ETHICAL ISUUES IN RESEARCH INVOLVING CHILDREN

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Abstract

This essay aims to explore some of the main ethical issues that arise in research involving children. After introducing basic concepts and definitions, the essay evolves around the importance of distinguishing between the needs and rights of children and adults as well as recognizing the fact that children should not be dealt as objects of protection but as subjects of rights, as active social actors. This constitutes one of the first and foremost ethical challenges in research involving children. In addition, the essay investigates the fundamentals of ethics, how ethics can be promoted and justified in research involving children while embarking on a more detailed account of ethical issues before, during and after research such as informed consent, power relations, and confidentiality. The last part suggests and recommends a new methodological approach to research involving children based on the scientific shift from research on children to research with or by children. To conclude, the essay insists on reflecting on the importance for children to remain at the centre of consideration and re-conceptualize children within the social sciences as active agents rather than as the objects of research.

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1. Introduction

Looking from a historical perspective at the vast field of social sciences, it is evident that formal investigation and research involving children have undoubtedly contributed not only to the generalization of knowledge but also towards the construction of a body of information that can provide scientists and researchers with an amazing insight into the minds and behaviors of children. There are numerous ways of achieving knowledge and various methods in conducting research involving children. However, it is necessary for the researcher to recognize the reality of studying children participants in the further pursuit of knowledge, that is, identify the difference between adult and children participants. Researches and their conclusions can promote and protect children's rights, while they can bring human rights abuse into the light. But the way of conducting such researches could ignore, most times unintentionally, children's rights. When children are presented as the 'silent' victims of a tragedy, or are included in clinical research without their consent, their human rights and their right to be protected are being jeopardized.

Research involving children has indeed many potential benefits and drawbacks. The benefits and drawbacks concern the children themselves, not just the science. Children can gain and loose too much at the same time. Thus, it is important to promote more thoughtful attention to the complex ethical problems that arise when conducting research that involves children. This essay will explore different ethical issues and situations in which children's rights are being put at risk, while providing foundations for a better understanding not only of the ethical issues but also of the children's special nature.

2. Definition of Children and their Rights

For the purposes of this essay, the definition of child and its rights are necessary. According to the United Nations Convention on the Rights of the Child (1989), a child is defined as "a human being below the age of 18 years unless under the law applicable to the child, majority is attained earlier". Children's rights are defined in various ways, covering a broad spectrum of civil, cultural, economic, social and political rights. Synoptically and according to Child Rights Information network (2007), the rights could also be categorized as the right of empowerment, that is, advocating for children as autonomous people under the law; the right of protection, that is, claiming on society and the state for protection from risks perpetrated on children because of their dependency; economic, social and cultural rights, which are related to the conditions that are essential to meet basic human needs, access to education, housing, food, work, health; environmental, cultural and developmental rights, which include the right to live in safe and healthy environments and the right to cultural, political and economic development. Apart from physical and collective rights, children have individual rights that "allow them to grow up healthy and free" (Calkins, 1972:327). These rights are: ownership over one's body, freedom of speech,

freedom of thought, freedom from fear, freedom of choice and the right to make decisions. All these rights should be safeguarded during researches involving children.

3. Fundamentals of Ethics

Before embarking on exploring the ethical issues in research involving children, it would be useful to understand the foundations of ethics in research. Usually, when one talks about ethics or morals, they relate them to a set of rules that could help them make the correct decision between right and wrong, a code of professional conduct, like the Hippocratic oath. The most common way of defining ethics is norms of conduct that distinguish between acceptable and unacceptable behavior. (Internet Encyclopedia of Philosophy). Ethics are at home, at school and at almost all social settings, they are acquired throughout life development and can be so ubiquitous that can be often regarded as simple common sense. If ethics were just common sense, there would not be so many ethical disputes in our society and so much philosophy written, which lead us to the conclusion that ethical norms may have a common ground but vary in the way individuals interpret, apply and balance them in their lives and professions.

