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Concerns about Child Subject Research in Botswana: A Call for Establishing Structures and Guidelines that Protect Children

Introduction

Over the years, African societies often have been criticised for the belief and practice that ‘children should be seen but not heard’, which, among other things, has contributed to little research being conducted on issues affecting children. This trend has changed dramatically in recent years. The number of studies that involve children is increasing at a dramatic rate, and this increase is associated with a set of complex factors.

Since the escalation of child-centred research is not something that has been anticipated in Botswana, there has not been adequate planning for monitoring such endeavours. This is reflected in a number of ways, but the problems associated with the situation in Botswana are amplified by the lack of delineated structures and guidelines for addressing research that involves children. Attempts to address such problems are still at an early stage, if not non-existent. Available guidelines relate to research in general; the current structure assumes a focus on adults and does not specify any special protocol for research that focuses on the child subject. On a related note, many academic research projects conducted by undergraduate and graduate students in Botswana’s institutions of higher learning do not operate under research advisory groups of any type. A great deal of work still needs to be done in this area, particularly taking into account that the involvement of children in research sometimes causes more harm than good.

Research with children can focus on a wide range of issues, including environmental, educational, economic, cultural, psycho-social, and moral. Issues that need attention vary according to the type of research. This manuscript focuses primarily on issues that need attention in researching the psycho-social concerns of children, that is, non-medical or non-body-invasive research, as the authors’ backgrounds are in counselling and social work.

Background factors associated with child subject research are identified and delineated in this manuscript, and arguments are advanced that favour the articulation of explicit guidelines and detailed protocols for research conducted with anyone under the age of emancipation. A brief history of the ethics of human subject research is offered, followed by a discussion of the reality of contemporary research with children in Botswana. This reality, and hence the discussion describing it, is imbued with a number of tensions – seeming contra-

dictions that are more paradoxical than contradictory, but nonetheless are in need of explication. The actual practices of research are examined against the backdrop of international ethical standards. The manuscript concludes with recommendations for policy making and implementation aimed at protecting the interests of children in Botswana, and perhaps by extension, in other African countries.

Background to the Problem

Upon examining the formal research landscape in Botswana, a number of concerns about research conducted with children emerge and need careful scrutiny. These concerns are associated with several complex factors and are elaborated in this section.

The Voices of Children

First, at a global level, researchers have realised that adults cannot adequately represent the views and experiences of children whom they observe with detachment. Others have asserted that the worlds of adults and children are different (Damon, 1977) and that the age and authority of the adult means that the child can never be a complete participant (Corsaro, 1985; Fine, 1987). As such, an increasing number of stakeholders conscientiously assert the notion that children are social actors in their own right (Wartofsky, 1981; Maundeni, 2000), have the abilities to understand and explain their world, and are not a homogenous group with one homogenous voice or culture. Yet most governments around the world have legally encoded emancipation age limits. Dr Richard E. Behrman, the executive chair of a paediatric committee that prepared a prestigious Institute of Medicine report on research involving children, stated that ... unlike most adults, children usually lack the legal right and the intellectual and emotional maturity to consent to research participation on their own behalf' (quoted in *USA Today*, 2004). Kodish (2004, p. 1) states the following: 'There is a long-standing moral and legal tradition that supports parents as the primary decision-makers for their minor children, including the right to make proxy decisions for children about participation in research'. Who speaks for the child is obviously a multi-faceted tension in research conducted with children.

International Agreements

Second, at a more localised level, Botswana has signed several international and regional treaties that focus on children's rights. These include the United Nations (UN) Convention on the Rights of the Child (CRC) (United Nations, 1989) and the African Charter on the Rights and Responsibilities of Children (ACRRC). The UN's CRC, Article 12, states that children not only have a right to articulate their opinions with regard to issues that affect them, but they also

have a right to have these opinions heard. This convention expresses the message that children's 'voices' should be listened to by adults who make decisions concerning children's lives. Yet huge gaps continue to exist between national policies and the services actually delivered to children (National Research Council and Institute of Medicine, 2000). Research is one mechanism for enabling children to voice their issues and concerns and for potentially bridging this gap. However, although research that involves children gives children an opportunity to voice issues of concern to them, the reality is that most research agendas are determined by researchers rather than by the children themselves.

