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PERCEPTIONS OF PARTICIPANTS AND COMMUNITY MEMBERS ABOUT RESEARCH ON GENDER-BASED VIOLENCE

YANDISA MSIMELELO SIKWEYIYA

(Student No: 501569)

Supervisor:

Professor Rachel K. Jewkes

Academic thesis completed by published work for the degree of Doctor of Philosophy in the Department of Public Health, Faculty of Health Sciences at the University of the Witwatersrand

March 2013

Declaration

Unless stated to the contrary in the text, this dissertation is the original work of the undersigned.

_____ _____

Yandisa Msimelelo Sikweyiya **Date**

I hereby declare that this dissertation has been submitted with my approval.

_____ _____

Professor Rachel Jewkes **Date**

DEDICATION

This work is dedicated to my late brother Apelele Sipetho Sikweyiya and friends Mthokozisi Madiya, Mvuyo Mayisela, Zola Mkhondweni, Sanele Mdlungu, Malibongwe Mbewu and Ntsikelelo Lungisa. Thank you all for your love.

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ABSTRACT

TITLE: Perceptions of participants and community members about research on gender-based violence

The goal of this thesis was to explore ethical issues in conducting gender-based violence (GBV) research with human participants in South Africa. We study this question from the perspectives of both the researchers and the research participants. This thesis has two specific aims. First, to critically review the applicability and usefulness of the WHO 2001 guidelines in regulating community based research from the perspective of the researchers who do GBV work globally. Second, to explore peoples' motivations for research participation, their perceptions of risks and benefits in participating in studies, the perceived psychological impact of answering sensitive questions, and adverse experiences of research participation.

Three studies were conducted to meet the study aims, and were carried out using the combination of qualitative and quantitative methods and techniques. In the first study, 12 in-depth Interviews were conducted with GBV researchers from various countries and a desk review was also conducted. Study two had two components. First, 26 in-depth interviews (adult 19 women and 07 men) were conducted, and data were also collected using participant observation over a period spanning three months. Additionally, a real life incident was analysed as a case study of ethical dilemmas faced by researchers when unsolicitated incriminating disclosures by participants occur during the course of data collection. Thereafter, 22 in-depth interviews were conducted with men and women (over 18) who had recently participated in a survey on gender-based violence. In study 3, data were collected from 1085 women and 985 men (between ages 15-26) using a structured questionnaire.

The results revealed no empirical evidence from published literature and from the accounts provided by **researchers** to support the view that GBV research is exceptionally risky when ethical guidelines are adhered to or that is has greater risks than other community based studies. From the perspective of the research **participants**, findings show that breach of confidentiality was viewed as a major concern in participating in studies. This was reported by both men and women, with, gender-differences. Women were more likely to fear violent reaction from their male partners for participating in the studies without man's approval, and some women were threatened by their partners, but this was not GBV specific. No man reported this fear or any adverse reaction by intimate partners or others. Men rather feared other negative ramifications like being shamed, stigmatized, humiliated, and embarrassed in the community if breach of confidentiality could occur.

Findings of this thesis reveal a complexity of people's reasons for participating in community based studies. Participants reported multiple and various, sometimes conflicting, reasons for participating in the studies. Most were motivated by self-interest to enroll while others reported reasons that were viewed as altruistic. For example, the chance to be tested for HIV, financial incentive for research participation (R20), hope for immediate financial assistance with municipal debts, assistance with their ill-health and intervention in abusive relationships, were some of the reasons given. Also, the desire to help advance knowledge,

to contribute to society, to provide information that would help others suffering from same illness or disease, or those in abusive relationships like them were also given as reasons by participants and in most cases, same individual participants gave reasons that overlapped or oscillated between altruistic and self-interest motives.

Emotional distress as a result of being asked questions about interpersonal violence histories and other traumatic experiences is viewed as major risk in GBV studies, and data from interviews with **researchers** in this thesis confirm this. Data from interviews with **participants** revealed that being asked in research interviews about such histories made the participants to feel sad and some reported that reflecting on these experiences was painful. Yet, none described the impact as harmful, rather most stated that such emotions occurred for a very limited time and that they did not need professional support to deal with the emotions. Many, including those who had emotional reaction to some research questions or had regretted participating in the research, also viewed the experience of participating in research as beneficial.

The findings in this thesis have implications for ethical and safety guidelines on GBV research and on future community based sensitive research in South Africa. Findings presented here provide support to the WHO 2001 guidelines that studies that are community based and researching sensitive issues with women, including partner violence, should keep secret the violence focus and other sensitive questions at community level, and such focus be divulged only to participating women. This thesis has shown that this recommendation may provide protection to a particularly vulnerable subgroup of women i.e. those in abusive or potentially abusive relationships from potential physical harm.

Keywords: gender-based violence, ethics, risks, research participation, South Africa

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CHAPTER ONE

INTRODUCTION

1.1 Overview

In many countries of the world, empirical research has been conducted to describe the magnitude, patterns and the various forms of violence against women (VAW) and its effect on victims (see Garcia-Moreno et al. 2005; Watts and Zimmerman 2002). Historically, most empirical work on VAW came from the Northern countries with less research published from the South. However, over the past two decades we have seen a proliferation of research reporting very high levels of VAW from all regions of the world (Garcia-Moreno et al. 2005).

The high prevalence of VAW is a major concern to policy makers, researchers and activists globally (Garcia-Moreno et al. 2005). This concern has led to renewed calls to prioritise the prevention and advocacy action and research to monitor VAW prevalence, with a view to reduce it (Garcia-Moreno et al. 2005; UN 1993).

The emergence of the VAW research has historically been accompanied by concerns about the ethics of the studies, in particular how they impact on people who volunteer as research participants (Ellsberg et al. 2001; Jewkes et al. 2000). VAW research has been recognised as particularly sensitive and risky (Lavery et al. 2007). Researchers have argued that VAW research has the potential to harm participants in a way that is different from other areas of community-based study and that for women participants, the process of being asked to share their victimisation experiences, which are mostly narrated with pain and sadness, may

have serious traumatic effects or psychologically distress them (Fontes 2004; Campbell 2002).

1.2 Historical context on the development of VAW ethical guidelines

As the research on VAW intensified and increased globally, researchers in the field, in particular those who were part of the International Research Network on Violence Against Women (IRNVAW), reflected on their work and shared their field experiences and challenges encountered in the field when conducting research with women in various settings. Their reports from the field led to a perception that GBV work is particularly sensitive and highlighted a number of important methodological and ethical challenges pertaining to the conduct of VAW research. Furthermore, this led to a view that this area of research needs special regulation in addition to the standard ethical codes and guidelines.

As a network of researchers from various countries of the world, IRNVAW held a number of meetings where issues including research findings and other challenges were shared and discussed, including methodological and ethical challenges. These experiences were discussed, and collated and used to inform the development of the ethical and methodological recommendations on conducting VAW research (Ellsberg and Heise 2005). The draft guidelines were then rigorously reviewed by various international bodies including the WHO Steering Committee for the Multi-Country Study on Women's Health and Domestic Violence Against Women (Garcia-Moreno et al. 2005), and also by key members of the Scientific and Ethical Review Group (SERG) of the Special Programme of Research, Development and Research Training in Human Reproduction (HRP), and were published by the World Health Organisation (see WHO 2001).

The VAW research guidelines were needed as the World Health Organisation was preparing to conduct a multi-country study to document the extent of violence against women and obtain reliable and comparative data from 10 countries around the globe (Garcia-Moreno et al. 2005). Furthermore, subsequent to the publishing of the WHO Guidelines (2001), other guidelines were developed for conducting research with specific populations in the field of violence against women. These include:

1. The WHO Ethical and Safety recommendations for Interviewing Trafficked Women (Zimmerman and Watts 2003); and
2. The WHO Ethical and Safety recommendations for research, documenting and monitoring sexual violence in emergencies (WHO 2007).

The core elements of the guidelines for research on domestic violence against women (WHO 2001) are presented in Box 1. This thesis will only focus on the WHO Guidelines (2001) as these are ones that are widely accepted and used as recommendations for conducting community based GBV research.

Box 1: Ethical and safety recommendations for research on domestic violence against women.

a. The safety of the respondents and the research team is paramount, and should guide all project decisions.
b. Prevalence studies need to be methodologically sound and to build upon current research experience about how to minimise the under-reporting of violence.
c. Protecting confidentiality is essential to ensure both women's safety and data quality.
d. All research team members should be carefully selected and receive specialised training and an on-going support.
e. The study design must include actions aimed at reducing any possible distress caused by the research.
f. Fieldworkers should be trained to refer women requesting assistance to available

local services and sources of support. Where few resources exist, it may be necessary for the study to create short-term support mechanisms.

g. Researchers and donors have an ethical obligation to help ensure that their findings are properly interpreted and used to advance policy and intervention development.

h. Violence questions should only be incorporated into surveys designed for other purposes when ethical and methodological requirements may be met.

These WHO Guidelines (2001), have been operationalised somewhat differently in varying contexts (Ellsberg and Heise 2005; Jewkes et al. 2000). As guidelines, they are not intended to be viewed as a prescription on how to conduct ethical research but a guide on good research practice. This distinction is important, as it is not known how often women participants or researchers may be at risk of some of the actions that these guidelines seek to protect them from, such as violent reprisals after being interviewed (Jewkes and Wagman 2007). It is now common practice in many parts of the world, for VAW researchers to follow the WHO Guidelines (2001) (Ellsberg and Heise 2005; Jewkes et al. 2006; Dunkle et al. 2004), but there has been little published empirical work investigating whether these guidelines offer the protection they should.

As there have been renewed calls for research and intervention work on VAW, equally important is the need to better understand the context in which such work is conducted, and the impact it has on the research participants from the perspective of the research participants (Fontes 2004). In particular, there is a need to better understand the risks, and their nature, and benefits perceived by research participants (women and men), including their experiences of participating in VAW research (Edwards et al. 2009). Empirically investigating the question whether asking women and men about their victimisation

(women and men) and perpetration (men) experiences is emotionally and or psychologically damaging is very important for understanding the ethics of VAW research and for the protection of research participants (Griffin et al. 2003; Johnson and Benight 2003).

Additionally, we need to gain an in-depth understanding of the usefulness and applicability of the WHO (2001) Guidelines in protecting research participants from various forms of potential harm (emotional and physical) in different settings, and whether there remain residual risks in undertaking VAW research when the guidelines are followed, which are greater than those pertaining to any other research work. Empirically answering these questions will provide data that may enable institutional review boards (IRBs) to make evidence-based decisions and to locate the facts about risk in VAW research and the level of safety needed by research respondents (Grady 2010; Devilly, Wright, and Varker 2009).

Most ethical guidelines and codes derive from moral philosophy. As such, the contribution of empirical ethics in the field of ethics has been questioned by rational or moral philosophers and scientist (Marsiglia 2008). Brock (2002 p, 653) argues that moral philosophers and normative theorists view empirical ethics as "irrelevant to establishing ethical and value judgements because they are normative not empirical claims and thus require normative argument for their support." However, other philosophers like Brand-Ballard (2009), highlight the importance of empirical ethics and the contribution this emerging area of ethics can make to our understanding of ethics. He argues that empirical ethics can provide facts and inform our assumptions and predictions about ethical issues and also allow scientists to empirically study the origins of our moral beliefs and viewpoints on what is ethically right or wrong. Marsiglia (2008) agrees that morality and ethics are derived from both subjective and intrinsic understanding of issues as well as empirical data.

This underscores the importance of subjecting to empirical testing the moral justifications and assumptions that underpinned the development of the existing research ethical guidelines in order to provide empirical foundation for these guidelines, and also to deepen our understanding on which aspects of the guidelines work or do not, and in which context or settings (Marsiglia 2008). In the area of gender-based violence research, not much empirical work has been done on the ethics of this work and this thesis-located within empirical ethics- aims to contribute to this body of knowledge.

1.3 Defining different forms of violence against women

There are various forms of violence against women (VAW), and terms used by authors to describe the phenomenon. Some of their definitions are briefly stated below. The United Nation's (UN 1993) Declaration on the Elimination of Violence against Women defines violence against women as:

> *"any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life." (UN 1993).*

The World Health Organisation in the report in 2002, define sexual violence as:

> *"Any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic, or otherwise direct against women's sexuality, using coercion (i.e. psychological intimidation, physical force or threats of harm), by a person, regardless of relationship to the victim, in any setting, including, but not limited to, home and work."(WHO 2002, 149).*

Intimate partner violence (IPV), a common form of GBV has been defined by some authors as:

> *Any range of sexually, psychologically, and physically coercive acts used against adult and adolescent women by current or former male intimate partners (Ellsberg and Heise 2005).*

Researchers have conceptualised gender based-violence (GBV) as an act of interpersonal violence involving both men and women, where women usually are the victims (Ellsberg and Heise 2005). The term gender is used to describe the social, cultural and economic attributes associated with being male or female (Baden, Hassim, and Meintjies 1999). This differs from sex because gender is socially and culturally constructed rather than biological (Baden, Hassim, and Meintjies 1999; Watts and Zimmerman 2002). Gender is mainly pronounced through specified roles that are expected to be played by either men or women in the society. For example, historically, in Black African communities, young women were expected to get married, bear children, stay at home and play a nurturing role to the children. This was not expected of men, who instead, were expected to work and provide for their families.

Depending on the setting to which the study is conducted, the terms: IPV, spousal abuse, domestic violence, wife battering, courtship violence are used interchangeably. The common element of these terms is that the violence is perpetrated by an intimate partner. However, their definitions may slightly differ from just IPV; for example, courtship violence is violence within intimate relationships, but one that occurs before marriage. Battering is often used to refer to a severe form of IPV e.g., repeated episodes of violence or violence that caused injuries to the victim.

The research areas that I will be discussing in this thesis will include that on rape and victimisation, sexual assault and child sexual abuse, physical and emotional violence.

1.4 Global prevalence estimates of gender-based violence

Gender-based violence has been experienced by many women across the globe (Jordan, Campbell, and Follingstad 2010). A review of nearly 80 population-based studies (published between 1982-2004) coming from around 50 countries estimates that between 10% and 60% of women who have ever been married or partnered have been physically abused at least once by a current or former partner (Ellsberg and Heise 2005). Similar estimates were found in the WHO multi-country study. In this study, authors reported a range of lifetime prevalence of physical violence between 13% and 61% for ever partnered women (Garcia-Moreno et al. 2005). Another example illustrating the high prevalence of VAW was the national telephone survey conducted in the US, where authors reported that women as compared to men were "*22.5 times more likely to report that they had been raped, 2.9 times more likely to report being physically assaulted, and 8.2 times more likely to report being stalked by a current or former marital or opposite-sex cohabiting partner at some point in their lives*"(Tjaden and Thoennes 2000).

Globally, there is now recognition that GBV is a serious public health and societal problem. There is consensus in published literature that VAW is gender-based (Garcia-Moreno et al. 2005; Jewkes and Abrahams 2002a; Hirschowitz, Worku, and Orkin 2000). Yet, historically, there has been debate in the literature that women and men's use of violence against intimate partners are directly comparable (see Tjaden and Thoennes 2000). However, a more recent consensus, based on empirical research, is that more women than men report experiencing partner violence (Watts and Zimmerman 2002), and that the nature and causes of violence on men by women differs from that on women by men (Watts and Zimmerman 2002; Tjaden and Thoennes 2000). For example, Watts and Zimmerman (2002)

argue that violence against women is often rooted in sex inequality, but is also perpetrated to maintain the unequal power balance between men and women, whereas men are more likely to suffer violence emanating from street violence, gang fights, and in times of war and ethnic conflicts.

1.5 Prevalence of gender-based violence in South Africa

Recent South African studies have consistently reported high rates of perpetration of violence on women and children, and the South African Police Services (SAPS) crime reports (SAPS 2010/2011) show the same. A clinic-based study with pregnant women (1, 395) in Soweto reported 55.0% prevalence of physical/sexual partner violence against women (Dunkle et al. 2004). In a population-based survey conducted in the Gauteng province '51.3% of women reported that they had experienced some form of GBV in their life time, while 75.5% of men said they had perpetrated some form of violence on women (Machisa et al. 2011). Furthermore, a total of 18.13% of women reported experiencing and 29.0% of men reported perpetrating GBV in the past 12 months (Machisa et al. 2011).

The rape of women, another form of GBV, is commonly reported in South African studies as well to the police. In the period 2010-2011, 56 272 rape cases were reported to the South African Police Services (SAPS 2010/2011), recording an increase of more than 2.0% when compared with the previous two financial years (SAPS 2010/2011).

Similarly, recent population based studies in South Africa have reported particularly high rates of rape by men and the victimisation of women. In a study in the Eastern Cape Province, 21.3% of men (ages between 15-26 years old) said they had raped a female partner (8.6%) or non-partner (16.2%). Furthermore, 13.9% of men reported that they had

gang-raped a woman who was not a partner. Additionally, 7.6% of men said they had attempted to rape someone and were not successful for different reasons (Jewkes et al. 2006). In a population-based survey in two South African provinces, 27.6% (466/1686) of adult men reported that they had forced a woman to engage in sexual intercourse against her will, and the victims were either women they were in an intimate relationship with, strangers or women they knew. At least 4.6% of men said they had committed a rape in the last year, 46.3% reported that they had raped more than one woman; some 2.9% of men reported that they had raped another man or boy (Jewkes et al. 2010, 2009). Full findings of this survey are presented in Jewkes et al's report (2009). In a similar survey in Gauteng, 25.3% of women said they had been raped by a man, and the perpetrator was either a husband, boyfriend, family relative, stranger, or someone they knew (Machisa et al. 2011). In this survey, 37.4% of men said they had ever raped a woman, with 31.0% of them saying they had ever raped a woman they were not intimately involved with (Machisa et al. 2011).

The statistics presented above describe a concerning and shocking picture about the state of interpersonal violence in South Africa. As such, post-apartheid, relevant government departments have called for more research and the development of evidence-based response strategies to monitor and curb GBV (Machisa et al. 2011).

In response to this need, some researchers in South Africa have increasingly been conducting research and intervention work to reduce the levels of GBV and other forms of interpersonal violence using community-based research designs (Jewkes et al. 2006; Wood and Jewkes 2001; Dunkle et al. 2004; Abrahams et al. 2006; Redpath et al. 2008; Vetten et al. 2008). Yet, while such research is urgently needed to inform the development of interventions to curb the perpetration of GBV in South Africa, the regulation of such

research through a rigorous review of research protocols by institutional review boards is equally important to make certain that such studies are done in an ethical and correct manner.

1.6 Patterns and effects of GBV on victims

GBV mostly arises from the unequal power relationships between men and women (Watts and Zimmerman 2002). It encompasses a number of violent and abusive acts that are often directed at women by men because they are women (Watts and Zimmerman 2002; Garcia-Moreno et al. 2005). GBV includes sexual, physical and psychological abuse and these three forms of abuse are often linked together (Jewkes and Abrahams 2002b; Garcia-Moreno et al. 2005; Watts and Zimmerman 2002). While an act of GBV may occur as an isolated one, it has been reported to also occur as a pattern of assaultive or coercive behaviours that may include inflicted physical injury, psychological abuse, sexual assault, progressive social isolation, stalking, deprivation, intimidation and threats to the victim (Kramer, Lorenzon, and Mueller 2004; Tjaden and Thoennes 1998).

GBV is known to have harmful effects on the physical, mental or sexual health of the victims and sometimes on all these aspects of the victim's life (Tjaden and Thoennes 2000; Jordan, Campbell, and Follingstad 2010; Garcia-Moreno et al. 2005). The degree of harm to the victim may range from mild to severe (Watts and Zimmerman 2002) and intimate femicide is increasingly being investigated and recognised (Mathews et al. 2009; Campbell et al. 2003). The adverse health effects to the victims, mostly women, described in the literature include physical injuries, gynaecological disorders, negative pregnancy outcome, sexually transmitted infections (Ellsberg and Heise 2005) and mental health problems like post-

traumatic stress disorder, severe emotional distress and being suicidal. All these have been reported in studies (Garcia-Moreno et al. 2005; Machisa et al. 2011; Jordan, Campbell, and Follingstad 2010).

1.7 Institutional Review Boards and research

Historically, research abuse in scientific research involving human participants is known to have happened in studies both in the Northern and Southern countries (CIOMS 2002; Macklin 2004). There are a number of prominent cases of research abuse and unethical practices published in literature. For example, about 65 years ago, following the Second World War, German, Nazi doctors were charged and appeared before the International Military Tribunal at Nuremberg, a case now famously known as the Nuremberg Trial of 1947. Between 1939 and 1945, the Nazi doctors had subjected people to a variety of deleterious experiments under very forceful conditions and thus without their consent. Several experiments were conducted on people including physiological experiments where doctors wanted to investigate the effects of extreme cold conditions, or the impact of abnormal diet, experimental use of X-ray sterilisation, without the informed consent of those who were coerced to be subjects in these experiments, and held in camps (Weindling 2008).

Another prominent case of medical research abuse is the Tuskegee study of untreated syphilis of 1932. The study which was conducted by the US Public Health Service enrolled 400 men who had syphilis and 200 others without the disease (as controls) and studied the natural progression of syphilis. However, when penicillin was widely available in early 1950 as a preferred and highly effective treatment of syphilis (Angell 1997), the doctors in the study did not offer the drug to men who had the disease in the study, rather it is purported

that they prevented them from accessing the drug, and many of the men died as a result of this (Brandt 1978).

In the aftermath of the Nuremberg trials, the Nuremberg code was developed to regulate any form of research with human subjects (Weindling 2008). While several recommendations for conducting medical research with human subjects are reflected in the Nuremberg code, arguably, the central one is that people should never again be subjected to medical experiments without their informed and voluntary consent (Weindling 2008; Elnimeiri 2008).

In settings where these research abuses received much media and political attention. There was a public outcry against such unethical practices. This left a problematic legacy for medical research (Weindling 2008; Thieren and Mauron 2007) as people developed a fear and distrust of participating in medical research (Brandt 1978). For example, even though most of these unethical studies including the Tuskegee study happened many decades ago, a recent study in the US showed that older people expressed a reluctance to participate in medical research because they still recalled the damaging effects of these atrocious studies, and thus fear that something similar might happen to them (Hamilton et al. 2006)(see also Zammar et al. 2010).

The emergence of the HIV in more than three decades ago, and its widespread in the developing world has led to a proliferation of trials investigating HIV vaccines and microbicides. Often these trials are conducted in developing countries and mainly led by scientists from the Northern Countries (Macklin 2004; Strode, Slack and Mushariwa 2005; Moodley 2007). Ethical concerns have increasingly been raised about the design of these studies (Varmus and Satcher 1997; Moodley 2007), and unethical practices have been

reported emanating from some of these studies. Available research has highlighted a number of ethical issues that need careful consideration in HIV research (Mamotte, Wassenaar, Koen and Essack 2010). For example, the use of placebo in trials conducted in poorly-resourced countries with no standard of care, informed consent and exploitation of research participants, confidentiality and privacy issues in research, stigmatization and discrimination and compensation of research participants (Varmas and Satcher 1997; Faden and Kass 1998; Strode, Slack, Mushariwa 2005). However, most of these issues are not be unique to HIV research, and may cut across many other areas of research including the field of VAW.

Providing a historical context on research abuse allows for a deeper understanding of where the concerns about the protection of research participants (Widom and Czaja 2005) originate from and the issues that informed the need to regulate research with human subjects (Edgar and Rothman 1995). Additional to this, authors have argued that research abuses have, and still occur because of the weak research regulations and numerous context specific factors that render people vulnerable to harm (Macklin 2004). Thus, research ethics codes and guidelines were viewed as a vital ethical framework for research regulation with a particular aim to maximise the safety and protection of research participants (Angell 1997).

The need for regulation was brought to the fore by the increasing recognition that research participation carries risks, and adverse consequences for research participants have been reported in studies, and that its regulation may, therefore, mitigate the excess risk (Widom and Czaja 2005). Among others, one organ that has been charged with the task of regulating research is the Institutional Review Board (IRB). As Edgar and Rothman (1995) posit, the key

responsibility of the IRB is to 'review whether the benefit of the proposed research outweigh the risks', and make a determination whether the proposed research is ethical or not.

While IRBs are often mandated by the laws of respective countries to perform the task of regulating research, at a practical level, to function, IRBs draw from codes and guidelines that have been developed by various internationals bodies. Such codes and guidelines are internationally accepted and used, although countries and institutions have also interpreted these for their contexts (see SAMRC 2001). Key international codes and guidelines include the Nuremberg code (1947), Declaration of Helsinki (WMA 2000), the Belmont Report (Department of Health 1979) and the Council for International Organisations of Medical Sciences (CIOMS 2002). These codes and guidelines are mainly grounded on four basic ethical principles that govern the conduct of all research with human participants (Elnimeiri 2008): The four principles are:

- Respect for persons' autonomy
- Beneficence
- Non-maleficence (do no harm)
- Justice

In providing a brief explanation of the four basic ethical principles above, I borrow from the interpretation by the US National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research' s Belmont Report (1979).

> **Respect for persons:** *incorporates at least two ethical convictions: First, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.*
>
> **Beneficence:** *Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being*

> **Non-maleficence:** *is a principle that says in our interaction with research participants, we should endeavour to do no harm to participants irrespective of the possible gains for others*
>
> **Justice:** *that there should be an equal balance and fairness in the distribution of burdens and benefits to those partaking in research*

These principles are viewed as carrying the same weight in terms of their importance when calculating risk-benefit ratios of research protocols, yet, in some instances; they may conflict when interpreted for certain types of research. Thus, the responsibility falls on the desk of the IRBs to rigorously and objectively review research protocols to ensure a favourable risk-benefit ratio for research participants (Edgar and Rothman 1995).

With the increase of studies on GBV, IRBs have raised ethical concerns globally. The common viewpoint IRBs have is that asking people in a research context, in particular women, about trauma histories and their interpersonal violence histories is inherently harmful (DePrince and Freyd 2004).

IRBs have the legal task and responsibility to protect human research participants (Jorm, Kelly, and Morgan 2007). In South Africa, this responsibility to IRBs is provided through the National Health Act, 2003 (Act No. 61 of 2003). However, the effectiveness of IRBs in carrying out this task has been called into question (Grady 2010). One issue that has been identified as weakening their effectiveness is the lack of empirical evidence on which IRBs may base their reasoning and decisions about the risk-benefit ratios of studies (Kuyper et al. 2012). IRBs have been criticised for relying on assumptions and subjective values, and political, cultural, religious or emotional grounds, rather that empirical evidence on the risk-benefit ratios of study protocols (Grady 2010; DePrince and Freyd 2004; Kuyper et al. 2012). Furthermore, IRBs and research have been criticised for overlooking the asking of actual and

potential participants about what is sensitive and distressing to talk about in a research context (Kuyper et al. 2012).

The fact that there is limited empirical research focusing on people's perceptions and experiences of research participation leaves a huge gap and challenge for IRBs in terms of understanding the risk-benefit ratios of studies (Savell, Kinder, and Young 2006). Consequently, in some occasions, researchers have complained that the risks involved in their study protocols are much lesser than commonly assumed to be by IRBs (Jorm, Kelly, and Morgan 2007).

1.8 Organisation of the thesis

This thesis focuses on community members, and actual research participants' perceptions on and experiences of participating in community based research on gender-based violence. It aims to contribute empirically to our understanding of how community members in general and actual research participants perceive risk in partaking in sensitive research and on the nature of actual problems encountered after research participation. Furthermore, it explores the participants' perceptions of the utility of ethical safeguards provided by researchers.

Chapter 2 presents a review of literature on ethics of doing research with human participants. The review focuses on various ethics issues and concerns that are related to conducting gender-based violence research with human participants. Firstly, a presentation of literature theorising gender and how it intersects with research ethics is given. Thereafter, literature that explores people's reasons and motivations for research participation is discussed. This is followed by a presentation of literature that attempts to

conceptualise, describe and define sensitive research topics. Furthermore, literature that highlights evidence on emotional impact of GBV research on participants is presented, followed by a literature discussing causes and effects of vicarious trauma on researchers who conduct research on sensitive topics. At the end of the chapter, gaps that have been noted in literature are highlighted, and aims and objectives of this thesis are presented.

Chapter 3 describes methods that have been employed to conduct this research. Three empirical studies have been conducted to meet the aims and objectives of this research. Two studies were qualitative and one was quantitative. ***Study 1***: Was a qualitative research based on in-depth interviews conducted with researchers who have conducted gender-based violence research in various regions and countries of the world. ***Study 2***: Was an ethnographic research that was conducted in Soshanguve Township, north of Pretoria. This study spanned a period of six months and had three components to it. **Study 3:** was quantitative. Data was collected from a cluster randomised controlled trial that was conducted in the rural Eastern Cape between the years 2002 and 2006. For each study, a detailed description of the methods and techniques used to collect the data and ethical considerations is presented.

Chapters 4, 5, 6, 7 and 8 present the five papers that were written from the three studies above. As a collective these papers contribute and advance our understanding of the ethics of involving human participants in social and health research. They specifically add to our knowledge on how adults from the community, including women and men who have participated in a GBV survey, perceive discussing violence in a research context, their perceptions on risks and concerns related to this.

Chapter 4: (Paper 1) contributes to the debates on safety and risks in GBV research by presenting a discussion on the meanings of safety, the basis of concerns and the nature and scope of empirical evidence on the presence of risks unique to GBV research from publications and GBV researchers.

Chapter 5: (**Paper 2)** contributes to the understanding of how people living in an urban South African township perceive discussing their experiences in particular sensitive issues, if any, including GBV in a research context. The paper explores people's perceptions of community based research including GBV research, on risks and benefits of research participation. It further explores their motivations to participate in research.

Chapter 6: (**Paper 3)** explores how actual research participants perceived their experiences with a community-based survey of men and women (over 18 years) on the prevalence of gender-based violence victimisation and perpetration in the Gauteng province of South Africa. The paper explores participants' perception on how the survey impacted them, how answering the survey questions had made them feel - whether they perceived the survey as distressing or helpful. Lastly, it explores whether participants experienced any adverse consequences resulting from their participation in the survey.

Chapter 7: (**Paper 4)** is a (co-authored) quantitative paper. This paper is significant and relevant for my doctoral research as it presents young people's reflections about and experiences of participating in a longitudinal HIV and behaviour change intervention evaluation.

Chapter 8: (Paper 5) is an ethics case study which debates the complexities and nuances around the principle of confidentiality in GBV research, highlighting its limitation through

providing a real life example where confidentiality was breached in research as informed by the ethical standards and the South African laws, including the Constitution of the Republic of South Africa of 1996, the Children's Amendment Act of 2007, and the Children's Act of 2005.

Chapter 9 discusses the findings of this thesis. The discussion highlights the contribution this doctoral research has made in advancing the understanding of ethics of GBV research with human participants in South Africa. Furthermore, in this chapter, implications of the findings for existing research ethics guidelines are discussed. Lastly directions for future ethics work on community based sensitive research are proposed.

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview of literature on the impact of research on participants

This Chapter discusses published papers that broadly focus on the ethics of GBV (human subjects) research. It particularly explores the focal point (content and issues) of these papers, the methodology or design that is often used in the studies and the limitation of the studies. Additionally, a discussion of the empirical evidence reported in these papers is presented and gaps in knowledge are identified and highlighted. I then show and discuss how the thesis may contribute in addressing the gaps identified.

A review of published literature yields articles mainly coming from the USA and Europe, and very little from Africa. Most papers are published from studies that had employed quantitative data collection methods e.g. whether computer administered or paper and pen surveys (see Kuyper et al. 2012; Johnson and Benight 2003; Kassam-Adams and Newman 2002; DePrince and Freyd 2004; Griffin et al. 2003), to examine participants' perceived risks, benefits, distress, regrets of participating in research (Johnson and Benight 2003; Kassam-Adams and Newman 2002), and their ability to provide informed consent (Taiwo and Kass 2009).

A popular design of these studies is an assessment immediately after the survey, examining the impact of answering the survey questions (Jorm, Kelly, and Morgan 2007). Not many qualitative studies have been published exploring these issues in depth (Hutchinson, Wilson, and Wilson 1994; Reynolds and Nelson 2007).

Published studies have mostly been conducted with adults from community samples, with very few studies done with children or adolescents (Jorm, Kelly, and Morgan 2007; Kuyper et al. 2012), and college women (Edwards et al. 2009).

Areas of concern that have been highlighted in the literature associated with participating in sensitive research, include research participants having strong emotional (e.g. distress and sadness) responses to sensitive questions (Johnson and Benight 2003), breach of confidentiality and the resultant adverse consequences (Fontes 2004). For example, authors have suggested that women may be physically beaten as punishment by their male partners for engaging in research without the men's approval (Ellsberg et al. 2001; Jewkes et al. 2000; Jewkes and Wagman 2007). Participants may be stigmatised and labelled for participating in studies that investigate HIV, mental health issues, VAW, sexuality and other sensitive topics, and this could lead to shame and embarrassment and being ridiculed by others in the community (Dickson-Swift, James, and Liamputtong 2008; CIOMS 2002, Guideline 21).

2.2 Gender-based violence research and ethics concerns

Internationally, there is an increased interest in epidemiological research focused on gender-based violence, and South Africa has been a setting for a great deal of research. Generally, GBV research has been viewed as unusually sensitive and also recognised to have at least the potential to be harmful to human participants in ways which differ from many other forms of research (Jewkes and Wagman 2007). The confidentiality of the information provided by participants and reporting data anonymously; minimising the potential for emotional distress, and providing emotional first aid and professional support to participants who demonstrate distress because of questions asked in the research, are

considered critically important for maximising the safety and protection of research participants, and are emphasised in the WHO Guidelines (2001) (See Box 1).

Studies on interpersonal violence and trauma often ask participants to recall and talk about their adverse experiences (Garcia-Moreno et al. 2005; Ellsberg et al. 2000; Ellsberg and Heise 2002; Wood and Jewkes 2001; Machisa et al. 2011; Jewkes et al. 2006; Dunkle et al. 2004). Authors have, however, argued that during the process of recalling painful and traumatic experiences, participants may relive these experiences leading to strong emotional responses (Fontes 2004). Other authors have also argued that research on GBV may raise distressing issues for the first time and generate a need for emotional and other support for research participants (Jewkes and Wagman 2007; Ellsberg and Heise 2002; Ellsberg et al. 2001; Jewkes et al. 2000). Furthermore, there exists a view that, for women participants, there may be other social and political risks in participating in research (Fontes 2004).

While there has been little research done on the ethics of asking research participants about sensitive issues, some researchers have begun to empirically address this question (DePrince and Freyd 2004). Such studies, however, have mainly come from disciplines such as psychology and psychiatry focusing on studying emotional and psychological impact of research on participants (Jorm, Kelly, and Morgan 2007), paying little or no attention to the risks of physical harm to particularly women research participants.

Although based on anecdotal evidence, researchers in the GBV field have often mentioned that research on GBV has a potential to aggravate an already violent situation in their relationships or homes, and expose participants, women in particular, to further physical violence from partners (Jewkes et al. 2000; Jewkes and Wagman 2007; Ellsberg et al. 2001;

Ellsberg and Heise 2002, 2005). However, it is important to note is that there are a few published studies that have empirically studied and described the magnitude of and nature of risks inherent in GBV studies. There is a need for more research which investigates the impact of and the nature of risks in GBV research on participants.

2.3 Gender and research ethics

To date, not many studies have explored the reasons why men and women enrol in research and their experiences of participating in research that ask about their experiences of perpetrating and being victims of gender-based violence (Edwards et al. 2009). This lack of focus on GBV research ethics, as Fontes states, is worrisome considering the amount of research that has been conducted in the area of GBV over the years (Fontes 2004). Understanding what motivates women and men to participate in GBV research, the barriers to participation and how they experience such research is considered important in understanding the ethics of GBV research (Sharp et al. 2006).

There have been concerns that women and men experience research participation in GBV studies differently (Fontes 2004), and the risks they take through participating in studies differ markedly. Authors are of the opinion that the risks associated with participating in GBV research could be particularly high (Lavery et al. 2007), and that women who are in abusive relationships may be at an increased risk of suffering violent reprisal from male partners for participating in GBV studies without the man's approval (Ellsberg et al. 2001). Jewkes and Wagman (2007), for example, argued that GBV research possesses the potential to make worse an already violent situation. A violent man may be offended when he recognises that his partner is discussing him and his violent behaviour in the research and thus react violently to the woman as punishment (Jewkes and Wagman 2007). All these

papers cited above are based on researchers' reflections and experiences on conducting GBV studies with women in various settings of the world. While these papers have been very useful as reference for researchers who plan to conduct GBV research with women, empirical studies to estimate the magnitude and nature of potential physical risk are lacking and are required by GBV researchers and IRBs (Jewkes and Wagman 2007).

A review of literature uncovered one published empirical study, focusing on the perceptions of risk by women and girls as participants in GBV research coming from Africa. The paper published by Ajuwon and Adegbite presented findings showing that women and adolescent girls in Nigeria perceived increased risk in participating in GBV research (Ajuwon and Adegbite 2008). In this study, women and adolescent girls reported fearing retaliatory violence from their husbands or boyfriends as a punishment for participating in research without the partner's approval (Ajuwon and Adegbite 2008). Similarly, literature review yielded no published work focusing on men's perceptions of risks in participating in research where they are asked about their experiences of perpetrating or being victims of GBV. In South Africa, the only exception known is a small qualitative study conducted by Sikweyiya, Jewkes and Morrell (2007). In this study, 20 men from a rural South African province were asked to comment on questions about attitudes towards and practices of non-consensual sex with women. Authors reported that while men demonstrated willingness to participate in studies which ask them about sexual violence perpetration and thought positively about the research, some men reported that the questions on perpetration practices had caused discomfort for them as they felt bad on reflecting on some issues. Additionally, men reported that they realised that if they answered affirmatively to questions on non-

consensual sex with women, they would be admitting to have raped, which they find disturbing and potentially stigmatising (Sikweyiya, Jewkes, and Morrell 2007).

As researchers increasingly study gender-based violence (GBV) using community-based designs (Abrahams et al. 2006; Dunkle et al. 2004; Jewkes et al. 2006; Jewkes et al. 2010), there is need for an in-depth understanding of how women and men as participants perceive discussing experiences of victimisation and perpetration of GBV and what implications of participating in such research has for them and their community. This is particularly imperative for understanding the ethics of GBV research and how researchers and IRBs may appropriately protect women and men as research participants in such studies.

2.4 People's reasons and motivations for research participation

Few published studies from non-Western countries have reported that some women (Ajuwon and Adegbite 2008) and men (Sikweyiya, Jewkes, and Morrell 2007) report having fears after participating in studies on GBV. Thus, a great deal of research is needed to find out why people still agree to participate (Osamor and Kass 2012) in GBV studies while having fears about participation.

Empirical data from published studies show that there is an array and complexity of factors that influence people to enrol in research (Hallowell et al. 2010). As such, varying reasons have been given by people as their motives for research participation (Braunack-Mayer 2002).

For example, in a study by Jefferson et al. (2011) 235 people, who were part of the Boston University Alzheimer Disease Centre (BU ADC) registry, were asked for their

reasons for participating or not in other BU ADC approved studies. Authors report that participants mainly endorsed three reasons for registry participation: 56% said they wanted to contribute to the advancement of knowledge about Alzheimer disease, which highlights they were considering the benefits to the society; 21% felt their participation might be of benefit to their family, friends and future generations; and 13% were motivated by a personal concern for memory. The two latter reasons highlight a motive to benefit personally from research participation (Jefferson et al. 2011). Several authors have presented similar findings showing that participants often are motivated to partake in studies by: a strong desire and willingness to help other people who have or may have the same health condition they have in future, to contribute towards furthering medical knowledge or research, to benefit family, friends or future generations, to obtain personal information or increased understanding about the result of a research experiment, condition or drug, and to do something worthwhile for interventions happening or aiding in curbing diseases prevalent in their communities (McCann, Campbell, and Entwistle 2010; Sharp et al. 2006; Funch and Marshall 1981; Ellis et al. 2001; Jefferson et al. 2011; Kneipp, Lutz, and Means 2009; Hallowell et al. 2010; Hamilton et al. 2006).

Some authors have presented findings showing that a small proportion of people report being motivated by only an altruistic reason (Viens 2001). For example, in a study by Rosenbaum and associates (Rosenbaum et al. 2005) 20.6% of their sample (475) gave an altruistic reason as their only motivation for trial participation. Additionally, a qualitative study in the US reported that some participants stated that they would participate in

research unconditionally or without direct material or monetary expectation (Hamilton et al. 2006).