Legal rules that govern behavior are the formal part of rules. Ethical norms are broader and more informal, and of course, cannot be enforced, as it is the case of legal rules. So ethics are not the law, meaning that, an action can be legal but unethical, or illegal and ethical. Ethical concepts can also be used to criticize, evaluate, propose or interpret laws and generally express different viewpoints. One may also define ethics as a method, procedure or perspective for deciding how to act and for analyzing complex problems and issues, as this essay does. In considering a complex issue like ethics in research involving children, we have to adopt various perspectives and examine the cost and benefits, the ethical values and the principles at stake.

There are different reasons why it is important to have and adhere to ethical norms in research. Firstly, ethic norms promote the aims of the research, such as knowledge, truth and avoidance of error (AIR, 1992). Secondly, ethics lay the foundations for the values that are essential to collaborative work; thirdly, many of the ethical norms help to ensure that researchers can be held accountable to the public, while at the same time they can help in building public support for research. Finally, ethics promote a variety of other important moral and social values, such as social responsibility, human rights, welfare, health and safety. Ethics have been proven so useful for yet another reason: people in general are more comfortable with dichotomies. However, as we shall see further down, in ethics, the issues are most often multifaceted and the best proposed actions address many different areas concurrently. In ethical decisions the answer is never 'yes' or 'no', a 'right' or 'wrong' statement. Many factors have to be taken into consideration so that the general research conditions are improved and not to the benefit of any particular party.

4. Ethical challenges before research

The general purpose of research that involves children is to obtain and produce scientific information about them. Some researches offer direct benefit to the subjects, while some other researches produce benefits only for other children and perhaps the subjects themselves will gain no benefit. In some cases, the benefits produced are long range and unpredictable. So the ethical questions that arise are about the best interests, the risks, the harm and the wrong, the justification of a research for subjects that do not benefit, along with the rights of the children and the authority of parents to give permission, the assent and consent which will be discussed further down, and the ethics of subject selection as they relate to children in research.

One important issue in ethical analysis of research is the definition of each individual, its duties and obligations. Since people with illness are usually called patients by the ones who provide them with health care, it is very important to understand the implications and the confusion between a patient and a research subject (Kodish, 2005:7). Patients are expected to get medical care and benefit directly, but as mentioned earlier, the subjects of a research do not always benefit from the research. The subjects of the research, that is, the children do not necessarily have to be at risk. They can be healthy individuals, who will not themselves receive any benefit from that research. The ethics to justify a selection of healthy children, rather than children at risk, can be found in the general assertion that much of the improvement and development in sciences has been based exactly on this kind of research. The Royal College of Paediatrics and Child health (RCPCH) recognizes the need for research in children (McIntosh, 2000) and has based its ethical guidance around some of the following principles:

- 1. Research involving children is important for the benefit of all children and should be supported, encouraged and conducted in an ethical manner,
- 2. Children are not small adults; they have an additional, unique set of interests.
- 3. Research should only be done on children if comparable research on adults could not answer the same question.
- 4. A research procedure, which is not intended directly to benefit the child subject, is not necessarily either unethical or illegal.

The issue of using healthy children for research is of considerable debate and principle 4 is based on the potential of either no or minimal 'harm' to the healthy child (McIntosh, 2000). Of course the minimal harm has to be determined beforehand, and sometimes this is not predictable, and even if the risks are reasonable in relation to the anticipated benefits, still, the children subjects have to have their rights ensured.

The set of ethical questions surrounding research involving children is extremely complex and requires extensive attention. The most important dilemmas that arise concern during the different stages of the research can be summarized as follows: obtaining consent for participation in the research; conducting interviews with or administering tests to the subjects; and providing information about test results to parents or others outside the research team (Kinard, 1985).

4.1 Consent

Consent is the permission given by the responsible adult to the interviewer, which allows the interviewer to approach the children participants (MRS, 2006). This consent is a very important step in the process of research and is one of the most common factors in all ethical considerations. Even the Nuremberg Code (1949) appears to introduce the concept of consent for the participation of children in research. In the first principle, it states:

"The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment".