Socio-economic Issues

Third, Botswana's well-documented economic success, combined with a high incidence of HIV/AIDS, has also contributed to an increase in the number of researchers from outside Botswana who conduct research on children. The country has drawn many development projects and extensive donor funding aimed at fighting the HIV/AIDS pandemic; therefore, for a variety of reasons, many foreign researchers are constantly moving into and out of Botswana. There have been so many, in fact, that it ostensibly has taxed the capacity of the nation's research review structure, which recently has decentralised out to the various Ministries.

Psycho-social Issues

Fourth, the numerous psycho-social problems that children experience in contemporary Botswana, as well as in some other African countries, has led to an increase in child subject research projects. These problems include HIV/AIDS, child abuse, parental divorce, orphan-hood and the status of other vulnerable children, incest, rape, war, and forced migration, just to name a few. And because countries throughout southern Africa, including Botswana, have been hard hit by HIV/AIDS, children face a plethora of psycho-social problems as a result of the pandemic. All the above issues are especially sensitive, as many researchers who focus on these child-centred issues tend to use qualitative methods. Although qualitative research can empower the children subjects and can make them active participants in the research process, it also can place children at a disadvantage.

The Need for Explicit Guidelines

Research with children raises a number of legal and ethical issues (Glantz, 1998; 2002). Based upon the above set of concerns and drawing from international policy concerning research with human subjects, the need arises for explicit structures and guidelines for conducting research with children in Botswana. These structures and guidelines need to be grounded in the

principles of child welfare and organised around sensibilities that advocate the best interests of the child.

A Brief History of the Ethic of Human Subject Research

Although laws vary from country to country, the ethical treatment of human subject research has a relatively short international history. This section outlines some of the significant events that have had an impact upon international policies relating to human subject research. A synopsis of important dates is offered.

The Nuremberg Code

The Nuremberg Code was established in 1948 and provides the foundation for protecting the rights of human subjects of research. The Code is an outcome of the criminal proceedings against Nazi doctors who conducted medical experiments on concentration camp prisoners without their consent. These experiments were a part of the Holocaust atrocities committed during the Second World War, and resulted in death or permanently disabling conditions for most of the subjects of these experiments. As a consequence, the Nuremberg Code makes clear that 'the voluntary consent of the human subject is absolutely essential', and that the benefits of research must outweigh any potential risks. These precepts remain basic to all ensuing policy concerning human subject research.

The Kefauver-Harris Bill

The Kefauver-Harris Bill was passed in the USA in 1962 to ensure greater safety in prescription drugs. This legislation came into effect as a result of the thousands of babies born throughout Europe and in the US with birth defects caused by thalidomide taken by their mothers. Drug manufacturers, for the first time, were required to prove the efficacy and safety of their products for human consumption to the Federal Drug Administration (FDA).

The Declaration of Helsinki

The World Medical Association met in 1964 in Helsinki, Finland. It was during this meeting that recommendations were established to guide medical doctors in their biomedical research involving human subjects. The resulting Declaration governs international research ethics and puts into effect a platform upon which 'good clinical practices' are promoted. In addition to the precepts of informed consent and benefits outweighing risks, as established by the Nuremberg Code, the Helsinki Declaration added the following: research conducted with humans should be based upon laboratory and animal experiment results, research protocols should be reviewed by an independent committee before being initiated, and research should only be conducted by scientifically qualified professionals.

The Tuskegee Syphilis Study

It was during the Tuskegee Syphilis Study, which took place in Tuskegee, Alabama (US) between 1932 and 1972 that a series of research abuses occurred. The project was conducted by the US Public Health Service and involved over 600 poor and under-educated African American males. Of these, 400 of the men had syphilis; they were not informed of the condition, and were then denied treatment, even after a cure was available by the 1950s. These abuses were not revealed publicly until 1972, and the experiment was stopped in 1973 by the US Department of Health, Education, and Welfare, but only under pressure and after the incident had become a political embarrassment. The ensuing impact became one of such public outrage that President Bill Clinton made an apology to the subjects and their families in 1997.