Pure altruism as a motive for research participation is not commonly reported in studies, rather there is evidence from a number of studies suggesting that there is often an overlap between altruistic and individual benefit motives reported by participants. Qualitative findings of a study in the US showed that the participants who agreed to be randomised into the Reflux trial, and had expressed that their motive to participate was because of an inclination to help others or to contribute to a good cause, yet the considerations on how the trial would be of benefit to them as individuals were also stated in their accounts (McCann, Campbell, and Entwistle 2010). Authors in this study thus concluded that it seemed trial participation was something of a win-win situation where participants felt the need to help others while they also hoped to benefit personally (McCann, Campbell, and Entwistle 2010).

These findings are supported by those of several other studies where a large number of participants had reported an altruistic reason as a motive for partaking in studies, but also reporting having an expectation to get clinical treatment or drugs for an illness (e.g. cancer or HIV) they have, to obtain a higher standard of care than the one locally available, to have their views or opinions on a particular matter heard, amongst other reasons (see Kneipp, Lutz, and Means 2009; Paradis, Phelan, and Brinich 2010; Viens 2001; Hallowell et al. 2010; Slack et al. 2004).

The limitation of many of these studies is that the overlap between self-interest and altruistic motives for research participation is often not unpacked and discussed in order to gain a better understanding of people's reasons for research participation and the

implication of this for research involving human subjects (McCann, Campbell, and Entwistle 2010). As such, not exploring in-depth the complexity around people's reasons for research participation has led to a limited understanding of this issue (McCann, Campbell, and Entwistle 2010; Sharp et al. 2006) and this points to the need for more targeted research to explore these issues further.

Almost all of the studies cited above were done from a clinical trials perspective; as such we know less about motivations for participation in observational epidemiology. Some authors have specifically emphasised the significance of investigating the motivations and barriers of women to participate in gender-focused studies (Sharp et al. 2006; Edwards et al. 2009). Yet, to date, there is still little scholarly focus on women's motivations for participating in VAW studies and what their experiences of this are (Fontes 2004; Edwards et al. 2009).

More targeted work is therefore needed to unpack these factors in order to get an in-depth and clear understanding of the people's reasons for partaking in research studies (Kneipp, Lutz, and Means 2009). This may help in enhancing the recruitment and retainment of participants in studies (Braunack-Mayer 2002; Rosenbaum et al. 2005; McCann, Campbell, and Entwistle 2010). Additionally, such data may enhance our understanding of the attitudes people have of research, generally, and their expectations in research participation. Furthermore, this may inform researchers on how to respond to the challenges presented by these factors (Jefferson et al. 2011).

Additionally, more research from the social science and epidemiological research perspective on GBV may enable researchers to develop evidence-based strategies to improve the recruitment and retention of participants in and their protection in GBV

studies, and also broadens our knowledge and understanding of ethics of involving women and men in GBV research (Fontes 2004).

2.5 What are sensitive research topics?

There is no consensus on what is meant by sensitive research (Dickson-Swift, James, and Liamputtong 2008). This has resulted in over reliance on researchers and IRBs defining certain research topics as sensitive without getting the perspectives of the research participants themselves.

The South African Medical Research Council (SAMRC 2001) Ethics Book 1 provides examples of categories of sensitive research information such as

> *"sexual attitudes, preferences or practices; use of addictive substances; illegal conduct; information that could damage an individual's financial standing, employability, or reputation; medical record information that could lead to stigmatisation or discrimination; any information about an individual's psychological well-being or mental health".*

In their article, Rosenbaum and Langhinrichsen-Rohling (2006) provide a list of topics that may be perceived as sensitive in research by research participants. These include IPV, child abuse, sexual abuse, suicidal behaviour, substance use and other forms of sexual behaviour. These authors argue that such topics might be viewed as sensitive in a research context because "*simply recalling such experiences and talking about them might be upsetting*"(Rosenbaum and Langhinrichsen-Rohling 2006). Furthermore, they argue that disclosing "*such information is potentially damaging, embarrassing, stigmatising or incriminating to the participants should it become public knowledge*"(Rosenbaum and Langhinrichsen-Rohling 2006). Consistent with this view, the SAMRC advises that

researchers need to ensure anonymity when studying such topics in order to protect the participants (SAMRC 2001).

While there is certainly no consensus on which topics are sensitive and how IRBs and researchers decide on which topics are sensitive, decisions about categorising research in particular GBV studies, as sensitive research is very common in IRBs' sittings.

Some authors suggest that more research is needed to explore whether topics that are non-violence related like food and income would be considered distressing and sensitive by participants (DePrince and Freyd 2004). For example, in South African black communities, although based on anecdotal evidence, cultural practices like traditional male circumcision, *ukuthwalwa* (wife abduction) and *lobola* practices (dowry), and others issues like undisclosed paternity, sexuality are some of the topics that are known to be perceived as private and thus sensitive to be discussed with outsiders including researchers . Some of these practices have, however, been shown empirically to have negative health consequences for people in particular women and children (Nduna and Jewkes 2012), as such authors have argued that it is important that social scientists conduct research on these issues in order to understand these and be able to develop evidence-based responses for these social problems (Dickson-Swift, James, and Liamputtong 2008).

Empirical research conducted with actual or potential research participants may help shed some light on how social scientists may engage with people on these issues while limiting the potential of people findings discussing these as distressing, invasive and sensitive in a research context (Dickson-Swift, James, and Liamputtong 2008).

2.6 Evidence of emotional impact of GBV research on participants

Concerns have been raised about the potential emotional harm of research on study participants who are asked questions about their experiences of GBV and other traumas (Black et al. 2006). The distress of participants because of partaking in studies on topics like sexuality and GBV remains a concern for IRBs and researchers alike (Savell, Kinder, and Young 2006). As such, because they are perceived as sensitive, invasive and personal, IRBs often call for additional scrutiny on research protocols investigating such topics (Savell, Kinder, and Young 2006).

However, despite the dearth of scholarly work focusing on ethics of asking research participants about sensitive issues, some researchers have begun to address empirically the question of relative risk and benefit in research involving human participants, in particular in topics that are traditionally viewed as sensitive, intrusive and upsetting (DePrince and Freyd 2004).

Some authors have presented findings describing the impact on participants of answering questionnaires on sexuality and sexual gender-based violence. For example, Kuyper et al. (2012) in their study with 889 sexually experienced young people (aged 14-26 years) in the Netherlands, reported that one in four participants reported distress (for instance, feeling down or sad), yet, the majority of the participants expressed positive feelings as a result of participation in sexuality research. In another study conducted in Colorado, in the United States of America, with 55 women recruited from centres servicing abused women and those with substance abuse problems, 25% of the participants said they were more upset that anticipated, and 6% indicated they regretted participating in the study (Johnson and Benight 2003). Furthermore, Griffin and colleagues (2003) examined data drawn from two

large trauma assessments studies. The one study had enrolled 170 women female survivors of interpersonal violence, of which 108 of them were rape survivors, and the other had enrolled 260 women who had suffered specifically intimate partner violence. Authors reported that the majority of participants who had suffered acute assault viewed the research participation experience as largely interesting and not distressing, with only 5% of them reporting that they did not think they would be or definitely would not be willing to participate and or be assessed in that manner again (Griffin et al. 2003).

Similarly, in the Newman et al. (1999) study, while the questionnaire had particular sensitive items, only 10.5% of the survey participants (women) reported unexpected upset (choosing 4 or 5 on the questionnaire), and only 5% reported regret. Almost similar findings were reported by Walker and colleagues (1997), where women had answered a questionnaire with sensitive items, and only 13% reported that the experience was more upsetting that they had thought. However, when the same respondents were asked if they would still complete the survey if they knew what it involved, only 5% reported that they would refuse (Walker et al. 1997). Consistent with these findings, a systematic review conducted by Jorm and colleagues (2007) estimates that most studies that investigate the impact of participating in trauma-focused research report around 10% of participants who report some form of distress resulting from participation.

Authors have argued that the people who experience negative effects resulting from research participation, may experience the same when asked similar questions in their everyday lives, thus arguing that asking people about their interpersonal violence and trauma histories in research may not necessarily place participants in more than minimal risk for emotional harm (Jorm, Kelly, and Morgan 2007; Newman, Walker, and Gefland

1999), and that if distress occurs, it may quickly fade away (Kuyper et al. 2012; Jorm, Kelly, and Morgan 2007).

In keeping with these findings, some authors argue that empirical data from targeted studies may help inform IRB's and researchers about risk-benefit ratios of studies (Jorm, Kelly, and Morgan 2007), and help IRBs not to be overly "protective and sensitive towards research (Kuyper et al. 2012; Walker et al. 1997). Kuyper and associates further warn that an overly protective attitude has a potential of sending an inaccurate message that may lead to a misconception that young people are incompetent to join sex research (Kuyper et al. 2012)

The major criticism of published studies has been that they mainly focused on traumatic experiences which may be categorised as severe and enduring, omitting to look at other factors which may in themselves be distressing for participants (Kuyper et al. 2012). Additional to this, most published studies do not unpack the notion of emotional harm reported by participants in terms of its nature, severity and duration. As such, there is still no clarity on what we mean by emotional harm or distress when reported by participants in studies.

To expand this knowledge base, it is imperative to empirically study and gain an in-depth understanding of the range of topics, issues, and life experiences that are viewed as outright sensitive and invasive to be asked about by research participants. Currently, we have a limited understanding as to why certain issues may stir up strong emotional responses for people, and the characteristics of those who may feel this way. As such, we need to explore empirically the individual (sex of the participant, victimisation or perpetration history etcetera) and structural factors that may predispose people to experience talking about

certain life experiences as emotional harmful, if any. Alternatively, understanding why women who have victimisation experiences may perceive talking about such experiences in a research context as beneficial may provide important data for decision-making on risk-benefit ratios of GBV studies.

2.7 Vicarious traumatisation in research

Vicarious trauma, another dimension of researcher safety, has been frequently reported as occurring on clinicians, counsellors, and other mental health workers who work with patients with traumatic histories (Vrklevski and Franklin 2008; Way et al. 2004). In-depth and explicit reports about child abuse, sexual violence, violent crime, torture, intimate partner violence, rape and sodomy are painful, distressing and traumatic to listen to and may have negative effects on the mental health of the listener (Sexton 1999). Vicarious traumatisation is viewed as the negative impact on the psychological health of those who work with the primary victims of trauma (Vrklevski and Franklin 2008).

Several terms have been interchangeably used to depict the harmful psychological effects that result from working with clients or patients with traumatic experiences or histories (Way et al. 2004; Vrklevski and Franklin 2008; Sexton 1999). The terms include vicarious trauma, secondary traumatic stress, countertransference, compassionate fatigue and burn-out (Way et al. 2004; Vrklevski and Franklin 2008). How these psychological reactions are defined and how to differentiate them is discussed in detail by Sexton (1999). The importance in distinguishing them lies in the fact that while they may have more or less similar features, and therefore seem the same, their causes may differ and may also differ in how they manifest (Way et al. 2004; Vrklevski and Franklin 2008).

Psychology literature on vicarious traumatisation has described the debilitating effects it has on the clinicians (Way et al. 2004). Clinical symptoms of vicarious traumatisation include "*feelings of anger, anxiety, depression, sadness, exhaustion, difficulty concentrating and making decisions, headaches and body aches, insomnia, increase intake and dependency on drug and alcohol, social isolation, loss of home, cynism*"(Sexton 1999; Coles et al. 2010).

Recent literature on vicarious trauma in researchers who work with research participants that share traumatic experiences suggest that such engagement may have a somewhat similar effect to the one described in psychology literature as occurring in clinicians (Campbell 2002; Fontes 2004), with the effects and symptoms on researchers resembling those of the primary victim (Sexton 1999). However, this view is not based on empirical evidence, and Coles and associates thus argue that such an understanding should not always be extended to those who study sexual violence (Coles et al. forthcoming). This highlights a need for more research focusing on the lived experiences of the researchers who conduct work on sexual violence.

In this thesis, I will only focus on and briefly discuss vicarious traumatisation experienced by researchers conducting GBV research and highlight the importance of recognising the potential for vicarious trauma in researchers (Vrklevski and Franklin 2008; Fontes 2004; Ellsberg et al. 2001). Expanding Pearlman & Saakvitne's (1995) definition of vicarious trauma on clinicians, to include vicarious trauma as experienced by researchers, Coles and associates define vicarious trauma as "*the transformation of the researcher's inner experience as a result of empathetic and/or repeated engagement with sexual violence survivors and their trauma materials*"(Coles et al. 2010).

To date, not much empirical work has been conducted with GBV researchers themselves to gain their perspectives on and in particular their experiences of researching sexual violence with victims and perpetrators. Few exceptions include a study by Coles et al. (2010; Coles et al. forthcoming) who conducted an internet-based study in a form of a moderated discussion where GBV researchers shared their experiences of researching sexual violence with survivors and perpetrators. In this study, authors report that researchers discussed physical risks but mainly focused on emotional risk of working in this field, and described particularly strong emotional reactions including '*anger, guilt and shame, fear, crying, and feeling sad and depressed*' as resulting from engaging with traumatic material shared by research participants (see also Campbell 2002). Additionally, in this study, researchers described physical symptoms and their impact on their physical and psychological health which included "*feelings of tiredness, exhaustion, headaches, nocturia, pain, congestion, flu like symptoms, nausea and vomiting*" (Coles et al. forthcoming).

However, it should be noted that not all researchers who work with trauma survivors suffer vicarious traumatisation and this is moderated by a number of factors (Way et al. 2004). Such factors may include the researcher's age, sex, professional coping abilities, sexual victimisation experience and available professional and family support (Coles et al. 2010; Coles et al. forthcoming).

Often, IRBs and research ethics guidelines have been viewed as only being concerned with the protection and wellbeing of human research participants. This focus on research participants is believed, by those involved in research and its regulation, to have somewhat increased the safety and protection of research participants from research related harm. However, its selective nature has resulted in the neglect of the safety and protection of

researchers who conduct the research (Fontes 2004). It is only recent that this gap has been acknowledged, resulting in some authors emphasising the need to recognise the potential psychological harm for researchers conducting research with human participants on sensitive topics like rape, sexual violence and other forms of gender-based violence (Coles et al. 2010; Campbell 2002; Fontes 2004; Ellsberg et al. 2001). Notwithstanding, empirical research focusing on vicarious trauma on researchers, is still very minimal (Vrklevski and Franklin 2008; Sexton 1999), and more research is needed in order to develop adequate and effective strategies to protect the mental health of researchers (Coles and Mudaly 2010; Coles et al. 2010; Sexton 1999).

2.8 Gaps in literature on ethics on GBV research

In this section, a number of ethical issues that have been highlighted in literature as worrisome or vexing and thus important for consideration in this field of research have been discussed. While this review is not exhaustive, it has allowed for an exploration and identification of gaps in the literature that need to be addressed through an empirical inquiry (Fontes 2004).

While there have been published papers exploring and debating ethical issues that pertain to GBV research, this review has shown that there is a lack of empirical evidence to which such debates are based (Fontes 2004). The following six areas have been identified as gaps in the literature.

I. There is very little empirical evidence on how people perceive talking about their experiences of victimisation and perpetration of GBV in a research context.
II. There is scant empirically based knowledge on how women and men perceive risks and benefits of participating in GBV research; this is often speculated in literature.

III. There is dearth of published data on the emotional and psychological impact on participant when asked to talk about their victimisation (women and men) and perpetration (men) experiences.

IV. The risk of physical retaliatory harm to women research participants has been highlighted in literature as a major concern in GBV research. Yet, this review yielded no published papers presenting empirical evidence on this. Such evidence is needed so to enhance our understanding of the magnitude, form and nature of this risk.

V. No published studies were found to have conducted gender analysis when exploring the issues (perceived risks and benefits) and such an analysis is important for a deeper understanding of these issues.

VI. The requirement to have referral support system in research projects is emphasised by the WHO Guidelines (2001) and researchers in the field, yet, there is little empirical evidence supporting that it is needed and or found useful by people who participate in studies.

Not having these data limits our understanding of the ethics of GBV research. Additionally, very few published papers which present empirical data came from South Africa, although there has been much focus on GBV research in this setting (see Wood and Jewkes 2001; Jewkes and Abrahams 2002a; Dunkle et al. 2004; Abrahams et al. 2006; Mathews et al. 2008; Machisa et al. 2011). Learning empirically about these issues will aid us in understanding which safeguards and strategies are appropriate and may be effective in protecting research participants in this setting. The little understanding we have on these ethical issues results from the scarcity of published data in this area of research (Fontes 2004).

2.9 Aims

This thesis presents research on the ethical issues of human subjects' participation in research on GBV in South Africa. It studies these issues using both qualitative and

quantitative methods and techniques. Three studies which were qualitative and one that was quantitative have been conducted to meet the aims and objectives of this research. A case study which explored an ethical dilemma is also presented to illustrate the complexities of confidentiality and its limits in GBV research (Paper 5). The first aim of the thesis is to critically review the applicability and usefulness of the WHO Guidelines (2001) in regulating community based research from the perspective of the researchers who do GBV work globally. The methods employed in this qualitative study are presented in Paper 1. The second aim is to analytically explore peoples' motivations for research participation, their perceptions of risks and benefits in partaking in studies, the perceived psychological impact of answering sensitive questions, and adverse experiences of research participation. Methods for the studies which met this aim are presented in Papers 2, 3 and 4.

2.10 Specific objectives

a. To explore the researchers' meanings of safety including vicarious traumatisation, the basis of concerns and the nature and scope of empirical evidence on the presence of risks in GBV research. (Paper 1)
b. To explore people's motivations for research participation, their perceptions on risks and benefits of research participation. (Paper 3)
c. To investigate how research participants perceived their experiences with a community-based survey on prevalence of gender-based violence victimisation and perpetration. (Paper 2)
d. To investigate the perceive psychological or emotional impact of survey participation by survey participants (Paper 2)
e. To conduct a gender analysis on the survey participants' experiences and perceptions of risks in research participation. (Papers 2 and 4)

f. To describe young people's (participants') motivations for participating in a longitudinal study on GBV and HIV. (Paper 4)

g. To describe the impact on participants of questions about childhood trauma and interpersonal violence. (Paper 4)

h. To explore factors associated with regretting participation among young people in a longitudinal study on GBV and HIV. (Paper 4)

i. To illustrate the complexities and nuances around the confidentiality principle in GBV research as influenced by ethical guidelines and South African laws. (Paper 5)

CHAPTER THREE

METHODS AND METHODOLOGY

3.1 Synopsis of the chapter

This chapter begins with a theoretical framework (Figure 1) which highlights the empirical evidence and other inputs I argue are required to inform the conduct of ethical GBV research. Furthermore, I indicate how my PhD thesis is covering some of the research that is needed in order to attain this overall goal.

Subsequently, this chapter describes the methodologies of the three studies that inform this thesis. Procedures and processes that were followed during fieldwork, and who the participants were, are described separately for each study. To orientate the reader with my PhD thesis, below I provide a brief summary of each study that is part of this thesis.

Study 1: Was a qualitative research based on in-depth interviews conducted with researchers who have conducted gender-based violence research in various regions and countries of the world. In the interviews they shared their experiences and ethical challenges they have encountered when conducting the studies. Furthermore, this study was also based on the review of four articles that were systematically selected and analysed as data in this study. Paper 1 has been written from this study.

Study 2: Was the main study for the thesis. This was an ethnographic research that was conducted in Soshanguve Township, north of Pretoria. This study had three components to it.

a) **Component a:** Unstructured interviews with community members and participant observation conducted over a period of more than 3 months. Paper 2 was written from this study.

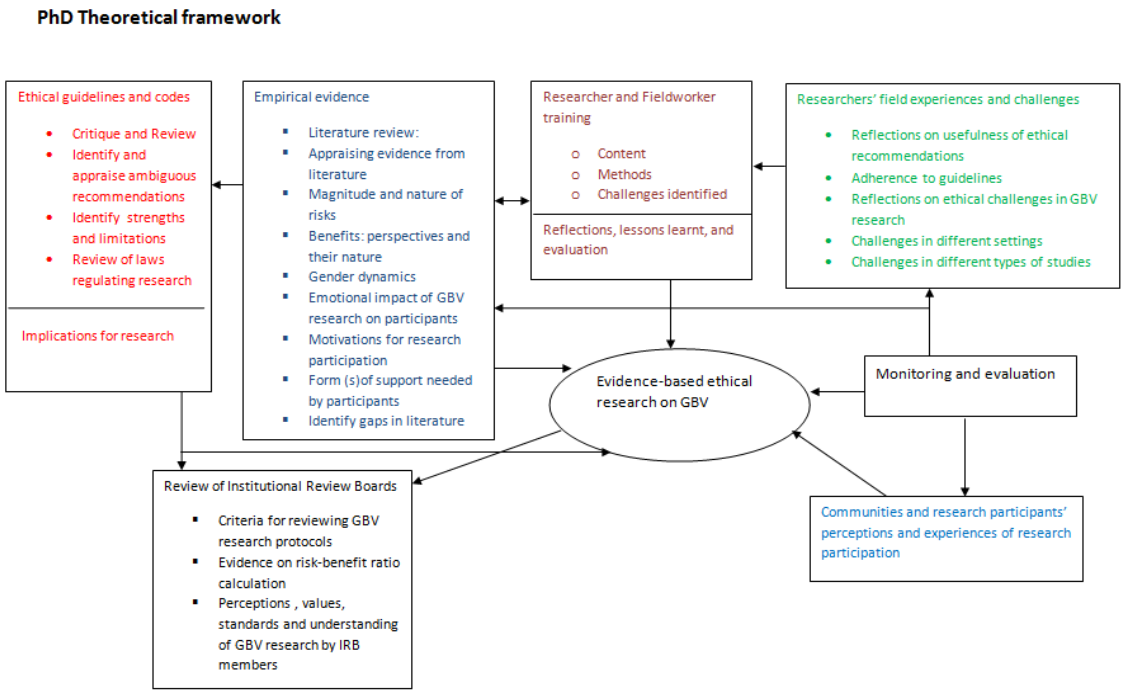
b) **Component b:** In-depth interviews were conducted with 22 people who had recently participated in a survey on gender-based violence. Paper 3 was written from this study

c) **Component c:** A case study which explored an ethical dilemma that had resulted from a disclosure of previously unreported incriminating information by a research participant to a fieldworker in a survey on gender-based violence. Paper 5 was written from this case study.

Study 3: Is the analysis of data that was collected in the Stepping Stones study. This study was a cluster randomised controlled trial that was conducted in the rural Eastern Cape between the years 2002 and 2006. The trial evaluated the effectiveness of a behavioural HIV prevention intervention termed Stepping Stones. Data that was used for study 3 in this thesis was collected in the last data collection point of the trial, at 24 months follow-up. Participants who had been retained were asked to share their perceptions of, and experiences of participating in the trial. Paper 4 was written from this study.

As shown in the next chapter, these three studies together raise implications for future research and GBV ethical guidelines and their relevance in protecting communities and participants in South Africa.

Figure 1: PhD Study Framework



3.1.1 What informed this doctoral research topic?

I began my doctoral study with a somewhat broad research topic. My interest lay in exploring empirically the ethics of involving human participants in gender-based violence research in South Africa. Over a period spanning 20 years, South Africa has been a host to a great deal of research on gender and various forms of gender-based violence. In particular, around the turn of the 21st century, researchers in South Africa shifted their focus towards studying gender, intimate partner violence (IPV), rape, child abuse and incest, sexual coercion, intimate femicide and more recently male rape perpetration and victimisation. This is evidenced by an increasingly growing body of published literature describing the epidemiology of gender-based violence in South African black communities spanning this period (Wood and Jewkes 2001; Jewkes et al. 2001; Dunkle et al. 2004; Abrahams et al. 2006; Jewkes et al. 2011; Machisa et al. 2011). Although, currently, there is extensive

scholarly work on GBV in South Africa, there remains a paucity of published literature on ethics coming from South Africa on how GBV research impacts human participants and researchers working in this area of research.

When I began my doctoral study, I was not aware of any empirical research from South Africa on ethical issues in conducting community based gender-based violence research. In particular, I was not aware of any research done on ways in which communities and research participants perceived risk in participating in GBV research and of actual problems encountered after research participation and perceptions of the utility of protections provided by researchers and research ethics guidelines. This was rather a neglected area of research in South Africa, but also one little studied globally. The lack of empirical evidence on this topic presents a particular challenge for researchers who plan and are conducting GBV research in South Africa as there is very limited evidence on how applicable the WHO Ethics Guidelines (WHO 2001) are on research with women in this setting. Additionally, the existing research ethics guidelines (WHO 2001; Zimmerman and Watts 2003; WHO 2007) were specifically developed for GBV research with women, yet over the years, they have been extrapolated and used in studies of GBV perpetration and victimisation with men (Wood and Jewkes 2001; Abrahams et al. 2006; Jewkes et al. 2006; Machisa et al. 2011). However, GBV research with men in South Africa has occurred without knowledge of whether the WHO Guidelines (2001) are applicable to men as participants in GBV research.

3.1.2 Study design (Study 1)

As I was conceptualising my PhD research, my doctoral supervisor and I decided that I should first review the WHO Guidelines (WHO 2001) (for these guidelines see box 1) to explore if there are any recommendations provided in the guidelines that needed to be

unpacked analytically to problematise their meaning in order to enhance my understanding of the recommendations and their applicability and usefulness in different settings and contexts.

A review of literature shows that the WHO Guidelines (2001) have been operationalised differently in various settings and contexts (see Garcia-Moreno et al. 2005; Jewkes et al. 2006; Machisa et al. 2011). This is because they are somewhat broad and thus open to various interpretations. To gain an in-depth understanding of how researchers from various settings and contexts have operationalised these guidelines, I conducted a small qualitative formative research study and interviewed gender-based violence researchers to document their accounts and views on the usefulness of the WHO Guidelines (2001) and the challenges they may have had in applying these guidelines in their studies in various contexts and settings of the world.

Qualitative methods (e.g. in-depth interviews and observations) are regarded as useful in exploring phenomena, issues, and questions that are hidden, less explored and not well understood by providing a nuanced and in-depth meaning and understanding to the question at hand (Hennink, Hutter, and Bailey 2011; Dahlgren, Emmelin, and Winkvist 2004). Thus, for this formative research, I employed in-depth interviews to gain an insight on the informants (researchers) perceptions and experiences of using the WHO Guidelines (2001). I asked them to reflect and comment on the following two questions:

- How have you operationalised the WHO Guidelines in your respective country?
- Did you get any evidence that these guidelines were useful?

In addition, during the interviews, I had robust discussions with researchers on the ethical issues pertaining to GBV research and on the challenges they had experienced in the field. I

asked them to reflect and share their views on why they think they encountered these challenges; whether they adhered to or at some point had deviated from the WHO Guidelines (2001) because of the demands of particular settings, and their views on the gaps and or limitations and strengths they identify in the WHO Guidelines (2001). This discussion was particularly helpful as it deepened my understanding of the ethical issues in this field of research. Additional to this, I specifically sought general advice from the researchers as to what ethical issues might be important to be addressed in the field of ethics of GBV research. Advice I got from discussions with some of the researchers helped shaped my PhD research.

3.1.3 How did I conduct this formative research?

First, I contacted the 10 researchers who were country leaders of the WHO multi-country household survey on Women's Health and Domestic Violence (Garcia-Moreno et al. 2005). This study was conducted in 10 countries from various regions of the world (WHO 2005; Garcia-Moreno et al. 2005). I got the names of the research leaders of each country that participated in the WHO multi-country study from the study report (see Garcia-Moreno et al. 2005). I then searched for their email address through the internet using their names and found some addresses. For those I could not find, I requested their email addresses from my doctoral supervisor and other colleagues in the field. At the end, I had all the email address of the 10 country leaders. However, I cannot rule out the possibility that perhaps some of the addresses were no longer used by the researchers, as some researchers might have changed affiliations or employment by the time I emailed them. Notwithstanding, I wrote to the 10 country researchers and explained the purpose of my research, and in the same correspondence, attached my research questions and asked them to respond to them,

and two researchers from this group emailed their responses back. Some of the researchers mentioned that they would be attending the Sexual Violence Research Initiative (SVRI) conference that was going to be held in South Africa in less than a month's time, and they indicated that they would be willing to discuss my research questions during the conference.

While the two responses that were emailed back were very informative, more information was needed to address and saturate the research questions for this formative exercise. In July 2009, the Sexual Violence Research Initiative conference was held in Johannesburg, South Africa (Dartnall and Loots 2009). According to the conference report, 194 GBV researchers and activists from various countries attended the conference (see Dartnall and Loots 2009). My supervisor and I saw the SVRI conference as an opportunity to collect more data for the formative research.

3.1.4 Who were the informants, and how these data were collected?

As the SVRI 2009 conference was approaching, I prepared study leaflets and informed consent forms to give to the researchers whom I would invite to participate in my study. I had planned to conduct 15 in-depth interviews with the researchers. During the conference, I approached researchers during the tea or lunch breaks, explained the purpose of my study to them, and requested their consent to participate in the study. All approached researchers accepted the invitation to participate, but due to time constraints of their schedules, some could not do interviews with me. At the end of the conference, I had managed to hold in-depth interviews with eight researchers from different countries of the world. None accepted the offer for written informed consent as they viewed the exercise as conversational and information sharing and not personal and intrusive.

From the eight researchers who were recruited in the SVRI 2009 conference, three of them had been part of the Core Research Team of the multi-country study (see Garcia-Moreno et al. 2005). Additionally, I conducted two telephonic interviews with two local individuals who were study nurses in the Stepping Stones Study, which had included extensive interviewing on GBV and had 2 800 participants (see Jewkes et al. 2006). The Stepping Stones Research nurses had, during the course of the trial, provided emotional and professional support and HIV counselling, including referral to local services, for the study participants. Participants were sometimes referred to them by the fieldworkers after demonstrating strong emotional reaction during the interviews. Others spoke to them after testing for HIV, but every participant had access to them as they had a cell phone that was accessible 24 hours a day and all participants had their contact number. As such, the perspectives of the nurses on what issues the participants raised as distressing about and perceived impact of trial participation, what form of support the participants needed was considered critical information for this study.

3.1.5 Data analysis

At the end of the SVRI 2009 conference, which signalled the end of this formative research, I had a total of eight audio-recorded interviews, two written responses and notes I wrote from the telephonic interviews with the two trial nurses. I then transcribed the audio-recorded interviews and typed the written notes into a word document. I cleaned all the data, preparing it for analysis, and analysed the data inductively following a latent content analysis approach (Graneheim and Lundman 2004). First, I read and re-read the text for a deeper understanding and identified and described themes I saw emerging in the text (Jewkes and Murcott 1998). Following the steps as advised by Graneheim and Lundman

(2004), I read the text identifying open codes, thereafter from the codes, I established a set of categories (see also Dahlgren, Emmelin, and Winkvist 2004; Silverman 2002)). I then defined the categories and engaged with them trying to grasp the underlying and different meanings of the categories (Graneheim and Lundman 2004; Dahlgren, Emmelin, and Winkvist 2004). To ensure credibility of the findings, my supervisor and I discussed the codes, categories and themes that had emerged and we agreed on them before I undertook further analysis. (Dahlgren, Emmelin, and Winkvist 2004). Subsequent to this, I linked the categories that fitted together through finding connections between them and interpreted what I saw as emerging (Graneheim and Lundman 2004; Silverman 2002). As a last step of the analysis, I compared the findings with published literature on the similar topic and made conclusions (Dahlgren, Emmelin, and Winkvist 2004).

3.1.6 Outputs

The primary purpose of this formative research was to inform the conceptualisation of the main PhD study through understanding the complexities in the WHO Guidelines (2001) as well as soliciting the advice of experienced GBV researchers on what might be important to explore in my main study. That purpose was achieved as the main study (below) and thematic guides (Appendix 4 and 5) were developed drawing largely from data collected in this formative research. Findings of this formative research have been written up and are presented as Paper 1 of this thesis.

Paper 1

The aim of Paper 1 is to contribute to the debates on safety and risks in GBV research by providing insights on researchers' meanings of safety, the basis of concerns and the nature and scope of empirical evidence on the presence of risks unique to GBV research from

publications and researchers who have worked in the field. The article below has been published from this work.

Sikweyiya Y, Jewkes R. Perceptions about safety and risks in gender-based violence research: implications for the ethics review process. Culture, Health & Sexuality, 2011. Vol. 13, issue 9. 1091-102*

*This article is printed with the permission of the publisher.

3.1.7 Ethical considerations

The ethical approval to conduct this formative research was given by the ethics committee of the South African Medical Research Council. Informants to whom the research questions were emailed were informed of the purpose of the study. They were further informed that answering and posting back their answers will be construed as meaning they gave informed consent. Informants who participated in the face to face in-depth interviews gave verbal consent to participate in the study.

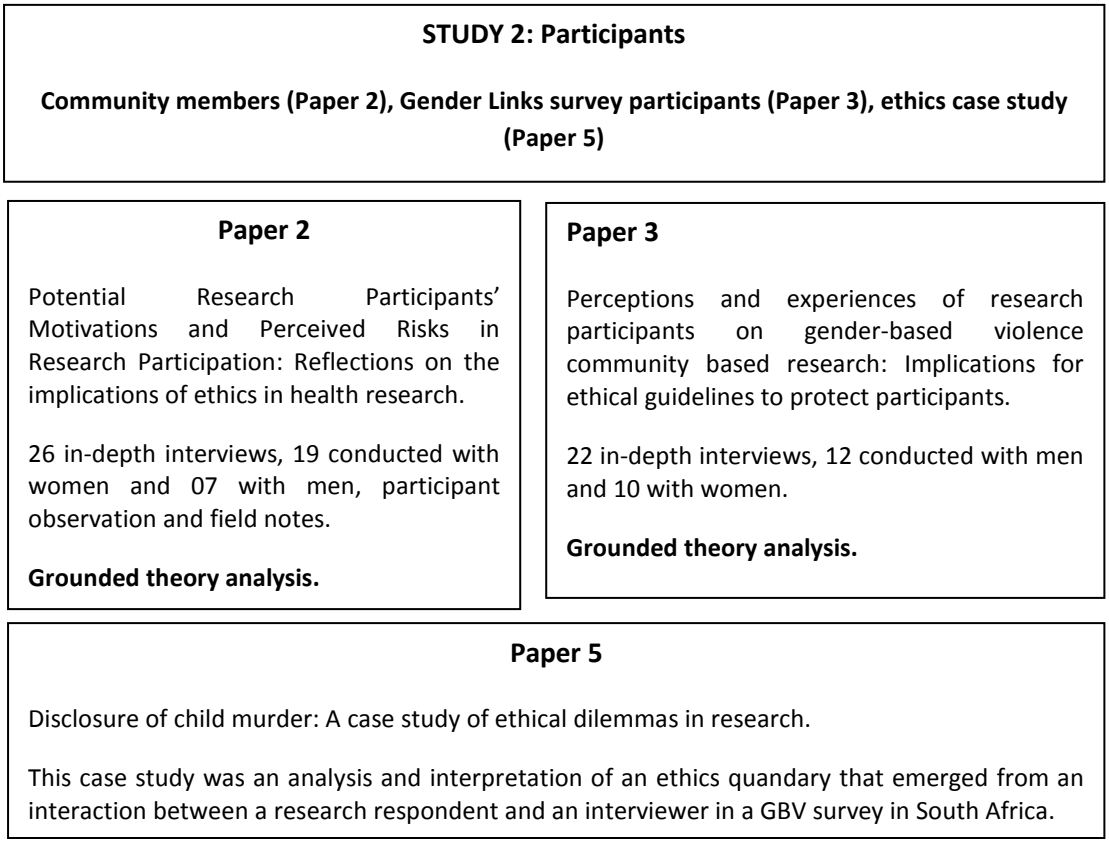
3.2 Study 2 (Papers 2, 3 and 5)

3.2.1 Aim

This was the main study for the PhD thesis. It aimed to investigate and understand how people from the community including people who had recently participated in a survey on gender-based violence perceive discussing violence in a research context and what their concerns were related to this. This study was specifically aimed at understanding the extent to which the ethical safeguards, as recommended by the WHO (WHO 2001), are relevant in this setting to address the community members and research participants' concerns and perceived risks of participation in research and the extent to which the safeguards provided in the survey protected survey participants with respect to issues of anonymity,

confidentiality, safety, informed consent. Three papers from the study 2 form part of this thesis.

Figure 2: Study 2 Participants



3.2.2 Epistemological and ontological assumptions of the study

Study 2 was informed by the qualitative interpretative paradigm (Dahlgren et al 2004). The qualitative interpretative paradigm is recognised to enable qualitative researchers to explore meanings from accessing people's understandings of and viewpoints about their own world (Hennink, Hutter, and Bailey 2011; Dahlgren, Emmelin, and Winkvist 2004). Epistemologically, qualitative-interpretative paradigm assumes a standpoint that realities are multiple, complex and social bound (Dahlgren, Emmelin, and Winkvist 2004), it takes as

a point of departure, the belief that realities and experiences are subjective and relative to the people being studied. Epistemologically, this paradigm is premised on empirical knowledge resulting from an interaction the researcher has with the researched, including the context and setting in which the researched live. Therefore, as I conceptualised this study, I was well aware that what I will find would be the subjective views and experiences of the informants and their construction and interpretation of their lives and reality as informed by society they live in and their experiences, and this was an ontological assumption that informed this study (Hennink, Hutter, and Bailey 2011).

As a researcher who accepts the qualitative-interpretivist ontology, I employed qualitative interactional methodologies (explained below). I was aware that to collect trustworthy data, I depended entirely on the relationship I will forge with the research participants, and this would enable me to uncover the subjective reasons and meanings that lie behind their views and opinions on and how they react to research participation (Hennink, Hutter, and Bailey 2011; Terre Blanche, Durrheim, and Painter 2006). I held a belief that reality is constructed inter-subjectively through the meanings and understanding that are developed socially and experimentally (Dahlgren, Emmelin, and Winkvist 2004), and that I cannot separate my research participants from their society or community, as the latter inform their interpretation and perceptions of what they know (Hennink, Hutter, and Bailey 2011; Terre Blanche, Durrheim, and Painter 2006). The positions of the interpretivists are grounded on the theoretical belief that reality is socially constructed and fluid and that what we know is often negotiated within cultures, social settings and the relationship with other people (Angen 2000). I therefore employed a qualitative approach drawing on a disciplinary perspective of qualitative sociology which is most suitable for this kind of research.

3.2.3 Contextualising study 2

Between April and July 2010 a South African Non-Governmental Organisation called Gender Links (GL) collaborating with the South African Medical Research Council and the University of the Witwatersrand undertook a population-based survey to study the prevalence of gender-based violence in the Gauteng province of South Africa (Machisa et al. 2011). Advised by Statistics South Africa and using census 2001 as a sampling frame, a two stage proportional stratified sampling strategy was employed to identify a representative sample of women and men yielding a sample of 1568 households from which 794 women and 774 men were sampled for the survey. The survey collected data in face to face interviews with a fieldworker using a structured questionnaire with women and men over the age 18 in 75 randomly sampled primary sampling units (PSU's) in the province (Machisa et al. 2011). A brief explanation of the design of this survey is presented below, however, for full methods and design of the GL survey, read Machisa et al. (2011).

Although my PhD study was totally independent of the GL survey, the survey presented an opportunity to investigate ethical issues in GBV survey research, as such I nested within it my PhD research and conducted it in two EA's (from the 75 PSU's).