According to the Declaration of Helsinki (World Medical Association, 2008), even though a child may not be legally competent to give consent, researchers should gain informed consent. This means that parental consent is not enough (UNICEF 2002:5) and that both the parents and child should be informed about the implications of the research. So informed consent is based on three features; the knowledge and information provided to the participants in a form they can understand; their voluntarily consent and competence to give this consent (Beresford, 1997). Informed consent ensures that if the children participants are capable of providing assent, in addition to the consent of the adult with parental responsibility, they know they have a choice as to whether to participate in the research, in other words that they are true volunteers. In order to promote informed consent, researchers should develop suitably customized information that children can understand, since children do not have the same cognitive capacities as adults and tend to view the worlds through their own experiences. So information provided must be according the developmental/chronological ages and needs (Beresford, 1997). Ensuring the voluntarily consent is also very important but informed consent

is quite problematic. The key word in informed consent is competency, and it is an area of concern as to what can be defined as competency. Robson (1993) maintains that there are particular ethical problems in relation with competency and informed concern, especially with vulnerable groups such as very young children. This is because it may be difficult for them to fully understand every aspect of the research. For Robson (1993:32) the issue relates to whether the can "rationally, knowingly and freely give informed consent". While one could argue that children are far more competent that this suggests, especially if adults take the trouble to ensure they explain things in a clear and understandable way, very young children and babies are not in a position to sign a consent form or provide their assent. Furthermore, they are unlikely to understand many aspects of the research in advance of it actually happening. This is where the ethical dilemma presents itself to the researcher. Although it is important to gain the consent of adults, there must be an effort to make children understand and obtain their consent as well. In such cases, researchers seek to get approval by an ethics committee, who would also act as gatekeepers. However, Langston et al. (2004) demonstrated that very young children and babies are able to give or withdraw their consent to research in a variety of ways, such as refusing to co-operate, become abnormally quiet, turn away and cry or sound distressed. Therefore the researcher needs to be sensitive to the moment in order to understand children behavior while a greater knowledge of the children is crucial. Researchers also need to be mindful that children may sometimes hide their dislike or try to please an adult, and may not appear as distressed as they are truly. Again the insights of adults and children who know the child better are invaluable. To conclude, informed consent should be regarded not as an a priori condition, but as an ongoing achievement, something that should be under discussion during the whole process of the research.

5. Ethics during Research

Many researchers, after obtaining consent and dealing with ethical issues before the research, they then focus on issues arising during research, such as the way of introducing the subject matter and take all reasonable precautions to ensure children will not be harmed or adversely affected by participating in the research. Also, researchers should inform the children that they respect their right to withdraw from the research at any stage. Furthermore, one of the key concerns is the subject matter of the actual research, which should be introduced in such a way that it will not disturb or frighten children. For example, issues relating to potentially sensitive family situations, racial, religious and similar social or political sensitive matters should be established in such a way that children will not be worried, confused, misled by the research and patronized. Such issues result from the fact that children understand and experience the world in their own way. Actually, there are differences in how children communicate and experience the unequal power relations that exist between adult researchers and children participants (Kirk, 2007; Mauthner, 1997; Thomas & O' Kane, 1998).

5.1 Power relations during research with children

Since researches can be described as social activities, that is, they involve more that one individual which are members of a particular society, it can be asserted that these individuals participating will eventually reproduce the power relations that perpetuate their relations outside the research context. According to Kirk (2007), the adult "centredness" of most societies and the unequal power relations that exist between children and adults are reproduced during research. So children may experience pressure, which is not conscious, but a result of the power relationships that are reproduced, and will not feel free to refuse participation, leave in the middle of the research or express their own opinions and share freely their experiences (McCrum & Bernal, 1994). They might think that they need to live up to the expectations of the adults, or believe that they are being judged and criticized, feel vulnerable, like someone is looking after them and they may not be able to experience research as subjects with rights, but as objects that need protection. Even the fact that parents or adult caregivers give consent, may drive them to experience and reproduce power relations. According to Harden et al. (2000), in most studies where a child is under 16 years of age, parents or other adults act as gatekeepers giving consent to their child's participation and as protectors who may deny children the opportunity for participation or, on the other hand, force them into participation, resulting in feelings of conflict, guilt, threat to self-esteem, fear for failure or embarrassment (Kirk, 2007). These power relations are inherent and somehow predefine behaviors and expectations. As in all societies, power structures are manifested in all social relationships, such as gender, age, class, and ethnicity. Researchers have to ensure that the children participating do so at their own free will and that the rights of the child are fully respected in the research process. They also have to be ready to deal with any negative emotions that the children may experience during their participation in the research by acknowledging the dynamics of the structures of power and fear that exist among adults and children, especially marginalized children.

