ethics committee as an end point to ethics.

Critics of this formalistic and bureaucratic approach to ethics in research speak of rule feticism (Haggerty 2004), arguing that the translation of ethics into codes does not help researchers to develop ethical behaviours (Small 2001). In contrast, some researchers defend the use of ethical guidelines, and the agency of committees, since these are thought necessary to regulate the behaviour of researchers (Balen et al. 2006; Scott, Wishart, and Bowyer 2006). Other researchers would prefer a more flexible reference to guidelines, using them not as a regulatory device but rather a tool for promoting and enhancing an ethical discussion (Gallagher et al. 2010).

As has been suggested, the first guidelines on ethics in research emerged in response to serious and unacceptable episodes of unethical conduct in medical research. However, what seems to now prevail in contemporary ethical oversight is an interpretation of ethics as a set of constraints that attempt to minimise the risk to potential participants. It would seem that this approach has resulted in research ethics becoming little more than a cautious process of risk assessment/management (Allen 2005) rather than a risk benefit analysis (Gill 2007). This article argues that it is necessary to move from a regulatory/surveillence interpretation of ethics, which fundamentally aims at avoiding damage and harm, to a promotional conception which invites potential positive experiential possibilities to the participants. In this way, ethical frameworks can be understood as a discourse that examines and offers suggestions as to how to establish conditions of ethical agency within a research endeavour, so as to pave the way for realising research conditions that permit the participants to engage in a positive research experience. To develop research work from this perspective involves interpreting one's ethical responsibility as a commitment. This means not only respecting the codified rules, but also cultivating sincere reciprocal relationships with the research participants and structuring contexts of inquiry where good experiences are possibile.

Assuming an ongoing ethical stance is a difficult task, since the researcher will frequently face problems and dilemmas in individual projects. Ethical problems appear when the conceptual or technical devices that can be drawn upon do not enable the researcher to find an adequate solution as regards a particular situation. That is, an ethical dilemma appears when a problematic situation arises where there are two opposite solutions: these are the 'horns' of the dilemma. One could almost say this is when a researcher gets 'stuck', where deep reflection is required. These ethical problems and dilemmas are frequent in research work, particularly when researching with children. The authors' position is that what appears essential is not just to have codes of conduct (the conceptual or technical) to apply in a formalistic and passive way, but to nourish a reflective posture in order to question any question, not merely to search for a technical or pre-defined solution. The real hallmark of ethical agency is viewed as a continuous and competent reflective practice (Alvesson and Sköldberg 2000; Davis 1998; Davis, Watson, and Cunningham-Burley 2000; Finlay and Gough 2003).

Ethics as protection

The UNCRC (United Nations 1989) offers children an ethical, moral and legal mandate for protection, provision and participation rights. In relation to research with children, one can draw upon Articles 12 and 13 which speak to the right for children to be involved in decision-making processes and to receive and impart information in a manner that matches their self-identified competence. In reference to formal ethical codes, it may well be found that as part of the risk management process, adults (parents, ethics committees, school principals, etc.) will make an initial protective decision on what is in the child's best interests (Article 3) in relation to a particular research proposal. Two sides of an ethcial question could be raised. Firstly, in what circumstances does adult gatekeeping, as protection, become interference in the mandated rights of children to (1) make a decision to participate in research and (2) impart information and ideas through that participation? On the other hand, given that parents are seen as the 'natural' protectors of their children, to what extent would bypassing parental consent (albeit in pursuit of according children greater autonomy) deprive children of their parents' protection? In addition, it could also suggest that since it is not readily apparent that participation in research is immediately in the individual child's best interest (other than giving the child a sense that their views are worth hearing). How it is then possible to justify involving children in research (Balen et al. 2006)? These are questions that the researchers should give priority in the agenda of epistemological reflection.

Informed consent

There is a shared concern that informed consent is used fundamentally to protect researchers and institutions from litigation, rather than as a tool for giving expression to an ethical committment (Homan 1991). Gallagher et al. (2010, 473) state that 'informed consent is more problematic than the dominant ethical paradigm acknowledges'.