The early work for this PhD research involved protocol development. During this period, I presented my PhD research ideas to my peers in the PhD seminar at the School of Public Health, University of Witwatersrand. This process and the feedback I received from my colleagues and lecturers helped me to develop and refine my research protocol. Subsequent to this, I gained protocol approval from the PhD committee and ethical approval, first from the ethics committee of the Medical Research Council, and later from the University of Witwatersrand ethics committee. The schematic diagram (Figure 3) below illustrates the

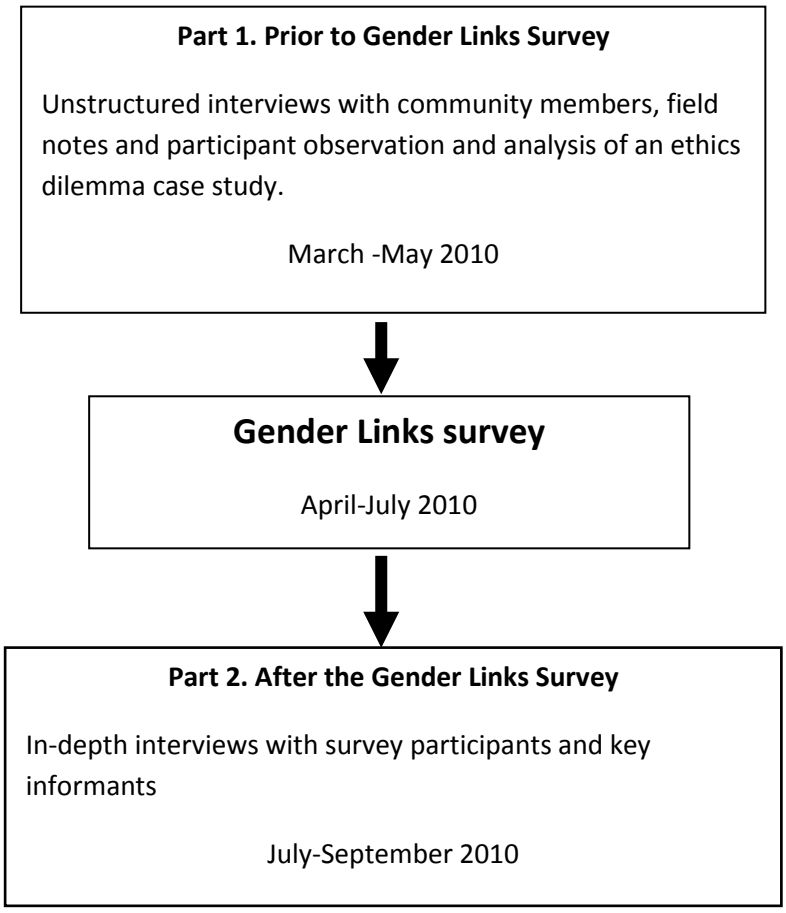
design of study 2. I began the ethnographic work in early March 2010 and conducted the first set of unstructured interviews and participant observation with community members (men and women over 18 years). These interviews were conducted a month before the GL survey came into the community. This was because, the purpose of the study was explore the community people's attitudes, awareness and understanding and views about community-based research in general, and the expectations they attach to research participation without being influenced by the presence of the survey in the community.

The second set of in-depth interviews, with men and women whom had participated in the GL survey, were conducted between July and September 2010 after the GL survey had been completed in the two communities. In this instance, I collected data only from people who had participated in the survey as the goal was to solicit their thoughts of the survey, whether they found the survey participation helpful or harmful, whether there were any adverse experiences for them resulting from survey participation, and whether the manner they perceived and experienced the survey differed according to their gender or age.

3.2.4 Research design

The survey in which study 2 was nested aimed to conduct a population-based survey to investigate the prevalence of gender-based violence in the Gauteng province of South Africa. The survey collected data in 75 randomly sampled primary sampling units in the Gauteng province.

Figure 3: Design of Study 2



3.2.5 Study setting

Study 2 was conducted in two sections of Soshanguve. Soshanguve is a large township located north of the city of Tshwane (Pretoria) and estimated to be 25 km from Pretoria (http://wikipedia.org/wiki/Soshanguve). Soshanguve was established in 1947 and built on a land that was intended to be integrated into the former Bantustan, Boputhatswana, although by year 1977, it eventually fell under the Northern Transvaal Administration (http://wikipedia.org/wiki/Soshanguve). Soshanguve is organised into numerous sections

and these are popularly known as blocks. The two sites (PSU's) in Soshanguve on which my PhD study was conducted were conveniently chosen as they were relatively close to Pretoria where the Medical Research Council, my place of work, is situated. Thus, I conducted my research in Thate Block G and Siyakhula Extension (pseudonyms to protect identity of participants and communities). These two blocks are approximately 4-6 kilometres apart. The Thate Block is a fairly established section of Soshanguve. It is predominantly a low-income area with few middle class families. Siyakhula Extension is comparatively a new residential area which has formerly been a squatter camp. It is essentially a poor area with some households living in shacks built of corrugated iron. While a number of South African and neighbouring countries' languages are spoken in Soshanguve, seSotho, Shangaan, seTswana, Zulu and Venda are dominant.

3.2.6 Methods

Study 2 was ethnographic in design (Silverman 2002) and community based. It employed various methods of collecting qualitative data including in-depth semi-structured interviews, participant observation, unstructured interviews and researcher's field diary (Silverman 2002; Dahlgren, Emmelin, and Winkvist 2004). These research methods are traditionally used in disciplines such as anthropology and sociology (Silverman 2002). They are, however, acceptable methods of collecting qualitative data in many disciplines of research. When these data collection techniques are employed together in one research study, they strengthen the quality of data and study findings. This process is referred to as triangulation because these techniques possess different strengths. Thus triangulating between them in data collection allows for the capturing of various forms of data that in turn allow for subjecting data to varying forms of analysis (Dahlgren, Emmelin, and Winkvist 2004). When

the researcher completes the qualitative research cycle (Hennink, Hutter, and Bailey 2011) having triangulated data collection methods, he/she is in a better position to gain a nuanced, in-depth and holistic understanding of the phenomena under study (Dahlgren, Emmelin, and Winkvist 2004; Silverman 2002).

3.2.7 Access to study area

Access to do the research was obtained from various local authorities. Permission to conduct research in Soshanguve was firstly granted by the local municipality. Thereafter, a letter of permission for conduct the study was obtained from the municipality and given to the respective community leaders. Local leadership in the two areas was not clearly structured; as such I sought permission to conduct the study from the South African National Civic Organisation (SANCO). In the Thate Block, I attended a SANCO meeting where I was provided an opportunity to introduce myself to the community and present the purpose of my study and its design. In Siyakhula Extension, I got community entry through a community policing forum (CPF) leader. While the community entry strategies I employed in the two sections seem somewhat different they both worked well as I felt immediately welcomed in the two PSU's and got a lot of cooperation and support from the community members.

3.2.8 Becoming part of the community: a research strategy

Researchers including doctoral students who have conducted ethnographic studies and stayed fulltime, for a prolonged period, within the communities they were studying, report methodological and scientific benefits from approaching their studies in this way (Wood and Jewkes 2001; Mfecane 2008; Braithwaite 2006; Wood 2003). For study 2, I decided to conduct an ethnographic study which lasted about 6 months. As outlined in Figure 2, this

period was divided into two parts. The first set of interviews was conducted before the survey and the second part of interviews after the survey.

The first set of interviews and participant observation, prior to the survey (component A), lasted about three months (March to May 2010), and findings are presented in Paper 2. For the first set of interviews, I lived fulltime in the community. I rented an inside bedroom in the Thate Block of Soshanguve paying a monthly rent of R500. The house had two bedrooms, a kitchen, sitting room, and a bathroom. I shared the house with a man who was in is early thirties, whom I did not know prior to living with him. He later became my research assistant.

To be known and accepted easily in the community, my doctoral supervisor and I decided that I should employ two research assistants who resided in these two sections of Soshanguve. The main requirement was that the research assistants should be people who are well known and respected in the community. As such, with the recommendations of community members, I identified and employed two young people (man and a woman in their early 30's), from each section. Specifically, in the Thate block, the man I employed to be my research assistant was recommended to me by his sister who had also offered me the place to stay, but she was not staying in the house. I first met her in one of my initial meetings with the community stakeholders. In the Siyakhula extension, my contact person was a community policing forum (CPF) leader, and he helped me to identify the research assistant.

Even though I was staying in the Thate Block, I frequently visited the Siyakhula extension, and spent hours in a day talking to community members and conducting interviews with others and would return to my rented room in the evenings. Sometimes, I had my private

car with me in Thate Block and I would use it to travel to the Siyakhula extension, but in other times, I used public transport (taxis) to travel there.

The research assistants were employed on services rendered contract for a period of 40 hours and paid R34.72 per hour of work. They signed a standard Medical Research Council services rendered contract and I briefed them that as part of their job, where appropriate, I would shadow them around the community as they visited the people and the places they normally frequented. Additionally, I indicated to them that I would need them to help me to identify prospective informants as per the study inclusion criteria I had (men and women 18 years and over residing in the community).

However, as I became more familiar with the community, and had established somewhat strong networks and relationships within the community, I sometimes travelled on my own to visit and mingle with people in their homes and observe them as they go on with their daily chores and sometimes participating in the social activities people were involved in. For example, I attended a couple of community meetings in which there were discussions about electricity, water, housing shortage and crime among other things. Even though I did not participate in these discussions, I sat and listened attentively to the discussions in an attempt to demonstrate interest to the community issues. Attending these meetings, made me to be known in the community and I sensed that it made people, to some extent, accept me as someone who was interested in their community, even though they knew I was there for a short period of time and to conduct research for my 'school project'.

During my fieldwork in the community I interacted with people of different ages and sex. However, it was easier to mingle with men and women of my age as I would sit with them in their 'hang-out' spots which included their homes, street corners, taverns, community halls,

local gym areas and sport grounds, and sometimes I would go out with them in the evenings to the bars and taverns and interact with them as they drink alcohol.

To involve myself deeper in the community, I often shared food with my male research assistant and friends. We would contribute money to buy food, cook together and eat before we go out to meet other people. On occasions when I left the house early in the morning, I would not return for meals. I rather shared food and ate with those I was with at that particular time. I strongly believe that this form of interaction, which was personal and intimate, with community members, allowed for a strong rapport and relationships to develop between me as the researcher and them as the researched. This in turn made them to accept me as a researcher who had come to learn about their ways of living. While I knew that they viewed me as an outsider, I observed that, with time, most of the people were comfortable to share with me freely about their lives including 'intimate and private' information that they said they would not easily share with others.

During these interactions with community members, when it was suitable, I specifically probed the issues of interest to my study. While some of the conversations with the people, with their permission, I audio-recorded, some were not; rather I would write them up as notes in my diary when I had returned to my room in the evenings.

Before commencing with the study, my doctoral supervisor and the ethics committee that approved the study at the University of the Witwatersrand suggested that I develop a researcher safety protocol on which I would outline how I intended to keep myself safe in the community - this was done. During my stay in the community, I tried to adhere to it and viewed this exercise as extremely helpful as I experienced no adverse event during my stay in the community.

3.2.9 Ethnicity and language

People in Soshanguve are generally multi-lingual. It is extremely unusual to find someone who has resided in Soshanguve for a lengthy period of time being unable to speak almost all the languages that are dominant in this setting (seSotho, seTswana, Shangaan, seTsonga, Zulu and Venda). Sections in Soghanguve were historically demarcated according to ethnic groups. This was done through apartheid segregation laws like the Bantu Homelands Citizenship Act of 1970, which sought to enforce ethnic distinction and or division among black people through being separated in terms of ethnicity and being prohibited to mix (*Bantu Homelands Citizenship Act* 1970). For example, in Soshanguve, a certain section or block was designated for either Shangaan speaking people only. This apartheid legacy is still visible in Soshanguve as certain sections are still dominated by particular ethnic groups, even though the boundaries are increasingly becoming blurred and there is some integration between the ethnic groups now.

In terms of ethnicity, I am of the Xhosa tribe, and historically, Xhosa speaking people were largely designated to stay in the Transkei, which was another homeland (*Bantu Homelands Citizenship Act* 1970), as such Xhosa speaking people were historically not and still are not many in Soshanguve. While it was not possible to ascertain from physical appearance that I did not belong to the dominant tribes in Soshanguve, my inability to speak fluently any of the dominant local languages made it apparent that I was either new or an outsider in this community. Additional to this, not many people understood and could speak isiXhosa in Soshanguve. However, isiXhosa, a Nguni language, is relatively similar to another Nguni language, isiZulu, which is spoken in Soshanguve.

However, throughout my stay in Soshanguve, people I met for the first time often assumed that I was from this community, and thus spoke to me in either seTswana, Shangaan or Sotho and this presented a communication challenge for me as I struggled to respond or engage in discussions with the people speaking in the local languages. Yet, because the vast majority of people could speak Zulu, I often requested to communicate with them in isiZulu. Although I had very limited vocabulary in seTswana and seSotho, I somewhat understood the two languages when spoken to me. As such, with the young men and women I often spent time with, I encouraged them to speak in their languages when I was with them, but in most cases they would speak to me in isiZulu or some, in English.

At the outset, I knew that the communication was going to be a challenge during my fieldwork in Soshaguve. I was conscious of the fact that I could only conduct interviews with the people who could speak isiZulu or were prepared to speak with me in English. As such, I indicated to the research assistants that they should help me identify people I could be able to converse with in isiZulu or English, although there were few interviews that became a mix of isiZulu and another local language.

3.2.10 Sexuality: situating a young male ethnographer

For data collection in the ethnographic study in Soshanguve, I spent a considerable amount of time with both young men and women, and occasionally visited older women in their homes for interviews. At the beginning of the research I had reflected on the implications of the fact that I was a young man, an outsider in the community who would be interviewing men and women. I imagined that some of the women may have relationship dynamics that may not allow them to speak to a man without their male intimate partner's approval or parent(s). I was aware that visiting some of these women in their homes may cause

problems for them. Additionally, for them to be seen talking with a young man in a private space, suitable for an interview, may be viewed as unacceptable, cause conflicts in their families and or intimate relationships. I also reflected that there may be a risk for physical harm for myself in doing this research with women. As such, on my initial visits to the community, I asked my key informants whether it would be acceptable in this community for a male researcher to interview women. There was no clear answer to this, rather they advised me that I should approach people, especially women, with great care and respect, ask them if it would be okay with them to be interviewed by a man, and whether she does not perceive risk in doing so. Throughout the six months I spent collecting data in Soshanguve, I did not experience any negative reaction from a man because I had interviewed his partner. However, on one occasion I approached a young woman who stayed in the same street with me for an interview, she warned me she can't be seen talking to a man "unless I wanted trouble", I respected her honesty, and thanked her before I went to other houses.

However, there is another methodological issue relating to my being a man interviewing women about their lives, circumstances, including their experiences of GBV. Whilst my interviews with women seemed open and free, there is a possibility that some women may have been uncomfortable with this, and thus might have withheld some information that, perhaps, would have disclosed to a female researcher. In particular, some women might have been uncomfortable to share intimate information like sexuality and GBV experiences, if any, with a male researcher.

3.3 Study population

3.3.1 Who were the research participants in this study?

I. **Component A interview**S (prior to the survey)

For these interviews, the whole community (Thate Block and Siyakhula Extension) was the study population. I conducted in-depth and unstructured interviews with adult men and women (aged 18 and above) living in the two PSU's. All were potential Gender Links survey participants, yet at the time of my component A interviews those who were to be interviewed in the survey had not been selected as survey sampling had not been done at the time of my study. Additionally, participant observation was another data collection technique in this study.

Community members who were 18 years and older, not mentally challenged, and thus capable of providing informed consent, were eligible to participate in this study. As I was living in the community full time during the fieldwork period, and with the help of the research assistant, I identified prospective participants and invited them to participate in the study. I employed convenience and purposive sampling techniques to recruit and enrol informants into the study. Informants ranged from being general community members, community leaders, two officials of local victim empowerment centres dealing with cases of domestic violence and child abuse, three officials of community police forum, and other key informants.

Interviews followed an emergent design (Dahlgren, Emmelin, and Winkvist 2004), issues of interest that came up in one interview were probed further in subsequent interviews until such a subject was saturated. This process continued throughout the data collection period. I stopped conducting interviews when I felt that I was not getting new information, in any of

the areas of inquiry or research questions, i.e. when I had reached data saturation. In the end, I had conducted a total of 26 in-depth interview, 19 with women and 07 with men. The reason I conducted more interviews with women was because most men were often not at home as they were working in nearby towns, with some residing in those towns during the week and only coming back during weekends or holidays, and this made it difficult to locate and interview them.

A. Scope of enquiry

While each interview proved to have a life of its own, before I began the fieldwork I had developed a scope of enquiry to guide the interviews. The scope of enquiry had questions that I considered important for this study. However, because this was designed as a grounded theory study, a number of issues or questions that emerged from initial interviews were incorporated into the scope of inquiry as the fieldwork progressed. In the interviews, participants were asked if they have ever been involved in research before. Those who said yes were asked to share their experience and thoughts and feelings related to research participation. Those who reported that they had never participated in research, were asked to think hypothetically what they thought research participation entailed; what they think would be done with the information they may share in research; what concerns and worries they may have about research participation; and what they thought they could benefit from research participation. I then asked the participants about the topics or personal issues they perceived were sensitive to talk about in research. For example, I asked them what issues they thought would be hard to talk about in research, what they thought were sensitive issues. I probed why they thought some issues or topics were sensitive while others were not and asked them to provide examples of issues they felt would be sensitive to talk about.

I further probed whether talking about how they raised their children and whether their children ever went to bed hungry, was a sensitive issue; whether being asked about gender-based violence was a sensitive issue and why. Participants were also asked what issues they would consider before disclosing experiencing or perpetrating gender-based violence in a research interview. I also asked them how they perceived being asked to talk to researchers about their experiences of IPV and sexual violence, and whether they thought they would benefit or be harmed by sharing these experiences.

II. **Component B interviews (post survey)**

All participants who participated in the Gender Links survey were eligible for participation. Initially, I planned to interview 40 participants (20 men and 20 women over the age of 18) who had previously been invited to participate in the Gender Links survey; this was approximately 20 participants from each section. However, sampling for component 2 interviews and recruitment of informants depended entirely on the number of people who were identified and agreed to be interviewed in the GL survey, and the survey only achieved 24 interviews. The survey had randomly selected 20 households in the Thate Block and the same in number of households in the Siyakhula Extension yielding 40 households. In each sampled household, one woman or man who met the inclusion criteria i.e. being over 18 years of age and mentally competent, was systematically selected from those who stayed four nights a week or more in a household (Machisa et al. 2011). If fieldworkers could not find an eligible person in the household, they did not replace the households or individuals. Similarly, they could not replace a selected eligible member if he or she was unavailable or unwilling to be interviewed (Machisa et al. 2011).

Before the GL survey got to the two EA's, I asked the GL survey fieldworkers to introduce my study and invite the survey participants to participate in my study. In total, 12 men and 12 women were interviewed in the GL survey, and all agreed to be contacted for my PhD study. They all provided their contact details and signed a slip indicating consent to be contacted (see appendix 6). For this set of qualitative interviews, I conducted all interviews with men and a female interviewer was hired to conduct interviews with women.

3.3.2 Sample (post Gender Links survey)

With the phone numbers that were given by the prospective participants and written in the intention to participate slips, I called all the 24 people to introduce myself and the study. However, some could not be located for interviews. In the end, after several attempts 10 women and 11 men had qualitative interviews and one man was interviewed twice after requesting a follow-up interview as he felt he had not been candid about some of the things in the first interview. In total 22 in-depth interviews were conducted for this phase.

Semi-structured open ended questions were used for these interviews and organised as an interview guide (see appendix 5). However, during the interviews, whenever a new interesting issue came up, I allowed it to be discussed and probed in-depth. This meant that, sometimes, during the interview, there were lots of digressions from the interview guide, and I valued such digressions as they allowed new issues to be explored and discussed and data to be grounded in the lives and realities of my informants (Dahlgren, Emmelin, and Winkvist 2004).

B. Scope of enquiry

For the participants who had participated in the survey, I first asked them about their overall views and perceptions of the survey. I then asked them to share the concerns and

feelings they had about the survey process. I probed in detail what they thought were good or bad things about the survey; whether there were consequences e.g. violence and intimidation, and trauma they experienced because of survey participation, if yes from who and what happened. I further asked the participants if there were any fears or concerns they remained having after they completed the survey and what those were.

I then probed specifically on the impact of research on the participants. I did this by asking the participants how answering the questions had made them feel emotionally; what types of feelings they had as they were asked to think and talk about personal experiences; and whether they thought the survey was helpful or harmful to them and why?

Issues of emotional support for research participants were central in this research. As such, I asked the participants whether thinking about the issues asked in the survey had caused them any discomfort. And for those who said yes, I asked them to describe how they felt and whether an opportunity for support was given to them by survey researchers; and what kind of support they felt they needed having thought about the things they were asked in the survey; and how they dealt with the emotions that were invoked by their thinking about personal issues asked in the survey.

3.3.3 My position as a researcher in the study

In my interaction and when conducting interviews with community members and GL participants respectively, I assumed a position of being a willing and enthusiastic listener. Although I had stayed within the community fulltime for three months, all the informants I interviewed in my PhD study were aware that I was an outsider, a researcher, who has come into the community to conduct research for a limited period of time, and would leave afterwards. I believe the awareness people had about me had benefits for this research.

During conversations with people, a number of informants told me that they were free and open to discuss intimate details of their lives with me because I was a stranger to them and would soon leave their community, and because of this they trusted that I will not divulge their information to others in the community. Some even went further to say that what they were telling me things they would not tell their neighbours or other people in the community. At the outset, I had some preconceived ideas on what could be the potential ethical issues to emerge from the interviews with participants from the review of literature and research for Paper 1. I imagined the potential ethical issues that could arise from GBV community based studies might include issues of informed consent with women, risk of abuse for research participation, risk of finding women who are currently in abusive relationships and how to react to that (Ellsberg et al. 2001; Ellsberg and Heise 2002; Jewkes et al. 2000; Jewkes and Wagman 2007).

Going into my PhD study having this understanding of the ethical issues was important for me, yet, it also presented a challenge for me as an interviewer as I had to keep myself in check not to introduce and or dictate my views and opinions in the interviews, and to keep an open mind in order to capture new information. This process is termed bracketing (Dahlgren, Emmelin, and Winkvist 2004).

During data collection, I avoided reading literature on human subject research (c.f. Holton 2009). Additionally, at all times, I constantly reminded myself that the informants understood their setting and context, their lived experiences and issues, far better than I did and that the exercise of interviewing them was to access their subjective viewpoints and perspectives.

The interviews with the informants were conducted in such as way that they were conversational and relaxed rather than formal and structured (Dahlgren, Emmelin, and Winkvist 2004). I was constantly conscious of the fact that, as a researcher, I was an important data collection tool and that whatever would come out of the interview would be the result of the interaction between me and the informant. Thus, during the interviews, I made a concerted effort to focus on the discussion emerging and demonstrated complete interest on what the informants were narrating. Throughout this process, I was curious to find and indeed probed for the meanings of the narratives of the informants (Dahlgren, Emmelin, and Winkvist 2004). Therefore, rather than assuming the meaning of what was said, I often probed in the following manner: *"you have said that life in Soshanguve is not for the faint hearted, what do you mean by that?*" With this probing, I ensured that I did not introduce my own interpretation and understanding of issues, but I wanted to learn everything from the people themselves (Dahlgren, Emmelin, and Winkvist 2004).

Constantly reflecting on my approach to interviews and the different and shifting positions I held with different people, as informants, was particularly useful as a strategy during the fieldwork. I was able to have conversations with young and old men and women and these different categories of people demanded that I be conscious of who I was speaking to and how to approach and speak to people who belonged to different age groups. For example, with young men in the community, I often used slang language which made them comfortable to converse with me, but I tended to me more formal and respectful with elderly people, which they appreciated. As such, I think that the way I positioned myself as a researcher in the community determined and influenced the data I was able to gather from

various people, and perhaps a different researcher who may position him/herself differently may not find the same.

3.3.4 Role power: Researcher versus participant

During the interviews, I was aware that there may be power dynamics between myself as a researcher and the research participants. Most of the participants knew that I was a doctoral student from the University of the Witwatersrand, one of South Africa's leading universities, as such, there is a possibility that my participants may have viewed me as a highly educated and knowledgeable person who may view their life experiences and issues as trivial and not worthy of my time. This label may have influenced the participants' willingness to share with me their life stories and engage in discussions with me. This constantly worried me during the fieldwork period. As such, I dealt with this by being availing myself for community activities including recreational activities happening in the community, spending time with other young people so that I could develop closer and intimate relationships with as many people as I can.

3.3.5 Data analysis: Grounded Theory

In analysing the qualitative data, I followed a grounded theory analysis approach and analysed the data inductively (Glaser and Strauss 1967; Corbin and Strauss 1990; Dahlgren et al. 2004).

While I primarily analysed the data, I discussed the codes and emerging findings with my PhD supervisor and this process strengthened the analysis and interpretation of the data.

For Paper 3, analysis was based on 22 in-depth interviews. With the permission of informants, all interviews were digitally recorded. I transcribed most of the audio-

recordings. However for interviews conducted in seTswana, I hired a seTswana speaking person to transcribe those. Transcription was done verbatim and translated to English.

The analysis followed the grounded theory steps of data analysis. First, I repeatedly read the transcripts familiarising myself with the content. Thereafter, I organised the text from the transcripts by grouping it according to the themes I had on the interview guide (Babbie and Mouton 2006). I then went through the data identifying open codes. I did this by breaking the sentences into small parts identifying several codes within the same sentence. At this early stage, I attempted to move up from the informants' words and was abstract in the labelling of the codes (Corbin and Strauss 1990; Babbie and Mouton 2006). I maintained consistency in labelling the codes so that it would be easy at the end to group similar codes together and produce categories (Dahlgren, Emmelin, and Winkvist 2004). At this advanced stage of grounded theory analysis, my supervisor and I came together and discussed the codes until we agreed about which codes seemed to fit together to form categories (Corbin and Strauss 1990). I then followed the advice of Dahlgren et al. (2004) and constructed concepts and the theory by finding axes between the codes and categories and thereafter identified the main category. I then explored what the data meant and interpreted it. In this final stage of the analysis, I compared the findings with the existing literature and made conclusions (Dahlgren, Emmelin, and Winkvist 2004; Silverman 2002).

3.3.6 Merits of ethnographic approach to the study

During the time I collected data for study 2; I lived fulltime in the community for a period of 03 months and continued to regularly visit the community for a further 03 months. This prolonged engagement with the community under study is one of the strengths of study 2. Living within the community fulltime positioned me better with my informants as it allowed

for rapport and strong relationships to be developed between me and my informants. This has been the experience of other authors who, at the time of their doctoral study, stayed within the community they studied for a lengthy period (see Wood and Jewkes 2001; Mfecane 2008; Wood 2003). There is a risk that ethnographers who spend prolonged periods of time in communities where they conduct studies may get too familiar with his or her research participants and setting. This prolonged engagement may lead to the ethnographer losing his or her curiosity about issues under study and taking them as for granted issues. This was not my experience in this study. The reason for this could be that during the fieldwork period, I often (fortnightly) went to meet with my PhD supervisor and discussed emerging issues with her. During these discussions with her, she advised me on the areas or issues I needed to probe in subsequent interviews. During fieldwork, I was able to develop good relationships and rapport with many of the community people, including those who became informants in my study. This presented me numerous opportunities to collect data that I would not have been able to if I was living outside the community and only coming in to conduct interviews. For example, I was able to capture data that was not directly reported to me, rather, acted out as people interacted with one another. I was able to collect as data what I had overheard and was able to watch events and incidents as they unfolded enabling me to capture these experiences as they naturally occurred. Braithwaite (2006) argues that this is a marker of a good ethnographer.

The data was critical in explaining and verifying certain issues that were reported in interviews by informants and such data was important in the contextualisation of the study results (Mfecane 2008; Wood and Jewkes 2001; Wood, Lambert, and Jewkes 2007). Additionally, through observing certain things being acted out, or issues hinted in informal

talks with or among people, I was able to probe for those issues in subsequent interviews leading to a deeper understanding of them (Mfecane 2008; Wood and Jewkes 2001; Wood, Lambert, and Jewkes 2007). For example, the manner in which men and women communicated with each other and how they resolved conflicts when they arose and relationships dynamics were captured through observations.

3.3.7 Validity and Reliability

As shown in the PhD Study Framework (figure1), I explored various topics and research areas which I thought were important to inform evidence based ethical research on GBV- which was the main focus of this PhD. Exploring these different topics and research areas enabled me to grasp the multiple realities emanating from the experiences and perspectives of both the GBV researchers and people who participate in the three studies I conducted for this thesis. For instance, in study 1 I focused on the views and perspectives of GBV researchers about the applicability and usefulness of WHO 2001 guidelines. In studies two and three I explored in-depth, understood and constructed the way the study participants perceived and attached meaning to issues as informed by their life experiences. As such, in the end I was able to compare and contrast the views of the researchers versus those of research participants highlighting as well areas of divergence and convergence in their views.

In this research, I collected data using various qualitative and quantitative research methods and techniques, including participant observation, in-depth qualitative interviews and structured. While these data collection tools have known strengths and weaknesses, I believe that by employing them together in this research, they were able complement one another and this approach aided in enhancing the validity of the findings of this research.

Furthermore, that I had a prolonged engagement in the field allowed me to be flexible in my data collection and allowed the research to direct me into different issues and topics which were important to answer the research questions. I welcomed this flexibility in data collection as I understood that qualitative research follows emerging design, that is, as a researcher one gets direction from the data that is being collected. For example, at the start of the data collection I had predetermined questions and issues that I wanted to explore, however, in the course of the fieldwork totally new issues emerged. I followed and explored those issues further until I believed I had reached saturation on each of them. Lastly, during the analysis of the data, while I was abstract in interpreting the data, I also made certain that I present a thick description of the context to which the studies were conducted and also substantiated my qualitative findings and interpretation by describing and presenting the verbal narratives of participants in great details. Undertaking these measures assured and made me to be confident that the findings I presented in this thesis are valid and reliable.

3.3.8 Ethical Considerations

This study adhered to the ethical principles provided by the World Medical Association Declaration of Helsinki (2008 revision) and the Belmont report (1979) which emphasises respect for a person's autonomy, beneficence, non-maleficence and justice. Ethical clearance for the study was granted by the Medical Research Council's Ethics Committee and the University of Witwatersrand's Faculty of Health Sciences Research Ethics Committee (M110543).

In order to ensure my safety and that of the research informants during data collection period, I had developed some measures which included a safety protocol.

I. Informed consent

Before each interview, I informed the informants about the purpose of the study, procedures involved in the study, risks and benefits of the study and their rights as informants. Informants were told that they did not have to participate in the study unless they were happy with the study procedures and understood what it was about. I provided all the informants with a study information leaflet (appendix 1) allowing time for them to read the leaflet and ask questions. Upon expressing satisfaction with the information and answers I provided them and had freely expressed interest in participating in the study, I asked them to sign a consent form. The consent form was written in simple English. Although all of the informants were able to read the English consent form, I discussed the study procedures and process with them mainly in IsiZulu and seTswana.

II. Support for research participants

In this study I conducted both unstructured and in-depth qualitative interviews which allowed for probing on interviewees' perceptions of participating in research that asks about gender-based violence victimisation and perpetration. From the outset, I envisaged that some of the questions may invoke anxiety and worry for the informants. As such, during interviews, I was careful in how I asked the questions and was constantly alert on identifying situations where informants showed strong emotional responses to interview questions. In such situations, I informed the informants that they did not to have to answer questions they are not comfortable with. I also informed them that they had a right to withdraw their consent in the study and that there will be no negative consequences for them or any form of prejudice.

All informants were informed of referral services that were available locally should they feel a need to talk to a professional counsellor after the interview. The study information leaflet had the toll free numbers of local services that provide counselling, child care services, and HIV VCT counselling and testing (Appendix 1).

III. Risk to informants

Participating in research may pose risks for research participants, though these vary according to the nature of the study. As such, it is advisable for researchers to note the potential for harm in their study and devise means to mitigate such risks.

The current study was introduced at community level as the study about 'Communities and Research', focusing on understanding how community members understand research and what do they make of researchers coming into the houses to conduct research. In the second phase (category B) interviews there were specific questions about various forms of gender-based violence (Appendix 5), and informants were informed that the interview would ask about partner violence, poverty, food, income, sex and other sensitive topics. Informants were informed that some participants may find these question invasive, and that if that happens, they were free not to answer questions they are uncomfortable with.

IV. Privacy and Confidentiality

Following the WHO Guidelines (2001), the interviews were conducted in a private place where audio privacy could be ensured. During interviews, no other person, including children of over 2 years (WHO 2001) were allowed to sit in while conducting the interview. I continuously reminded the informants that the information they provided in the study will be held in strict confidence and that no one else, apart from those involved in the study, will

have access to the audio tapes and transcripts. During the transcription of audio-recordings, the names of the informants and other information that could identify them were removed and replaced with pseudonyms.

V. Psychological support for the researcher

When I conceptualised the study, I envisaged that I might listen to painful and traumatic stories by respondents (Campbell 2002; Coles et al. 2010). Thus measures were incorporated into the study design to limit the potential for vicarious trauma. Interviews were structured in such a way that there was a gap (2-3 days) in-between the interviews. This allowed time for researchers to psychologically process and deal with the stories told by respondents. I met the female researcher who assisted me with women's interviews frequently to discuss the issues that came up in the interviews and also to debrief. My supervisor was also available if I needed to talk and debrief.

VI. Financial compensation

There was no financial compensation for participating in this study. I informed the informants about this when I requested their consent to participate in my study. I conducted interviews mainly at the informants' homes, at a time convenient for them; as such they did not incur any costs resulting from participating in the study.

Paper 5

Paper 5 is a case study that presented and analysed an ethical dilemma that occurred during the Gender Links survey (methods described above). The survey had employed a face-to-face questionnaire to collect data on GBV victimisation (women) and victimisation and perpetration (men). While one interview was on-going, a female respondent made an

unsolicited disclosure that a few months earlier she had intentionally made her two children to consume poison with the intention of killing them. As a result of this, one child died while the other survived with medical help. The respondent further confided to the interviewer than no one else knew about this and that to her knowledge no police docket had been opened regarding this case. As obligated by the South African law, the interviewer reported the disclosure to the research managers who agreed that there was an obligation on their part to report this to the South African Police Services. This was done.

This case study **(Paper 5)** explores laws and ethical codes that set out researchers' duty to report disclosures of unreported incriminating information by respondents. Ethical and practical reasons for a decision to report or not to report a disclosure are discussed, and implications for research are highlighted.

3.3.9 Ethical considerations

The case study was analysed anonymously and all information that could potentially identify the respondent and the interviewer was removed. No ethics approval was needed to analyse this case.

3.3.10 Outputs of study 2

Three original papers have been produced by study 2, namely:

Paper 2: Sikweyiya Y, Jewkes R. Potential Research Participants' Motivations for and Perceived Risks in Research Participation: Reflections on the implications of ethics in health research. Qualitative Health Research. Under review. **

Paper 3: Sikweyiya Y, Jewkes R. Perceptions and Experiences of Research Participants on Gender-based Violence Community based Survey: Implications for ethical guidelines. PLoS ONE, 2012, Vol.7. No 4. 1-9 *

Paper 5: Sikweyiya Y, Jewkes R. Disclosure of Child Murder: A case study of ethical dilemmas in research. South African Medical Journal. 2010. Vol. 100. No. 6. 34-38 *

*The papers have been published in open access journals.

Study 3: Methods (Stepping Stones study)

3.3.11 Study setting

The Stepping Stones study was conducted in the rural Eastern Cape Province of South Africa between 2003-2006 (Jewkes et al. 2006). The study was a cluster randomised controlled trial conducted in 70 clusters (villages or townships) around the town of Mthatha, which was the capital town of the former Transkei homeland. The Stepping stones trial project office was set up in Mthatha. All the clusters that were selected for the trial fell under the OR Tambo District Municipality and within a radius of 1.5 hours drive from Mthatha (Jewkes et al. 2006).

The goal of the Stepping Stones trial was to evaluate the effectiveness of the Stepping Stones behavioural intervention in averting new HIV infections among young people in the rural Eastern Cape Province of South Africa (Jewkes et al. 2006).

3.3.12 What is Stepping Stones Intervention?

The South African 2nd edition of Stepping Stones (Jewkes, Nduna, and Jama 2002), which was evaluated (Jewkes et al. 2006), was adapted from Alice Welbourn's original Stepping Stones curriculum (Welbourn 1995). It uses participatory learning approaches, including critical reflection, role play, and drama and draws the everyday reality of participants' lives into the sessions. It had 13 main sessions given in single sex workshops, lasting about 3 hours, as well as some meetings of both male and female groups, and was held over 6-8 weeks (Jewkes, Nduna, and Jama 2002). The sessions covered: how we act and what shapes it; sex and love; conception and contraception; taking risks and sexual problems; unwanted pregnancy; sexually transmitted diseases and HIV; safer sex and condoms; gender-based violence; motivations for sexual behaviour; dealing with grief and loss; and communication

skills. The control clusters received a single 2-3 hours session on HIV and safe sex practices drawn from the Stepping Stones curriculum (Jewkes, Nduna, and Jama 2002).

3.3.13 Study design

The trial was longitudinal and had three data collection time points. The main outcome measure was HIV incidence. Data was collected at baseline, 12 months and 24 months, and at each data collection time point, HIV incidence was assessed by collecting dried blood spots and testing them for HIV antibodies and a questionnaire was administered (Jewkes et al. 2006).

3.3.14 Clusters

In the trial, eligible and selected villages and townships were randomly allocated to the two study arms after they were grouped into seven strata (Jewkes et al. 2006; Nduna et al. 2010; Dunkle et al. 2007). In each cluster about 40 volunteer participants (20 women and 20 men) were recruited giving a sample of 1367 men and 1415 women. Eligible participants were aged 16-23 years, normally resident in the area where they schooled and mature enough to understand the study and consent process. There was a difference between the actual (15-26 years) and intended age of participants which is discussed in detail elsewhere (Jewkes et al. 2006).

3.3.15 Sample and participants

Young people who participated in this trial were volunteers and recruited mostly in schools and, to a lesser extent, out-of-school, and recruitment followed multiple stages. In each cluster project staff invited 60 or more young people to a meeting where they were briefed on the study (Dunkle et al. 2007; Jewkes et al. 2006). In most clusters, a list of all eligible prospective participants was generated and 40 people more able to participate in the study

were chosen by the project staff after some discussion among the youth about who would more easily participate, for example those who lived nearer the school, as in the area commonly students could live over an hour's walk from school (Jewkes et al. 2006). Then a separate meeting was held with the selected people and they were given further information about the study and its procedures; allowing them to ask questions and the research staff providing answers; and thereafter seeking written consent to participate in the study.

Participants were informed that the trial was going to run for two years and would have multiple rounds of data collection (see Jewkes et al. 2006). To maximise the potential for cohort retention, participants were asked to provide their home contact details, telephone numbers of friends or relatives and they were further requested to inform the project staff if they changed their home address or contact details or asked to provide an alternative number on which they may be reached (Jewkes et al. 2006).

3.3.16 Methods

Interviewer administered questionnaire was the main instrument of collecting the quantitative data. At the beginning of the trial, a total of four fieldworkers were recruited and employed. Two were females and two males and were slightly older that the trial participants. Three of the fieldworkers had university degree and one had incomplete tertiary education at the time of trial.

Prior to the commencement of the trial, fieldworkers were trained on data collection using a structured questionnaire, gender and gender-based violence, HIV/AIDS and on how to provide emotional support to or refer participants that demonstrate a need for professional help.

During data collection, fieldworkers were gender-matched, meaning that, for example, a male fieldworker conducted interviews with a male respondent. Field supervisor were at the field to ensure quality control and this involved checking the completed questionnaires for errors while in the field, and having the problematic questionnaires corrected by fieldworkers by going back to the relevant respondent for verification of information.

3.3.17 My role in the Stepping Stones study

When the Stepping Stones trial opened its project office in 2002, I was one the four fieldworkers that were employed to collect the quantitative data. At the time, I held an undergraduate degree from a local university and had limited theoretical knowledge and practical experience of research. Initially, I received three weeks training on data collection using a structured questionnaire. I remained in the employ of the trial from its conception in 2002 until it was completed in 2006, and collected data at each point of data collection. However, between 2004 and 2005 (12 months) I had obtained a scholarship and went to study for a Master's degree at Umea University, Sweden.

Data for Paper 4 was collected in the last phase of the trial, at 24 months, but I was not part of the investigators who conceptualised the ethics questions. Variables that were explored in Paper 4 are explained below (questions on research participation). My PhD supervisor is the lead author on this paper, and while we discussed together and planned the analysis and findings together, she conducted the analysis. Additionally, she wrote the method sections (above) that I have included in this thesis. In addition to being involved in data collection and co-planning the data analysis, I conducted the literature search, wrote the introduction, discussion and conclusion sections for Paper 4. I was the corresponding author for reviewers during the publication stages of the article.