The National Research Act (USA)

The National Research Act was passed by the US Congress in 1974, primarily as an aftermath to the negative publicity from the Tuskegee Syphilis Study. This Act created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The purpose of the Commission was to identify basic ethical principles aimed at protecting human subjects of research. Through this Act, Institutional Review Boards (IRBs) were established at the local level; the Act required IRB review and approval of all federally sponsored research involving human subjects.

The Belmont Report

The Belmont Report was drafted by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission's report was named for the Smithsonian's Belmont Conference Center, where the Commission met between 1974 and 1978. In 1981, the regulations became encoded by their addition to the Code of Federal Regulations, and these were revised in 1991. Universities and other research institutions in the US must follow these federal regulations and supply written assurances to the Office for Human Research Protections, Department of Health and Human Services.

Research with Children

There has been a recent impetus for conducting research with children. In some cases, the research is well considered and undertaken with a cautious eye toward ethical interactions with the child subject. Unfortunately, in other cases, the interests of the research project are placed ahead of the interests of the children involved. It is easier for this to occur in a developing context than in developed countries, but no less exploitative. Some cultural aspects associated with childhood are potentially different in a developing versus developed

context; this and other mitigating psycho-social and socio-economic issues needing special attention are discussed in this section.

Defining Childhood

It is necessary to define what is meant by childhood so that this important discussion starts on a common ground. It is worth mentioning that in an African context, childhood is not conceptualised in terms of age, but in terms of inter-generational obligations of support and reciprocity (Ncube, 1998). In other words, an African child is always a child in relation to his or her parents, who expect, and are traditionally entitled to, all forms of support in times of need and old age (Rwezaura, 1989).

There is no standard legal definition of a child in Botswana. Various policies, acts and statutes define children differently. For example, the Children's Act defines a child as any person under the age of fourteen; the Adoption Act defines a child as someone below the age of nineteen; the Matrimonial Causes Act defines a child as a person below the age of twenty-one; and the Affiliation Proceedings Act defines a child as someone below the age of sixteen. Moving beyond the statutes of Botswana, the African Charter on the Rights of the Child defines a child as anyone below the age of eighteen. For the purpose of this paper, a child is regarded as any person below the age of eighteen.

Issues that need attention

Since the drastic rise in the number of research projects involving children has not been adequately planned for, there are numerous issues that need to be attended to in order to avoid hurting children as a result of their participation in research. This section focuses on these issues. These include the following: (i) how to avoid exposing children to the stress that results from interviewing the same children about their traumatic experiences more than once; (ii) how to ensure that children's rights are protected in the whole research process; and, (iii) how to ensure that scientifically qualified researchers are also adequately trained and qualified in relevant aspects of child development and related child concerns. The above three issues are politically loaded and emotionally charged. Implicit in them are other issues such as the absence of a body or bodies that monitor(s) child-related research, as well as the absence of guidelines that focus on research involving children in Botswana.

One of the primary questions that needs attention is 'How do researchers avoid involving the same children in research more than once?' There are many answers to this question. These include literature review, talking to people (both formally and informally), and attending presentations. Although these avenues are available, they are not adequately used by all researchers, and not all research projects are deposited in libraries. When applying for a research permit in Botswana, the researcher acknowledges an obligation to deposit a

copy of all reports associated with the request at the relevant national archives. Yet many holders of research permits fail to comply, and many researchers do not bother to obtain the requisite research permit. Incidentally, there is a legally sanctioned penalty in Botswana for conducting research without the proper permit; however the fine is only Pula 300 (\$60).

Exposing the same children to multiple research events is an important issue, because duplication of topics and methodologies prevail in Botswana. This is partly so because of a variety of reasons. First, there is a poor dissemination of research findings. For example, not all University of Botswana students' research projects are kept in the library. Departments such as social work and sociology deposit only those dissertations that are 'good' in the library. In addition, not all researchers have access to such projects. Similarly, research projects conducted by students in other institutions of higher learning locally and regionally are not accessible to all potential researchers.

Second, the chances that the same children could be interviewed more than once are exacerbated by circumstances that arise from some researchers' failure to disclose to others information about the research they are doing or have done. This reluctance stems primarily from fears about competition, demonstrating how some researchers put their own interests before the welfare and best interests of the children. The authors have interacted with several social science investigators who were unable to gain access to relevant information about completed research projects as a result of other researchers' refusals to disclose information about their projects.