From research in the health field, the 'Gillick competence' (Gillick v West Norfolk and Wisbech Area Health Authority [1985] 3 All ER 402) is used to establish that a person under 16 years is able to give consent to medical treatment without parental knowledge or consent if she/he is deemed to be of 'sufficient maturity and understanding' to comprehend what is proposed (Balen et al. 2006, 32). Medical authorities across many Commonwealth countries endorse this recommendation but maintain that 'even when the young person is judged competent, parental consent should be sought for any research procedure' (Royal College of Physicians as cited in British Medical Association 2001, 192). But, is it possible to determine with adequate precision what constitutes sufficient maturity and understanding? If we hypothesised that this definition was in fact possible, are there conditions for verifying with any degree of certainty that the young person possesses this competence? When we read a statement such as 'A working party of medical ethicists suggests that most children aged 14 years have the necessary competence to give consent and most children aged 7 years or over understand enough to be able to give or refuse assent' (Balen et al. 2006, 34), we must be ethically reflective and ask:

- On what scientific evidence is this statement based?
- What data confirm this statement?
- How were the data generated and gathered?
- Do the data give voice with fidelity to the thought and feelings of the participants?

Another example is when an international scientific association, such as the British Educational Research Association (BERA), sees fit to attribute teachers with a gatekeeping role for ethical guidance/clearance. However, in the same context, it renders children and their informed consent as a secondary consideration (or even not necessary to obtain). In its 1992 ethical guidelines, BERA suggests that care should be taken when interviewing children and students up to school leaving age (i.e. 16 years); permission should be obtained from the school, and if they so suggest, the parents. This is not interpretable as a lack of ethical consideration, but rather a way of underlining the ethical responsibility of adults. For us, the critical ethical act is not to obtain the informed consent of the gatekeepers and/or the participants, but the ethical posture the researcher assumes throughout the time of research in their relationships and actions.

Anderman et al. (1995) argue that requiring parental consent may raise threats to the validity of the research findings. In life, there are times in which the human being is maximally fragile and vulnerable: childhood is viewed one of these (Balen et al. 2006). Parents have the responsbility to care for their children and therefore to protect them. At the same time, parents have a responsibility to offer children better existential experiences. Given this anthropological position, what ethical stance supports researchers in being able, or even willing, to bypass parents in obtaining the informed consent of children to participate in research? Is it more important, ethicially, to assume the child as the only interlocutor or should the researcher also engage in dialogue with the persons having the primary responsibility of the child? The authors do not propose to know the answers to these questions but find these dilemmas worthy of consideration.

When research is undertaken within an institutional environment (school, social service, hospital, etc.) the research team must acknolwledge the disciplinary/authoritarian power that can be exercised by that institution. It must therefore be asked, when children give their informed consent is it clear that they have done so in a free and independent way or have they felt pressured because of the power imbalance or the persuasive language used by the adult (Harcourt and Conroy 2011)? Children are often disciplined subjects, used to obeying the requests they receive from an adult. Even when the request arrives from an outsider (as a researcher essentially is) children may well frame the request within the climate of the institution where they exist as student/client/patient/etc. If this situation is examined critically, then the request of informed consent in schools, social services, other educational contexts or hospitals requires specific attention because of its institutionalised context. The creation of a welcoming and authentic setting for the research enterprise, first of all obligates the researcher to give value to this act by assuming the responsibility to monitor, in each relational moment, the verification that the children are at ease in the inquiry action and that they are freely giving their consent. Flewitt (2005) suggests that informed consent should be replaced by provisional consent, which is continually negotiated along the entire research. Both Harcourt and Conroy (2011) and Sargeant and Harcourt (2012) identify the ongoing nature of consent, which places the onus on the researcher to take an ethical stance at each engagement related to the research project.

Using video data

Robson (2011, 180) focuses on 'ethical questions and practical challenges arising out of the production of video data with young children, especially as a way of eliciting their thoughts about themselves and what they do in early childhood settings'. In regard to the use of video, it seems that one of the major ethical problems is whether anonymity and confidentiality can be protected. This is a problem, but is not the only nor even the most important. A basic question here is: what is the rationale that legitimates the use of video data in research that investigates the thoughts of children about themselves and about what they do in their contexts of life? It could be argued that even the most interesting or fascinating question for research is not sufficient to legitimate involving children in a research project, let alone the use of video for data collection. Before enacting a particular research process/method, it is necessary for the researcher to assess if the question itself is worthy of inquiry. That is, if it is right to ask to others to dedicate some time and effort in their life to the research project. This should be the fundamental ethical question.