3.3.18 Quantitative questionnaire

A structured questionnaire was administered by same-sex interviewers who were the same age or slightly older than the participants. The baseline questionnaire was administered prior to commencing the study and participants also gave blood for HIV testing. The questionnaire asked about age and level of completed education (presented here dichotomised as up to grade 10 and beyond grade 10). Socio-economic status was measured on a scale derived for the study after extensive discussion of the problems with use of standard measures (such as housing quality indices) in the study area and with the age group. The scale captured household goods ownership (TV, radio and car), frequency of hunger, frequency of having meat to eat, and perceived difficulty accessing a fairly small (but not trivial) sum of money for a medical emergency (R100 ~ £9). This was derived into a scale and factor weighted (Cronbach's alpha for men =0.60 and for women = 0.55). Among the background questions was a scale on exposure to childhood trauma, this measured physical, sexual and emotional abuse and neglect and was adapted from Bernstein et al. (1994). Cronbach's alpha for men 0.73, for women 0.72). The questionnaire had a detailed section on sexual behaviour, including the number and types of partners, condom use, contraception use and transactional sex. The questionnaire covered many gender issues including experience of emotional, physical or sexual intimate partner violence (as a victim for women or, for men, a perpetrator), assessed using a modified version of the WHO multi-country study's instrument (Garcia-Moreno et al. 2005).

3.3.19 Questions on research participation

The quantitative data presented in Paper 4 was collected during the final phase of a cluster randomised controlled trial (RCT) of a HIV behavioural intervention conducted in 70 rural

South African villages. In this RCT a total of 1085 women and 985 men (aged 15-26) answered a survey that included added questions about their perceptions and experiences of and motivations for participation in the RCT. They were asked about their motivations for research participation, regrets and adverse (and positive) consequences they perceived and experienced. These items were developed for this trial. Each item took the form of a statement scored on a four-point Likert scale of strongly agree, agree, disagree or strongly disagree. Participants who reported experiencing violence as a result of trial participation were asked follow up questions that were open ended probing the circumstances under which violence occurred and the responses were recorded in narrative and transposed from the questionnaire and analysed as text. Participants were asked a statement to capture their views on research participation in hindsight "*If I had understood everything about the research and what would happen afterwards I would not have agreed to participate*". This was the main outcome variable for the analysis of participation regrets.

3.3.20 Statistical analysis

Quantitative data was analysed using Stata release 10.0. All procedures used in data analysis took into account the study design, viewing the study as a stratified, two stage survey with participants clustered within villages. The datasets for men and women were analysed separately. Firstly, descriptive analyses were carried out on background variables collected during the baseline round of data collection, these were summarised as percentages with 95% confidence limits. Categorical variables were compared using Pearsons Chi. These estimates were carried out using standard methods for estimating confidence intervals from complex multistage sample surveys (Taylor linearisation).

To examine the motivations for and consequences of participation, responses to each statement were dichotomised so the proportion strongly agreeing or agreeing versus disagreeing or strongly disagreeing could be presented. Responses between men and women were compared using a Pearson's chi.

Generalised linear mixed models (xtlogit) were fitted to account for clustering of respondents within villages in investigating factors associated with regretting study participation. Candidate variables for these models with the social demographic, violence and childhood trauma variables were explored in the analysis and presented in table formats. Modelling fitted followed a process of backwards elimination after all variables were included, with elimination initially at $p<0.2$ and the subsequently at $p<$ or $= 0.05$.

3.3.21 Ethical considerations

Ethics approval for Paper 4 was given by the research ethics committees (REC's) of the Universities of Pretoria and the Witwatersrand. These committees also monitored the progress of the trial until its completion. The Eastern Cape Provincial Department of Education gave approval to recruit through public schools, and access to villages was provided by the local traditional and political leadership.

Throughout the trial period, two professional nurses were employed to support the study participants (mentioned above under Study 1). They carried a cell phone and were available for calls at all times. All participants were given their phone numbers and invited to call if anything concerned them. Participants gave written informed consent to participate in the study and were given R20 (~US$3) as an incentive for participating. A Community Advisory Board was formed comprising stakeholders from various local organisations and its main responsibility was that of advising the investigators on the local context and observing the

overall progress of the study. All participants were told participation was voluntary, agreement could be withdrawn at any time and no consequences would ensue.

3.3.22 Outputs of Study 3

One original paper was produced from study 3.

The aim of Paper 4 is to describe participants' motivations for participating in the study and the prevalence of negative reactions from others to participants' involvement in the study. We also explore whether participants expressed pressure to learn their results, whether there were regrets associated with study involvement, and describe the impact on participants of questions about childhood trauma and violence on people. Finally, we explore factors associated with regretting participation.

Paper 4: Jewkes R, Sikweyiya Y, Nduna M, Jama Shai N, Dunkle K. Motivations for, and perceptions and experiences of participating in a cluster randomised controlled trial of a HIV behavioural intervention in rural South Africa. Culture, Health and Sexuality, 2012. 1-16.

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3.3.23 Conclusion

I began this chapter by presenting a theoretical framework that informed this PhD research. In the framework, I attempted to draw an overview of the different aspects of knowledge I suggested the need to deepen our understanding of the field of ethics in GBV research. Additionally, in the framework, I highlighted the knowledge areas that my PhD thesis will contribute to.

This chapter also provided a description of the methodological strategies that I employed for each of the three studies that informed this thesis. I have described how I approached

participants and data collection for each study, and highlighted the strengths and weaknesses for each study design.

For study 2, which is the main study for this thesis, I reflected extensively on the methodology I followed, how I positioned myself as an ethnographer in a setting and spoken languages I was not familiar with, the manner I was viewed by the people in the community, and how I responded to the challenges I encountered in the field. Additionally, as a research strategy, I described how I shifted and occupied different positions when interacting with different people and in different times and spaces in the community and how that benefited this research.

In the next chapters (5-8), I present the five papers that inform this thesis and in chapter nine I discuss the findings of this PhD research. The goal is to highlight my contribution to knowledge in this field of research, and later link my findings with what is already known and lastly recommend agenda for future research.

CHAPTER FOUR

PERCEPTIONS ABOUT SAFETY AND RISKS IN GENDER-BASED VIOLENCE RESEARCH: IMPLICATIONS FOR THE ETHICS REVIEW PROCESS

*Yandisa Sikweyiya and Rachel Jewkes

**Gender and Health Unit, South Africa Medical Council, Pretoria, South Africa*

Abstract

Does research on gender-based violence pose greater than minimal risk to researchers and participants? This question needs to be understood particularly in light of hesitancy by Institutional Review Boards to approve research on Gender-Based Violence (GBV). The Safety and risks of doing GBV studies and the implications for the ethical review process have not been a focus of much research. This qualitative study collected data through in-depth interviews with 12 experienced GBV researchers from various countries and a desk review. This paper explores researchers' interpretation of and meanings of the safety recommendations as provided in the WHO guidelines, and whether there is empirical evidence on the presence of risks and safety concerns unique to GBV research. Informants raised a number of safety concerns about GBV research, yet in the interviews there were very few examples of problems having occurred, possibly because of the precautions applied. Furthermore, there seemed to be some basic assumptions underlying informants' concerns. This paper argues that the notion that GBV studies carry greater than minimal risk when ethics precautions are followed is based on speculation, not evidence. It highlights the need for empirical evidence to support assertions of risk in research.

***Keywords**: Gender-Based Violence, GBV, safety, risk, ethics*

Introduction

Does doing research on gender-based violence (GBV) pose greater than minimal risk for researchers and participants? This question is pertinent in the light of hesitancy by Institutional Review Boards (IRBs) to approve research on GBV. Although several authors have raised concerns about the sensitivity of such studies (Ellsberg and Heise, 2005, Ellsberg and Heise, 2002, Jewkes et al., 2000), the safety and risks involved in GBV studies, and their implications for the ethics review process, have not been a focus of much research (Sullivan and Cain, 2004). IRBs have been accused of creating unnecessary barriers to the conduct of important and ethically correct research, when there are actually few instances of harm stemming from conducting research described in the literature (Grady, 2010). It is thus very important to understand whether concerns about the safety of GBV research are realistic.

Gender-based violence research has been identified as an area that is particularly sensitive. Researchers have argued that it has the potential to harm respondents in a way that is different from other areas of community-based study, and that for women respondents, the process of being interviewed about painful and sad events, may have serious traumatic effects or psychologically distress them. In response to these concerns, researchers have developed guidelines for conducting research on this topic and these have been published by the World Health Organization (WHO, 2001). The WHO Ethical and Safety Recommendations for Research on Domestic Violence Against Women (Box 1) were developed through consultative discussions with stakeholders including the Steering Committee for the WHO multi-country study on women's health and domestic violence against women and members of the Scientific and Ethical Review Group of the various international organizations (WHO, 2005)

Figure 1: ETHICAL AND SAFETY RECOMMENDATIONS FOR RESEARCH ON DOMESTIC VIOLENCE AGAINST WOMEN.

a. The safety of the respondents and the research team is paramount, and should guide all project decisions.
b. Prevalence studies need to be methodologically sound and to build upon current research experience about how to minimise the under-reporting of violence.
c. Protecting confidentiality is essential to ensure both women's safety and data quality.
d. All research team members should be carefully selected and receive specialised training and an on-going support.
e. The study design must include actions aimed at reducing any possible distress caused by the research.
f. Fieldworkers should be trained to refer women requesting assistance to available local services and sources of support. Where few resources exist, it may be necessary for the study to create short-term support mechanisms.

g. Researchers and donors have an ethical obligation to help ensure that their findings are properly interpreted and used to advance policy and intervention development.
h. Violence questions should only be incorporated into surveys designed for other purposes when ethical and methodological requirements can be met.

These guidelines, have been operationalised somewhat differently in different contexts (Ellsberg and Heise, 2005, Jewkes et al., 2000). As guidelines, they are not intended to be viewed as a prescription on how to do ethical research but a guide on good research practice. This distinction is important as it is not known how often women participants or researchers may be at risk of some of the actions that these guidelines seek to protect them from, such as violent reprisals after being interviewed (Jewkes and Wagman, 2007a).

It is now common practice in many parts of the world, for GBV researchers to follow the WHO guidelines (Ellsberg and Heise, 2005, Jewkes et al., 2006, Dunkle et al., 2004). However there is a need to better understand the risks from which they seek to protect as well as the question of whether there remain residual risks in undertaking GBV research when the guidelines are followed, which are greater than those pertaining in any other research work. This will enable IRBs to make evidence-based decisions and to locate the facts about risk in research and the level of safety needed by research respondents (Grady, 2010, Devilly et al., 2009).

The aim of this paper is to contribute to the debates on safety and risks in GBV research by gathering empirical data on the meanings of safety, the basis of concerns and the nature and scope of empirical evidence on the presence of risks unique to GBV research from publications and researchers who have worked in the field.

Method

This paper is based on data gathered through in-depth interviews and a review of four articles on ethics in GBV research (Box 2). Articles were selected based on their scientific rigour and relevance to this study (Sale, 2008, Ryan et al., 2007).

At first, through email correspondence, we asked information from ten researchers of the Multi-Country Study on Women's Health and Domestic Violence, which was a household survey of women that was conducted in 10 countries from different regions of the world (for a full description of the WHO study see WHO (2005) or Ellsberg and Heise (2005) . Two researchers from this group emailed their responses back.

Further to this, ten in-depth interviews were conducted. Eight with GBV researchers from various countries who attended the Sexual Violence Research Initiative (SVRI) Forum in South Africa in July

2009. Among these, we interviewed three of the five researchers who formed the Core Research Team of the Multi-Country Study (see (Ellsberg and Heise, 2005) who attended the SVRI forum. The SVRI forum provided a platform for 194 people from different countries of the world to share and discuss research on sexual violence (Dartnall and Loots, 2009). Interviews were conducted during the conference breaks or in the evenings after the conference sessions had ended. Two telephonic interviews were also done with local researchers who were study nurses in the South African Stepping Stones Study (Jewkes et al., 2006).

All interviews, and the email inquiry, were conducted with a thematic guide that had two broad questions with several possible probes. We asked the informants to respond to the following questions: How have you operationalised the safety guidelines in your respective country? Did you get any evidence that these guidelines were useful? With the consent of the informants, interviews were digitally recorded.

We present findings derived through a latent content analysis (Graneheim and Lundman, 2004). Analysis was performed by both authors separately. We read and re-read the text identifying open codes. Thereafter we established a set of categories and defined those (Dahlgren et al., 2004b). With categories clearly defined, we engaged with them attempting to understand the underlying and different meanings the categories could be having (Graneheim and Lundman, 2004). At this stage the authors came together to discuss the categories that had emerged in the data. Thereafter we linked the categories that fitted together and identified the main category. We then interpreted what we saw emerging. Findings were then compared with existing literature and conclusions made.

Ethics approval was provided by the South African Medical Research Council's ethics review committee.

Results

What were the researchers' concerns about safety?

In the interviews, informants discussed concerns that poorly planned GBV community-based studies put women participants at risk of further victimisation. The concerns were mainly about potential harm to respondents, and, to lesser extent, to researchers. Notably the psychological and emotional safety of fieldworkers or researchers was generally not mentioned as a safety concern.

Safety concerns for respondents.

The dominant issue raised was fear of consequences if there was a breach of confidentiality during data collection. Two informants explained the underlying concern:

…what worried one is that there could be breach of confidentiality. Meaning that people might know about the study and that it asks about partner violence and that could lead to more violence for women participants. (Female researcher, USA).

> … if we talk about the respondents, respondents are women in the households whom you do not know if they have been victims of violence or not, participating in a survey can put them in a situation in which they can get more violence like if the husband would find out if she has been talking about him, she could be at risk of more violence. (Female researcher, Switzerland#1).

Other informants mentioned that GBV research has a potential to be psychologically harmful to respondents as it asks people to think and talk about violent, degrading, shameful, painful and traumatic experiences in their lives. One informant explained:

> …it is one of the riskiest ones, it is a sensitive topic, and it is a topic that hurts at the end. I mean to everybody, even to the ones who are researchers, it hurts us, but even more to the ones we are interviewing, women and men. I think it is serious, I mean it (GBV) is one of the worst things that could happen in life. (Male researcher, Mexico)

Safety concerns for researchers

Concerns about safety for interviewers or researchers featured scantily in interviews. One female researcher from USA spoke at length of a particular study where psychological safety needs for fieldworkers were neglected. She explained:

> I interviewed the supervisors and the fieldworkers about their experiences and they started to cry…it was so difficult, we had such a hard time, it was so painful, and we got no support from our supervisors.

Another informant had this to say about lack of fieldworker consideration:

> …but these are actually measures that are necessary to ensure that the data is good quality, and that includes taking care of the fieldworkers emotionally, which nobody does. (Female researcher, USA).

Two informants raised concerns for physical safety for researchers. One posited:

> …more specifically, research procedures ensured quick communication among field teams, and between field teams and the coordination at the office; private places for the interviews; work-shifts and commuting procedures that observed strategies to ensure more safety in risky areas such as slums or very distant places (Female researcher, Brazil)

One of them perceived that important role players in research, like IRBs and research institutions, understood less about safety needs of researchers than experienced GBV researchers did. She posited:

> …Ethics committees generally are much more interested in the safety of the participant and they don't have sections on the safety of the researchers, just does not happen. It is like you know it is not part of the research, the researchers are not part of the research" (Female researcher, Australia).

Highlighting a resulting lack of consideration for researcher safety, very few informants mentioned as an ethical concern their safety or that of their staff in the course of data collection.

What precautions were taken to reduce risk?

Informants spoke of the need to carefully prepare for GBV studies. They described how, when preparing to undertake studies in communities, they would reflect on the setting on which they will be basing their studies, assessing the threats and risks they could encounter during fieldwork, and managing their studies based on the anticipated risks of physical danger. The following narrative from a researcher from Brazil demonstrates the careful planning that was done prior to their study to ensure respondent safety. She explained:

> Interviews were always conducted privately, and field teams took all necessary precautions to ensure such privacy. Supervisors would even take care of the children so that the interview could be conducted. Cars were also adapted to be used as almost an office for the interviews (we put inside them some small tables)… the teams worked close to each other and that all team-workers were prepared to help interviewees and to face more risky situations. (Female researcher, Brazil).

Other informants mentioned that introducing the study, at a community level, as one about GBV, might increase the risk of violence for women participants. For example, one informant who was part of the WHO multi-country study said:

> …so another thing for the safety which was extremely important and which was quite similar across the board was to not frame the study as a study of domestic violence. So in every country, they changed in the field the title of the study and in many countries it would be something like "a study on women's health and life experiences or a study of women and family or a study on women and safety". This is an easy way to introduce the study to the community and not to spread the word that they will be asking about domestic violence. (Female researcher Switzerland #2).

In the interviews, informants consistently mentioned that the true nature of the study should only be revealed when talking to the selected participant. They further posited that it must be explained to the woman that this is important for her safety and that the content of the interview should be kept a secret. This narrative is illustrative:

> We… [GBV researchers] say it is okay to introduce it like that in the household, when you talk with the individual woman, we then tell her we will be asking about some difficult things, and then when you get to the violence part, yes the questions on violence, then you ask again her informed consent. (Female researcher Switzerland#1).

Informants mentioned that having complete privacy for the interviews was essential. Even children two years and older, if present during the interview, might place women in danger as children could tell their fathers or others that their mother was talking about experiences of violence in the interview. One informant explained:

> …it [interview] has to be in a place where she is alone, and no children over 2 years old. Because we kept imagining things like the children are walking in and out and then later on they say "Daddy mommy was talking about… you know? They do not know what is happening." (Female researcher, USA).

To meet psychological needs, a number of informants raised the importance of establishing a referral support system for research participants. One informant explained how they provided support to women participants in their study. She said:

> "Interviewees were offered psychological, social, juridical and medical assistance through partnerships with Non-Governmental Organisations which offer assistance to women in situations of violence as well as with other specialised services available, previously agreed upon, to offer assistance to women with or without a prior history of violence." (Female researcher, Brazil).

What was the evidence of the magnitude of the risk?

In the interviews, it was apparent that most of the informants had based their views about the risky nature of gender-based violence research on the WHO guidelines (2001) and the little published literature (e.g. (Zimmerman and Watts, 2003, Ellsberg et al., 2001, Jewkes et al., 2000). Very few informants provided examples based on their fieldwork experiences, yet this does not preclude the possibility that they may have had such experiences and been influenced by these, but merely did not report them in the interviews.

An informant who formed part of the core research team of the WHO Multi-country Study, and experience with all the 10 participating countries, explained the threatening situations they encountered in the field:

> There were couple of bad situations, difficult situations where the husband came in and he was angry, but they were very few. You know relatively speaking they were very few. (Female researcher Switzerland#1)

In these cases it seems unlikely that the husband would have known that there were GBV questions in the survey, rather his response was anger at his wife's involvement in any research. Given the many thousands of women interviewed in this survey, this narrative suggests that such risk is not necessarily high in GBV studies, which is not to deny that these situations could be quite threatening when they occur.

In keeping with the WHO guidelines, informants felt it was important to have a referral support system in place in order to help respondents who needed emotional and or psychological support. A female researcher from Brazil explained how they ensured this in their study: 'Help to interviewees was foreseen and it was previously scheduled for those who requested it. Support to the interviewers was also anticipated'.

There was a general perception that this is vital for research on GBV, yet the narratives from informants below provided little evidence that respondents used available referral systems. As one informant explained:

> But somewhat we know, somewhat we know, there was little, there was very little uptakes of referral, so uhm…several studies have found the same thing. (Female researcher, Switzerland).

Another informant had this to say:

> What we did not set in place that would have been very helpful would have been a system to track if anybody actually used the referral. We think that nobody did, we think that nobody did, but we don't have that verified.…uhm, women very rarely use these services, they don't come, it's kind of too far away or maybe the violence took place a long time ago, there are, you know it is a lot of expense and not a lot of use and on the other hand we are not ready to take that out of the requirements because it does seem everyone knows you can have someone who is in a bad shape. (Female researcher from the US).

A study nurse who provided support to the participants in the Stepping Stones study, which was a randomised controlled trial (RCT), conducted in the rural Eastern Cape Province, South Africa, to test a HIV behavioural intervention that had a GBV intervention component (Jewkes et al., 2006),

mentioned that on the few occasions they saw informants who had been raped they followed a prescribed response:

> We then counseled them and referred them to rape care centers. However, when it came to referring them, I would say some participants did go to the centers we had referred them to. But in most cases, they would come back to us telling us that they were not happy with the services they got from those centers.

Two informants also mentioned that research is needed to better understand whether the referral support system requirement should be central in judging the ethics of a GBV protocol by IRBs, as it seems to be the norm currently.

Discussion

Research on GBV has been recognised to have at least the potential for being harmful to participants in ways which differ from many other forms of research (Lavery et al., 2007). This concern underpinned the development of the WHO guidelines. Many IRBs are concerned that these may not be sufficient to enable safe GBV research, yet in this study, informants provided very few examples of risks encountered when conducting studies having followed the WHO guidelines. Where problems were discussed, they were largely not linked to the subject matter of GBV.

In the interviews, informants raised the safety of participants as a major concern and in particular, they feared disclosure of the focus on GBV during data collection. Yet there were very few examples of problems having occurred. It is possible that this was because of the precautions applied and women heeded the cautions not to disclose the nature of the questions to others (Ellsberg and Heise, 2005). However, researchers did not know if women did discuss the fact they were asked about violence with anyone. It is also possible that given the fact that the questionnaires asked about a large range of different aspects of women's health and lives, women did not particularly view the research as 'about violence' or see anything more unusual about being asked about experiences of IPV than about how many sexual partners they had had or whether they had had an abortion. It the extent that embarrassment can follow it being publically known that any one of a range of sensitive questions have been discussed in an interviews and it may be desirable more generally to conceal the specific focus of questions from those who are not being interviewed. We suggest that concern is valid for all types of community based research and not just GBV research.

However, it is possible that women did reveal the fact that they were asked about violence and yet did not experience further violence that came to the attention of research teams. Concerns here stem from an assumption that interviewing women in a research on GBV might put her in danger of

physical harm from her partner (Wasunna, 2007b), and more specifically that violent and controlling men would specifically object to their partners disclosing their abusive behaviour (Jewkes and Wagman, 2007a). This assumption is premised on a supposition that violent men are embarrassed about their behaviour and want it concealed. Yet this premise does not seem to take into account the observation that men who use violence usually justify its use – commonly in terms of the woman 'deserving' it or seeing their use of violence as 'punishment' that given their superior hierarchical position could be legitimately meted out (Wood et al., 2007). Even sexual violence is usually justified by men who rape and often not thought of as being 'rape' (Jewkes et al., 2010b, Jewkes et al., 2006, Sikweyiya et al., 2007).

Literature regarding abusive and controlling men suggests that such men may disapprove of their partners talking to anyone without their approval (social isolation), irrespective of the nature of interaction (Goodkind et al., 2004). In this case any research with the women partners of abusive and controlling men might be risky and not just research on GBV.

Researchers working on other issues generally trust that the informed consent process will be sufficient to enable those who may have concerns about research participation to indicate that they do not wish to participate. This would include any who feared partner anger as a result of research participation. It is not clear why it should be imagined that this safeguard should be adequate for other forms of research and yet not for research on GBV. Indeed it is also worth considering that men who have used violence or controlling behaviours are a very diverse group and their practices lie on a spectrum. Not all men who have been violent prevent their female partners from talking to other women; generally the risk of sexual jealousy is seen as a greater one. As such, although such men may be socially isolating at times, they may not behave in that manner continuously and consistently and it's not clear how real this threat is in practice.

Ensuring that interviews can be conducted in private assists with confidentiality. The presence of children over two years of age was raised as a risk, for women respondents as they could potentially repeat things said during the course of interview (Ellsberg and Heise, 2005, Jewkes et al., 2000). This should not be used as an example of exceptional risks of GBV research. We suggest it is good practice in all community based studies for interviews to be conducted in privacy and for that to mean that children over two years should not to be present during interviews in order to allow respondents to feel free and be candid with their answers.

The WHO guidelines (2001) emphasise the importance of having an ability to make referrals to services and suggest setting up short term services for projects if none exist. A number of

informants mentioned that referral support system for participants should be incorporated in the design of studies, for respondents who might need it. It is a view of many people including IRBs that research on GBV should not be conducted if there is no referral support system in place. Yet it is not clear to what extent women who may have experienced abuse in the past or may have more recent experiences that they are living with want to seek help from external agencies after an initial disclosure of violence in a survey. The limited evidence of women using referral agencies when these are available questions whether this is an identified need.

Data from our interviews suggest that research participants seem not to perceive a referral support system to be as useful and important as widely claimed. There could be various reasons for this, one of which could be that these services are not of high enough quality and people may have had negative experiences using them. For example, calling a hot line and not receiving a reply. Yet the reason is probably more complex than this, as many people will not have prior knowledge of such services. Jewkes and Wagman reported the experience of South African researchers in a study in Soweto, where there was no discernable uptake of local referral services by over 400 participants who had disclosed abuse. The investigators concluded that 'access to support services after interview on intimate partner violence was not perceived to be valuable by most women in abusive relationships' (Jewkes and Wagman, 2007a).

Whilst it can be argued that it is desirable for women to be given service referrals or contact details when they are available. It becomes more difficult if research is conducted over a wide geographical base where services may be few and fieldwork logistics and budget may require rapid movement of teams through an area. Wasunna has argued that there is an absolute obligation on researchers who know they will encounter abused women to arrange to have professional counselors employed. But it is difficult to sustain an argument that it is ethically essential to provide a service that women interviewees themselves rarely perceive they need (Wasunna, 2007b).

One of the interviewees described GBV research as "one of the riskiest" areas of research, but in the interview clearly failed to distinguish between research invoked sadness or tearfulness, and more severe and enduring psychological distress that may benefit from counseling or psychotherapy. We argue that the two are quite different. Research on traumatic experiences often invokes tearfulness, as may questions about hunger, orphaning and many other areas. This is quite different from research causing psychological harm which may need treatment. A supposition that asking about a previous experience could cause harm is premised on a very paternalistic view of the weakness of women participants. This is a view quite at odds with the strength that is actually required to endure an abusive relationship or survive rape. Furthermore, this viewpoint seems not to take into account

the potential benefits that research participation seem to offer participants. The evidence from literature shows that participants see value in being asked about abuse, personal or sensitive, and traumatic experiences in research (Becker-Blease and Freyd, 2006, Beck, 2005, Hutchinson et al., 1994). In a longitudinal population-based study in Leon, Nicaragua, of the (229) women who had been previously exposed to violence, 41 (18%) reported that being asked about abuse in the baseline interviews conducted three years earlier had assisted them in their process to be free of partner abuse (Salazar et al., 2009). Similarly, in her qualitative internet-based research with 40 women, on birth trauma, across the globe, Beck reported several benefits that women enjoyed from participating in the research (Beck, 2005). These included women: feeling being cared for by being listened to and acknowledged, a sense of belonging, opportunity to make sense of their experiences, being empowered to let go and to deal with their situation. Additionally, in her book about the impact of researching rape, Campbell (2002) argues that, for participants [abused women], the 'process of telling their stories with an interested, engaged, and emphatic researcher can be incredibly validating and beneficial as research can provide participants with a supportive environment for catharsis'.

It is important that researchers and IRBs distinguish between invoked tearfulness and psychological trauma. Providing professional counseling and referral for the former is of doubtful value in the context of research. However all fieldworkers should be equipped to respond sensitively and provide emotional first aid when surveys include any questions asked that may make respondents recall emotionally painful and sad experiences. We therefore suggest that fieldworkers conducting any research that includes sensitive questions should be trained to recognise when respondents are disturbed by the questions and be able to respond by providing an empathetic emotional response, and offering to take a break or offering to stop the interview if the respondent so wishes (Ellsberg and Heise, 2005).

Having referral support system in place may possibly serve another purpose, that of alleviating some of the psychological stress that could possibly result for researchers who perceive themselves powerless in the face of accounts of trauma (Devilly et al., 2009). Knowing that there is a place that participants can be referred to if the need arises may prevent a feeling of helplessness for researchers (Coles et al., 2010). This could be valid even if few respondents actually use the referral system, but it might influence decisions around resource allocation to such a service.

The perception that there may be major safety and risk concerns with GBV research largely seemed to result from assumptions, anticipation and pre-study visualisation of risks (Langford, 2000), rather than empirical experience. In instances where there have been problems encountered in GBV research they have been mainly reported by researchers who have encountered them while conducting studies in politically unstable settings (Paterson et al., 1999) or with women who are still in trafficked situation or have just left the trafficked situation (Zimmerman and Watts, 2003). We suggest that for studies in other settings, particularly where the WHO guidelines have been followed, there should be an awareness that such a risk averse and defensive thinking may be offering protection against very small and or negligible risks.

This paper is based on a small qualitative research conducted with GBV researchers. A strength is that between them they had managed surveys with many thousands of women on GBV across all global regions. However it is possible that there had been safety issues arising during their work that they had not been informed about. It is possible that risks and safety needs of research respondents in different settings in the world may be different and so the breadth of their experience is of value. Most of their work was quantitative and we recognise that it is also important to provide empirical evidence about risks in qualitative research. It has been suggested by some researchers that qualitative in-depth interviews, due of their nature, have more risk of emotional and psychological harm for respondents and researchers, than quantitative survey questions might (Coles and mudaly, 2010). However, such a statement also needs to be interrogated in the light of comments that are repeatedly made to researchers that women welcome a chance to talk about experiences of abuse with a sympathetic listener (Jewkes et al., 2000).

Conclusion

GBV research is largely perceived as risky. Safety concerns dominate pre-study phase resulting in researchers setting up safeguards to guide research processes (Langford, 2000). In this paper we have argued that the notion that GBV studies carry more than minimal risk might be based on supposition and speculation. Yet, we do not suggest that the risk is not there and that violence cannot result, but argue that such risk remains minimal when protocols are followed as shown in Ellsberg and Heise (2005) and Jewkes et al. (2000). We recommend that more research should be done to understand research risks and their extent in different settings. For GBV research, such information will help us to better understand whether GBV studies pose more than minimal risk to respondents and researchers and make further recommendations based on that.

Figure 2: Research articles analysed.

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CHAPTER FIVE

POTENTIAL RESEARCH PARTICIPANTS' MOTIVATIONS FOR AND PERCEIVED RISKS IN RESEARCH PARTICIPATION: ETHICS IN HEALTH RESEARCH

Yandisa Sikweyiya [1], Rachel Jewkes [1]

[1] Gender and Health Research Unit, Medical Research Council, Pretoria, South Africa.

Corresponding author: Yandisa Sikweyiya

Email: ysikweyiya@mrc.ac.za

Abstract

In a South African urban township-based ethnographic study with adult 19 women and 07 men we explored motivations for and experiences of research participation and perceptions on being asked about sensitive experiences, including gender-based violence, and implications of participation for respondents. Several informants were motivated by self-interest to participate in research, others were more altruistic, yet with many there was a complex overlap. We found that that altruism, as a motivation to participate in research, is a muddled and multifaceted issue that needs careful unpacking and nuanced discussion to understand. Breach of confidentiality was perceived as a main risk, and gender-differences were apparent in reporting feared consequences, with women primarily fearing possible violent reprisals from partners. We conclude that the decision to participate in research seems to be a balanced and conditional process where people assess the potential individual benefits to themselves, contribution to others, and potential risks to themselves.

Keywords: Africa, South; Altruism; research participation; risk, perceptions; sensitive topics

All research with human participants carries a degree of risk. Research regulatory bodies including research ethics committees (RECs) and researchers have raised concerns about the potential negative impact of research on participants (Black, Kresnow, Simon, Arias, & Shelley, 2006; Jorm, Kelly, & Morgan, 2007; Widom & Czaja, 2005). However, very little is known about participants' perspectives on this topic. Participants enrollment is critical for research, so it is important to learn and understand what motivates people to enroll in research and what are barriers , and how research participation is experienced (DePrince & Freyd, 2004; Jefferson et al., 2011; Kneipp, Lutz, & Means, 2009; Rosenbaum et al., 2005).

To date, few studies have investigated the factors that influence participation and non-participation in research from the perspectives of actual participants (Kneipp, et al., 2009; Sharp et al., 2006). Available research suggests that research participant's motivations are multifaceted and complex (Hallowell et al., 2010).

Published studies have reported varying reasons given by actual participants as their motivation for research participation. These include altruistic reasons, which have been described by participants as the desire to help others, chance to help their community, and to contribute toward furthering scientific knowledge (Jewkes, Sikweyiya, Nduna, Jama Shai, & Dunkle, 2012; McCann, Campbell, & Entwistle, 2010; Sharp, et al., 2006; Sikweyiya & Jewkes, 2012).

In some studies participants' decision to partake is given when they perceive some benefit to themselves (Jefferson, et al., 2011; McCann, et al., 2010). For example, in a HIV behavioral intervention trial with young men and women (aged 15-26) in a rural province in South Africa, 66.9% of participants stated they were motivated by an opportunity to be tested for HIV (Jewkes, et al., 2012). Consistent with the findings by Jewkes and colleagues, some authors have commented that people might participate in clinical trials because of the belief that they might get a better treatment from the trial than what is locally available (Slack et al., 2004).

Although some authors seem to hold a view that monetary incentive for research participation does not compromise people's ability to provide informed consent (Grady, 2001), other authors oppose this view. For example, Viens (2001) argued that factors like poverty, low literacy levels and poor health can influence people to enroll in studies that offer large sums of money or other commodities as participation incentive without considering risks involved in such studies (see also Sharp, et al., 2006). This might be so because of having their judgment compromised by the amount of money being offered as an incentive for participation (Viens, 2001).

In the Jewkes et al. (2012) trial with young people (15-26) in the rural Eastern Cape province, participants who had been retained in the trial, at the last evaluation phase, were asked what had motivated them to participate in the trial, the majority of them indicated that the R20 (~US$3) incentive (given at each interview point) had been a part of the motivation, with many more women (66.9%), than men (40.9%) stating this. And for women, having been motivated by a desire for R20 was associated with regretting participation at the end of the trial. Noteworthy, however, is that, some of the participants who stated they were motivated by the monetary incentive to participate also mentioned altruistic reasons (Jewkes, et al., 2012). This highlights the multiplicity and complexity of people's motivation to participate in studies (Hallowell, et al., 2010).

Studies have mainly investigated people's reasons for participation in clinical trials, and have included both people who have participated and those who were potential participants in clinical trials (Ellis, Butow, Tattersall, Dunn, & Houssammi, 2001). In most cases, clinical trials compare new and established drugs or medicines using randomization techniques to allocate participants to different study arms. As such there is an equal chance for participants in clinical trials to get clinical benefit from participating in such trials (Hallowell, et al., 2010). In contrast, participants in social scientific and epidemiological studies are less likely to get direct and clinical benefits from research participation as they use observational designs which are non-

therapeutic. Therefore reasons and motivations for people to participate in clinical trials might not be the same as those for participating in observational studies (Hallowell, et al., 2010).

Presently, not many such studies have explored reasons for research participation in social science or epidemiological research, more so, in the area of violence against women (VAW) (Edwards, Kearns, Calhourn, & Gidycz, 2009). Several authors have emphasized the importance of investigating the motivations and barriers of women to participating in research (Sharp, et al., 2006). Additionally, some researchers have commented on the potential risks of enrolling women in sexual violence or gender-based violence research (Ellsberg, Heise, Pena, Agurto, & Winkvist, 2001; Jewkes & Wagman, 2007).

More recently, few studies have shown that women and adolescent girls perceive increased risk in participating in gender-based violence research. In particular, women and adolescent girls fear retaliatory violence from their husbands or boyfriends as a punishment for participating in research without the partners' approval (Ajuwon & Adegbite, 2008; Sikweyiya & Jewkes, 2012).

As researchers increasingly study gender-based violence (GBV) using community-based designs (Abrahams, Jewkes, Laubscher, & Hoffman, 2006; Dunkle et al., 2004; Jewkes et al., 2006; Jewkes, Sikweyiya, Morrell, & Dunkle, 2010), a greater understanding on how participants (women and men) perceive discussing experiences of victimization and perpetration of GBV and what implications of participating in such research has for the participants and community more broadly is very important for unpacking the ethics of GBV research and the appropriate protection of research participants.

With this article we aim to contribute to our understanding of how people living in an urban South African township perceive discussing their experiences in particular sensitive issues, if any, including gender-based violence in a research context. We explored their perceptions of research

including GBV research, on risks and benefits of research participation. We also explored their motivations to participate in research.

Setting

We conducted this research in Soshanguve Township in the Gauteng Province of South Africa. In the year 2010 a South African Non-Governmental Organization called GenderLinks (GL) collaborating with the South African Medical Research Council (SAMRC) conducted a community-based survey to study the prevalence of gender-based violence in the Gauteng province of South Africa.

The survey collected data in face to face interviews with fieldworkers completing a structured questionnaire with women and men more than the age 18, in 75 randomly sampled enumeration areas (EAs) in the province. Two of the EAs sampled were in Soshanguve. For the qualitative study we conducted the research in both these sections (Thate Block and Siyakhula Extension: pseudonyms) of Soshanguve using multiple methods of data collection. We conducted the qualitative interviews 2-3 months before survey interviews were conducted in Soshanguve. At this stage community members were not aware that there was an upcoming survey.

The Thate Block is a fairly established section of Soshanguve. It is predominantly a low-income area with few middle class families. Siyakhula Extension is relatively a new residential area which has originally been a squatter camp; mainly a poor area with a number of households still shack dwellings built of corrugated iron. These two sections (blocks) are approximately 4-6 kilometers apart.

Method

We designed this research as an ethnographic study borrowing methods and techniques, for data collection and analysis, from disciplines of anthropology and sociology (Silverman, 2002). At the start of the research the first author introduced himself to the community as a researcher and sought permission to conduct the study.

The first author spent approximately 03 months (March to May) in 2010 collecting data in the community. For these months, he rented a room in the Thate Block and lived fulltime in the community. He frequently visited the Siyakhula Extension spending the day conducting interviews and mingling with people and only returned to his flat in the evening.

With suggestions from community members, the first author identified two young people (man and a woman in their early 30's) in the two sections to be his research assistants and explained that this would include shadowing them around the community and helping identify potential

informants. During his three months stay in the community, the first author also participated in community activities attending community meetings and visited nearby houses and sometimes taverns with young men and women in the community.

Sampling

We conveniently and purposefully sampled women and men who were above the age of 18. Community members, community leaders, two officials of local victim empowerment centers dealing with cases of abuse, three officials of community police forum, and other key informants were interviewed. All these people were potential survey participants but at the time of the qualitative study those who were to be interviewed in the survey had not yet been selected.

For the qualitative study, we explained the purpose of the study to the potential informants and invited them to participate. All informants in the study signed informed consent to participate in the study.

We approached participant's recruitment and data collection fully aware that we were aiming for varying and diverse perspectives (Hennink, Hutter, & Bailey, 2011, pp. 88-90) in terms of participants' experiences and perceptions about research participation. As such, during fieldwork, we employed theoretical sampling as we intentionally sought people with different characteristics (Hennink, et al., 2011, p. 92), for example, we approached older people, young people, women and men, and professionals who were working within the community.

Although we were aware that education might be important information in this study, it was difficult to identify and target people using education as a criterion. We approached the issue of education sensitively as we felt people might be offended if we directly ask them about their schooling and educational levels. However, within the categories above, we attempted to interview as many people as we could until the first author felt the information he was getting from the participants in each category began to repeat itself in subsequent interviews (Silverman, 2002, p. 71).

Procedure

All interviews were conducted by the first author. He conducted interviews mainly in Zulu and few informants spoke in Setswana, using a thematic guide and he audio-recorded the interviews with the permission of informants. A total of 26 in-depth interviews were conducted. 19 women and 07 men were interviewed in this study. The first author kept field notes in his diary throughout his stay in the community and these notes were included in this analysis.

Furthermore, in his interaction with study informants, he also documented how people spoke about issues and what kind of emotions they displayed when speaking about certain issues and experiences (Hennink, et al., 2011, p. 75). These emotions, for example, joy, sadness and worry, were documented in the first author's diary and used as data. Documenting participants' emotions as data is consistent with the viewpoint of Braithwaite that a good ethnographer documents how he felt during the interaction with others and what he hears or observes occurring as people interact among themselves (Braithwaite, 2006).