Third, certain locations in Botswana are becoming over-saturated in relation to child subject research, for instance, Gaborone and the surrounding metropolitan area. This is so because quite often researchers conduct projects under financial and time constraints. As the capital city of the country and as the urban area with the highest-density population, Gaborone is also a place where numerous psycho-social problems exist.

Another thorny question that needs immediate attention is 'How do researchers ensure that children's rights are protected in the whole research process?' This question is crucial when taking into account the following trends.

First, although Botswana has signed several international treaties on children's rights, a majority of children in the country are not aware of their rights. This phenomenon has been highlighted in numerous seminars, workshops, and conferences that the authors have attended. It is also well documented in existing literature (cf. Ministry of Local Government, 2001; Maundeni, forthcoming). It has been associated with, among other things, the scarcity of pressure groups and a weak civil society to lobby for children's rights. Childline is the leading vocal NGO in Botswana that focuses on children's rights. Other NGOs and church-based organisations such as Botshabelo Rape Rehabilitation Centre, BOCAIP, Save Our Souls (SOS) and

Tirisanyo Catholic Commission also lobby and advocate for children's rights, but not to such an extent as Childline. The latter largely concentrates on service provision. Although Childline is doing a good job in relation to advocacy and lobbying on behalf of children's rights, its efforts are limited by the fact that it is based in Gaborone with a centralised service structure. Therefore, many people in the country are unable to access or to benefit from its services. It is also worth mentioning that some women-centred NGOs also pursue advocacy around children's rights in Botswana; however, these NGOs largely focus on women's rights. In addition, their ability to educate children about their rights is hampered by a shortage of resources.

Second, many parents in Botswana do not believe that children have rights. They still believe that children are their property. In recent radio shows where child welfare workers were called to Radio Botswana to educate the public about children's rights, numerous callers repeatedly pointed out that children do not have rights. Some expressed their sentiments in very explicit terms, for example: 'My children are my property'. 'Our government has signed documents without understanding their implications.' 'I brought my children into this world and no one is going to tell me how to raise them or tell me that they have rights.' 'The reason why our children are uncontrollable is that they are told that they have rights.'

Third, the fact that many adults in Botswana resist the idea of children's rights indicates that some parents may deny their children opportunities to participate in research (Maundeni, Forthcoming). How then do researchers ensure that children are not over-protected against their right to participate in research? This is a valid issue because an over-protective stance towards children may reduce their ability to participate in research. The prevention of some children from taking part in research by adults is not peculiar to Botswana; it is documented in the existing professional literature (cf. Thomas and O' Kane, 1998). The critical question is: Should we collude with adults and silence children?

Fourth, there is no rigorous legislative body that coordinates research with children in Botswana. In the past, the Office of the President was responsible for assessing applications of people who intended to conduct research in Botswana. The committee that assessed the applications did not only assess child-centred research, but all types of research. As such, members were not experts on children's issues. The permission process used to take a long time; one of the authors had to wait for over eight months to obtain a research permit for a one-year project. The process recently has been decentralised, with responsibilities assigned to the various Ministries. Since this is a recent move, it remains to be seen how child-related research applications will be handled under the new system.

Fifth, there are no guidelines for researchers doing research with children in Botswana. In the absence of these structures, some researchers may abuse

children's rights. Frequently, children do not realise that they have rights because they are vulnerable due to their social status. In addition, this may arise from the fact that they are sometimes desperate to talk about traumatic experiences because they previously may never have talked about them with anyone. For example, most children who participated in interviews for a study on children's experiences of divorce in Botswana (Maundeni, 2000), revealed that they had never talked about their experiences of parental violence with any adult. The children had the impression that family violence was a secret and should not be discussed with people outside the home. Another type of example is a study conducted in Namibia (Levers, 2002). When the researcher discovered how fragile the children were on her first scheduled day of the investigation, she scrapped her original research plan and shifted to interviewing teachers about the children rather than the children themselves.