6. Ethics after Research & Confidentiality

Ethics after research is of equal importance. The researcher has to ensure the ethical processing of data, the way this data will be stored and will be made available to others. Personal data are usually protected by data protection laws, but there could be situations where a parent, who has provided consent, requires information about the research results, while the child participating in the research has been assured that his/her answers will not be revealed. In such situations the researcher has to achieve "a balance between the parent's right to know and the child's right to

privacy" (Kinard, 1985). Apart from the parents issue, the researcher must adhere to the ethics around sharing the results with other researchers and other studies. The topic of confidentiality is very problematic, not only in achieving the previously mentioned balance, but also in protecting children participants. One striking example is in research with abused children where the relationship between parent-child is awkward and even if abusing parents are presented with the results of the research, this may not make them reconsider their behavior, but could make them more angry with their children, something that could also affect the results of the research, since abused children may feel less free to give honest answers (Kinard, 1985). One way of getting over this challenge is to ask for permission of the child subject to disclose information about the research afterwards, even though this is not utterly unquestionable, since children's understanding can be very different.

So confidentiality is very important since disclosure of information can put the children and their rights at risk. Most of the researchers and researchers treat all information as confidential, but confidentiality cannot be guaranteed (Beresford, 997). For example a parent may require access to the confidential results of the research before providing consent. So in order to ensure the actual research, some researchers may think that compromising the results to parents and caregivers is not something that could harm the children subjects. Another issue of confidentiality evolves around the kind of information provided to children participating in the research. Should children know about their performance and will they be able to deal with it? This question is very tricky and there is no answer applicable at all times. There could be cases where children suffer a loss of self-esteem as a result of misconception. In such cases, children's feelings must be protected and children must be reassured that their performance was acceptable, otherwise, they will experience negative effects from research participation (Kinard, 1985).

7. Suggestions & Recommendations

7.1 A change in perspective: Children as active agents

Ethical challenges, as presented in this essay tend to develop around the construction of children as vulnerable and incompetent, as objects that need protection. It is necessary to acknowledge children under a new framework. The various definitions of children's rights as well as the change in the conceptualization of children as expressed through new theories and approaches, have aided in the reconceptualization of children as social actors who play an important part in their own representation. Children, according to the socialization theory, were conceived as 'empty' and 'unfinished', ready to be filled with ideas of the society they belong, as part of the process of socialization (Waksler, 1991). However, this theory missed the fact that children experience the world in their own terms (ibid). Progress in the field of psychology provided a more universal perception of children, influencing both sociology and psychology to a large extend, establishing ideas such as natural

growth, progression from simplicity to complexity of thought and from irrational to rational behavior (James & Prout, 1997, James, 2001). Before this shift, children were conceptualized as incompetent, immature and passive, as objects of a socialization process that was going only one way. This theoretical approach came into question, allowing for more interactive and constructionist frameworks to replace it, that resulted in rethinking children, childhood, children's rights, children's position and social status (ibid). These new perspectives view childhood as the result of different childhood variables, such as society, culture and history, interacting and forming together a socially constructed childhood (James & Prout, 1997). In this way, children experience and understand the world in a different way than adults, but they have an active role in the construction of their social worlds.