In an analysis of the scholarly reporting on research involving children it is generally found that the author gives epistemological and methodological arguments for grounding her/his work, but rarely forwards existentive reasons. For example, Morgan (2007) states that it is important to give the children an opportunity to talk about their learning or reflect on their thinking. One could argue in support that this cognitive activity is important for children, but in order to be ethical research must justify itself primarily on an existential level. To justify research at an existential level would mean arguing that the participation of children is of worth to them, in the sense that this experience would give them opportunities to grow and learn from the participatory experience.

The litanies in the research account

Literature reporting research with children reveals some litanies (i.e. routine statements) that are written because they enable the author to offer his or her scholarship in a tradition of discourse, but when simply treated, or overused, begins to lose its crticial value. For example, in many articles it has been noted that the author frames his/her discourse in the 'contemporary tradition' of research with children. Authors state, for example, that participation rights of children are important; young children are a competent subject; and/or listening to children is imperative (see e.g. Clark 2005; Harcourt 2011). It could be argued that perhaps a decade ago, when research with children was emerging as a new field of research, it was necessary to begin a scholary discussion with such justifications in order to overcome a generalist view that devalued children's views and opinions. The disscussants here believe, however, that it is now necessary to question what seems to have become routine, and overused, assertions in research with children.

To conclude here, and upon reflecting in a critical way about authors' use of justification statements, an ethical question emerges. If there are a group of researchers who underline and stress the child as competent subject, is it not possible that children's fragilities, vulnerabilities, need to be cared for, and their need to be passive and receptive are at times being overshadowed by adult researchers' need to always position children as demonstrating competence?

The ethics of justice and the ethics of care

No discourse, no theory can resolve the unpredictable complexity of ethical dilemmas in research in human sciences. Guidelines, codes and rules can help the researcher to have some reference points, but they are of minimum help. What is required of the researcher is to have the capacity and the disposition to keep in view all of what happens in the field. In addition, the researcher must interrogate their actions from an ethical viewpoint and dedicate thoughtful attention to these decisions. In order to do this, the researcher must become an ethical tool in him/herself. The authors would argue that the act of research, before being a methodological action and choice-of-inquiry technique, is a relational agency: to undertake research with children is to enter into relation with them. The relation can be either ethical or unethical, and the ethical quality of research depends on the ethical quality of the way in which the researcher builds the relation with children. But what ethical view should guide the research act? For the purposes of this article, it is held that in contemporary research, the main debate is around the ethics of justice and the ethics of care.

If it can be accepted, only as a basis for beginning a discourse, to simplify the difference between the two ethics, it can be stated that to adopt an ethics of justice means that ethical decisions are made on the basis of universal principles and rules. The culture of guidelines, protocols, codes and rules can be referred to as the ethics of justice. In the ethics of care, the main aim is not to guarantee the respect of rules, but the beneficience of the individual person towards whom the agency is directed. The ethics of care is interested in singular concrete situations and to reason in relation with actual persons towards whom the moral subject perceives to be obliged to search for what is good for her/him. The thesis presented here is that the ethics of justice is useful in many cases, but this is not sufficient to undertake ethical agency in research, what is also necessary is to embrace an ethics of care. In order to ground this thesis this article asks: What is the essence of the ethics of care and why it is relevant for the research? In what ways does the ethics of care support the research act?

To enter an ethical relationship is to search for that which is good for the other which requires the moral agent the authors refer to as ‘other-regarding’. To assume this position in relationship with the other is to embrace an ethic of care. The essence of the ethics of care is searching for that which is good: what makes the life of others something which is worthy. Children inescapably need to receive care in order to have a good quality of life. It can be argued that research inspired by the ethics of care is committed to offering children a worthy experience. The ethics of caring in research is motivated, therefore, by the intention to treat the other well so that, in turn, the researcher themselves feels good. In this way, to be other-regarding is not to devalue ourselves; the opposition between the I and the other is conceivable only in a dualistic ontology, that which considers reality composed by distinct individuals, each pursuing her/his own specific good. Instead, the notion of care is rooted in a relational ontolgy that does not separate self and other since it positions each being as greatly interconnected with others. Consequently, adopting an ethics of care means ackowledging not only that the other’s needs exist in a good ethical environment but also one’s own. Thus, to act in an ethical way is a good thing not only for the child participants, but also for the researcher.