The chances that children may be revealing or sharing their experiences of traumatic situations for the first time are increased by the fact that programmes that address the psychological well-being of children in Botswana are very scarce. For instance, there are no counselling services for children attending pre-schools. Some primary schools do not have guidance and counselling teachers, and although most secondary schools have such teachers, to date most of them are not trained sufficiently. The fact that children may be desperate to talk about experiences of traumatic events may lead them to accept whatever the researchers say or does without question. Conversely, children who are not ready to talk about their traumatic experiences may feel forced to do so out of respect for an adult.

In fact, it is highly possible that children's rights may be abused during the research process, because of the extent to which children in Botswana are socialised to respect adults. This socialisation process is referred to in Setswana as *Botho*; and when a Motswana child has conducted himself or herself in a less-than-respectful way, the child is chastised with the phrase 'Ga ona botho' (bad manners), a very serious admonishment. While it is acknowledged that socialisation of children varies among families, there are several key aspects that characterise the socialisation of children in Botswana, as well as in other African countries. One of these features is the emphasis on children's obedience and respect for adults in general, not only their parents (Brown, 1977; Matovu et al., 1998; Maundeni, 2002). As a result some children may participate in research not because they voluntarily want to, but because they believe that their refusal would be seen as a sign of disrespect.

It should be noted, however, that various areas within Botswana (especially urban ones) are undergoing socio-cultural changes, as evidenced by the increase in nuclear families and the weakening of the extended family system, an increase in the number of people living in urban areas, people's adoption of new ideas and values, and increased contact with foreigners and urbanisation, which are all associated with modernisation (Brown, 1977). As the process

continues, some of the cherished values about the socialisation of children may be weakened. Because of the socio-cultural changes that are taking place in different parts of Botswana, the country comprises a mix of modern and traditional communities and ideologies of family relationships and childhood.

Finally, children's rights potentially may be abused by researchers, because many children in rural and remote areas experience the research situation as a new one, so they are unclear about what is expected of them and what they should expect from the researcher. For these reasons, it is the researcher's responsibility to protect children's rights and teach them about their rights. Researchers should not take the rights of children for granted. They should educate children about their rights and responsibilities in the research process. They should, for example, ensure that children give their informed consent to participating in research; not assume that a guardian or caretaker's decision to allow children to participate in research automatically mean that children have agreed to participate. Researchers should inform children that they have the right to withdraw their participation in the research, and also that they do not have to answer all questions and that they do not have to agree to tape recording.

There is of course a need to ensure that scientifically qualified researchers also are adequately trained and qualified in relevant aspects of child development and related child concerns. Researchers who are not sufficiently trained in doing research with children may harm children through the research process. At the University of Botswana, for example, some undergraduate and graduate students conduct research in fulfilment of their degrees. Unfortunately, some are not exposed to adequate training in the area of research with children. This situation is exacerbated by the fact that the semesterisation programme has limited the amount of time allocated to courses as well as the time that students spend collecting data. Research with children is a very sensitive area, and as such we should not do 'quick research' with them.

The lack of training on research with children is also evidenced by the fact that by and large the research techniques that are used in such research are somewhat limited and narrow. Most student researchers use face-to-face interviews with children. They rarely use other communication strategies that may meet the needs and preferences of various children. Since there is no one research tool best suited to gaining children's opinions, there is need for researchers to conduct research with children using various strategies. This line of thinking has been emphasised by scholars (Davis, 1998; James, 1995) who have pointed out that child researchers should employ a number of tools, because children are not familiar with the social scientific tradition of face-to-face interview techniques. Others suggest that interviews are best carried out within the context of or alongside everyday activity or by using pictures or photographs as prompts (Curray and Russ, 1985; Backett and Alexander, 1991). Still others argue that paintings and stories, rather than interviews, should be used when doing research with children, because children are

threatened by formal occasions (Cavet, 1996). Additional techniques that enable children to be active participants in the research process include focus groups, role-plays, requesting children to write about hypothetical or real situations, as well as to use toys in telling or ending a story. The need to use various techniques to collect information from children has been clearly outlined by Mauthner (1997), who pointed out that children possess greater or lesser expertise in the verbal setting, the drawing technique, or the writing approach, and that this relates to aspects of their respective cultures.