The 26 audio-recorded interviews, together with the field notes, were transcribed verbatim; notes were typed, and translated to English by the first author. During transcription the first author anonymysed the data removing all the information that could potential identify the participants and prepared the data for analysis.

The fact that more women than men were interviewed in this study could be reflecting gender dynamics in these communities. A larger proportion of women than men was unemployed and stayed at home; and was thus more available during the day for interviews. Men were difficult to find as they worked in nearby towns and would come home very late in the night or during the weekends.

Initially, the interview guide included only a few broad questions with possible probes drafted. We first asked the informants if they had ever been involved in research, if yes, we asked for the accounts of research participation and thoughts and feelings related to this. If no, we asked

them to think hypothetically what they thought research participation would involve and their general feeling about research. We also asked whether there were any issues they perceived sensitive to talk about in research, what issues would be those and why. We then asked whether being asked to talk about how they raised their children, and whether children ever went to bed hungry, was a sensitive issue and why. We asked them if GBV was a sensitive topic to talk about and why, and what would be their concerns related such research. We specifically asked them how they perceive being asked about experiences of intimate partner violence (IPV) and sexual violence. We did not ask them to provide personal accounts of violence; however some voluntarily gave accounts of interpersonal violence.

We quickly analyzed the data that we had gathered in the first interview through memoeing (Darke, Shanks, & Broadbent, 1998), and added themes that we deemed interesting and worthy of more exploration to the interview guide and probed those issues more in subsequent interviews (Hennink, et al., 2011). This process continued throughout data collection and provided us with assurance that we attained data saturation in each variable of interest in the study (Hennink, et al., 2011).

Data analysis

We employed a grounded theory analysis to analyze the data (Dahlgren, Emmelin, & Winkvist, 2004; Hennink, et al., 2011). We analyzed the data inductively (Silverman, 2002). Initial analysis was performed by the first author and checked by the second, and it included data from 26 in-depth interviews and the first author's field notes (Hennink, et al., 2011). The first author transcribed the audio-tapes verbatim and translated them to English and during transcription, he removed all information that could identify the informants.

Initial codes generally corresponded with themes as set out in the interview guide. We read and re-read the transcripts and extracted relevant text. We then grouped similar text under a theme that seemed to represent that particular text (Hennink, et al., 2011). We then explored the data

identifying open codes. We did this by breaking the sentences into small parts identifying several codes within the same sentence (Hennink, et al., 2011). At this early stage, we attempted to move up from the informants' words and were abstract in labeling the codes.

We maintained consistency in labeling the codes so that it would be possible at the end to group similar codes together and produce categories (Dahlgren, et al., 2004). At this stage, we came together and compared and discussed the codes until we agreed on which codes seemed to fit together to form categories (Hennink, et al., 2011).

Following the advice of Dahlgren et al. (2004), we constructed concepts and the theory by finding axes between the codes and categories and thereafter identified the main category. We then explored what these data mean and interpreted them. In this last stage of the analysis, we compared the findings with the existing literature and made conclusions (Dahlgren, et al., 2004; Hennink, et al., 2011; Silverman, 2002).

In the results section we present findings by organizing them into themes that inductively emerged from the data. However, in line with a qualitative grounded theory study, themes like "sensitivity of the research", and "concerns and risks involved in research participation" were concepts that were derived from published literature and we included these themes in the study interview guide and tested them through interviews whether they were important variables for this study.

Ethical considerations

We gained ethics approval from the ethics committees of the South African Medical Research Council and the University of the Witwatersrand. We explained the purpose of the study, risks and benefits, informants' rights, and the procedures involved in the study to the informants and invited them to participate. All informants signed an informed consent form. All in-depth interviews were held in private.

The first author informed the informants that the information they share with him would be held in strict confidence and that only he would know it is they who gave that information. To guarantee confidentiality and anonymity of the data presented in this article, we have changed names of all the informants and the names presented in this article are all pseudonyms.

We did not give incentive to the informants to participate in this research and we are not aware of any research adverse event having occurred during the period of data collection. After conducting these interviews, although he was no longer residing within the community, the first author continued to visit the community for another 3 months, and during this period, no research-related adverse event was brought to his attention.

Even though we did not view this research as risky, we put in place measures to deal with participants who might have strong emotional responses to the interview discussion (SAMRC, 2001). Soshanguve Township and Pretoria, the nearest town, are well resourced in terms of psychological services, social services including rape crisis and HIV centers. As such, in the study leaflet we had listed relevant centers where, with the consent of the participants, we could refer them depending on the nature of the problem. No participants needed psychological support because of the discussions in the interviews.

Findings

In the interviews, thirteen (13) informants had not previously participated in research. Nine informants had had survey interviews. A number of women had participated in clinics or hospital-based pregnancy related interviews; one woman, Ntombi had participated in a vaginal microbicide trial. The remaining three had either participated in interviews about their social services needs or on levels of crime in their communities.

Expectations in research participation

The vast majority of informants (22) mentioned varying expectations of benefits after participating in research, mainly of direct and immediate benefit. However, a few had expectations that there will be benefits for the whole community.

Our analysis revealed interesting distinctions between the informants who mentioned this from those who did not. The nine informants with prior research participation and the one who had some tertiary education were less likely to report expecting direct personal benefit from research participation than those with no prior research participation. The latter group was the majority and had generally demonstrated a lack of understanding of research. Our analysis revealed no difference according to informants' gender in having this perception.

In terms of socio-demographic and economic status, we found that older informants and those who reported financial difficulties were more likely to expect an immediate and individual benefit from research participation. For example, Dineo was clearly struggling financially, explained her expectations in research:

> You know when I tell you; maybe you can feel for me and help me with something that would make a little difference. Maybe I talk to you and tell you that there is no maize-meal, no sugar, no paraffin, maybe you will then reflect on that and say, this woman is staying here with children, and there is no food in the house and if the electricity is switched off, there won't be money for paraffin, but I am eating at home, and even throw away some food; maybe I should take the little I have and share with her so that she can be able to feed the children.

Informants who reported this were more likely to also report that they were sole bread winners in their homes, were unemployed, or doing menial jobs, and were struggling to pay the monthly municipality bills. Perhaps owing to these challenges, some reported that they hoped they

might benefit in the form of: “being offered jobs,” help with their “ill-health and other “economic problems.” This narrative from Nomusa explains this expectation. She said:

> You [researcher] come and say you are going to do research in the community, like after you have interviewed them, and what what, they want something because you know people are poor so they do not give information for nothing.

The expectation to benefit personally and materially was held irrespective of the gender of the informants, suggesting that it was because of the socio-economic challenges that were prevalent in this community. However, not all informants expected to benefit materially from research participation. Some reported that they hoped that having disclosed their personal problems, prompt interventions will be made to remedy their situations, and women informants were more likely to mention this. Furthermore, these women were more likely to be those who had reported to have been victims of interpersonal violence or had witnessed it at their homes. For example, Angelina had reported a long history of partner abuse from different relationships including the current one, and she mentioned that she disclosed abuse hoping that an intervention will follow. She explained:

> The very issue I’m uncomfortable with is the one he [researcher] should know. He should know about it and do something about it, if he can. If he cannot then he can tell someone else about it. Tell him that I’m doing research about this and let us see what we can do about it.

Joyce, who reported witnessing a lot of violence between her parents when younger, attached importance in speaking out about interpersonal violence even in the research context. She had reported that whenever there was an episode of violence between her parents, which happened often, no one would come to intervene. She believed that had timely intervention been made, it would have prevented the deleterious consequences including: “her father being badly burnt by water thrown by her mother and the divorce that ensued.” Her narrative suggests that she

would disclose partner violence in research expecting than an intervention to her situation will be made. She explained: “I would be open and talk about experiencing partner violence. I would not think about anything, I would be open. Yes I would be open knowing that I’m talking to the person who is going to help me.”

Perceptions on risks involved

A number of informants perceived a range of risks in research participation, with breach of confidentiality being the main one. Our analysis revealed no gender-differences in reporting this concern. However, gender-differences in feared consequences of breach of confidentiality were prominent. A number of women mentioned that research participation might cause or exacerbate violence in their homes or relationships. They said that if their partners came to know that they had discussed their relationships in the interview, there was a potential for suffering physical harm or other forms of punishment from their partners.

To illustrate this more, during the interview with Angelina, her boyfriend arrived and Angelina panicked and requested to stop the interview and talk about something else. When he had left, she was able to continue with the interview. She did not explain at the time that the man was his boyfriend, rather said she did not want her personal issues to be known by others. However, she was clearly frightened by his sudden arrival.

Two other women informants shared the same worry about possible reprisals from their partners should there be a breach. However, neither of these women had mentioned histories of partner abuse:

> Whatever I tell you must just remain between us or maybe I tell you about my boyfriend and maybe he would say’ no, no you go around telling our business’ so it should be a secret between you and me. (Bulelwa)

As well, Matlakala explained:

If you are able to arrest him, if you can arrest him maybe as a police officer, but if you are not a police officer, why would I tell you? What would you do after I have told you my problems? Because you are going to reprimand him, and he will stop for that day and after you are gone, he starts again. So now, how have you helped, how have you helped? You did not help at all. You have just wasted your words.

However, we did not set out to collect informants' accounts of partner violence, so we are not sure if these two women had experienced violence and do not know why they were worried about possible violent reprisals from their partners. However, in this setting, prevalence of partner violence perpetration is high (Machisa, Jewkes, Morna, & Rama, 2011); therefore it might be that these women had perceived a potential for violence if their partners were to know they had reported their violent behavior in the interviews.

Similarly, men mentioned breach of confidentiality as a great worry for them. However, men projected ramifications that contrasted with those predicted by women. Their fears were not related to physical harm they could suffer from their partners as women had expressed. Rather, men were principally concerned that their integrity might be tarnished and would suffer embarrassment in the community if their personal information, including their identity, could be exposed. They were particularly worried that they might be perceived as weak, stigmatized, pitied and ridiculed by others.

What is sensitive to talk about in research?

Few informants mentioned that there were no issues they perceived as sensitive or difficult to talk about in a research interview. These informants stated that they would freely discuss personal issues. They included both women and men, and there was no distinction according to age and personal experiences from those who were cautious.

Notwithstanding, a number of informants, men and women, reported that there were particular experiences in their lives they would be embarrassed or uncomfortable to talk about in a

research interview. They stated that they would be ashamed to report negative life experiences fearing being judged harshly by the researcher, and if confidentiality breach occurs, others in the community. This narrative from James is explanatory:

> No those topics [poverty, no food at home] are not sensitive to talk about. But other people may be embarrassed. I am a man, you[researcher] as well you are a man, and it could happen that as you enter my house, I would think that if I tell him that I am struggling to make ends meet here, he will look down on me.

We asked which life experiences were perceived as sensitive by these informants. Broadly, with regards to partner violence, informants mentioned that disclosing abuse, either as a perpetrator or victim is equivalent to admitting being an abuser or a victim. They were not comfortable with this. This was because of the shame and blame that is normally attached to experiencing abuse, either as a victim or perpetrator. Thus informants mentioned they feared being labeled negatively and stigmatized.

Some informants stated that it would be difficult to talk about the experiences they deemed painful, degrading and traumatic. In reporting this, gender-differences were observed in the data. For women informants, having children while still very young and not married, having a large number of lifetime sexual partners, intimate relationships and sex, being a victim of sexual abuse would be embarrassing and difficult to talk about. Dineo and Karabo (both women) explain:

> It is not easy for those who are being violated, because it embarrasses her. You will find that the husband is beating the woman because she is refusing to have sex with him, so it is not something that you would speak about to others and say we fought because I refused to have sex with him. So when you refuse, he will ask you why are you refusing, who are you going to give it too? Things like those, so that is why you find that they are not able to talk about it. (Dineo)

But you know I do not think there is something that is more sensitive than the issue of sexual abuse, nothing beats that one. No I do not think there are other ones. But if I may ask you, do you think there is? (Karabo)

In contrast, although a few women also mentioned this, the majority of men said that talking about their socio-economic circumstances, which they viewed as poor, would bring shame and embarrassment to them. They asserted that they would protect their dignity by concealing information pertaining to such issues. However, many informants also mentioned the significance of honesty and openness, and highlighted the importance of talking about personal and sensitive issues in a research context. Many had perceived talking about sensitive information in research as beneficial.

What opportunities were perceived by participants?

In the interviews we asked the informants how they thought they would benefit from research participation. Matlakala strongly emphasized she did not see any benefit, was suspicious of research and not happy that she had been interviewed.

Notwithstanding Matlakala's misgivings, the vast majority of informants mentioned that they perceived benefits. This viewpoint was held by many irrespective of age, gender and personal experiences. Informants generally perceived research participation as an opportunity to talk about their personal issues and be listened to by someone who is keen to do so and not intending to judge them. They explained that through research participation, they derive a rare opportunity to talk about the issues that are bothering them in their lives, ones they normally would not have people to talk to about. Bulelwa explained:

> No I would tell you [about partner abuse] so it's out of my soul, like one would not have anyone to talk to like your parents, we do not feel free talking to them even if you have a problem they judge you before you even finish, uhm like they would say 'I told you so.'

Similarly, Yvonne had reported experiencing partner abuse in particular from the father of her children whom she described as a very violent man who often beat her. She viewed research participation as an opportunity to talk about her experiences in a safe environment. She explained:

> I should tell you the truth, because if I lie to you, the thing would eat me inside. If I tell you the truth, then it is better because it is now out. But if I lie and say he was not beating me, while he was doing so much abuse, do you see that he will end up killing me? It is better if I speak because I'll be free. Yes I become free because I have told somebody what my problem was. I told him/her without planning to and the person understands that I have a problem of this nature.

The experience of being asked about painful and adversarial experiences was viewed as cathartic by a large number of informants. In particular they perceived talking about such experiences, to a willing, non-judgmental and emphatic listener, therapeutic. As such, many had equated research interviews with therapy and often used such terms as spiritual relieving and healing to describe this emotion reaction to the interviews.

What motivates participation?

There was an element of altruism that could act, and for some acted, as a motivation to participate in research. A total of nine informants gave reasons that were broadly altruistic as their motivation to participate in research. We viewed statements like: "with my information I may be helping someone," "I think [with my information] you will advise other people who are abused the same way I was," "this information will help those it will help," as altruistic. We noted no particular differential characteristics in informants who reported altruistic motives in terms of gender, age, and personal experiences.

Gracia, who had disclosed history of abuse in her intimate relationship, mentioned that she was motivated to disclose her abuse history in this study because such information might help other

women who have been abused. She posited: “It’s like you see, uhm it’s not a problem because I think you will advise other people who are abused the same way I was.”

Similarly, although Bulelwa had not directly reported partner abuse in the interview, she highlighted the importance of sharing life experiences in research interviews: She said:

> Then you will write an article and help other people in the future who cannot speak for themselves and when they read it they will see that there is someone who had the same problem as me and maybe talk about it.

George, possibly referring to his socio-economic hardships, hoped the information he disclosed in the research might be useful to others. He explained: “Then maybe some other day you can be able to write about my experiences and teach others on how to deal with their problems.”

Even though some informants might have primarily been motivated by the desire to help unknown others (contribute to knowledge generation and general society), or significant others (family and community), with a number of informants we observed a complex overlap between this altruistic motive and self interest. Some informants who reported altruism as a motivation also expected benefits to themselves, or to immediate family. An example was George, who expressed the desire to contribute to the society through his information [above narrative], but he also expressed hope to personally benefit: “Now you will be able to look at this information and say in George’s house, it seems the problem is this and that, then we should help him this way. That would be very good.”

Discussion

In this analysis we have shown that the vast majority of informants in this study would, and some had, participated in research with expectations to benefit in various ways. We have shown that for some self-interest would be, or was, the sole reason, while for others there was an overlap between altruism and self-interest.

This finding gives support to those reported in other studies (McCann, et al., 2010; Rosenbaum, et al., 2005). These studies have shown that, save for the few people who enroll in research studies for purely altruistic reasons, many participate in research to gain either financially, medically or some other way (Viens, 2001). For example, in their study McCann and associates (McCann, et al., 2010) reported that for those participants who had agreed to be randomized into the trial, 'participation seemed to be something of a win: win situation, where they could contribute to the betterment of others while also self-benefiting.'

In the present study, we did not collect enough data on educational background of informants to allow us to interrogate data through making comparison by education level, yet we found that the informants who had prior experience of research participation, were younger, had reported some tertiary education, were less likely to be motivated by self-interest to participate in research studies. In contrast, those who were older and had reported economic challenges were more likely to be motivated by self-interest to participate in research. The former group, perhaps because of previous research participation or exposure to research at school, had a better understanding of what research might entail, and thus were able to anticipate better what might or might not be yielded from research participation.

Altruism as a motivation for research participation is a muddled and complex issue that needs careful unpacking and nuanced discussion to understand (Braunack-Mayer, 2002). Many authors have reported that some people enroll in research studies motivated by altruistic reasons (McCann, et al., 2010; Rosenbaum, et al., 2005; Sharp, et al., 2006), however, without unpacking what altruism might mean in the research context (Braunack-Mayer, 2002; Hallowell, et al., 2010).

Our analysis reveals that altruism is not a straightforward phenomenon. We have found that in many cases altruism and self-interest as motives for research participation were intricably linked (Braunack-Mayer, 2002). A number of informants reported that they would or were motivated by a desire to help unknown others while at the same time anticipating benefits directly to themselves or

to their families or community (McCann, et al., 2010). Thus, we concur with Hallowell et al. (2010, p. 44) that because research participants are "social actors who exist within a network of social relations", their motivations for research participation exist in an interdependent relationship, that overlaps, as such can be presented as interleaved and interlocking. Various factors, including socio-economic needs, education level, previous research exposure, and other social factors, that pertain in individual people's situations, circumstances and context might act to influence people's decisions to participate or not in research studies. Additionally, such factors might also moderate people's expectations in research participation.

During participant recruitment adequate time should be invested in explaining the purpose of the study focusing, as well, on identifying and dispelling expectations that might not be met by the research (Paradis, Phelan, & Brinich, 2010). This will ensure that research participants are not left with unmet expectations when the project had ended.

In this study, some women, especially those who had been or were currently in abusive relationships, participated carrying hopes that an immediate intervention will be provided to remedy their situation, particularly to stop the violence. We suggest that informed consent, as a continuous process, should be utilized as an opportunity to remind research participants of the purpose of the research, and with that clarifying what might or might not result from research participation, in particular the risks and benefits that might accrue to participants.

We have shown that breach of confidentiality was perceived as a main risk by informants in this study. Several authors have previously argued that GBV research has the potential to place women at risk of physical harm from third parties (in particular partners) or aggravate an already violent situation (CIOMS, 2002; Ellsberg & Heise, 2005; Jewkes & Wagman, 2007; Jewkes, Watts, Abrahams, Penn-Kekana, & Garcia-Moreno, 2000; Wasunna, 2007).

In showing that women themselves fear this risk, this finding has significant implications for research conducted with women in this setting. (CIOMS, 2002 Guideline 16). As such, we suggest that researchers should consider this risk and that special precautions be followed to maximize the protection of these women (Ellsberg, et al., 2001; Jewkes, et al., 2000). We argue that this should be a practice in all community-based research that involve women as it is currently not well understood what might trigger reprisal (from third parties) and under what circumstances.

Some authors have commented that asking participants about their personal, sensitive or painful experiences carries a potential to emotionally and psychologically damage respondents (Black, et al., 2006; Savell, Kinder, & Young, 2006; Widom & Czaja, 2005). In this study we have found that asking participants about negative or adversarial experiences might cause discomfort, tearfulness and pain. However, informants felt they could talk about such experiences, and some did, and did not perceive or report being emotional damaged by this.

These findings suggest that discomfort and pain from answering sensitive questions do not equate psychological harm. These emotional reactions are dissimilar in terms of duration and severity (Jorm, et al., 2007; Kuyper, de Wit, Adam, & Woertman, 2012). Consistent with this argument, findings from other studies have shown that research participants, irrespective of adverse personal experiences, do not get psychologically or emotionally damaged from talking about their traumatic histories in research (DePrince & Freyd, 2004; Griffin, Resick, Waldrop, & Mechanic, 2003).

The agency of research participants and their ability to protect themselves from research related harms is often overlooked or not recognised (Macklin, 2004, p. 1). In the present study a number of informants said that should they be uncomfortable with a research question or think the question was invasive or sensitive, they would inform the researcher that they are unwilling to answer the question, or end the interview. Some reported that they would not answer the question factually. Indeed, we learned that two men who were HIV positive initially did not answer factually about their HIV status when asked, yet in subsequent interactions with the first author, they

disclosed their HIV status and stated they had been uncomfortable and were suspicious of him in the first interview. The responses of these informants reflect some degree of agency and power of participants to protect themselves from perceived harm (Sikweyiya, Jewkes, & Morrell, 2007).

Published data support the view that research participation is perceived as beneficial by a large proportion of research participants, including those who have had experience of major adversity (Edwards, et al., 2009; Johnson & Benight, 2003; Kuyper, et al., 2012), and with recent traumatic experiences in their lives (Griffin, et al., 2003). Our finding adds to this growing body of evidence. The vast majority of informants in this study perceived research participation as a welcome opportunity and saw benefit in participating in research. Only one informant perceived no benefit in research participation, rather viewed it as burdensome.

In the present study we enrolled two groups of informants. Some had participated in research before, while some had not (c.f. Kim, Millard, Nisbet, & Caine, 2004). Thus, we collected real life accounts from one group, and hypothetical ones from the other. This opens the possibility that some informants, in particular those who gave hypothetical accounts, might have reported what they thought was desirable to be said to the researcher. However, we concur with Hallowell et al. (2010, p. 45) that approaching research in this manner is "scientifically acceptable because both accounts (real and hypothetical) are underpinned by similar (ethical) reasoning and also informed by the social context in which they are produced."

Living in the community fulltime allowed the first author to capture data that was unspoken, rather, acted out as people interacted with one another. The first author was able to overhear and or observe events and incidents as they unfold enabling him to capture these experiences as they naturally occurred. These data were useful in explaining and verifying certain issues that were reported in interviews by informants or issues of interest to the study assisting in the contextualization of the findings (Mfecane, 2008; Wood & Jewkes, 2001; Wood, Lambert, & Jewkes, 2007).

Additionally, through observing certain things being acted out, or issues hinted in informal talks with or among people, the first author was able to probe for those in subsequent interviews leading to a deeper understanding of the context and issues (Mfecane, 2008; Wood & Jewkes, 2001; Wood, et al., 2007). For example, the manner in which men and women communicated with each other and how they resolved conflicts when they arise and relationships dynamics were captured through observations.

Interviews in this study were conducted by a man interviewer. Thus a possibility exist that this might have influenced the data collected in interviews with women as they might have been uncomfortable to share intimate information with a man interviewer.

Conclusion

We have shown that the decision to participate in research is mostly a balanced and conditional process (Hallowell, et al., 2010) where people assess the potential individual benefits to themselves, alongside contribution to others (McCann, et al., 2010), and the potential risks to themselves (Ellsberg & Heise, 2002; Ellsberg, et al., 2001; Jewkes, et al., 2000). Even though some topics were perceived as sensitive and difficult to talk about by many informants in this study, they did not view discussing such experiences as emotionally harmful. Furthermore, the vast majority did not only appreciate the opportunity to talk about such experiences, but perceived benefit in doing so in a safe environment as that provided by the research.

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Bios

Yandisa Sikweyiya, MPH, is a Senior Scientist at the South African Medical Research Council.

Rachel Jewkes, MD, is director of the Gender and Health Research Unit at the South African Medical Research Council and an honorary professor at the School of Public Health, University of the Witwatersrand, Johannesburg, South Africa.

CHAPTER SIX

PERCEPTIONS AND EXPERIENCES OF RESEARCH PARTICIPANTS ON GENDER-BASED VIOLENCE COMMUNITY BASED SURVEY: IMPLICATIONS FOR ETHICAL GUIDELINES TO PROTECT PARTICIPANTS

Yandisa Sikweyiya [1], Rachel Jewkes [1]

[1] Gender and Health Research Unit, Medical Research Council, Pretoria, South Africa.

Corresponding author: Yandisa Sikweyiya

Email: ysikweyiya@mrc.ac.za

Abstract

Objective: To explore how survey respondents perceived their experiences and the impact of participating in a survey, and to assess adverse consequences resulting from participation.

Design: Qualitative study involving purposefully selected participants who had participated in a household-based survey.

Methods: This qualitative study was nested within a survey that investigated the prevalence of gender-based violence perpetration and victimization with adult men and women in South Africa. 12 male- and 10 female-in-depth interviews were conducted with survey respondents.

Results: A majority of informants, without gender-differences, perceived the survey interview as a rare opportunity to share their adverse and or personal experiences in a 'safe' space. However, gender-differences were noted in reporting perceptions of risks involved with survey participation. Some women remained fearful after completing the survey, that should breach of confidentiality or full survey content disclosure occur, they may be victimized by partners as a form of punishment for survey participation without men's approval. A number of informants generally discussed their survey participation with others. However, among women with interpersonal violence history or currently in abusive relationships, full survey content disclosure was done with fear; the partner responses were negative, and few women reported receiving threatening remarks but none reported being assaulted. In contrast no man reported adverse reaction by others.

Informants with major life adversities reported that the survey had made them to relive the experiences causing them sadness and pain at the time. Yet, most felt these emotions were time-limited and not overwhelming. No informant perceived the survey as emotionally harmful or needed professional support because of survey questions. Rather the vast majority perceived benefit from survey participation.

Conclusion: This article argues that asking participants, including survivors of interpersonal violence and other traumas, about their adverse histories is not deleterious; rather can be valued and perceived as beneficial by research participants.

Introduction

In the past few decades, worldwide, there has been an increase in research on interpersonal violence and trauma histories [1, 2]. With this increase, institutional review boards (IRBs) and researchers have raised ethical concerns about the studies [3, 4], in particular the potential negative impact (emotional reaction and distress) they may have on research participants [2, 5]. This concern has prompted some researchers to shift their attention towards empirically studying the impact of such research on participants [3, 4, 6].

At present, not much is known about how participants perceive being asked about interpersonal violence and trauma histories [7-9]. There has been little research on this area [1, 5]. Thus, distress and emotional harm of participants due to their participation in research remain a concern for all involved in research [8].

We have an obligation to both the field of research on violence against women, and in particular to the participants, to understand how being asked about their adverse experiences impact them [9]. Yet, the lack of data creates a major gap [10]. Very little is known about either adverse consequences or benefits derived by participants who have violence or trauma histories when participating in research that asks about such histories [4, 11].

Some authors argue that this leaves IRBs to make judgments about risks of research participation based on personal experiences, conjunctive assumptions and guesses, rather than on empirical evidence [4, 5, 7, 11, 12]. Researchers and IRBs have an important responsibility in ensuring that harm to research participants is minimized, while benefits are maximized [9, 11]. In order to carry out this task, researchers and IRBs need to, primarily, encourage and engage with research to better understand how participants themselves perceive risks and benefits in participating in research [5, 10-12]. Evidence from such studies can guide IRBs and researchers in making decisions about risk-benefit ratio of research proposals that aim to study interpersonal violence and other sensitive topics [3, 5, 7, 11, 12].

Whilst not much research has been done in this area, recent empirical evidence suggest that research participation for interpersonal and trauma survivors does not overwhelmingly distress participants, rather, participants report experiencing such research as beneficial [5, 6, 13]. This finding is consistent with findings from other studies which report that research participants, in particular those who have reported experiencing interpersonal violence and other traumas, seem to benefit from participating in research [1, 3, 6, 7].

This, however, does mean research participants do not get upset or distressed when asked sensitive questions or about their trauma histories [2, 12]. Yet, literature shows that a low percentage of participants report being distressed and or upset by research participation, and the negative effects, such as feeling distressed or upset, seem to be time limited and not overwhelming [2, 11]. Several studies report around 10% [3] of participants reporting some form of distress as a result of participation in research on interpersonal violence and other traumatic histories, but a few studies have reported higher percentages. For example, Johnson and Benight [6] enrolled 55 women (aged 18-65) currently recovering from domestic violence and recruited from domestic violence (DV) shelters, DV support groups, and other centers servicing abused women. They reported that 25% of participants reported being upset by research participation. Interpreting these statistics is complex as the distress of research participation may also be accompanied by a perception of benefit. Thus evidence suggests that most participants value being asked about violence and trauma histories in research and report that they would be willing to participate in such studies in future [2, 3, 5].

Purpose of the study

This study aimed to explore how participants perceived their experiences with a community-based survey of men and women (over 18 years) on prevalence of gender-based violence victimization and perpetration in the Gauteng province of South Africa. We wanted to understand participants' perception on how the survey impacted them, how answering the survey questions had made them feel, and to establish whether they perceived the survey as distressing or helpful. Lastly we wanted to understand if they had experienced any adverse consequences resulting from their participation in the survey.

The interviews were conducted 4 to 12 weeks (July-September 2010) after the main survey was administered. The survey questionnaires for men and women slightly differed in particular on phrasing questions on gender-based violence experiences. The questionnaire included items on socio-demographic characteristics, dimensions of adversity or trauma in childhood (emotional neglect and abuse, physical hardship and abuse; sexual abuse). There were questions on gender relations, control by the male partner in the relationship, sexual harassment, sexual relations and about witnessing domestic violence. Men were asked about the first time they ever raped, rape in the past year, whether they had ever raped a woman with peers, and attempted rape. Men were also asked about being victims of sexual coercion by other men. Women were asked about being victims of rape, relationship with the rape

perpetrator, their age when it happened, where it happened, and whether the incident was reported to police. Men and women were asked questions on emotional, physical and sexual intimate partner violence perpetration (men) and victimization (women).

Setting

This research was conducted in Soshanguve Township in the Gauteng Province, South Africa. Soshanguve was chosen for convenience as it is close to the South African Medical Research Council offices (place of work for both authors). In the year 2010 a South African Non-Governmental Organization called GenderLinks (GL) collaborating with the South African Medical Research Council and the University of the Witwatersrand undertook a community-based survey to study the prevalence of gender-based violence in the Gauteng province of South Africa. The survey collected data in face to face interviews with a fieldworker using a structured questionnaire with women and men over the age 18, in 75 randomly sampled enumeration (EA's) areas in the province. For the present qualitative study we conducted the research in two EAs that were in Soshanguve using multiple methods of data collection. Thus the qualitative study was conducted in the Thate Block and Siyakhula Extension (pseudonyms).

The Thate Block is predominantly a low-income area with few middle class families. Siyakhula Extension is relatively a new residential area which has originally been a squatter camp. It is mainly a poor area with some households being shack dwellings built of corrugated iron. These two sections (blocks) are approximately 4-6 kilometers apart.

Methods

The article is based on 22 in-depth interviews, 12 conducted with men and 10 with women. The GL survey, to which this qualitative study was nested, randomly selected 20 households per EA for interview. One eligible men or female was systematically selected from those who slept four nights a week or more in the household [14]. The GL fieldworkers managed to interview 12 men in the Thathe Block and 12 women in Siyakhula Extension. Before the commencement of survey in these two EAs, YS requested the fieldworkers to invite the survey participants for the qualitative study and all 24 participants agreed to be contacted. They were initially contacted telephonically and thereafter met face to face for interviews. 12

men were interviewed by YS and 10 females were interviewed by a female researcher. Two females could not be located for interview after several attempts. One man was interviewed twice after he requested another interview as he felt he had been dishonest in the first interview. (see Box 1 for informants' background information). Interviews with men were conducted in isiZulu and those with women were a mixture of Zulu and seTswana. All interviews used a thematic guide and we audio-recorded the interviews. The guide for interviews with men was slightly different from that with women interviews. Informants were asked how the survey had impacted them, how answering the sensitive questions had made them feel, whether the research, directly or indirectly, was harmful or helpful to them and how, and whether they experienced adverse consequences as a result of their participation in the survey. They were asked to give life histories of violence, men were asked about violence perpetration and victimization and women victimization.

Data analysis

A grounded theory analysis was employed to analyze the data [15-17]. Data were analysed inductively. Initial analysis was performed by both authors separately and it included data from 23 in-depth interviews [17]. All interviews were digitally recorded. Audio-tapes were transcribed verbatim and translated to English by the first author and for the seTswana audio-tapes, we hired a seTswana speaking person to translate and transcribe the interviews. All transcripts were anonymysed and prepared for data analysis by the first author.

Initial codes generally corresponded with themes as set out in the interview guide. We went into the data and extracted relevant text and we grouped similar text under a theme that seemed to represent that particular text [17]. We then ran through the data identifying open codes. We did this by breaking the sentences into small segments identifying several codes within the same sentence [17]. At this early stage, we attempted to move up from the informants' words and were abstract in labeling the codes [18]. We maintained consistency in labeling the codes so that it would be possible, at the end, to group similar codes together and produce categories [16]. At this stage, we came together and compared and discussed the codes until we agreed on which codes seemed to fit together to form categories [17]. We then followed the advice of Dahlgren et al. [16] and constructed concepts and the theory by finding axes between the codes and categories and thereafter identified the main category. We then explored what these data mean and interpreted them. In this last stage of the

analysis, we compared the findings with the existing literature and made conclusions [16, 17, 19].

We present the findings by building a comparative argument through juxtaposing narratives of male and female informants, highlighting similarities and differences in their perceptions and experiences [17] of participating in the survey.

Results

Many informants in this study reported to have appreciated the opportunity to participate in the survey. Some mentioned that the research afforded them an opportunity to talk about issues they don't normally talk about. For example, Mapaseka (age 64) was raped when she was a teenager and got pregnant. She reported that at her home her grandmother and mother did not want to talk about her rape experience. As such she had kept it inside her and this affected her life tremendously. The survey interview provided her a rare opportunity to talk about the rape incident and this healed her somewhat. She explained:

> Because as mothers, us mothers who are aged 64 we have met with many troubles in our lives. And you know when a person come from afar and she does not know you and she asked what are the things that you have experienced. I told her things and I felt pain as I was telling her and she was listening to what I was saying. My heart was sore but I told myself I have to talk about this, I have to talk about it so that it can come out of my soul (kumele ngiyikhulume ukuze iphume la emphefumlweni wami) because it caused me so much pain.

Other informants who had traumatic or life threatening experiences like Mapaseka, they too, reported that through the survey, they had an uncommon opportunity to talk. Nonhlanhla, a widow with five children who was HIV positive and had reported a history of being in abusive intimate relationships in her adult life, mentioned that she found the survey content to be relevant to her and saw it as an unusual opportunity to talk about her HIV status something she did not do often. Two male informants Sipho and Kelebogile, both in their early 40's, had a similar perception; both were HIV+ and reported that the survey interview had provided them a rare opportunity to talk about their HIV status in a space they perceived as safe.

Attitudes, perpetration, and experiences of gender-based violence

The majority of women had an understanding that partner abuse comprised only physical and sexual abuse using physical force. For example, Mirriam reported that she had a boyfriend and perceived him as a good man who never gives her trouble. Yet when she was asked later in the interview "*How is your life with him?*", she said: "*A lot of the time we fight, but not*

physically". Similarly, Mathapelo maintained in the interviews she had a non-abusive marriage, yet she later reported that her husband sometimes used non-aggressive methods of coercing her into sex, such as persistent pleading, subtle threats, accusations of infidelity and emotional blackmail; even though she had told him she was tired and did not want to have sex at the time. She explained:

> …no, he does not force me with his hands (to have sex). He'll say things like, "…just once…" things like that… The thing is he's the type of person who wants something like it's been forever and I don't like being rushed and I don't like being forced into something that I don't want…for instance he sometimes come home and he wants to have sex and when you're tired, you're tired - he shouldn't force you, shout at you, accuse you of sleeping around.

Other women reported in the interviews to be in abusive relationships or marriages or had had experienced partner abuse in their lives. Mapaseka had been raped when she was 19 years old by a man she knew from her community. Margaret reported that her husband often beat her. Nonhlanhla had also been in abusive relationships including in her marriage.

Seven men had fairly gender-equitable attitudes and views. In their narratives, they expressed disagreement with beating women, did not approve of it and expressed concern that it was very common in their community. Yet, Thabo a young man in mid 20's clearly had gender inequitable views, attitudes and practices. In his interview he mentioned beating her girlfriend and felt justified beating her as she had cheated on him. He said:

> Uhm the thing is she had made me angry you see? She had made me angry and I beat her. But it was not that kind of beating as if I'm mad, I beat her up in a good way (ngamshaya kahle nje)…Uhm just slapping her, something like that. But I would not take a stone and beat her with it. I just slap her, you see? I'm just putting discipline in her (ngifaka icontrol kuphela) (laughing)… Ooh she was cheating, yes she was cheating.

Concerns and feelings about the survey process

In the interviews we asked the informants what their concerns and feelings were about the survey process; if there were any consequences, violence, distress and intimidation they experienced resulting from survey participation.

Data suggest that some women were left with fear post survey. They reported to have had fears that should their identities and information be disclosed, they may suffer violent reprisal from their partners.

In contrast men did not report this fear. Yet, they had felt that some questions were somewhat shocking to them, but not unusually invasive, and had understood why they were asked.

Notwithstanding, five men reported that there were questions which had caused them conspicuous discomfort, although they had answered them. They viewed the questions as sensitive and personal. For them it was taboo to be asked about sex, condoms, HIV, intimate relationships and partner abuse. And some had feared negative ramifications that could potentially result from their disclosures. Our analysis reveals these men perceived such questions negatively because they were not used to being asked such questions.

Resulting from this discomfort, Thabo lied in the survey and reported that he had never beaten a partner whilst he had. He explained:

> He asked whether "have I ever beaten a girl?" I told him "no" whilst I know that I have beaten a girl …eish I thought of many things, I thought of police, eish I really thought of many things (ngicabange izinto eziningi mfethu) my friend (laughing)

Other men reported that their discomfort was brought about by their fear of being judged or labeled negatively by the researcher because of their disclosures. For example, Kelebogile and Sipho reported discomfort in disclosing their HIV status in the survey, as such, the latter reported in our interviews to have been dishonest in answering the questions on HIV testing and status. Sipho explained:

> Yes I did not tell him much, even with him I concealed a lot from him. ..that I have AIDS; I don't think I told him that. I did not tell him… I can't really remember. But I think the thing that I did not tell him was that I have AIDS, no I did not tell him.

Disclosure of research participation

A number of informants discussed their participation in the survey or were known by others (e.g. children, boyfriends, girlfriends, mothers and husbands and wives) to have participated in the survey. However, our data suggest that disclosure was done with fear by some women. Some women reported that they did not disclose much content of the survey; they had chosen to conceal particular information. It seems this was for different reasons. One informant Thandaza who described her marriage as non-abusive said that she did not see a need to tell her husband as the interview was about her. However, Margaret who reported to be in an abusive marriage and often beaten by her husband, reported that she did not disclose some particulars about the survey because she feared her husband would beat her. She explained:

> I can tell him (my husband) but there are things I'll tell him and other things that I won't.
>
> Interviewer: Why are there things that you won't tell him?

Margaret: I couldn't because he would hit me.

Mirriam, a young unmarried woman currently in an abusive relationship, told her boyfriend about the full content of the interview and she felt threatened by the remarks he made. She posited:

> I only told him that…that day when they did the interview, he asked me why they asked me if he'd ever hit me, did I want them or what, and I said don't talk like that. He asked whether they wanted people to get kicked out of their homes or what… I felt bad when he said do I want [for a sexual/intimate relationship] those people… I felt bad because he's not supposed to speak that way, he should have just said okay.

Nonhlanhla, a widow, who had been in abusive marriage and relationships in the past, but did not describe the present relationship as abusive, stated that she did not inform her new boyfriend that she was asked about rape because it was not important for him to know. Mathapelo and Busisiwe reported that they discussed everything they were asked in the survey with their husbands without negative reaction from them. Both women had reported that their husbands were not physically abusive.

Most men did not discuss their survey participation with anyone, yet giving reasons that differed from those of women. Young men like Thabo, Rorisang and Thato who stay only with their mothers stated that they did not feel comfortable to discuss some survey questions with their mothers. Rorisang who reported to be addicted to nyaope- a cocktail of dagga and cheap heroin- which is very popular in this setting mentioned that he did not discuss his survey experience with his friends as they undermine him and don't take him seriously. Also, he did not have the kind of relationship with his mother that would allow him to talk about personal issues.

However, other men reported to have discussed their participation in the survey with their mothers, wives, friends, and girlfriends. These men said they had a special relationship with the people they told and trusted them, so they felt comfortable to talk about the content of the survey with them.