It is this relational vocation of care that makes it possible to challenge the individualism of western culture. That is, the belief to pursue good as good that pertains to oneself and is, in a minimal way, constrained by a common good that is guaranteed by legal apparatus that enforces contracts and protects individuals from undue interference by others (Bayer 1995 [1987]). An individualistic conception of the good life puts at risk subjects deemed weak/vulnerable, such as children and young people, those with a disablity or illness and the elderly. As has been suggested, the ethics of care is grounded on a relational ontology that views the person entrenched in a series of dependencies by and with others, consequently conceives the good, not as a condition possessed by the individual, but something that is diffused in the relational essence of life. In the perspective of Rawls’ (1971) theory of justice, ethics must guarantee that each individual can pursue his or her own rational life plan with minimal possible interference by others who are viewed not as a community but as other individuals with their distinct plan of life. In Gilligan’s (1982) perspective on the ethics of care, ‘the concept of identity expand to include the experience of interconnetion’ (173), where the good can be pursued only in a relational way through the cultivation of ‘affiliative relationships’ (170). In the field of research with children, the researcher therefore adopts an ethical stance when they assume the responsibility to search for the well-being of the children.

Adopting an ethics of care actualises ways of being with the other. Different from the ethics of justice, which requires the moral agent to obey rules and codes (an external way of conceiving the ethical act), the ethics of care asks the moral agent to conduct her/himself in a way that embodies ethical values. If Erlandson et al.'s (1993) assumption of the naturalistic inquiry is accepted (where the researcher is the real tool of inquiry) then to build a research setting which is ethically oriented, it is necessary that the researcher shapes her/his way of being in an ethical manner. One becomes ethical as researcher if the gestures of the mind (thoughts and feelings) and the gestures of the body embody the essence of care.

What is the essence of care?

The ethical principles that inform the ethics of care are the same that inform the ethics of justice: *responsibility*, *respect*, *beneficience*. What changes is the way of interpreting the adherence to these principles. In the ethics of justice there are rules and procedures that the moral agent must apply; in the ethics of care the moral agent must shape her/his ways of being in relation with the other in order to enact the qualities of caring ethics.

- To be responsible for the other means to feel oneself obliged towards the other. To develop an ethical posture is possible if he/she is percieved as inclusive of his or her fragility and vulnerability.
- To have respect for the other is when the other is considered as having intrinsic value as a person: when the rsearcher is in the 'mood' to feel the ontological need to respecting the other.
- To give beneficience to the other is to have an ethical posture to search for that which is good. In research, searching for what is good for the other means committing to creating the conditions for the other to grow and flourish. To act in this directionality requires the researcher to be orientated towards developing a 'giver' posture.

To build an ethical relationship requires not only a cognitive, but also an emotional investment. By accepting the simplification for the sake of opening a discourse, it is affirmed that there are both positive and negative emotions. When, in meeting with the other what prevails are negative emotions, then the relationship suffers such that it becomes an uncomfortable setting. To nourish an ethical relation where the other is at ease, it is necessary to dedicate onelf to cultivating positive sentiments, one of which the authors believe is tenderness. When a child perceives to be welcomed with tenderness by the adult (researcher), they feel accepted and, in the face of the sentiment of such acceptance, then releases her/himself in an authentic way to the inquiry context. Noddings (1984) suggests that the ethic of care is an ethic of tenderness, and because of this essential quality is a formidible ethic.

Conclusion

If the ethic of care is very close to the Aristotelian ethic of virtue (Mortari 2006), then a researcher who is capable of an ethical posture first at all should cultivate the caring virtues: respect, generosity, responsibility and a positive emotional mood. If as Murdoch (1970, p.87) affirms ‘nothing in life is of any value except the attempt to be virtuous’, then the only thing which is of real importance in human life is the ability to contact and respond to the other with justice and care and all that is inseparable from virtue.

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