All of the above suggested strategies can go a long way in improving the quality of information collected from children, enabling children to be active participants in the research process, and helping children to relax during the data collection process. However, the authors' perusal of numerous students' research projects showed that research strategies other than interviews are rarely used in research involving children.

International Ethical Standards

International ethical standards suggest that the very nature of conducting research with children require that protocols maintain the best interests of the child. For example, the Society for Research in Child Development has recommended sixteen principles for research with children:

- (i) The researcher should only use non-harmful procedures.
- (ii) The researcher should fully inform the child about all aspects of the research.
- (iii) The informed consent of parents or guardians of children should be obtained.
- (iv) The additional informed consent should be obtained from any persons whose interaction with the child is a part of the research focus.
- (v) Incentives to participate should be fair and not excessive to what is normal for the child.
- (vi) When deception or withholding information is essential to a study, it is the responsibility of the researcher to satisfy peer reviewers that the deception is necessary.
- (vii) Anonymity of information derived from records must be preserved.
- (viii) The mutual responsibilities of all parties – researcher, parent or guardian, and child – should be clearly articulated at the onset of the investigation.
- (ix) The researcher has a responsibility to bring any information that may jeopardise a child and that comes to light as a result of the investigation to the attention of the parent or guardian.
- (x) The researcher should take measures to correct any unforeseen consequences of the study.
- (xi) Confidentiality must be preserved.

- (xii) After data are collected, the researcher has a responsibility to inform participants of findings and to clear up any misconceptions.
- (xiii) Reporting results should be done as non-judgmentally as possible.
- (xiv) Researchers should be mindful of the implications of reporting results.
- (xv) Researchers should avoid any intentional scientific misconduct.
- (xvi) Researchers should avoid any intentional personal misconduct.

Challenges, Policy, and Recommendations for a Way Forward

The paper has argued that the drastic rise in the number of research projects involving children in Botswana has not been adequately planned for. Therefore, there are numerous politically loaded and emotionally charged issues that need to be attended to in order to ensure that the best interests of children are protected or to avoid hurting children as a result of their participation in research. Three of such issues that are discussed in this paper are: how to avoid exposing children to the stress that results from interviewing the same children about their traumatic experiences more than once; how to ensure that children's rights are protected in the whole research process; and how to ensure that scientifically qualified researchers also are adequately trained and qualified in relevant aspects of child development and related child concerns. Taking into account the above issues, the following recommendations are made.

First, there is a need for a unit or department that will take charge of children's research issues. Some of the crucial questions that need to be ironed out are: who will be members of the body that handles children's research issues? And where will the body be based – under which ministry? Currently, issues affecting children's welfare are handled by the ministry of local government's social welfare department. However, psycho-social issues of children cut across various sectors and disciplines. Therefore membership of the board that focuses on children's research issues should be multi-disciplinary in nature.

Second, there is a need to train researchers doing research with children on ethical issues and child development as well as child welfare issues. Such training should also include, *inter alia*, how to avoid hurting children during the research process. It should also emphasise the need for researchers to question both their research methods and the academic and personal assumptions that they carry with them into the field.

Third, there is the need for an increase in outreach workers to help children with psycho-social problems such as orphan-hood, divorce and abuse. This is particularly important taking into account that the process of social change has among other things weakened the extended family as well as its role of meeting children's psycho-social needs. The availability of such professionals can go a long way in reducing situations whereby children talk about traumatic experi-

ences for the first time during the research interviews. The increase in human service professionals who can help children with psycho-social problems should be accompanied by a similar expansion of education and prevention programmes that reach remote areas and villages. Most programmes and services, particularly those run by non-governmental organisations, are found in cities and towns.

Fourth, there is a need to think about whether it is important for undergraduates in various institutions of higher learning to do human subjects research. Do they have adequate training and resources such as the time, knowledge, skills and funds? Our argument is that most do not have adequate resources and as such they end up doing quick research with human subjects. Quick research can harm respondents irrespective of whether they are children or adults. The situation can be more pronounced if respondents are children. The long period that elapses before a researcher is granted permission to do the research also contributes to some researchers conducting 'quick research'.

Lastly, it is important that programmes that focus on children's rights are expanded. As mentioned elsewhere in this paper, the current situation whereby most children are not aware of their rights can result in abuse.

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