Men reported positive reactions from the people they told about their survey participation. For example, Kelebogile's mother was happy that he had participated in the survey and was particularly keen to know if he had reported that he was HIV positive. She was pleased to learn he had. In contrast, Vuyile's girlfriend was not bothered by his participation in the study, yet she was unhappy that he had reported about their private life.

Impact of research on participants

Mapaseka did not experience overwhelming and prolonged distress resulting from the survey questions, even though she had spoken about her rape: She explained.

> what I can say is that I feel very happy. I don't have regrets in anyway, my spirit is at ease, (ngizizwa ngikhululeke kabe, angisoli ndawo, kushukuthi umoya wami umnandi kabi), maybe with time, it will heal completely in my heart and in my spirit. Maybe it will heal completely and no longer think about it (rape incident)… It is better to speak than keeping quiet about a matter.

From this narrative, it is apparent that speaking about the rape incident caused Mapaseka pain, yet she attached value in talking and had perceived it cathartic.

Similarly, for Nonhlanhla the survey had made her to think about her husband's death, and this caused her pain at that time. She was HIV positive and had suspected that her husband died of AIDS related illness, but he had not told her he had AIDS. She explained:

> I spoke to her but I felt that pain, because it reminded me of something I had forgotten that happened a long time ago…they [questions] were not hard to answer because they are things of the past but it was hard talking about his death but otherwise the talking about being HIV positive didn't bother me at all because I know which stage I am in.

Mathapelo mentioned that the interview caused her to think about the abuse she witnessed when she was a child, where her uncle was physically and emotionally abusing her aunt, and reflecting on this had made her to feel sad.

Similarly, some men reported that some survey questions had made them reflect on painful experiences about their lives. For example, Sipho and Kelebogile mentioned that the survey had made them to think about their health condition, that they were HIV positive, something they prefer not doing. Thabo who had reported to be physically abusive to his girlfriend reported that the questions about partner abuse had made him to reflect on his own actions of beating his partner, and had a realization that he had abused her. As well, Rorisang mentioned that the survey made him to think about his drug addiction problem and he felt sad being reminded it was harmful to his health.

Our data suggest that women like Mapaseka, Cleopatra and Nonhlanhla who had reported to have experienced relatively major adversities in their lives, [rape, death of a loved one, and HIV], the survey made them to relive those painful experiences causing them sadness and pain at the time.

In the interviews informants were asked how the survey had impacted them. Although some informants had mentioned that talking about some experiences caused them sadness and pain, they felt the pain was temporary and not overwhelming. Furthermore most informants mentioned that the interview itself provided catharsis for them in different ways. It seems informants appreciated the opportunity to speak freely about the problems they have been bottling inside; a safe environment like the one seemingly provided by the survey interview, allowed them space to do this.

For some women, the experience of participating in the survey and the information they derived from the survey, had an empowering effect on them. For example, Mathapelo reported that after the survey she tried to communicate her displeasure to her husband about him *forcing her to have sex when she is unwilling.*

We found the same for men. Many said the survey was somewhat educational and empowering as it made them to reflect on important aspects of their lives, in particular implications of their behaviours, something they don't normally do.

On the referral support system

In the interviews we asked the informants: did thinking about the issues that were asked in the survey cause you any distress? If yes, we asked: what kind of support they felt they needed.

Three informants (two women and a man) did not recall being given a list of referral support services they could go to by the field workers. However, many women, including those who reported to have had experienced partner violence or were in abusive relationships, reported having needed support for non-violence or study related issues. For example, Thandaza had needed assistance for the arthritis she was suffering from. She also mentioned that she needed help with the financial challenges at her home and being assisted with organizing a grant as she was ill.

Mapaseka said she needed help with claiming maintenance from the man who raped and impregnated her. It was evident that whilst Mapaseka had reported to have been emotionally and psychologically affected by her rape experience, the interview itself did not cause her overwhelming distress that may have warranted professional intervention. It may be that she had healed over the years. Her narrative supports this interpretation:

yes they gave me the paper (list of local referral services) but I have not looked at it properly…there was no help I needed for the things the researcher asked me about.

Nonhlanhla, who had reported that the interview had caused her to think about the death of her husband, said she would have been happy if the researchers had offered her a job and help with her municipal debt. Mirriam, who reported being in an abusive relationship, mentioned that she did not know the kind of support she needed because of the survey questions. This is congruent with what Margaret said. She had reported to be in an abusive marriage in which her husband beats her. Yet she said she did not need support resulting from answering survey questions. Likewise, although Mathapelo had said she often felt her husband forces her to have sex with him, and herself had equated this to rape, when asked the same question she posited:

no there isn't help I needed because of the things I was asked in the survey…I've been alright after the interview; because I was able to explain what happened to someone else.

Almost all men in the study said they did not need any support because of the questions they were asked in the survey. Therefore, we asked them to think hypothetically if they had been affected negatively by the survey questions, what form of support they would have needed. Almost all reported that talking to significant people in their lives was their first preference. Mobutho's narrative is illustrative:

Well I think the main support is still to talk to family members around. I think they are the ones who can support you all the way with that problem and comfort you. They are the ones who can comfort you when experiencing that thing; that is my belief; only family members can help you.

He further said:

counseling is better, counseling is one of the cures that can heal those wounds. I support even counseling, but my first preference is to talk to family members. Then if you are not happy with their support, then you can take plan B and go for counseling. But my first preference is family members and plan B is counseling.

Rorisang was an exception here as he felt if he had been distressed he would have sought comfort from smoking nyaope as he had no one to speak to. Sipho and Kelebogile, who were both HIV positive, however felt they would have needed support related to their ill-health and financial assistance.

Discussion

Our findings suggest that some women remained with fear after the completion of the survey. From these women narratives, it was apparent that they were particularly scared of the

potential physical harm that could result as retaliation, mainly from their partners, if there could be a breach of confidentiality. Our analysis shows that mostly these women had a history of partner violence or other forms of GBV. The only excerption here was Busisiwe who reported not experiencing abuse from her marriage. Despite not experiencing physical abuse in her marriage, she feared some form of retaliation if her husband discovered she discussed their "private" information in the survey.

In contrast, no man reported fearing physical retaliation from a partner. This, perhaps, is unsurprising considering the patriarchal nature of the South African setting where men mostly have control and dominance over women and often perpetrates violence against women [20]. This may explain why only female informants reported fearing possible retaliation from their partners.

Many men in this study reported to have been shocked by the type of questions they were asked in the survey. They found some survey questions too personal and sensitive (e.g. questions on sex, number of sexual partners, HIV and partner abuse), and this caused conspicuous discomfort for them. Our analysis reveals that the few men who reported emotional reaction to these questions, had also reported perpetrating intimate partner violence or were HIV positive, and thus, may have been uncomfortable to talk about these issues as that either reminded them of and invited them to confront and evaluate their own actions [21] and, for the others, illnesses.

Our data suggests that whilst a number of informants had emotional reaction to some survey questions, the vast majority thought the survey had a positive effect on them. This is similar to a finding reported by Griffin et al. [13] that whilst participants in their study had recently suffered acute sexual and domestic abuse and were subjected to extensive psychological and physiological assessments there was a high level of interest in the study with low levels of distress to assessment procedure.

Whilst many authors have studied the perceptions of or risks of research participation in interpersonal violence or trauma survivors, their focus has mainly been on emotional reaction or psychological risks [3, 4, 10, 13], with lack of focus on risk for physical harm to participants. Women research participants have been viewed as a vulnerable group and that, often, may be exposed to, as Wasunna [22] argued, immediate or perpetual danger of abuse through their participation in research [23-26].

In an effort to protect research participants, (especially women) from potential abuse, researchers often do not introduce their studies as that on GBV at community level, and only reveal the actual focus of the research to the selected women only [23, 25]. Additionally, researchers often advise the participants to not divulge the focus of the research to others, explaining that this is done to maximize participant protection [25]. However, IRBs and others have raised concerns that this may be construed as deception, and view this safeguard as ethically questionable. Jewkes and Wagman [26] have, however, argued that in the South African setting, community gatekeepers are often men, whom themselves could be perpetrators of GBV and may hold such views that legitimate dominance and control of women by men. Therefore they argue that under these circumstances, this 'form' of deception on community gatekeepers is justified; both in terms of concealing the true focus of the research and in terms of concealing the identity of individual research participants.

In keeping with Jewkes and Wagman [26], we support a view that this form of deception should be for community gatekeepers, and not the participants. The survey was broadly termed and had included many other questions that were not GBV related (e.g. income, abortion, schooling, food etc), yet in the qualitative interviews, informants generally understood the focus of the research as being on issues of gender, sexuality, women abuse, gender relations, which all fall in the realm of GBV.

Whilst some informants, may have had heeded the advice not to tell others about the focus of the survey, the vast majority reported to have discussed their research participation, with some disclosing the full content of the survey. Therefore, in the interviews, we probed informants in order to understand whether this placed them at risk of physical harm or other form of abuse by third parties.

In terms of perceived risks of disclosing research participation and content we found gender differences. All men reported no negative reaction, in particular, from their wives or girlfriends. The same reason we gave about control and dominance of men over women in this setting should explain this phenomenon. In contrast, although not for all women, our data suggest that some women perceived risk in disclosing the full content of the survey, and indeed some received negative responses from their intimate partners, that were somewhat threatening. One woman [Margaret] who reported in her interview to be in an abusive marriage, stated that she did not disclose the survey content because she feared being

physically assaulted by her husband. We also think she may have also heeded the advice from the fieldworker not to disclose the survey content.

Among women who had disclosed the full content of the survey, we noted differences according to interpersonal violence histories. Women who were in abusive relationships reported negative reactions that were relatively threatening from their partners. In contrast, women who had reported no abuse in their relationships reported that their partners were not bothered by the survey content. Whilst no woman reported being physically assaulted by an intimate partner because of participating in a GBV survey, this finding suggests that some women may be put at risk of harm if the content of the GBV survey is known by violent and controlling men [22]. Jewkes and Wagman [26] argue that violent men may be offended upon knowing that his partner had discussed his violent behavior in the study, and thus react by physically assaulting her as a form of punishment.

Our findings support the WHO [27] recommendation that the actual focus of GBV survey should be concealed at community level, told only to participating women, and that women participants should be advised not to disclose the focus of GBV in the survey. This recommendation protects a particularly vulnerable subgroup of women i.e. those in abusive or potentially abusive relationships. Our data reveal that full disclosure of GBV focus of survey to abusive and controlling men, may trigger violence, and lead to harm for women participants. This aspect of risk to research participants is of particular importance in our understanding of risks to research participants. Our study provides important evidence on this risk; however, more research is needed, from this setting and elsewhere, in order to adequately understand the characteristics of participants who are more vulnerable to physical harm and the circumstances under which this harm could occur. This can maximize participants' protection.

IRBs and researchers have raised concern that interpersonal violence and trauma survivors as research participants may be emotionally or psychologically harmed by being asked about their adversarial histories [2, 11, 13]. This concern is, however, based on anecdotal evidence, or often, assumptions and worst case scenarios of research atrocities [11, 13]. Our study findings reveal that although there was no remarkable difference between men and women in reporting distress resulting from research participation, slightly more women reported sadness or pain when reflecting on painful experiences, than males. This finding is analogous to that reported by Kuyper et al. [11] in their study with young people in the Netherlands.

They reported that women expressed more distress because of the questions asked as compared to men.

While in their study DePrince and Freyd [4] did not find evidence that cultural taboo may be the cause of upset for survivors of abuse and interpersonal violence, in the present study some men felt it was taboo to talk about some of the things asked in the survey, with strangers. However, we also think some men may have been upset with the partner abuse questions because they perceived such questions as somewhat incriminating [10, 21], and for others, questions on HIV status [Sipho and Kelebogile] and drug abuse [Rorisang] may have made them to reflect on their actions and to think they were to blame for their current conditions.

Authors have argued that the 'mere presence of sexual abuse history does not predict women's negative emotional reactions to research, but that assault characteristics and post assault attributions and distress levels also play a role' [1]. Griffin and colleagues [13] concur, they reported that while women in their study had recently suffered acute sexual and domestic abuse and were subjected to extensive psychological and psychophysiological assessments, they did not get damaging effects from this experience. Similarly, Johnson and Benight [6] found that the recent domestic violence victims tolerate trauma research fairly well. In the present study, although some informants had reported about traumas that had happened years ago, some were still in abusive relationships and others had HIV or had AIDS, yet they did not find it emotionally damaging to talk about such experiences in the survey. In support of this reasoning, Johnson and Benight [6] argue that 'the ability to tolerate research that asks about sensitive and traumatic experiences may be related to coping self efficacy, the perceived ability to cope with recovery demands.'

Our data suggest that the emotional reaction to survey questions, to those who reported it, was temporal and not deleterious, and thus would not be categorized as emotionally or psychologically harmful [4]. Jorm et al. [3] did a systematic review of literature investigating whether there is evidence that participation in psychiatric research causes harm. Particularly focusing on long-term effects of research participation, these authors concluded that there appears to be little evidence to show any long-term harm to participants even if research studies traumatic experiences. In the current study, not a single informant, reported effects of survey questions that suggested that the impact would have warranted intervention. Kuyper et al. [11] argue that emotional effects resulting from research participation may quickly fade away, and this may explain why our informants, even though had reported distress, also

stated that they did not feel they needed any help. We argue that the distinction between sadness and pain and being psychologically damaged in the research context is important to make as the former seems not to equate the latter, as often assumed.

Our data shows that whilst a number of informants had felt discomfort with some survey questions, none regretted participating in the survey. Rather, including those who had reported distress, an overwhelming majority reported positive feelings about the survey [3]; with a number of informants mentioning that the survey interview itself had provided catharsis for them. In Edwards et al. [1] study, women who had experienced child sexual abuse and those who experienced adult sexual abuse reported more personal benefits to research participation as compared to women without abuse histories. Similarly, although with a somewhat younger sample, Kuyper and associates [11] enrolled 889 sexually experienced young people in the Netherlands examining the effects of asking the participants about various sexual topics in a large-scale sexuality study. They found that the overwhelming majority of participants reported positive feelings and benefits from research participation [11].

In the current study, a number of informants, in particular those who had major adversities in their lives (e.g. sexual assault, IPV, HIV), mentioned that they do not often get a safe space to talk about their traumatic experiences, and for them, the survey had provided this. As such, they found research participation cathartic as it allowed them space to relate their experiences to a person who was willing to listen and empathetic. This finding is consistent with Johnson and Benight [6] view that research participation may serve as a catharsis and or a motivation to seek help. Additionally, Campbell [28] in her book about the impact of researching rape argues that the 'very act of research participation is something of an intervention in its own right." Our data provide support to this notion. In a setting like South Africa where women often do not have a "voice", our findings show that women in this study felt acknowledged by being given a safe space to voice out their inner and commonly suppressed feelings.

In 2001 the WHO published the Ethical and Safety Recommendations for Research on Domestic Violence Against Women guidelines. Reflected in these guidelines is also a recommendation that 'field researchers should be trained to refer women requesting assistance to available local services and sources of support. Where few resources exist, it may be necessary for the study to create short-term support mechanisms'. This recommendation provides a duty for GBV researchers, but does not clearly articulate the

boundaries of such a duty thus opening it to various interpretations [22]. The dominant interpretation has been that for GBV research with women to meet the ethical requirements, it has to make a provision for referral to local services [22, 26]. As such, studies on interpersonal violence often employ varying safeguards that include offering to provide referrals to local counseling services [9]. This has been the case even though there has been little or no empirical evidence suggesting it is a needed and useful safeguard in this field [26].

Adhering to this recommendation, the survey had made a provision for referral to local services for all participants in the survey [14]. The setting of the survey is well resourced thus services were readily available; and therefore not necessary to create short-term mechanisms. In the present study we explored whether the participants perceived the emotional reaction they had to the survey questions warranted professional intervention, and which participants needed this. We had anticipated that those who reported major adversities in their lives would be more likely to report needing help after the survey, yet none of the informants reported having needed support because of the survey questions. This is consistent with the findings from a study in Netherlands where Kuyper et al. [11] reported that of the 889 participants, one in four reported distress (like feeling down or sad), yet only 3.5% of the sample experienced a need for help.

In the current study we found no difference according to interpersonal violence or trauma experiences or gender in reporting the need for help. However, some informants reported that had they felt they needed emotional support because of the survey questions, they would have preferred to talk to family members rather than attending professional counseling. They perceived that family members knew them better and would thus provide better support.

Much of the published research on this area is from North America and Europe and we are not aware of any from South Africa. Therefore data from the current study is important as it provides evidence for risks and benefits perceived by research participants from a South African perspective. This will aid, as well, South African IRBs and researchers in their decision making about the risk-benefit ratio of studies on interpersonal violence and trauma in South Africa and similar settings.

This qualitative study was conducted one to three months after the survey; therefore it could not capture participants' long-term reactions to and consequences of survey participation. As discussed above, some women had remained with fear (of violent reprisals) after participating

in the survey. Yet during the period between one to three months post survey, in the qualitative interviews, none reported these fears being realized. Specifically, none reported being physical harmed as a punishment for research participation.

Studies that require people to recall and report about past events, especially feelings and emotions, after some time had passed, may have a problem of recall bias. In the current study, few informants could not recall survey questions that distressed or upset them. We argue that, had the experiences been deleterious with long-lasting effects, informants would still be experiencing the effects and thus able to report those in the interviews. Findings of this study can not be generalized but their importance is that they may be relevant to a similar setting elsewhere [16].

Conclusion

Our findings suggest that asking participants, including survivors of interpersonal violence and other adversities, about their trauma histories may cause them distress, but this seems temporal and not deleterious. Equally important is to note that the majority of informants perceived positives and gains from participating in the survey [3, 11]. As such, we support the notion that rather than militating against the conduct of research on GBV, IRBs and researchers should be wary of and question the dangers of not asking abuse victims about their experiences and traumas [1, 29]. Yet, we also suggest that even in the light of compelling evidence that some participants get distressed because of research participation, albeit temporal, research protocols need to put in place safeguards where appropriate so that this group receives support and protection.

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Box 1: Sketches of research participants

Women	Age	Relationship and Health status	Social position	GBV experience	Survey experience
Mathapelo	34	Married	Not working	Forced sex by husband	Positive
Mapaseka	64	Single	Not working	Raped when young	Positive
Thandaza	50	Married	Not working	No	Positive
Busisiwe	38	Married	Not working	No	Positive
Cleopatra	62	Married	Not working	No	Positive
Nonhlahla	49	Widowed & HIV+	Not working	Abusive marriage	Positive
Mirriam	22	Dating	College	Abusive relationship	
Margaret	46	Married	Not working	Abusive marriage	Negative
Nomusa	33	Single	Not working	No	Positive
Lebo	31	Dating	Not working	No	Positive
Men					
Thato	29	Dating	College	No	Positive
Papi	28	Dating	College	No	Positive
Mobutho	43	Dating	Not working	No	Positive
Vuyile	28	Cohabiting	College	No	Positive
Thato	26	Dating	Not working	Perpetrated IPV	Negative
Rorisang	29	Single	Selling cigarettes	No	Negative
Kelebogile	41	Dating & HIV+	Not working	Perpetrated IPV	Negative
Njabulo	43	Married	Not working	No	Positive
Oom-Dan	67	Married	Not working	No	Positive
Sipho	40	Cohabiting & HIV+	Social grant	No	Negative
Joe	45	Married	Working	Refused to answer	Positive

CHAPTER SEVEN

MOTIVATIONS FOR, AND PERCEPTIONS AND EXPERIENCES OF PARTICIPATING IN A CLUSTER RANDOMIZED CONTROLLED TRIAL OF A HIV BEHAVIOURAL INTERVENTION IN RURAL SOUTH AFRICA

Jewkes R, Sikweyiya Y, Nduna M, Jama Shai N, Dunkle K.

Corresponding author: Yandisa Sikweyiya

Email: ysikweyiya@mrc.ac.za

Abstract

Empirical research on ethical issues in HIV prevention and gender-based violence research is limited, critical for honing ethical and safety guidelines. We describe South African adolescents' motivations for participating in randomized controlled trial (RCT), the prevalence of negative occurrences, participation regrets, and associated factors. This trial partly followed, but also deviated from, the WHO safety guidelines for research on violence against women. 1085 women and 985 men provided information two years after the trial start. Most participated for HIV testing and to help their community. Fewer reported motivation by the $3 incentive. Minor adverse events included upset from questions on childhood experiences and arguments at home with siblings. Just under 1 in 10 (8.1% women, 9.8% men) regretted participation. Factors were associated with this were keeping some questions secret from their partners, feeling sad about questions on childhood, quarrelling at home and for women, being motivated by the incentive. Men who had been physically violent to a partner were twice as likely to regret participation. There were no recorded adverse effects from the deviations from the ethical guidelines. Participation regrets mostly stemmed from problems in participants' families preceding the research. There was no evidence that the research had been unsafe.

Key words: Research participation, Perceptions, Experiences, Research ethics, South Africa

Introduction

In Sub-Saharan Africa, where more than two-thirds (68%) of all HIV infections are located (UNAIDS, 2011) , very few HIV prevention behavior-change interventions have been empirically evaluated, especially using randomized controlled trials (Ross, 2010). This limits our ability to identify effective HIV prevention programmes (PWG, 2008). With gender-based violence identified as a driver of the HIV epidemic in women (Jewkes et al., 2010a), there is an urgent need for more, and more rigorous, evaluations of behavior change interventions for HIV and gender-based violence (Ross, 2010, Jewkes et al., 2006).

Conducting RCTs, particularly in resource poor settings presents numerous challenges. These include issues of informed consent (Taiwo and Kass, 2009) and worries about undue inducement (Emanuel, 2004) and coercion (Vanderpool, 2001, Ashcroft, 2001) of people to enroll and participate in research trials; ensuring that sufficient numbers of willing participants are recruited and retained (Rosenbaum et al., 2005, Kim et al., 2004); and concerns that researching gender-based violence may place participants at risk of further violence or distress from the research questions (Fontes, 2004). For research to be conducted ethically, researchers and institutional review boards (IRBs) need enough understanding of the challenges to innovatively navigate them, appreciate the risk-benefit ratio and assess the relative benefits in research planning and protocols. Gaining a better understanding of the experiences of research participants with RCTs of HIV prevention interventions which also address GBV may provide us with insight on how to address some of these challenges.

There are very few published studies on participants' motivations for enrolling and experiences of participating in research (Kneipp et al., 2009). This gap in the research literature limits our understanding of what motivates people to participate (or not) in research (Kneipp et al., 2009); how participants make meaning of studies they partake in (Taiwo and Kass, 2009); and their experiences of participating in such research (DePrince and Freyd, 2004). Little empirical research has been conducted on the ethics of research into gender-based violence (Sullivan and Cain, 2004, Sikweyiya and Jewkes, 2011, Fontes, 2004) and very few studies have sought to explore longitudinally (Jorm et al., 2007) whether respondents experience negative consequences as a result of participating in research that explores violence victimization (Ellsberg et al., 2001, Griffin et al., 2003, Johnson and Benight, 2003).

Most published papers on ethics of research on violence against women have been theoretical or contain researcher's reflections and professional experiences of undertaking research in different regions of the world (see Ellsberg et al., 2001, Ellsberg and Heise, 2002, Jewkes et al., 2000, Jewkes and Wagman, 2007b, Wasunna, 2007a) .

Kuyper et al (2011) assert that the absence of empirical data on the impact on participants of participation in research may result in a situation where 'judgments about the risks and benefits of research participation are based on political, cultural, religious and emotional grounds' (see also DePrince and Freyd, 2004, Kassam-Adams and Newman, 2002), rather than empirical evidence (see also Griffin et al., 2003). Research on participants' experiences of participation in research can empirically inform efforts to address these concerns, as well as providing guidance on how to recruit and retain participants without coercion. Similarly, such research can help both future investigators and IRBs better understand the potential risks and benefits for participants when conducting research that address sensitive topics such as sexuality and violence (Kuyper et al., 2011).

The most extensively used ethical guidelines are the WHO Ethical and Safety Recommendations for Research on Domestic Violence Against Women (see WHO, 2001, Ellsberg and Heise, 2005), which have at times been extrapolated to research with men (Wood et al., 2007, Wood and Jewkes, 2001, Machisa et al., 2011, Jewkes et al., 2010b). The WHO recommendations emphasise the need to conceal the violence focus of the research in order to protect participants. There are a number of ways in which this is done, including interviewing only one woman per household, not conducting interviews with men and women from the same locale and concealing the focus on violence from non-participants.

This requirement is very feasible to implement in survey research (Ellsberg and Heise, 2005), yet it poses problems for intervention evaluation. For example, if the intervention has gender-based violence prevention as a primary objective, it may not be possible to conceal a violence focus. If it has men and women in the study, then both will be asked questions on violence. Whilst it may be possible to geographically separate male and female clusters in a cluster trial, in other studies, such as school-based violence intervention evaluations such separation may be impossible. Inevitably some of the study participants will be dating. It is very important that we understand whether such deviations from the WHO guidelines in clinical trials place participants at risk, and to understand the implications of this for interpretation of the guidelines in research more generally.

Stepping Stones is a participatory intervention for HIV prevention that seeks to build stronger, more gender equitable relationships, with prevention of violence an important goal (Jewkes et al., 2002). The intervention was evaluated in South Africa in a cluster randomized controlled trial with two years of follow up (Jewkes et al., 2006). This provided an opportunity to examine ethical issues related to the participation and to reflect on evidence of the impact of protocol deviations from the WHO guidelines. The study had both men and women, recruited from the same locale, who were asked about gender-based violence on multiple occasions. Some of them were dating and generally

the focus on violence was not concealed, although the intervention was seen as predominantly concerned with HIV.

The aim of this paper is to describe participants' motivations for participating in the study and the prevalence of negative reactions from others to participants' involvement in the study. We also explore whether participants' experienced pressure to learn their HIV results, whether there were regrets associated with study involvement, and describe the impact on participants of questions about childhood trauma and violence on people. Finally, explore factors associated with regretting participation.

Methods

Study Setting

The Stepping Stones study was conducted in the rural Eastern Cape Province of South Africa between 2003-2006 (Jewkes et al., 2006). The study was a cluster randomized controlled trial conducted in 70 villages or townships around the town of Mthatha. The goal of the Stepping Stones trial was to evaluate the effectiveness of the Stepping Stones behavioral intervention in averting new HIV infections among young people in the rural Eastern Cape Province of South Africa (Jewkes et al., 2006).

Villages were randomly allocated to the two study arms after they were grouped into seven strata (Jewkes et al., 2006, Nduna et al., 2010, Dunkle et al., 2007). In each cluster about 40 volunteer participants (20 women and 20 men) were recruited giving a sample of 1367 men and 1415 women. Eligible participants were aged 16-23 years, normally resident in the area where they schooled and mature enough to understand the study and consent process. There was a difference between the actual (15-26 years) and intended age of participants which is discussed in detail elsewhere (Jewkes et al., 2006) .

Recruitment was mostly undertaken in schools and followed multiple stages. In each cluster project staff invited 60 or more young people to a meeting where they were briefed on the study (Dunkle et al., 2007, Jewkes et al., 2006). In most clusters, a list of all eligible prospective participants was generated and 40 people more able to participate in the study were chosen by the project staff after some discussion among the youth about who would more easily participate, for example those who lived nearer the school, as in the area commonly students could live over an hour's walk from school (Jewkes et al., 2006). Then a separate meeting was held with the selected people and they were given further information about the study and its procedures; allowing them to ask questions and

the research staff providing answers; and thereafter seeking written consent to participate in the study.

Participants were informed that the trial was going to run for two years and would have multiple rounds of data collection (see Jewkes et al., 2006). To maximize the potential for cohort retention, participants were asked to provide their home contact details, telephone numbers of friends or relatives and they were further requested to inform the project staff if they changed their home address or contact details or asked to provide an alternative number on which they can be reached (Jewkes et al., 2006).

The South African 2nd edition of Stepping Stones (Jewkes et al., 2002), which was evaluated (Jewkes et al., 2006), was adapted from Alice Welbourn's original Stepping Stones curriculum (Welbourn, 1995). It uses participatory learning approaches, including critical reflection, role play, and drama and draws the everyday reality of participants' lives into the sessions. It had 13 main sessions given in single sex workshops, lasting about 3 hours, as well as some meetings of both male and female groups, and was held over 6-8 weeks (Jewkes et al., 2002). The sessions covered: how we act and what shapes it; sex and love; conception and contraception; taking risks and sexual problems; unwanted pregnancy; sexually transmitted diseases and HIV; safer sex and condoms; gender-based violence; motivations for sexual behaviour; dealing with grief and loss; and communication skills. The control clusters received a single 2-3 hours session on HIV and safe sex practices drawn from the Stepping Stones curriculum (Jewkes et al., 2002). For a detailed description of the Stepping Stones curriculum see (Jewkes et al., 2002) and see Jewkes and associates for the complete account of the trial design, methods and results (Jewkes et al., 2010c, Jewkes et al., 2008, Jewkes et al., 2006).

Questionnaire

A structured questionnaire was administered by same-sex interviewers who were the same age or slightly older than the participants. The baseline questionnaire was administered prior to commencing the study and participants also gave blood for HIV testing. The questionnaire asked about age and level of completed education (presented here dichotomized as up to grade 10 and beyond grade 10). Socio-economic status was measured on a scale derived for the study after extensive discussion of the problems with use of standard measures (such as housing quality indices) in the study area and with the age group. The scale captured household goods ownership (TV, radio and car), frequency of hunger, frequency of having meat to eat, and perceived difficulty accessing a fairly small (but not trivial) sum of money for a medical emergency (R100 ~ £9). This was derived into a scale and factor weighted (Cronbach's alpha for men =0.60 and for women = 0.55). Among the

background questions was a scale on exposure to childhood trauma, this measured physical, sexual and emotional abuse and neglect and was adapted from Bernstein et al. (1994). Cronbach's alpha for men 0.73, for women 0.72). The questionnaire had a detailed section on sexual behavior, including number and types of partners, condom use, contraception use, and transactional sex. The questionnaire covered many gender issues including experience of emotional, physical or sexual intimate partner violence (as a victim for women or, for men, a perpetrator), assessed using a modified version of the WHO multi-country study's instrument (Garcia-Moreno et al., 2005).

Questions on research participation

In the last round of evaluation, 24 months after the study started, the survey instrument included questions that explored motivations for participation, regrets and adverse (and positive) consequences perceived and experienced by the participants. These items were developed for this study. Each took the form of a statement scored on a four-point Likert scale of strongly agree, agree, disagree or strongly disagree. If participants had said they experience of violence as a result of study participation, follow up questions were asked to probe and the answers recorded in narrative. These were transposed from the questionnaire and analysed as text. Participants were asked a statement to capture their views on research participation in hindsight "If I had understood everything about the research and what would happen afterwards I would not have agreed to participate". This was the main outcome variable for the analysis of participation regrets.

Research ethics

Throughout the trial period, two professional nurses were employed to support the study participants. They carried a cell phone and were available for calls at all times. All participants were given their number and invited to call if anything concerned them. The ethics review committees (REC's) of the Universities of Pretoria and the Witwatersrand granted ethics approval and monitored the progress of the trial. The Eastern Cape Provincial Department of Education gave approval to recruit through public schools, and access to villages was provided by the local traditional and political leadership. Participants gave written informed consent to participate in the study and were given R20 (~US$3) as an incentive for participating. A Community Advisory Board was formed comprising stakeholders from various local organizations and its main responsibility was that of advising the investigators on the local context and observing the overall progress of the study. All participants were told participation was voluntary, agreement could be withdrawn at any time and no consequences would ensue.

Statistical analysis

Analyses were carried out using Stata release 10.0. All procedures used in data analysis took into account the study design, viewing the study as a stratified, two stage survey with participants clustered within villages. The datasets for men and women were analysed separately. First descriptive analyses were carried out on background variables collected during the baseline round of data collection, these were summarised as percentages with 95% confidence limits. Categorical variables were compared using Pearsons Chi. These estimates were carried out using standard methods for estimating confidence intervals from complex multistage sample surveys (Taylor linearization).

To examine the motivations for and consequences of participation, responses to each statement were dichotomized so the proportion strongly agreeing or agreeing versus disagreeing or strongly disagreeing could be presented. Responses between men and women were compared using a Pearson's chi.

Generalised linear mixed models (xtlogit) were fitted to account for clustering of respondents within villages in investigating factors associated with regretting study participation. Candidate variables for these models with the social demographic, violence and childhood trauma variables are presented in Table 1 and the variables in Table 2. Modelling fitted followed a process of backwards elimination after all variables were included, with elimination initially at $p<0.2$ and the subsequently at $p<$ or $= 0.05$.

Results

Table one describes the characteristics of participants who were retained and interviewed two years after the study commenced and those lost to follow up. Among women, 1085 were interviewed and 332 had been lost to follow up. Among men, 985 were interviewed and 386 lost to follow up. There were no significance differences between the women retained and lost in age, education, socio-economic status, history of exposure to trauma in childhood, sexual activity, or in exposure to physical or sexual intimate partner violence. The one area of difference in men was in education: more men who were above Grade 10 (i.e. in the last two years of school) at the time of recruitment were lost to follow up. Overall 6% of participants at baseline said they had partners in the study.

Motivations for participating in the study differed between men and women, but the magnitude of this difference was very small (Table 2). Almost all participants reported that they were motivated by the opportunity to get an HIV test and to have a chance to help their community. Many indicated

that the R20 incentive had been a part of the motivation, with many more women (66.9%), than men (40.9%), agreeing with this statement.

Men and women didn't differ in their general perceptions of the study (Table 2). They almost all were glad to have had a chance to be in it, felt the interviews helped them, the study had helped them at school, and the workshops were more interesting than they had expected. Many of the participants said they had never told anyone about some of the things that were asked them in the questionnaire. This was more common for women (43% of women vs 34% of men, p =0.0008).

More than half of participants said the interviews had asked them about painful things which they had tried to forget; this proportion did not differ between men and women (60.4 v. 56.3%) (Table 2). More women than men (14% v. 7%, p <0.0001) had found the questions about their childhood made them sad. Whereas about a quarter of participants felt they should keep some of the questions secret from their partner, this proportion did not differ between men and women (27.6 v. 23.7%). Women who had experienced physical or sexual intimate partner violence were not more likely to perceive the need for secrecy (p=0.127), nor were those who had experienced more severe (multiple episodes of) partner violence (p=0.304). In contrast men who had perpetrated physical or sexual intimate partner violence were more concerned about keeping questions secret from their partner (p=0.024). The correlation was not seen among those perpetrating more severe violence (p=0.101).

The proportion who had told their partner about the questionnaire and he or she had become cross was larger for women than men (10.6% v. 4.7%), but still relatively small. About one in five participants felt they were pressurized by their partner to take their HIV test results, a proportion similar for men and women (19.7 v. 22.9%). More women than men reported that their partner had tried to stop them taking their HIV test results, although this was still relatively uncommon (8.7% of women v 2.3% of men).

Some of the participants had experienced arguments at home as a result of their participation. This was more common for women than men (11.3% v. 5.7%). Significantly more women than men were beaten for participating, although the absolute proportion was less than 1%. All beatings for which the perpetrator was known were meted out by brothers. Participants were asked about their regrets with hindsight, and just under one in ten (8.1% of women and 9.8% of men), a proportion not differing by gender, said they would not have participated if they had known everything they do now.

We examined whether the study arm influenced men and women's experiences of the study and their perceptions and overall assessment of participation (Table 3). Women in the Stepping Stones

arm were more positive than those in the control arm about the intervention, the study, and its impact on them. They were more pleased to have been in the study (98.9 v 96.7%), found the workshops more interesting than expected (99.3 v 95.3%), and felt the interviews had helped them (99.3 v 96.5%). Fewer said they had never previously told someone about some of the things asked in the questionnaire. For both men and women more participants in the Stepping Stones arm said participation had helped them at school (94.8 v 93.7%). There were no differences between study arms for either women or men in perceived adverse consequences or regrets about participation. In all 9% of men and women in Stepping Stones regretted participation and 7% of women and 11% of men in the control arm.

The factors that were associated with regretting participation for women were having been motivated by a desire for R20, having to keep some of the questions in the questionnaire secret from their partner, feeling sad about questions from childhood and having arguments at home. For men, regretting participation was also associated with having to keep some of the questions in the questionnaire secret from their partner, feeling sad about questions from childhood and having arguments at home, but in addition, having been physically violent to a partner was associated with being twice as likely to regret participation.

Discussion

The majority of participants in the Stepping Stones study who completed the interview at 24 months follow-up expressed highly positive views about having participated in the research. As other authors have shown (Vanderpool and Weiss, 1984, Olin et al., 2006), they indicated multiple reasons for engaging in research. Most of them had started the trial from altruistic reasons but the offer of R20 for participation was also important, especially for women. The gender difference here may have reflected the local practice of mothers giving pocket money to boy children, whilst expecting girls to make do.

Both men and women found their experience of involvement in the study to be overwhelmingly positive and expressed a perception that it had positively impacted on their schooling. This was higher among those in the Stepping Stones intervention arm and supports reports from teachers and school principals of the positive effect of the materials on scholars (Jewkes et al., 2010c). There was no evidence of any serious adverse events related to study participation after all had been scrutinized by the Data Safety and Monitoring Board (Jewkes et al., 2008).

A substantial minority (about 1 in 4) indicated that they felt concerned that their partner would learn what was in the survey, but we did not have information about what they were afraid of

sharing. The proportion of participants concerned about sharing with their partner was about the same for men and women. Qualitative research undertaken in another province in South Africa with research participants has highlighted concerns related to disclosure of experience of violence and details of sexual relationships by both men (as violence perpetrators) and women (as violence victims). It is possible that these were the concerns of the Stepping Stones study participants (Sikweyiya and Jewkes, 2012). Whilst questions on victimization experience of gender-based violence may have provoked fear of retaliatory violence, our findings suggest that women who were not victims may equally have had other concerns about sections of the questionnaire as violence exposure was not associated with a higher prevalence of concerns. We did have evidence that men who had perpetrated were more likely to fear their partner knowing about what was in the survey. This suggests that men's fear of reputational damage if their violence was known was a particular violence related concern with respect to questionnaire content that is not much discussed in the literature. The lack of correlation between concerns about content and perpetration of more severe violence furthermore suggests that concerns about reputation may be related to perceptions of non-acceptability of violence among generally less violent men.

The analysis of factors associated with regretting study participation, and the correlation with experiences of violence, reflect this same pattern. Violence victimization experiences of women were not associated with participation regrets. However men who had perpetrated physical, but not sexual, intimate partner violence (nor both), were more likely to regret study participation (Sikweyiya and Jewkes, 2012). This further supports the idea that an intervention on gender-based violence may be more discomforting for men who have been violent but are able to feel remorse and regret it, than it is for men who have been more severely violent and, we can speculate, may feel less remorse. We would suggest that these experiences of discomfort and regret should not be reasons to dissuade anyone from providing gender-based violence prevention interventions, or doing research, with men on whom these interventions may be more impactful.

Despite the deviation from some of the WHO guidelines necessary to conduct a behavioral RCT of this nature, the proportion of participants who had experienced serious adverse events or beating due to the study was small. There was no evidence that any participant was beaten by a partner due to study participation, although we acknowledge that many of the original study subjects (23% of women) did not complete the final interview. However, there was no difference in baseline exposure to violence between those who did and did not complete the 24 months interview, suggesting there had not been differential drop out by intimate partner violence exposure. The equally low rates of beating as a result of study participation between study arms suggests that trial participation posed

an overall low risk of violence, and this cannot be explained by protection given to participants through the gender-focus of the Stepping Stones intervention.

The overall proportion of participants who with hindsight regretted participation was fairly small. Further, many who expressed regret also acknowledged benefits from participation, as have participants in previous research (Edwards et al., 2009b). Nonetheless analysis of factors associated with participation shows that women who participated for money were much more likely to regret it. Similarly those who had had arguments at home as a result of participation and those who had been made sad by questions about childhood were more likely to regret participation. These associations are not explained by an objective assessment of childhood trauma using the study's childhood trauma scale, nor by questions death of parents, nor by an assessment of depression (data not shown). It seems likely, that they reflect slightly different aspects of disharmony and pain at home, which may have been in part triggered by the decision to participate in the study, and pertained irrespective of age (most participants were legal adults so did not need parental consent). Qualitative research in the study area has highlighted the severe domestic discord with which many young people like the study participants live (Nduna and Jewkes, 2012). It is possible that for some study participation was a choice as a distraction from the discord.