Accordingly, research that involves children should be dealing with them as active agents, not passive objects of research. Children, like adults "can and do participate in structures and unstructured interviews, they fill in questionnaires, they use new media; they are involved in action-research; and, on their own terms, they allow the participant observer to join with them in their daily lives" (Christensen & James, 2008:2). However, the traditional way of exploring children's lives calls for adults to be used as proxies for children, that is, construct meanings through their views and understandings, rather of children. But if researchers need to learn about children experiences, they need to exclude their representations and ask for information directly from children (Mahon et al, 1996). Children are not objects and cannot be excluded from the research process. Even though they possess distinctive cognitive and social developmental characteristics, something that can be considered in designing a research or adopting a particular methodology, children are integral to the process, they are reflexive participants (Christensen & James, 2008:3). These characteristics, such as age, cannot act as exclusion factors: "our concept of such qualities should not influence ways of approaching children in social science research, it should be open to empirical investigation to explore the significance of age and status within different contexts and situations, to explore doing rather than being" (Solberg, 1996:63-4).

The way adults view the world is very different to the way children view it. This reconceptualization has been supported not only by theories but by research as well, leading to the conclusion that children experience and view events and situations differently, and that adults' accounts cannot provide valid accounts of children's worldviews. Under these guidelines, research involving children does not necessarily entail the use of different methodologies, but an adjustments in the way of approaching the research, always taking into consideration the different reality of children, that is, for example the distinction between child and adult. So it is not a matter of age, but rather the methodologies selected should be appropriate for the people involved in the study, their social and cultural context as well as the subject under investigation. Children are part of a society and their lives are naturally complex, so a holistic perspective of the child must be taken, one that can recognize the many different variables that influence development and behavior (Greig et al. 2007:4).

7.2. Research with or by children

There are recent studies and literature that move the scientific focus towards children's rights and emphasizes ways of involving children and young people more directly in decisions that affect their lives, that is, "the shift from 'research on' to 'research with', and 'research by' children and young people" (Brownlie et al). This particular framework of children's participation in research is being supported by arguments based on efficiency, that is, that participation will produce better outcomes, as well as arguments on empowerment, that is children and young people making decisions that will affect their own lives, are more aware of their position in society and their rights, can defend their rights and are more capable citizens. Of course there is always dispute as to whether children can be trained and become researchers themselves. This dispute is, once more, based on the perspective that young children are too immature to be able to become researchers, make decisions that will affect their lives and be aware, especially if we are talking about children of a very young age. However, Kellett (2005) argues that children can be taught the skills that will enable them to become researchers, especially when there are numerous examples of children's curiosity, their inbuilt desire to explore and creativity. This new approach in research involving children may not be directly applicable in all types of research, but it incorporates a very important aspect: listening to children. When listening to children, ethical issues, such as the ones relating to power can be limited and helps us reflect on the importance for children to remain at the center of consideration and aid in re-conceptualizing children within the social sciences as active agents rather than as the objects of research.

8. Conclusions

The key objective for researchers who involve children in their research is to use tools and methods that could empower and enable children to be active participants in the research process, not just objects of protection. Children should be given the chance to express their opinions, learn about themselves and their rights, while research activity must be regulated and the researchers must ensure that their rights of consent, confidentiality and unobstructed communication are protected at all times. On the same grounds, what also needs to be emphasized is the difference between conducting research with children and with adults. Children are more sensitive and ethical issues are of equal importance with methodological issues. However, and despite the differences, researches involving children can also function as examples of good practice, even for research involving adults, with close attention paid to the process of obtaining informed consent and to providing understandable information for research participants, attention to the unequal power relations between participants and researchers, etc. Thus, research involving children, when ethical, can set the standards for all types of researches, while at the same time help researchers learn even more about childhood systematically and without the danger of putting children at risk, especially the very young ones or the very vulnerable ones, such as abused children.

These vulnerable children should acquire a special status in society (Greig et al. 2007:6). They can be exceptionally gifted of have a physical or psychological dysfunction, or be very vulnerable. Along with other children, these very special children "have been, and are, the focus of a great deal of research activity which aims to discover why they are different, and the effects of their difference in terms of their present and future development" (ibid). In exploring the ethical grounds of how such researches are and should be undertaken, what should be emphasized is that the researchers should always take into consideration the children's right, which should be the same for all children. Even more specifically, the ethical challenge the researcher has to deal with is "that of balancing the need for children's participation and inclusion in research activity with the need to protect very vulnerable children" (ibid).

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