Participants who felt they had to keep questions secret from their partner were more likely to regret study participation, although the majority of men and women who kept survey content secret did not do so. Although there is considerable speculation in the literature about the need for women experiencing gender-based violence to keep questions on this secret from their partner (Ellsberg and Heise, 2002, Jewkes et al., 2000, Jewkes and Wagman, 2007b, Fontes, 2004), we have no evidence here to support the idea that violence was concealed more often than other questionnaire content. The portion of women who had experienced abuse greatly exceeded those who felt the need to conceal, and many men expressed the same feeling. It is more likely that this variable reflects relative relationship disharmony and distrust, which may provide more fertile ground for arguing over the study or feeling the study was a burden.

This study required HIV testing of school going (although mostly adult) participants. Whist this is often viewed as problematic, we found it to have been a specific motivator of study participation. This may have reflected the more limited availability of HIV testing in Government clinics in 2003 when the study started. Whilst most participants indicated that their partners had not been told about it, there was pressure from partners to get results in 1 in 5 of cases. This may have been related to the often reported vicarious HIV testing (i.e. pressuring a partner to test and assuming sero-concordance (Jewkes and Morrell, 2010). The small group encouraged not to get their HIV

results may have had partner influenced by similar ideas, but ones who were dominantly fearful of being found to be HIV positive. The gender differences in partners trying to stop results taking may reflect gender power norms whereby men expect to be able to control their partner (Jewkes and Morrell, 2010).

The key strengths of the evaluation presented here include the large size of the study, the inclusion of both men and women, the long follow up period (24 months), and repeated (usually three) measures of gender-based violence and other sensitive measures of experience of violence and sexual behavior. However, information on experiences of participation in the study was only available for participants who completed the 24 month interview and so we have no information on the motivations and study experiences of those who were lost to follow up. The main reason for loss to follow up was participants moving to a different school or village; many also moved to completely different parts of South Africa. Such moves are very unlikely to have been related to study participation experiences. The similarity between those lost to follow up and those retained in all characteristics including exposure to gender-based violence and childhood trauma further supports a view that those lost to follow up would be similar to those retained with respect to main areas of concern in this paper.

Our questions about experience of study participation required retrospection over two years may have led to some recall bias. However, they did allow us to assess participants' long-term reflections on their involvement in our research. The general perception that almost everyone was happy at the end of the study was confirmed when we asked participants if they would be willing to have their details retained by the researchers so they could be invited for further research. Almost everyone agreed (see also Griffin et al., 2003, Edwards et al., 2009b).

The quantitative methods used enabled data to be collected from many participants with subgroup comparison and multivariable regression modeling. They do not allow a more nuanced exploration of the issues as available data are necessarily restricted to the largely closed questions that were used.

Conclusion

This study provides valuable insights into research participants' motivations and experiences for enrolling and remaining in a long-term HIV prevention trial. Importantly, it offers considerable reassurance for those organizing evaluation studies that include measures of gender-based violence and stigmatized sexual behavior. In this study, the risks associated with research on gender-based violence and potentially stigmatized sexual behavior were few, even though it was necessary to

somewhat deviate from the WHO guidelines about concealing the study's interest in violence and not recruiting partners or men and women from one locale because of the nature of the RCT evaluation. This provides considerable reassurance for other researchers who are unable to follow these recommendations. However, we have also provided further evidence that research participants have concerns about their partners learning what they are asked in sensitive questionnaires, and this concern can be mitigated by following the WHO guidance. We thus recommend that in circumstances where it is relatively easy to follow the WHO recommendations, such as in most community survey research, recommendations about geographically separating male and female participants, not recruiting partners, and concealing questionnaire context should be followed. However, our experience here shows minimal risk associated with careful deviations from these protocols when necessitated over-rising considerations of study design, such as those in this large trial of a community-level HIV prevention intervention designed to include both male and female participants.

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Table 1: Characteristics of the sample comparing those lost and not lost to follow up

	Women			Men		
	retained in sample (n=1085)	lost to follow up (n=332)		retained in sample (n=985)	lost to follow up (n=386)	p value
	%	%	p value	%	%	p value
Mean age	18.54	18.75	0.061	19.11	19.25	0.191
Educated to grade 10	86.4	85.5	0.702	88.7	83.9	0.037
socio-economic status (mean)	0.003	0.017	0.879	0.007	-0.018	0.786
childhood trauma scale (mean)	-0.012	0.031	0.506	-0.029	0.073	0.071
Ever had sex	90.5	92.5	0.197	94.0	93.8	0.863
Intimate partner violence ever: none	59.2	56.1	0.104	68.1	68.0	0.093
Physical	24.1	29.6		22.6	23.6	
sexual	5.7	3.1		3.3	5.2	
physical & sexual	11.0	11.2		6.0	3.3	

Table 2: Comparison of perceptions and consequences of participation between men and women

		Women		Men	
		Strongly agree or agree		Strongly agree or agree	
Motivation to participate	**n**	%	n	%	P value
A chance to help the community	1076	99.2	964	97.9	0.025
Chance to get a HIV test	1053	97.1	920	93.4	0.004
The R20 incentive	723	66.6	403	40.9	<0.0001
General perceptions of research participation					
Pleased to have had a chance to be in the study	1061	97.8	962	97.8	0.97
Found workshops more interesting than expected	1055	97.2	959	97.4	0.88
The research helped me at school	1006	92.7	891	90.5	0.103
Interviews really helped me	1062	97.9	960	97.6	0.606
Never previously had told someone about some of the things asked in the questionnaire	466	43.0	338	34.4	0.0008
Adverse consequences of research participation					
I had tried to forget painful things asked in interview	611	56.3	594	60.4	0.124
Questions about childhood made me sad	153	14.1	69	7	<0.0001
I had to keep some of the content secret to avoid getting into trouble with my partner	257	23.7	272	27.6	0.097
Intimate partner became cross after hearing about the questionnaire	124	10.6	46	4.7	<0.0001
Was pressurised to take HIV results by partner	256	22.9	148	19.7	0.238
Partner tried to prevent me taking HIV test results	94	8.7	23	2.3	<0.0001
Arguments at home about participation	123	11.3	57	5.8	0.0002
Beaten for participation in the study	10	0.9	2	0.2	0.029

With hindsight, I would have preferred not to have participated	88	8.1	96	9.8	0.204

Table 3: Comparison of perceptions and consequences of participation by gender and study arm

	Women			Men		
	Stepping Stones	Control		Stepping Stones	Control	
	% Strongly agree or agree	% Strongly agree or agree	p value	% Strongly agree or agree	% Strongly agree or agree	p value
General perceptions of research participation						
Pleased to have had a chance to be in the study	98.9	96.7	0.014	97.6	97.9	0.767
Found workshops more interesting than expected	99.3	95.3	0.0001	97.8	96.9	0.427
The research helped me do better at school	94.8	90.7	0.019	93.7	87.1	0.002
Interviews really helped me	99.3	96.5	0.019	96.8	98.3	0.096
Never previously had told someone about some of the things asked in the questionnaire	41.2	44.7	0.001	30.6	38.3	0.144
Adverse consequences of research participation						
I had tried to forget painful things asked in interview	57.2	55.5	0.648	57.5	63.3	0.422
Questions about childhood made me sad	15.3	13	0.347	6.4	7.7	0.354
I had to keep some of the content secret to avoid getting into trouble with my boyfriend	24.6	22.7	0.522	29	26.2	0.877
Intimate partner became cross after hearing about the questionnaire	10.8	10.4	0.864	4.6	4.8	0.263
Was pressurised to take HIV results by partner	21.2	24.5	0.46	17.3	22.3	0.311

Partner tried to prevent me taking HIV test results	7.3	10	0.142	2.8	1.9	0.418
Arguments at home about participation	12.7	10	0.231	6.8	4.8	0.298
Beaten for participation in the study	0.7	1.1	0.582	0.2	0.2	0.975
With hindsight, I would have preferred not to have participated	8.9	7.3	0.376	8.5	11	0.158

Table 4: Logistic regression model of factors associated with regretting participation, by gender adjusted for age and study arm

	Women (N=1030)				Men (N=984)			
	Odds ratio	95% Confidence Interval		P value	Odds ratio	95% Confidence Interval		P value
Motivated by R20	3.26	1.63	6.53	0.001				
I had to keep some of the content secret to avoid getting into trouble with my partner	2.39	1.46	3.90	<0.0001	2.72	1.71	4.30	<0.0001
Questions about childhood made me sad	2.11	1.22	3.66	0.008	2.81	1.44	5.46	0.002
I had arguments at home about my participation	3.27	1.89	5.66	<0.0001	2.49	1.19	5.19	0.015
Perpetrated intimate partner violence ever: none					1.00			0.004
Physical					2.06	1.26	3.38	
sexual					1.50	0.48	4.73	
physical & sexual					0.92	0.31	2.73	

CHAPTER EIGHT

DISCLOSURE OF CHILD MURDER: A CASE STUDY OF ETHICAL DILEMMAS IN RESEARCH

Sikweyiya, Yandisa M

Gender and Health Research Unit

Medical Research Council

Pretoria, South Africa

Jewkes, Rachel K

Gender and Health Research Unit

Medical Research Council, Pretoria, South Africa

University of Witwatersrand, South Africa.

Address for correspondence: Sikweyiya Yandisa

Gender and Health Research Unit

Medical Research Council, Pretoria, South Africa

Email: yandisa.sikweyiya@mrc.ac.za

Tel: 012 339 8619

Fax: 012 339 8582

Abstract

Disclosures of unreported incriminating information are not commonly documented in research. As a result researchers often do not know how to respond when cases arise. In the course of an interview, it may occur when respondents volunteer incriminating information, without necessarily being asked, and this presents an ethical dilemma. When such a disclosure occurs, researchers must choose between maintaining confidentiality and public protection. Through a South African case study, this article explores laws and ethical codes that provide the duty for researchers to report disclosures of unreported incriminating information by respondents. It then discusses the ethical and practical reasons that could guide a decision to report or not to report a disclosure. It further highlights implications of such decisions for research.

Key words: Incriminating information, disclosure, duty to report, case study

Introduction

Disclosures of unreported incriminating information are not commonly documented in research; as a result researchers often do not know how to respond when cases arise. This may occur when respondents volunteer information, without necessarily being asked, and presents an ethical dilemma. Researchers must choose between maintaining confidentiality and public protection. Debate on confidentiality in research has been ongoing for a number of years. Some advocate for totally preserving confidentiality[1], while others argued that certain situations warrant breach of confidentiality.[2]

Although laws and ethics codes exist to guide how we behave in a research context, sometimes they are insufficient to cover complex situations; they may conflict or be hard to interpret.[3] Breaking confidentiality is a very complex issue and needs careful deliberation and sensitive handling. Beyrer and Kass have highlighted negative consequences that could result from breach of confidentiality; these include death (presumably of the participant), expatriation or other severe forms of harm.[4] Cowburn[2] suggests three main issues that need to be considered before breaching confidentiality with a report to authorities. First checking whether the disclosure identifies a specific offender, and a specific victim. He suggests that if it does, then one should consider the nature of the offence, the identity of the perpetrator, the identity of the victim and when the offence occurred or is threatened to occur and make a determination on whether to report based on the balance of these issues. There is paucity of literature on this area of research and we need this body of knowledge documented.

Through a case study, this article explores laws and ethical codes that provide the duty for researchers to report disclosures of unreported incriminating information by respondents. It then discusses the ethical and practical reasons that could guide a decision to report or not to report a disclosure. It further highlights implications of such decisions for research.

Case study

An event has occurred of which it is difficult to speak and impossible to remain silent. Edmund Burke, on the impeachment of Warren ***Hastings,*** *1788*

In a large community in South Africa where a survey was being undertaken, in the course of a face to face questionnaire-based interview, a respondent disclosed to the interviewer that she had poisoned her two children with the intention of killing them. Four months earlier, she had given the children (both less than 5 years old) poison. The youngest had died in hospital whilst the other, with medical

intervention had survived. What prompted this disclosure is unclear as in the survey questionnaire there were no items which asked about child murder. Yet the respondent voluntarily disclosed the information to the interviewer. This was the first time, we understand, she had made such a disclosure to anyone. She explained to the interviewer that she was a struggling black woman with limited economic and social support. She lived with her extended family, had HIV and was on ART, and had been pre-occupied with thoughts of her death. She said she had poisoned the children so that they should not remain alive with her family after her death.

The interviewer reported the disclosure to the research project managers. They discussed the matter and concluded that it probably should be reported to the South African Police Services. The chairperson of the research ethics committee (REC) that had approved the study was contacted and the matter discussed. He advised the researcher to seek advice from the REC's legal adviser. All parties agreed that it should be reported to the South African Police Services (SAPS). This was done.

Several reasons informed the decision to report the matter to police services. The researchers felt this was a very serious case as it involved murder and attempted murder. Another major concern was that the child who survived still lived with the mother and so could still be at risk. Another factor was that the South African law requires the reporting of cases of child ill-treatment. Lastly, at the time of the disclosure, the research participant had intimated that to her knowledge no police case had been opened and there had been no inquest into the death of the child.

Legislative framework providing duty for researchers to report child victimization

Section 28 (d) of the Constitution of the Republic of South Africa provides that "*every child has a right to be protected from maltreatment, neglect, abuse or degradation*."[5] Complementing the constitution, the Children's Amendment Act[6] makes it a duty for professionals such as medical practitioners, psychologists, social workers, nurses, and others who come into contact with abused children to report child abuse to the relevant child protection organizations or a police official. Interpreting South African laws, Strode et al[7] in their document "a directory of the legal rights of child & adolescent research participants in South Africa" mention legal obligations concerning researchers who work with children. These include that researchers have an obligation to *(1) Respond in a lawful and appropriate manner including reporting where required; (2) Intervene and assist or refer children for assistance where needed, and tell parents or guardians of children of their obligations at the outset, as reporting may result in breaches of confidentiality*.

The Children's Amendment Act[6] requires any one in South Africa to report any suspicion of ill-treatment or injuries inflicted deliberately on children. In section 25 of the Children's Act[8], both subsections (7) and

(9) stipulate that in all matters relating to the care, protection and wellbeing of children, the child's best interest must be the guiding principle. There is certainly a legal duty to report maltreatment of children[6]. Since no legislation specifically dealing with the duty for researchers to report child maltreatment, this is established through interpretation of various laws that this duty for researchers is found.

Why we should report

Violence against children remains a concerning and pervasive problem worldwide.[9] Age, developmental stage, physical strength and societal status render children vulnerable to various forms of violence including physical, sexual and emotional.[9] Therefore, special protection of children is necessary to shield them from preventable and deliberate harm.[10]

South African law provides a legal duty for adult citizens to report child abuse to authorities. Whilst there are no specific laws obligating researchers, these laws are phrased generally and so as citizens, researchers are expected to comply with.

In this case the disclosure of the respondent was sufficiently comprehensive to meet the criteria, as suggested by Cowburn[2], for assessing whether a disclosure should be reported to the police. A serious crime had been committed by a known perpetrator against known victims and a child remained at risk. With this in mind the researchers decided that reporting this case to the police was legally and ethically correct. Furthermore the confession made to the fieldworker would have been admissible as evidence in court and helped to bring about justice for the dead child.

Why we should not report

Arguments against reporting relate to the social circumstances of the interviewee. It is important to explore and understand her situation and her perceived vulnerability.[10]

Women in South Africa, as in most African communities, occupy a low position in society. South Africa is characterized by the widespread subordination, and control of women by men.[11] From the case study, the same can be assumed for the respondent. The respondent had had a rather difficult life. She had a life threatening disease, which by her own account she had not disclosed to her family, she also had problems at home where she lived. She was therefore highly vulnerable, and she may have been psychologically distressed at the time she committed the act. She clearly felt remorse for this, a punishment in itself, and so may not have been an ongoing risk to the remaining child.

There are a number of explanations for her disclosure. She may have been overwhelmed by guilt and felt that uncovering the act would ease her. Alternatively she may have wanted some sort of intervention, but not necessarily one provided by the criminal-justice system. Furthermore, in the consent process, the respondent was promised anonymity and confidentiality of the information she would give. Thus we can assume that it may be that she may have disclosed in good faith assuming that her confession would go no further.

The fieldworker to whom the incriminating information was disclosed was on a three months contract employed for the survey. She resided in one section of the large community a number of kilometers away from where she conducted this particular interview. This was her first experience in conducting face to face interviews in a gender-based violence study and this disclosure happened in the early stages (week 2) of data collection.

Whilst fieldworkers are trained for data collection such training does not normally focus on explaining these types of professional responsibilities of fieldworkers, on highlighting aspects of laws obligating reporting of previously unreported incriminating information, or discussing the risks and implications of this for fieldworkers. The fieldworker may have had an ethical, although not legal, obligation, to try and prevent disclosure, which she did not meet. It seems she was not prepared for such a disclosure, it may have been difficult for her to anticipate or even prevent, the disclosure as Cowburn describes being able to in his research with convicted sex offenders.[2]

The decision to report the case was not supported by the fieldworker as she was fearful for her safety. What she saw was a major step and she feared retaliation, a risk she had not considered when taking the job. She felt strongly that her fears should be paramount in the decision to report. Additionally, her fears were greater as she had left a copy of the consent form with the woman on which she had signed her name as witness. Further, she had probably told the woman where she lived as an 'off script' part of ice-breaking at the start of the interview. Potentially she may have been traceable.

Furthermore, the fieldworker was fearful of reporting the incident to the police services, fearing being implicated in causing adverse consequences for the respondent. On being told that her responsibility might extend to going to the police station, giving a statement that a disclosure of this nature was made to her, as well as naming and describing the respondent, she had misgivings. She felt the interviewee who committed the crime would clearly know she is the one who reported the matter to the police.

Preserving confidentiality is very crucial in research.[12,13] Yet fulfilling this obligation is complex[1]. Reporting to authorities incriminating information about a respondent could be interpreted as breach of confidentiality by some including the respondent in question. The Medical Research Council[i](book1)[14] posits that researchers have a duty to ensure that participants' information remains confidential, and further mentions that "*failure to safeguard information may render a researcher liable for breach of confidentiality*". They warn that "*legal exceptions may be imposed in terms of the law*". This is because, arguably, the respondent and others may feel she disclosed the information in confidence.

In an ongoing survey where data collection is still continuing, negative ramifications to the study could be an eventuality. Although to some this act could be viewed as morally praiseworthy and seen as a right response, others may develop mistrust towards research.

Discussion

The American Anthropological Association[15] asserts that the obligation to preserve the welfare of others should supersede knowledge generation in research and that researchers should make such choices that would maximize benefits for and minimize harm to the greater society. In reporting the case to the police, we perceived we acted in accordance with this guidance as well as with South African law. Furthermore, we concur with Hearn et al.,[16] when they argue that although there are principle-based approaches to guide research processes, it is imperative that researchers discuss ethical dilemmas[17] and are prepared to make open the assumptions and facts on which those are based to scrutiny.[10]

In this case, there was a need to strike a balance between safeguarding the participant's privacy and confidentiality and obligations to public safety and protection. Whilst the respondent was young and vulnerable and her mental state may have been unstable at the time she committed the act, she was responsible for her children's care and at the time of the interview was still the primary carer of one child. By killing and attempting to kill her children, she committed a very serious offence against both the child and society. Hull et al.,[18] argue that due to their vulnerability, children are often unable to express their needs or defend their interests; therefore they need special protection from law and others. As such whilst recognizing that there can be arguments for not reporting the case to the authorities, and that there is a particular need to preserve confidentiality in research[13,14], the law is unambiguous in obligating for reporting of child abuse to authorities

We further argue that the woman's vulnerability would appropriately be taken into account by social workers in assessing risk to her remaining child and the courts in passing judgment (if the case goes to court). Researchers are not trained and equipped to evaluate legal cases[19]. Researchers, like other citizens, have a legal duty to protect children from harm and that extends to reporting any case of suspected or known child abuse.[7]

As such, whilst considering the interviewer's fears the research team argued that by working for a research project, she took on a set of professional responsibilities and these placed her responsibility to the child over her own safety. The research team's assessment of the risk to her was that it was likely to be small and that, as an adult, she was inherently more powerful than the child and should prioritize the child's interests. We further argue that, unlike a child, she could take precautions and protect herself, as she had agency and autonomy. Furthermore, as a citizen herself, the legal duty obligating reporting of child abuse fell on her too.[19]

We believe reporting the incident to the police services had, in some way, provided justice to the murdered child and the remaining child whose life was potentially endangered. Furthermore, as McQuoid-Mason[19] noted, failure to report to authorities such a disclosure, as provided by South African laws, could amount to a "criminal offence for which the person (researcher) may be liable to a fine or imprisonment."

Implications for research

This case study raises a number of implications for community based research, especially on sensitive topics. We will briefly highlight three important implications.

First for training. Interviewer training should include mention of possibility of disclosures of unreported incriminating information to fieldworkers. It should include discussion of the desirability of warning about the implications of, or preventing a disclosure when it may be occurring in an interview. It should also include a general discussion of professionalism and what that entails in research. Fieldworkers must be made aware of laws obligating disclosure of previously unreported incriminating information.

Secondly, confidentiality: in almost all countries confidentiality is potentially limited and research participants should not be told it is assured when it may not be. Examples of cases where researchers may be obliged to report disclosure(s) by respondents to authorities should be given to research

participants. For example in the initial consent phase, it should be mentioned that “there are laws that compel researchers to report incriminating information, therefore all information you provide will be confidential unless you provide details of serious crimes against identifiable person(s)”. We encourage a debate on this question and recommend that such debate should focus on two issues. (1) Whether such a statement would deter respondents from speaking freely and candid about their experiences, and (2) whether it would be effective in stopping respondents from disclosing incriminating information in qualitative face to face conversational interviews.

Thirdly, consent and the signing of consent forms. In this case the fieldworker may have been rendered vulnerable by leaving a signed consent form in the participant’s house. We have an obligation not to expose fieldworkers to possible recrimination by asking them to sign as witnesses in consent forms. Whilst information is usually left in a home with details of the study principal investigator, these people generally have more financial resources and so are better able to protect themselves. More thought needs to be given to avoidance of exposure of fieldworkers to potential risk at work.

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CHAPTER NINE

DISCUSSION AND CONCLUSION

This chapter presents and discusses findings that are drawn from three different empirical studies. From these studies, three qualitative papers, one quantitative and a case study were written. In this chapter, I synthesise the findings from the different studies and construct a whole story about this research (Mouton and Marais 1990; Hennink, Hutter, and Bailey 2011). First, I will present a synthesis of the findings from the different studies and discuss how they connect or contrast with each other and therefore how the thesis, as a whole, contributes to the body of knowledge in research ethics on GBV research and provide concluding remarks. I will then discuss the implications of the findings for existing research ethics guidelines, in particular to the WHO Guidelines (2001), and propose directions for future ethics work on community based sensitive research.

5.1 Concerns and worries about risks in GBV research

I. Concerns about safety of respondents

Findings presented in this thesis show that researchers who work in the GBV field view this area of research as particularly sensitive and risky, in particular for research participants (Paper 1). Findings suggest that the safety and protection of research participants is viewed as a major ethical concern in GBV studies. In the interviews, researchers indicated that they were often worried about the potential for violent reprisal by the male partners of women participants if there was a breach of confidentiality (Paper 1). This concern emerged repeatedly in the

narratives of the researchers, and they mainly feared for negative consequences that could result for women as research participants (Paper 1). The potential for women respondents in GBV research to suffer violent reprisal, from male partners, has been highlighted in a few other papers (Ellsberg et al. 2001; Jewkes et al. 2000; Fontes 2004), and the findings of this research adds to this body of literature.

Another worry expressed by the researchers was that GBV research had an increased potential to emotionally and psychologically damage women respondents as it required women, who often are victims of GBV, to think about and share their violence experiences which are often painful, degrading, shameful and traumatic (Campbell 2002). Findings suggest that psychological harm or damage to research participants was considered as a major risk in GBV research (Paper 1).

The findings reported in Paper 1 are an important contribution to knowledge as they are views and perceptions of researchers who had conducted GBV research in many countries and settings, and on different forms of GBV (Coles et al. 2010). The findings demonstrate that, generally, researchers seem to worry about two major risks in GBV research i.e. risk of physical harm and psychological harm to research participants, in particular women (Paper 1).

II. Safety concerns for researchers

Not much has been published on how conducting GBV research impacts researchers. The emotional/psychological impact and the physical risks of conducting such studies have not received much attention. Consequently, we have, presently, a limited understanding about the safety needs of researchers who conduct this work. Notwithstanding this, however, it is

important to note that some authors have written about the importance of having considerations about researchers' psychological health and physical safety when planning GBV studies (Fontes 2004; Jewkes et al. 2000; Ellsberg et al. 2001; Coles et al. 2010; Coles et al. forthcoming).

More empirical work conducted with GBV researchers is needed to better understand their perspectives on and experiences of risks when conducting the studies (Dunn, Candilis, and Roberts 2006). This will help us to devise appropriate measures and safeguards for researchers who conduct sensitive research (Coles and Mudaly 2010). In most interviews, researchers did not mention their physical and psychological safety including that of fieldworkers as an essential risk in GBV research (Paper 1). As researchers noted, the availability of empirical data on risks and burdens carried by researchers when conducting studies may inform IRBs to consider the safety and welfare of researchers when reviewing protocols on GBV studies (Paper 1).

III. Was there evidence to support concerns and worries about risk?

In this study it was important to gain an understanding of where the risks concerns are located and whether such risks are unique to GBV research, or whether these are risks that may be found in other community based studies with women and men.

Findings in Paper 1 suggested that the notion that GBV studies carry more than minimal risk [for participants] seems to be based on assumptions and speculations. Data in this study revealed no evidence pointing towards an increased risk of psychological or emotional harm for participants in GBV research. Researchers who were interviewed in this study and had argued

that GBV research is inherently risky, seemed to base their arguments and views about risks on the WHO Guidelines (2001) and few published, and not on empirical evidence (Paper 1).

It seems that the view that gender-based violence research is exceptionally risky, as often assumed by IRBs and researchers, may be based on their subjective opinions regarding the 'sensitivity' of the topic of GBV, but this seems not to supported by empirical evidence (Paper 1). Additionally, the findings presented in Paper 1 seem to suggest that risks in GBV research remain minimal when study protocols and ethics guidelines are adhered to. In the interviews, no adverse consequences, for participants, were reported by researchers to have happened in their studies when guidelines were followed (Paper 1).

Thus, I argue that, for us to develop an in-depth understanding of concerns about and risks in GBV research, the subjective views and experiences of researchers about the riskiness of this field of research should be balanced against those of men and women who participate (Dunn, Candilis, and Roberts 2006) in GBV studies. Exploring the different perspectives of the researchers and the participants may provide us with insights whether GBV research is particularly risky in a way that differs from that of other community based studies, as has been suggested by other authors (Fontes 2004; Campbell 2002; Jewkes et al. 2000; Ellsberg et al. 2001).

5.2 How participants perceived research participation?

The majority of participants expressed positive feelings about the survey, with many reporting to have appreciated the opportunity to participate in the survey (Paper 3). This finding is consistent with a finding of a study in the US where the majority of the young people (aged 14-

26) who were asked about their sexual experiences, including negative ones, reported positive experiences from study participation even though some of them had also reported distress on being asked certain questions (Kuyper et al. 2012) . In this thesis, many participants said the survey had afforded them a chance to talk about issues they do not normally talk about in their everyday lives (Paper 3).

Participants who had traumatic histories or life threatening experiences had reported that, through survey participation, they derived an uncommon opportunity to talk about their adverse experiences, and thus found this exercise beneficial (Paper 3). Similar findings have been reported in other studies. For example, Griffin and colleagues (2003) reported that, in their study, the majority of participants who had been victims of severe assault experienced research participation as interesting and not harmful. In this thesis, participants reported that sharing these experiences with someone who was willing to listen and empathetic was cathartic for them (Ellsberg and Heise 2002; Campbell 2002) (Paper 3).

In this thesis, specifically, participants who had been raped, had experienced IPV, or had HIV reported that being interviewed in the survey gave them an uncommon opportunity to talk about these experiences in a space they perceived as safe and unthreatening, thus comforting (Paper 3). These findings are consistent with those presented in Paper 2 where a number of women, in particular those with abuse histories, equated research interviews with therapy and frequently used terms like healing to describe their emotional reaction to the interviews (Paper 2).

Some authors have commented about the potential for research participation to have a therapeutic effect on respondents, especially women who have had traumatic histories (Campbell 2002; Campbell and Adams 2009), and some report that many women disclose for the first time their violence victimisation experiences in research studies, which makes them value research participation (Campbell 2002). Similarly, in this thesis, some women said they did not often have people they could confide in about certain sensitive issues; as such the research interview had offered them a very rare chance to express how they felt. Voices of women in South Africa often get suppressed and women, in particular, in intimate relationships, are not given the space to express how they feel. This is related to gender and power issues and roles within relationships. Women therefore, in this research, valued the opportunity to be heard by someone they perceived as a willing, non-judgemental and an empathetic listener (Paper 2).

Positive experiences with research participation were also reported by participants in Paper 4. Quantitative data show that almost all the trial participants (women 97.8% vs men 97.8%, p=0.97) were happy to have had a chance to participate in the Stepping Stones trial (Paper 4). They perceived that the interviews had helped them to do better in their school work (women 92.7 vs men 90.5, p=0.103), though the trial was not designed to impact on this (see also Jewkes, Wood, and Duvurry 2010).

Psychology literature supports these findings. A number of authors have presented findings showing that a large proportion of research participants, including those who have experienced major traumas or adversities (Kuyper et al. 2012; Edwards et al. 2009; Johnson and Benight

2003; Campbell 2002), or with recent traumatic experiences in their lives perceive talking about such issues in a research context as not psychologically damaging but beneficial (Griffin et al. 2003). As such, findings of this research are very important in the field of GBV as they add to a very limited body of knowledge on this topic worldwide (Fontes 2004; Edwards et al. 2009).

In this thesis, while most of the participants reported positive feelings and experiences about research participation, some, albeit being few, expressed discomfort with research participation, and in particular with what they were asked in the research. For example, in Paper 3, some men reported that the survey questions that asked them whether or not they have had sex and with whom, how many women they had slept with, whether they had used condoms, about their HIV status, whether they perpetrated partner violence, and the nature of their intimate relationships, and criminal behaviour, had caused them uneasiness. For example, Vuyile, a young man in his late 20s, explained: "*uhm…sex life, my sex life, my parents, those kinds of things…yes just that…uhm I just get a certain discomfort from talking about them*". On the other hand, Thabo, a 29 year old man, explained which questions made him angry and the reasons for his anger regarding being asked the questions. He said: "*yes, why is he [interviewer] asking me about my girlfriends, how many women have I slept with, am I using a condom? Yes those are the questions that made me angry*" (Paper 3).

Some women also mentioned that it is embarrassing, and possibly stigmatising, to disclose in research interviews that they were being beaten by their husbands or partners, and that the reasons for such beatings may be very personal (like refusing to have sex with the husband) and thus extremely shameful to report in interviews (Paper 2).

With regards to partner abuse, some participants reported that disclosing abuse either as a perpetrator or victim, in a research interview is like acknowledging that they are victims or perpetrators (Paper 2). Participants were not comfortable with this assumed identity, and reported that they feared being viewed in that manner (Paper 2). A study conducted in Cape Town, South Africa, with young University students reported a similar finding. Marais (2009) reported that younger women who had abuse histories rejected the identity of being victims by resisting to acknowledge their experiences as abuse.

In this thesis, in terms of which specific questions caused this discomfort, some participants said it was difficult to talk about the experiences they deemed painful, degrading and traumatic. Of the participants who said this, we noted gender-differences. For women, having children out of wedlock and while still young, having a large number of lifetime sexual partners, intimate relationships, and sex, being a victim of sexual abuse and spouse abuse would be embarrassing and difficult to talk about in a research context (Paper 2). In contrast, while a few women also reported this, the majority of men said reporting about their socio-economic circumstances, which they perceived as poor, would bring shame and embarrassment to them (Paper 2).

Similarly, in Paper 3, some men expressed that their discomfort, with some questions, was brought about by the fear of being judged harshly or labelled negatively by the researchers who were interviewing them in the survey (Paper 3). This discomfort is apparent in Sipho's narrative. He was a middle aged man and was HIV positive and he said that: "*he was concerned how the researcher was going to perceive certain things he wanted to tell him, as a result he concealed*

those in the interview" (Paper 3). The fear of being judged harshly by researchers has being given as a source of worry and discomfort by men in other settings as well. For example, in the rural Eastern Cape, men who were interviewed on sexual violence perpetration and were asked to share their thoughts and experiences on responding to such questions, mentioned that being judged negatively, labelled as perpetrators of GBV, and stigmatised by the researchers, would be their major anxiety (Sikweyiya, Jewkes, and Morrell 2007).

In Paper 3 I explored analytically why some participants perceived certain questions to be sensitive and embarrassing to discuss in research interviews. Findings show that some of the men who felt certain questions were sensitive and had reported discomfort with those questions, had also reported perpetrating intimate partner violence or were HIV positive (Paper 3). It is thus possible that they may have been uncomfortable to discuss these issues as that may have invited them to confront and evaluate their own violent behaviours (Sikweyiya, Jewkes, and Morrell 2007) or others, illnesses.

Literature suggests that people may employ strategies to avoid confronting realities about themselves as prompted by research questions. For example, Hearn (1998) argues that for men who have perpetrated interpersonal violence, a language of denial may be used to distance themselves from their own violence and to excuse or even justify it. In this research, men, like Thabo, who had perpetrated partner violence, used some language to trivialise the violence by saying he was disciplining his girlfriend and justified his actions by stating that she deserved the beating as she had cheated on him (Paper 3).

Another strategy used by some of the men who had viewed some survey questions as causing discomfort, was being dishonest in answering those questions. For example, Sipho who was HIV positive and had felt discomfort to disclose his sero-positive HIV status in the survey, did not answer factually the question on HIV status and rather reported that he was HIV negative (Paper 3). Similarly, in Paper 2, some men stated that, because of the fear of being embarrassed, they would protect their dignity by concealing information pertaining to issues they were ashamed to talk about.

This thesis argues that men like Sipho and Thabo who said that they felt uncomfortable with some research questions and those who reported to be upset with being asked some questions in the research may have perceived these questions as relatively incriminating (Ybarra et al. 2009; Sikweyiya, Jewkes, and Morrell 2007) and for others, questions on HIV status and drug abuse may have made them reflect on their actions and think they were to blame for their current conditions.

Similar data to the one presented in this thesis are scant from a social science perspective. As such, findings of this research are very important in the field of GBV as they add to a very limited body of knowledge on this topic worldwide (Fontes 2004; Edwards et al. 2009; Jewkes and Wagman 2007; Jewkes et al. 2000; Ellsberg et al. 2001; Lavery et al. 2007).

5.3 Motivations for research participation

Findings suggest that people seem to be motivated to participate in research by several reasons and factors (Kost et al. 2011; Osamor and Kass 2012; Masiye et al. 2008). Findings in Paper 2

show that, a total of 22 (out of 26) reported that they would participate in research with expectations to benefit financially, being offered a job, or helped with another social need.

Most of the participants reported that they would mainly expect direct benefit, with few of them saying they would like their community to benefit from their research participation (Paper 2) (Kneipp, Lutz, and Means 2009). Analysis revealed no difference according to the participants' gender in having these expectations. Yet, what was observed in the qualitative data was that older participants and those who had financial difficulties were more likely to expect an immediate and individual benefit from research participation. In contrast, participants with previous research participation or those who had some tertiary education were less likely to report expecting direct personal benefit from research participation than those with no prior research participation. The former group was the majority and had generally demonstrated a lack of understanding of research (Paper 2). Furthermore, that the expectation to benefit individually was held irrespective of gender, may suggest that what drove this expectation was the socio-economic challenges that were prevalent in this community (Paper 2). Alternatively, it may be that participants generally had hoped that some form of intervention would automatically follow their participation in research (Slack et al. 2004; Mfutso-Bengo et al. 2008; Osamor and Kass 2012).

In the Stepping Stones study, motivations for trial participation differed between men and women, but the magnitude of this difference was negligible (Paper 4). Almost all participants reported that they were motivated by the opportunity to get an HIV test (women 97.1% vs men 93.4%); and to have a chance to help their community (women 99.2% vs men 97.9%). A large

number said a R20 incentive had been part of motivation, with more women (66.9%) vs men (40.9%) reporting this. The findings show that the majority of participants were motivated by self-interest, while altruism also seems to be a strong motive to participate in the trial [discussed more below], and no gender-differences were observed in reporting these reasons (Paper 4).

What could be noted from these data is that there are a multiplicity of reasons (Kost et al. 2011) given by young people for engaging in research on HIV and GBV. We also think that the finding that women were more likely to be motivated by the offer of R20 to participate in the trial may have reflected the local practice of mothers giving pocket money to boy children, while expecting girls to make do without it (Paper 4).

In South Africa, debate is ongoing about whether it is a correct public health approach to have a mass programme on HIV Voluntary Counseling and Testing in secondary schools. Currently there is a view that testing (for HIV) of school going children is problematic. Participants in the Stepping Stones study were adolescents recruited from secondary schools, and findings presented in Paper 4 show that the chance to have an HIV test in the study was a specific motivator for them to participate in the trial. However, this may been because of the limited availability of HIV testing in government clinics, in the rural Eastern Cape setting, in 2003 when the study began (Paper 4)(see also Dunn, Candilis, and Roberts 2006; Masiye et al. 2008; Mfutso-Bengo et al. 2008). This finding is congruent with findings of a study in Malawi where mothers reported that they enrolled their children in Malaria research in order to access better medical care (Masiye et al. 2008). Authors reporting this finding argued that in a setting like

Malawi, where service delivery is relatively poor, it may be anticipated that medical care accessed through research participation will be considered better than what is locally available (Masiye et al. 2008).

5.3.1 Altruism

Altruism has been reported as a motivation for participation in many clinical trials (Kost et al. 2011; McCann, Campbell, and Entwistle 2010), however, these data mainly come from the developed Western countries (Zammar et al. 2010; Osamor and Kass 2012). There is little information on altruism as a research motive coming from non-Western countries (Osamor and Kass 2012), even though some authors have highlighted the significance of altruistic motives for research participation (McCann, Campbell, and Entwistle 2010; Kost et al. 2011), and of better understanding these motives (Osamor and Kass 2012).

In this thesis, reasons for research participation that were viewed as altruistic were reported by many participants. In Paper 2 nearly half of participants (09 out of 22) reported reasons that were interpreted as selfless and with the intention to benefit others**.** However, a complex overlap between altruism and self-interest motives was observed in this thesis, and this included participants who were primarily motivated by altruism. For example, in Paper 2, while the majority of the participants had reported that they would participate in research studies with some expectations to personally benefit from it, some of them also mentioned altruistic motives (see also Rosenbaum et al. 2005). Quantitative data provided strong support for these qualitative findings. In the Stepping Stones study, the overwhelming majority (more than 90%) of young people reported, at 24 months follow-up, that the desire to have an HIV test

motivated their participation, yet almost all (women 99.2% vs men 97.9%) also said that by taking part in the trial, they obtained an opportunity to contribute to the betterment of their community (Paper 4).

It is not easy to interpret these findings and to understand what primarily motivates people to take part in research. Literature on research participation suggests that some people enrol in studies motivated by altruistic reasons (Kost et al. 2011; Zammar et al. 2010). Yet most authors do not unpack what they mean by altruistic motives in a research context (Braunack-Mayer 2002; Hallowell et al. 2010). This lack of clarity on this concept provides a challenge for us to interrogate and answer this question empirically.

There is much literature on human altruism resulting from many decades of scholarly work and academic debates by classical and contemporary philosophers, ethicists and researchers (Rogers 1997; Thompson 2006; Braunack-Mayer 2002; Kost et al. 2011; Funch and Marshall 1981). However, this debate is still ongoing as there seems to be no definitional clarity on the concept, and no consensus on what is meant by altruism as a human behaviour (Costello 2001; Hoffman 2011). In his article, Costello (2001) attempts to provide some clarity on the definition of altruism. Costello mentions that while there seems to be no consensus on what altruism is, varying definitions of altruism seem to 'allow for benefit to the actor (donor) as long as the act of self-sacrifice is done for the recipient, while the benefit to the actor is not the primary motivation' (Costello 2001). While Costello's attempt to clarify this concept is useful, it may be difficult to ascertain or determine which motive precedes the other. Nevertheless, some

authors believe that people may and do act solely for the benefit of others (Zammar et al. 2010), while others totally reject this view (see Thompson 2006; Rogers 1997).

The complexity regarding the concept of human altruism is brought about by the difficulty to ascertain whether, when people act to help others, they are primarily and purely motivated by the desire to help without anticipating reciprocity or benefits to themselves (Costello 2001). It has been argued in philosophical debates that individuals who donate food, money, body organs or in other ways to help others, often anticipate and some report benefits to themselves from such performing acts (Schulz et al. 2009). Consistent with this view, Hoffman (2011) argues that a large number of organ donors donate body organs to unknown or known others as a method of enhancing their own self-worth by attracting positive attention to themselves. Congruent with this view, Schulz and associates (2009) posit that a number of organ donors report deriving psychological benefits which include a boost in their in self-esteem resulting from knowing that they have acted in a way that saved the recipient's life (see also Dunn, Candilis, and Roberts 2006). Costello (2001) and Hoffman (2011) further argue that, for an act to be altruistic, the end goal should be to help the other individual or make a contribution to society, and the benefit to the actor should not be a primary motivation.

Another complexity to altruism is that people may be pressured or coerced to act altruistically by the expectations of their family, friends and community (Hoffman 2011). In the research context, this may occur when people participate in studies because they believed that they 'have to' or 'need to' take part as it is something that is desirable to do or expected of them (Hoffman 2011).

The findings of this thesis add to this debate and body of knowledge on altruism. In this thesis I have shown that altruism as a motive for research participation is not a straightforward phenomenon (Paper 2 and 4). In a number of narrative accounts and reports of the participants, altruism and self-interest motives for research participation were inextricably linked (Paper 2 and 4) (Braunack-Mayer 2002). A possible explanation of this complex web may perhaps be found in an assertion by Hallowell and colleagues (2010) that because research participants are "*social actors who exist within a network of social relations, their motivations for research participation exist in an interdependent relationship, that overlaps, as such may be presented as interleaved and interlocking*".

I argue that in this setting, including for individuals with altruistic ideals, various factors, including socio-economic needs, education level, previous research exposure, and other social factors, that pertain to individual people's situations, circumstances and context might act to influence people's decisions to participate or not in research studies. Additionally, such factors might also moderate people's expectations in research participation.

5.4 Psychological and emotional impact of survey participation

IRBs and researchers alike have historically viewed research on GBV as having a potential to harm respondents in a way which differs from other forms of research (Lavery et al. 2007; Black et al. 2006). There is an understanding that asking research participants, in particular women, about painful and sad personal histories in a research context may have serious traumatic effects or psychologically distress them (Black et al. 2006; Fontes 2004). It is such concerns that have informed and underpinned the development of the WHO Guidelines (2001) (described in

chapter1). Yet, the literature review presented in chapter 1 shows that empirical data on the effects of GBV studies on the psychological health of respondents is rather limited (Savell, Kinder, and Young 2006). As such, some authors recommend more work to be conducted to assess the impact of violence and trauma focused studies on participants (Savell, Kinder, and Young 2006; Rojas and Kinder 2007).

In this thesis, distress as a result of talking about painful and traumatic experiences was reported by some participants in Paper 3 and gender-differences were observed in the data. Slightly more women than men reported distress. In Paper 3, women who had experienced relatively major adversities in their lives (rape, death of a loved one, HIV+ diagnosis) reported that the survey made them to relive those experiences causing them sadness and pain at the time. Congruent with this, some men who were HIV+, had perpetrated partner violence or had a drug addiction problem, mentioned that the survey had made them to reflect on these painful experiences in their lives (Paper 3). These findings receive support from the quantitative data in Paper 4. In the Stepping Stones trial, more than half of participants said the interviews had asked them about painful things which they had tried to forget; this proportion did not differ significantly between men and women (women 56.3% vs men 60.4%, p=0.124). However, more women than men (14% vs 7%, p <0.0001) reported that the questions about their childhood made them sad (Paper 4). Similar findings have been reported by authors in the field of psychology and psychiatry. In the psychology literature, evidence has been presented showing that asking research participants, in particular those with traumatic and adversarial histories, about such experiences may cause them to have feelings of pain and distress at the time of interview (Nduna and Jewkes 2010; Johnson and Benight 2003; Kuyper et al. 2012).

Notwithstanding this evidence, however, qualitative data presented in this thesis suggest that emotional reactions or distress related to survey questions, by those who reported it, seem to be time-limited, and not overwhelming or harmful. This finding adds to a growing body of knowledge that argues that asking people about their adverse experiences, in a research context is not deleterious, rather it seems to be viewed as beneficial by trauma and interpersonal violence victims (Campbell 2002). Furthermore, this finding is analogous to the findings of a systematic review of evidence on long-term effects on participants due to research participation reported by Jorm, Kelly and Morgan (2007). These authors concluded that there appears to be little evidence to show any long-term harm to participants even if research is investigating traumatic experience (Jorm, Kelly, and Morgan 2007).

The findings presented in Paper 3 suggest that while some participants had an emotional reaction to some survey questions, many of them also viewed the survey positively (Griffin et al. 2003; Newman, Walker, and Gefland 1999; Walker et al. 1997). The narrative from Vuyile's interview, a 28 year old man, illustrate how he perceived benefit from participating in the survey. He explained: "*for me the good thing about it [the survey] was that I got this opportunity to express things that I never expressed because no one has ever asked me those questions before. But because of the survey, I got that chance…Yes too; I like to express my inner self*" (Paper 3).

In this thesis I have shown that even among those who reported distress because of questions asked in the survey, such emotional reactions could not be construed as harmful as none of the participants reported in the interviews to have needed professional help to deal with such

emotions (Jorm, Kelly, and Morgan 2007). Most participants had viewed their emotional (sadness, anxiety, tearfulness and pain) reaction to some survey questions as a natural response to thinking about unpleasant personal histories (Paper 3).

The findings presented in this thesis are important in this emerging field of ethics of GBV research as they highlight the importance of locating facts about the risks of and their nature in asking people questions about their sexuality, trauma and interpersonal violence histories.

The knowledge that this thesis contributes is that emotional reactions like sadness and tearfulness should not be viewed as emotional or psychological harm (DePrince and Freyd 2004). In both Paper 3 and the Stepping Stones study (Paper 4), there was no evidence that suggested that asking people about their traumatic and violence histories, in a research context, put such individuals in more than minimal risk for psychological harm (Black et al. 2006; Jorm, Kelly, and Morgan 2007; Edwards et al. 2009). As such, I argue that the distinction between sadness or pain and being psychologically damaged in the research context is important to make as the former seems not to equate to the latter, as often assumed (Jorm, Kelly, and Morgan 2007).

5.5 Gender analysis on perceptions and experiences of risks

Literature presented in Chapter 1 has shown that there is a general view that women have an increased risk of suffering physical harm through research participation compared to men. The understanding that women may be put at risk of physical harm through participating in GBV research has been alluded to in several published papers, although this understanding has often been based on researchers and IRB members' personal reflections and research experiences,

therefore anecdotal evidence (Fontes 2004; Ellsberg et al. 2001; Jewkes et al. 2000; Jewkes and Wagman 2007). An analysis conducted in this research revealed evidence that risks perceived by women differed markedly from those perceived by men when participating in community-based studies (Paper 3).

The findings show that a breach of confidentiality was viewed as a major risk by both men and women; yet, gender differences were noted in reported feared consequences resulting from such a breach. In Paper 3 some women reported that they were fearful after participating in the survey, and said that they feared retaliatory violence from their male partners. In particular, women who reported being in abusive or potentially abusive relationships, or having abuse histories, reported that they disclosed research participation and or the full contents of the survey to their partners having fear that their partners may react violently to this (Lavery et al. 2007; Jewkes and Wagman 2007; Ellsberg et al. 2001). Some women who were in abusive or potentially abusive relationships and had disclosed the content of the survey to their partners reported negative and threatening responses from their partners. This is illustrated in a narrative by Mirriam, a 22 year old woman. She posited:

> *"I only told him [boyfriend] that…that day when they did the interview, he asked me why they asked me if he'd ever hit me, did I want them [sexually] or what, and I said don't talk like that. He asked whether they wanted people to get kicked out of their homes or what…I felt bad when he said do I want [for sexual/intimate relationships] those people"* (Paper 3).

However, some of the women mentioned that they chose not to disclose much content of the survey to their male partners when they asked them what the survey was all about. For example, one woman, Margaret, who was in an abusive marriage said there were things asked in the survey that she would not tell her husband. When asked by the interviewer: *"Why were*

there things that you would not tell him?", Margaret responded: "I could not because he would hit me".

A contrast was seen with women who reported to being in gender-equitable relationships and not experiencing IPV. This group of women said that they told their husbands or boyfriends about their research participation, had freely discussed the content of the survey and, at that time, feared no violence. During qualitative interviews none reported being violated because of the disclosure of survey content (Paper 3). An example here is a narrative given by Mathapelo. She was a married woman and said that she was not experiencing any abuse in her marriage. She said she told her husband that the survey asked about partner abuse and reported that his response was positive. An extract from her interview is illustrative: "*Yes, I told him (husband). I explained to him that the people were here on a project and they wanted to know about abuse and things like that. Interviewer: …and what did he say? Mathapelo: He didn't have a problem, he just said ok*" (Paper 3).

In contrast, no men reported fearing physical harm from their partners as a result of participating in the survey (Paper 3). Yet some men did have concerns about the possible ramifications of their participation post survey. They were worried about the information they divulged in the survey, which they viewed as personal and sensitive and thus potentially damaging if it were known by others outside the research team. They felt they would be ridiculed, shamed, stigmatised, and embarrassed in their community if a breach of confidentiality occurred (Paper 3).

In this thesis I have shown that there are gender differences in perceived risks of violent reprisal from others because of research participation. Some authors have argued that violent and controlling men react violently towards their women partners upon knowing or assuming that the partners had discussed him and his behavior in the interview (Ellsberg et al. 2001; Jewkes and Wagman 2007). In South Africa, such a violent response by men may be based on the dominant understanding that partner beatings and any quarrelling that occurs within intimate relationships concerns only the man and woman in that relationship, and that any outside intervention is an intrusion (Wood 2003). For example, in an ethnographic research study with youth in rural Eastern Cape, abusive young township men "*complained about unwarranted disclosure about violence on the part of their partners, who, being 'easy' 'tell things they are not supposed to talk about*" (Wood 2003, 100).

While findings in Paper 3 suggest that no woman reported actually being beaten for participating in the survey, some perceived this risk suggesting that physical retaliatory violence could potentially occur. In the Stepping Stones study, more women than men reported being beaten because of participating in the trial, even though they were beaten at their homes, by a family member and not by their male partners, and this difference highlights the perceived lower status of women in this setting, and the vulnerability to abuse that results from this gendered status (Paper 4).

The gender analysis conducted in this thesis contributes unique and new evidence in this area of research (Rojas and Kinder 2007). In this thesis I have been able to show that in non-violent relationships, research participation in GBV studies is unlikely to introduce violence (Papers 2

and 4). Additionally, I showed that it is extremely rare that participants get beaten from participating in GBV studies (<1%) (Paper 4), and that the GBV content in the questionnaire, on its own, seems not to put women at risk of retaliatory violence, rather the dynamics and nature of intimate relationships, whether it is abusive or not, may determine whether women are physically beaten because of their participation in studies (Paper 3).

Additionally, findings presented here provide supporting evidence to existing knowledge that, for women, participating in community-based studies including those on 'GBV may exacerbate violence in already abusive or potentially abusive relationships and lead to harm for women participants' (Ellsberg et al. 2001; Jewkes et al. 2000; Jewkes and Wagman 2007). Furthermore, findings suggest that, in this setting, men do not perceive such risk and are less likely to be beaten by their partners for participating in research (Papers 3 and 4).

While this thesis has been able to show that GBV research poses no more than minimal risk for participants, in light of evidence that some women feared menacing reactions from their partners including being physically beaten (Paper 3), research protocols need to be put in place to protect this sub-group of women.

This research has also been able to show that a careful diversion from the WHO Guidelines (2001), where it may not be avoided, does not increase risk of retaliatory physical harm for participants (Paper 4). The Stepping Stones study somewhat diverted from the WHO Guidelines (2001) regarding concealing the study's focus and recruiting partners or men and women from the same locale because of the nature of the RCT evaluation, and findings presented here show

that the risks associated with research on GBV and potentially stigmatised sexual behavior were minimal (Paper 4).

The findings in this thesis are a notable contribution to the emerging field of ethics in GBV research as they clearly show that a gender analysis is important when studying risks and benefits in research participation. In this thesis I have been able to present findings that suggest that women may perceive risks and experience research differently from men (Rojas and Kinder 2007; Dunn, Candilis, and Roberts 2006).

5.6 Findings on factors associated with regretting research participation

Some authors recommend that researchers who conduct GBV studies with young people should regularly include questions about their experiences of and distress related to participating in such studies (Ybarra et al. 2009). Asking such questions in research will yield data that will allow us to know which young participants are more likely to be distressed or upset and what would make them regret participating in studies. Such data will enable IRBs and researchers to provide adequate support for young research participants (Ybarra et al. 2009) and help researchers to devise strategies to retain adequate number of participants in studies.

Most studies which have empirically studied the impact on participants of participating in interpersonal violence and trauma research have mainly focused on women and to a lesser extent on children and adolescents and very rarely have these studies included males (Rojas and Kinder 2007; Kuyper et al. 2012). Including males in such studies, allows for the exploration of gender differences (Rojas and Kinder 2007).

In the Stepping Stones study, we explored which factors were associated with regretting trial participation among adolescent and young people and whether the gender of the participants played a role in how they perceived and experienced research participation (Paper 4).

The findings reported in Paper 4 show that 9% of men and women in the intervention arm regretted participation, compared to 7% of women and 11% of men in the control arm. From these findings, it seems that the factors associated with regretting trial participation were mainly similar between men and women, although a slight difference was observed.

In Paper 4, we found that, for women, having been motivated by a desire for R20 (OR=3.26 p=0.0001), having to keep some questions secret from partner (OR 2.39 p=<0.0001), feeling sad about questions on childhood and having arguments at home (OR 3.27 p=0.0001), were associated with regretting participation. For men, having to keep some questions secret from their partner (OR 2.72 p=<0.0001), feeling sad about questions on childhood and having arguments at home (OR 2.49 p=0.015) were similarly associated with regretting participation. However, additional to that, having been physically violent to partner was associated with being twice as likely to regret participation (OR 2.06).

What we learn from these findings is that only a negligible number of young people regretted participation in sexuality, HIV and GBV studies (Paper 4) (see also Edwards et al. 2009; Kuyper et al. 2012). The findings presented in Paper 4 also supported the view that men and women may experience research differently. In addition, findings in Paper 4 suggested that, for women, while questions on victimisation experience of GBV may have provoked a fear of retaliatory violence, there was evidence that women who were not victims may equally have had been

worried by other sections of the questionnaire as violence exposure was not associated with a higher prevalence of concerns. Similarly, some authors have argued that although there exists evidence suggesting that participating in research on interpersonal violence histories may be distressing to a few women, negative emotional reactions are not limited to those with sexual victimisation histories (Edwards et al. 2009).

In this study, men who had perpetrated physical, but not sexual, IPV (nor both) were more likely to regret study participation, yet, there was no correlation between concerns about questionnaire content and perpetration of more severe violence. This suggests that concerns about reputation may be related to perceptions of non-acceptability of violence among generally less violent men (Paper 4).

5.7 Complexities and nuances around confidentiality in GBV research

Paper 5 presents findings of an analysis of a case study which explored an ethical dilemma that resulted from an unsolicited disclosure of a previously undisclosed child murder by a research participant in a survey interview.

The analysis focussed on critically analysing the existing South African laws and the international ethical guidelines, standards and codes to explore whether these could inform the deliberations to resolve in a legal and ethical correct manner a dilemma presented by an incriminating disclosure (Paper 5).

In this analysis the following laws, guidelines, codes and standards were found to be relevant for the exploration of the case study: the South African Children's Amendment Act No. 41 of

2007; Constitutional Law, Constitution of the Republic of South Africa, No. 108 of 1996; and the Children's Act, Act No. 38 of 2005. On the other hand, the codes, guidelines and standards that were explored include: International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS 2002); Ethical Approaches to Gathering Information from Children and Adolescents in International Settings; Medical Research Council: Guidelines on ethics of medical research: General Principles, 2001 (Paper 5).

Unreported incriminating disclosure about child maltreatment during the course of studies may cause an ethical quandary for researchers and demand careful but urgent decision-making during fieldwork. In this thesis, it has been found that there seems to be no harmonisation between the South African laws and the international guidelines, codes and standards. These were found to conflict on the interpretation of the concept of confidentiality in research (Emanuel et al. 2003). There is no clear guidance whether confidentiality in research is absolute or limited and in particular which situations allow for breach to occur with reporting to authorities.

Furthermore, findings show that South African laws and the international ethical codes and standards are ambiguous on how researchers should act when there is a conflict between preserving confidentiality and legal obligation (Paper 5). Furthermore, findings show that, while ethical standards, codes and guidelines promote preserving confidentiality, South African laws allow for a breach of confidentiality in certain situations (e.g. child maltreatment cases). A conclusion arrived at upon analysing the case study was that confidentiality in research is a complex concept that demands nuanced discussion and interpretation (Emanuel et al. 2003).

While there are no laws in South Africa that specifically provide the legal obligation for researchers to report information that is provided by participants in a research context, and under the promise of confidentiality, existing laws could be interpreted to provide this obligation and could be legally enforced (McQuoid-Mason 2008). Thus researchers who conduct work on sensitive, criminal, and illegal activities should be aware of such laws and be able to correctly interpret these and respond lawfully (McQuoid-Mason 2008). As illustrated in Paper 5, reporting such information to authorities may have legal implications for researchers, participants and fieldworkers involved. Additional to this, researchers may be accused by research participants of breaching confidentiality they promised at the beginning of the research. To prevent this from occurring, researchers should handle the breach of confidentiality with a report to authorities with great care and sensitivity. Furthermore, throughout the informed consent process, researchers should continuously inform research participants that researchers may be legally obliged to report to authorities incriminating information reported by the participants. To make this clear to research participants, researchers should provide clear examples of incriminating information.

Furthermore, this case study has highlighted the need for researchers to have adequate awareness of country laws as not acting in a lawful manner in situations where there is an obligation to report, could amount to a criminal offence for which the researcher or fieldworker may be liable to a fine or imprisonment (McQuoid-Mason 2008).

5.8 Is referral support system a needed requirement in GBV research?

As advised in the WHO Guidelines (2001), research studies that focus on GBV often put in place measures or utilise local services to refer research participants who may be emotionally or psychologically affected by research participation for counselling (see also Rosenbaum and Langhinrichsen-Rohling 2006).

The question whether a referral support system is a needed requirement in GBV research studies is increasingly being raised by researchers. The WHO Guidelines (2001) recommends this requirement and views it as important for research on GBV, as this area of research is assumed to have the potential to invoke strong emotional responses for research participants (Campbell 2002; Ellsberg et al. 2001; Jewkes et al. 2000; Lavery et al. 2007). Generally, there is little published knowledge on the usage of referrals by participants in GBV studies.

As such, in the qualitative interviews with researchers, some suggested that empirical research is needed to explore whether a referral support system is needed by research participants themselves and whether there is evidence that it should be central in judging the ethics of GBV protocols by IRBs, as seems to be the norm currently (Paper 1). As such, in this thesis I explored this question with people who were participants in a GBV survey (Paper 3).

Findings show that a number of women who participated in the survey, including those who reported to have ever experienced partner violence or were at the time of the interview, in abusive relationships reported that they had needed support for non-violence or study related issues (Paper 3). None of them said she needed professional support because of the emotional reaction she had had on the questions asked in the survey (Paper 3). The narrative accounts of

women suggest that they did not perceive the effects of being asked about their traumatic and painful histories, warranted professional support (Paper 3). These quotes are illustrative:

Mapaseka said she needed help with claiming maintenance from the man who raped and impregnated her. Nonhlanhla, who had reported that the interview had caused her to think about the death of her husband, said she would have been happy if the researchers had offered her a job and help with her municipal debt. Mirriam, who reported being currently in an abusive relationship, mentioned that she did not know the kind of support she needed because of the survey questions. This is similar to what Margaret said. She had reported to be in an abusive marriage in which her husband beats her; however, she said she did not need support resulting from answering the survey questions. The same was said by Mathapelo who had reported that her husband often forced her to have sex with him even if she does not want to (Paper 3).

Similarly, almost all men reported that they did not need any support because of the questions they were asked in the survey. When they were asked to think hypothetically, what form of support they would have needed if they had been affected by the survey questions, most said they would have preferred to talk to significant people in their lives. Other men who had health problems indicated that the support they needed was help with their ill-health and financial support (Paper 3).

Published studies support the Stepping Stones study findings (Paper 4). The published studies have shown that there is a very low proportion of research participants who report needing professional help after participation in sensitive research. For example, Kuyper et al.(2012)

reported that in their study in the US, one in four participants reported distress (like feeling down or sad) after answering questions on various sexual topics, but a very low number (3.5%) of the sample experienced a need for help. Similarly, Nduna and Jewkes (2010) reported the experiences of young people who participated in a qualitative study in the rural Eastern Cape and were asked to share their experiences of not knowing their biological fathers. Authors reported that the narrative accounts of these young people were characterised by emotional pain as a number of them appeared to be very distressed as they narrated the stories. As such, these authors reported that they offered the participants who were visibly distressed referral to local social workers, yet not a single participant took the offer (Nduna and Jewkes 2010). Additionally, Jewkes and Wagman (2007) reported the experiences of South African researchers in a study in Soweto, where there was no discernable uptake of local referral services by over 400 participants (pregnant women attending antenatal care) who had disclosed abuse . The researchers concluded that *"access to support services after interview on intimate partner violence was not perceived to be valuable by most women in abusive relationships"* (Dunkle et al. 2004; Jewkes and Wagman 2007).

Data from this research suggested that research participants seemed not to perceive a referral support system to be as useful and important as widely claimed. A number of reasons could explain this phenomenon in this setting. One could be that the services were not of high enough quality and people may have had negative experiences using them, for example calling a hotline and not receiving a reply. Yet the reason is probably more complex than this, as many people will not have had prior knowledge of such services. As such, the finding that none of the research participants perceived the need for professional support should not be interpreted as

meaning that professional support may have not been necessary for some of these participants. Available literature on help seeking behaviour highlights a number of factors that may affect people's help seeking behaviour. For example, some authors have argued that Black African men often associate being sick and seeking help with weakness and unmanliness (Skovdal et al. 2011; Snow et al. 2010).

Furthermore, in this thesis I have shown that some women were not always open to their partners about what their participation entailed and they did this to protect themselves from potential physical harm (Paper 3). Thus, it may be that, considering that counselling services usually entailed a prolonged engagement and repeated sessions with the service provider, women may have perceived taking referral letters and seeking help as putting themselves at risk of further abuse by their partners as they would find it difficult to justify their constant contact with the service.

In contrast, men in this setting are generally unlikely to seek help as they perceive it as unmanly. This may be more difficult for violent and controlling men as accepting referrals and seeking help may undermine their masculinity ideal of being strong and in control of their affairs at all times.

Literature presented in Chapter One of this thesis showed that violence against women is highly prevalent in South Africa. Thus, this suggests that studies that investigate GBV in South Africa are likely to obtain very high reports of its perpetration and victimisation (Machisa et al. 2011; Jewkes et al. 2009). Against this backdrop, Wasunna (2007) has argued that there is an absolute obligation on researchers who know they will encounter abused women to arrange to have professional counsellors employed. But I argue that it is difficult to sustain an argument that it

is ethically essential to provide a service that research participants (both women and men) themselves rarely perceive they need (Paper 1 and 2).

Furthermore, I argue that it is important that researchers and IRB's distinguish between invoked tearfulness and psychological trauma. Providing professional counselling and referral to the former is of doubtful value in the context of research. I also argue that what may be needed is that fieldworkers in GBV studies should be equipped to respond sensitively and provide emotional first aid when studies include any questions asked that may make respondents recall emotionally painful and sad experiences (Paper 1). However, having a referral support system in place may serve another purpose: that of alleviating some of the psychological stress that could possibly result for researchers who perceive themselves powerless in the face of trauma (Devilly, Wright, and Varker 2009). Knowing that there is a place that participants may be referred to if the need arises, may prevent a feeling of helplessness for researchers (Coles et al. 2010). This could be valid even if few respondents actually use the referral system, but it might influence decisions around resource allocation to such a service (Paper 1). Furthermore, prior to commencing with studies, GBV researchers should prepare themselves for the possibility of hearing traumatic and sensitive responses from the participants and equip themselves with skills to better handle their own distress that may result from being exposed to traumatic material. Furthermore, researchers should set up 'trauma support mechanisms like debriefing sessions and group relaxation exercises', in keeping with Coles et al. (2010) recommendation.

5.9 Implications for researchers and ethical guidelines

In Chapter One of this thesis, I have shown that the WHO Guidelines (2001) strongly recommend that the risk of physical violence to women, as a result of taking part in studies, should be considered when planning studies on GBV. In this thesis I have presented supporting data to this recommendation and have shown that some women fear that they could be harmed, and others were threatened, when male partners became aware of their participation in or the subject matter of the research (Paper 3). These findings have significant implications for community-based research conducted in this setting, and they provide support to the WHO (2001) recommendation that the actual focus of GBV research should be concealed at community level, told only to participating women, and that women participants should be advised not to disclose the focus of GBV in the survey. In this thesis I have argued that, in this setting, this recommendation protects a particularly vulnerable sub-group of women i.e. those in abusive or potentially abusive relationships from potential physical harm (see also Jewkes and Wagman 2007). I argue that concealing the focus of the subject matter, in particular for studies that investigates sensitive topics, should be done in all community-based research that involves women, as it is currently not well understood what might trigger reprisal (from third parties) and under what circumstances.

The aim of the Stepping Stones trial was to evaluate the effectiveness of the Stepping stones behavioural intervention, which had a GBV prevention component, in averting new HIV infections among young people (men and women) in a rural province of South Africa. The design of the trial was such that both men and women from the same locality were recruited into the trial (for full methods see Jewkes et al. 2006). This was a deviation from the WHO

Guidelines (2001) that recommend that studies should not enrol men and women from the same locality in a GBV study. This recommendation is in place to maximise the safety of women as research participants.

During the course of the trial, stepping Stones investigators learned that some of the participants in the trial were actually intimate partners. The current research however has shown that no woman reported being physically assaulted by a partner who was also a participant in the trial because of her trial participation or because of the focus on GBV in the trial (Paper 4). I therefore argue that this evidence provides considerable reassurance for other researchers who are unable to follow this recommendation from the WHO Guidelines (2001). Yet, in this thesis I also presented evidence that research participants (in particular women) had concerns about their partners knowing what they were asked in the survey, and this concern may be mitigated by adhering to the WHO Guidelines (2001). Therefore, I recommend that in circumstances where it is relatively easy to follow the WHO recommendations in community based studies, recommendations about geographically separating male and female participants, not recruiting partners, and concealing questionnaire content should be followed (Paper 4).

The WHO Guidelines (2001) emphasise the importance of having an ability to make referrals to services and suggest that researchers should set up short-term services for projects if none exist. Yet, findings in this thesis suggest that there seems to be very low uptake of referrals even by the participants who become distressed by research questions (Papers 3 and 4). While I do not support the view that referral support system requirement should not be a requirement

in GBV studies, I also argue that IRBs should not use this recommendation as an ultimate measure of the ethics of GBV protocols. More targeted studies are needed to better address the question of referral uptake and usage in GBV research projects. Such studies may also be able to recommend other means of ensuring support for the participants who may need support.

Provided in the WHO Guidelines (2001) is the recommendation that: 'protecting confidentiality of participants' information is essential to ensure both women's safety and data quality.' In this thesis I have shown that in South Africa, confidentiality of participants' information is not absolute, that laws exist that may be interpreted to enforce confidentiality breach with a report to authorities. As such, basing from this finding, I recommend that the WHO Guidelines (2001) should rephrased this recommendation to reflect the limited nature of confidentiality in research (Paper 5).

Breach of confidentiality was mentioned as a major worry by both community research participants (Papers 2, 3 and 4) and researchers (Paper 1) in this research. Research ethics guidelines emphasise the importance of ensuring confidentiality of the information provided by research participants (SAMRC 2001). In the qualitative research here, participants reported being worried that the information that they report in the study may be told to others thereby compromising their safety and dignity in the community (Papers 2 and 3). This thesis argues that maintaining confidentiality in research is an effective measure of protecting and maximising the safety of the participants. Notwithstanding, it is also important in research to inform the research participants that their right to confidentiality as research participants is not

absolute, rather limited (Paper 5). Researchers should clearly inform research participants that in South Africa, laws exist that in certain circumstances, compel researchers to breach confidentiality and report the participants' information together with his or identity to the authorities. Research participants should be provided with examples where researchers may be obliged to break confidentiality and report their information (Paper 5).

5.10 Limitations of the thesis

Study 1 was qualitative and designed as a small formative research which had two broad questions (Paper 1). The study was conducted to inform the main study (Silverman 2002) through identifying or highlighting pertinent ethical issues in GBV research that could be empirically explored. Data that was collected depended largely on what was subjectively reported by the researchers as they perceived was important for this area of research (Hennink, Hutter, and Bailey 2011). However, the strength of this data lies in that between them, the researchers had conducted and managed surveys with thousands of women and men on GBV across global regions; encountered and resolved numerous ethical challenges during fieldwork and engagement with sensitive information, as such, their inputs were important information for my doctoral research.

In study 1, most of the work that the researchers had conducted was quantitative, thus, the examples they provided in the interviews may have largely pertained to challenges experienced with quantitative surveys. As such, perspectives of GBV researchers who have conducted qualitative studies and the risk involved in qualitative studies may have not been adequately represented in the data (Paper 1) (see also Coles and Mudaly 2010).

Generally, studies that ask people to recall and report about past events, especially feelings and emotions, after some time had passed, may have a problem of recall bias. In study 2, which was the main study for this thesis, some informants could not recall survey questions that distressed or upset them. While Funch and Marshall (1981) argue that it is possible that participants may have not wanted to indicate negative experiences, or may have rationalised the distressing components of the survey after some time had passed, I argue that, within the three months I conducted the interviews, had the experiences of participating in the survey been harmful with long-lasting effects, participants would still be experiencing the effects and therefore been able to report those in the interviews.

While the participants in study 2 had initially been randomly selected to participate in the survey (Machisa et al. 2011), it is the nature of qualitative research that the findings are not generalisable (Dahlgren, Emmelin, and Winkvist 2004). Yet, the importance of these findings is that they are the lived experiences and perspectives of the people who had participated in the survey (Paper 3). Dunn et al. (2006) concurs with this view as they argue that the perspectives of participants should be 'sought on the risks and burdens' of participating in sensitive studies. Empirical evidence produced from these studies may be important to guide researchers on how to approach community-based studies involving human participants in South Africa and similar settings elsewhere (Dahlgren, Emmelin, and Winkvist 2004; Hennink, Hutter, and Bailey 2011).

That I was a male researcher and conducted in-depth interviews with women in (Paper 2) might have introduced a challenge in the data collection as this might have made the women not to be keen or uncomfortable to share personal and intimate information with a male researcher.

The qualitative interviews (Paper 2) involved interviewing two groups of participants. Some had participated in research before, while others had not (c.f. Kim et al. 2004). Therefore, in the interviews, I collected real life accounts of research participants from one group, and hypothetical ones from the other. This opens a possibility that some participants, in particular those who gave hypothetical accounts, might have reported what they thought was desirable to be said to the researcher (Funch and Marshall 1981). Yet, this should not be viewed as a weakness of this study as Hallowell and associates (2010) argued that 'approaching research in this manner is scientifically acceptable because both accounts (real and hypothetical) are underpinned by similar (ethical) reasoning and also informed by the social context in which they are produced'.

In this research I explored the impact of survey participation on participants after a somewhat short period of time (1-3 months) post survey participation (Paper 3). Authors have argued that this is the weakness in studies of this nature as they fail to establish the long-term effects (i.e. duration of distress and other harmful consequences) of research participation, but only capture emotional reactions immediately after the end of the research participation (Jorm, Kelly, and Morgan 2007). However, for this thesis, the Stepping Stones study allowed for an exploration of long-term effects of trial participation as it asked trial participants to reflect on their participation in the trial 24 months after their initial enrolment in the trial (Paper 4). Nonetheless, it may be desirable in future to conduct qualitative studies to explore long-term effects of study participation in order to be able to learn whether there may be a difference in how people perceived their experiences of research participation after a lengthy period had passed.

5.11 Strengths of the thesis

This thesis explored the perspectives and experiences of both adult and young men and women about research participation (Papers 2, 3 and 4) (Hennink, Hutter, and Bailey 2011). This research design has yielded data that offer a unique and important contribution to the scant knowledge about ethics of GBV research (Fontes 2004), including its risk-benefit ratio, as it allowed for an exploration of gender and age differences and comparisons (Rojas and Kinder 2007).

Employing qualitative methods in this research is viewed as a strength. This is because perceptions and experiences of risks and benefits in social science research is a subjective issue (Reynolds and Nelson 2007), and qualitative methods are most suitable for exploring the meanings people attach to their lived experiences (Hennink, Hutter, and Bailey 2011).

Methodologically, this thesis has been strengthened by the ethnographic approach that was followed to collect data for study 2. This approach allowed me to obtain a holistic understanding of the community in which the research participants lived (Dahlgren, Emmelin, and Winkvist 2004). As such, I was able to get an in-depth understanding of the 'social, cultural and economic context of the community' (Hennink, Hutter, and Bailey 2011). Living in the community fulltime (3 months) allowed me to capture data that was unspoken, rather, acted out as people interacted with one another (Braithwaite 2006). Through a constant interaction with the people, I was able to overhear and or observe events and incidents as they unfolded enabling me to capture these experiences as they occurred naturally (Braithwaite 2006).

This data was particularly useful in explaining and verifying certain issues that were reported in the interviews by informants or other issues of interest to the research thereby assisting in the contextualisation of the findings (Mfecane 2008; Wood and Jewkes 2001; Wood, Lambert, and Jewkes 2007; Mfecane 2012). Furthermore, through observing certain things being acted, or issues hinted in informal talks with or among people, I was able to probe for those issues in subsequent interviews leading to a deeper understanding of the context and issues (Mfecane 2012, 2008; Wood, Lambert, and Jewkes 2007; Wood and Jewkes 2001).

5.12 Conclusion

The topic of this thesis is of great significance to the field of gender-based violence research. In Chapter 1, I showed that not much ethics research had been done in this area despite the years of epidemiological research that had been conducted on gender-based violence globally (Fontes 2004). The aim of this doctoral research was two-fold. Firstly, it was to conduct a formative study to explore the applicability and usefulness of the WHO Guidelines (2001) in regulating community-based research from the perspective of the researchers who do GBV work globally. The findings of the formative study were used to inform the conceptualisation of the main PhD study. Secondly, it was to analytically explore potential and actual research participants' motivations for research participation, their perceptions of risks and benefits in partaking in the studies, the perceived psychological impact of answering sensitive questions including GBV, and adverse experiences of research participation.

The research employed a multi-method approach, and used various techniques for data collection and analysis that are traditionally found in both qualitative and quantitative

paradigms. By studying the perspectives of researchers, young and adult men and women, allowed for an in-depth exploration of the issues under study. For example, in this research, I was able to compare and contrast the perspectives of researchers against those of people who participate in studies. Furthermore, including men and women allowed for gender analysis to be conducted in this research. Additionally, having different age groups in my sample provided me with an opportunity to compare and contrast young peoples' perceptions on risks and against those of older people.

In the overall, the richness of data derived from the perspectives of different research actors allowed for the problematisation of the issues in order to get a deeper understanding of these, and to learn how, when woven together, they inform the field of ethics in GBV research.

Below I present a selection of the main findings and provide concluding remarks on these. Subsequent to this, I highlight the implications of my findings to the existing ethical guidelines on GBV research and also provide recommendations for future research on ethics in GBV research.

In Chapter 1, I presented literature showing that there exists a perception that there may be major safety and risk concerns with GBV research. In Paper 1 of this thesis, I presented evidence showing that while researchers spoke of increased risks for women research participants in GBV research, they rarely provided examples of risky situations they encountered when conducting the studies, and seemed to be basing their views about the riskiness of this area of research on the WHO Guidelines (2001) and other few published studies commenting on the potential for risks in GBV work. In Paper 3, basing my argument from

evidence derived from the perspectives of participants about their sense of safety and risks in GBV research participation, I argued that this notion of excessive riskiness of GBV research may be incorrect and that this view may largely be stemming from assumptions and anticipation of risks (Langford 2000), rather than empirical experience. As such, I highlighted the importance of conducting further research in order to better understand people's motives for research participation and their perceptions of risks in GBV research.

In this thesis I have demonstrated the complexity and multiplicity of reasons people report for taking part in studies. I have described a number of factors that may influence and or mitigate people's reasons for participation. I have also problematised the issue of altruism as a motive for research participation by demonstrating that decision-making about research participation in research is mostly a balanced and conditional process (Hallowell et al. 2010) where people assess the potential individual benefits to themselves, alongside the contribution to others (McCann, Campbell, and Entwistle 2010), and the potential risks to themselves (Ellsberg et al. 2001; Ellsberg and Heise 2002; Jewkes et al. 2000).

This thesis has shown that although participants in the study 2 and 3 did express discomfort or emotional reaction to some research questions, most of them viewed the studies positively, had valued the chance to take part in studies and largely perceived therapeutic and personal benefit from taking part in the studies and in particular talking about their adverse experiences in an environment they considered as safe (Widom and Czaja 2005).

Evidence from published studies have also shown that studies on sexuality, interpersonal violence and trauma are not perceived and experienced as psychologically damaging by

participants (Jorm, Kelly, and Morgan 2007), regardless of participants' initial emotional reaction (Black et al. 2006). Consistent with the findings from the above studies, in this thesis, the majority of participants in including those who had endured partner and stranger interpersonal violence, and were mainly women, did not feel answering the survey questions had caused them emotional or physical harm. Some had reported feeling sad and upset on reflecting on painful life experiences during the survey interview, but they felt these emotions quickly went away, and most of them perceived participating in the survey positively. Because of this emerging evidence, Edwards and colleagues recommended the conduct of this type of studies as they viewed them as critically important (Edwards et al. 2009). However, even though there is convincing evidence, from this thesis and other published work, showing that asking participants about interpersonal violence and other trauma histories in a research context is not psychologically damaging, researchers should observe strong emotional reactions by participants to research questions and respond appropriately to minimise any potential for adverse impact on research participants (Black et al. 2006).

In this thesis I have argued that, empirically studying, from the perspective of the people who are or may be affected by research questions, what forms of support would or do they need when distressed by research topics, is important, as the availability of such information will allow researchers to devise appropriate response strategies. In this thesis I have shown that participants, both men and women, and both those who have traumatic and violence experiences, and those without, did not differ in their perception regarding the need for professional help, as a result of being asked questions about their adverse experiences in a research context. In this research (Papers 2, 3 and 4), not a single participant reported a need

for professional intervention because of being negatively affected by research questions. Rather, some said that if they had been emotionally harmed by the survey questions, they would have preferred to talk to their loved ones about how they felt.

There is consensus that all research with human subjects carries some degree of risk. Yet, there is little evidence-based understanding of the nature and form of risks involved in GBV. Thus, studying risks and burdens of participating in GBV studies is an important contribution to this area of research. In this thesis while some findings had confirmed and supported what had been reported in other studies, new knowledge that advances our understanding of the ethics of gender-based violence research has been produced and presented.

This thesis has clearly demonstrated the importance of conducting gender analysis when studying risks in research participation. For example, findings in this thesis suggest that, not all women but a particular sub-group of them i.e. those in abusive and potentially abusive relationships may be put at risk of further victimisation by their partners in this setting. In this research, this group of women strongly perceived these risks, and as I have shown, some of them were actually threatened by their partners. It is thus pertinent that researchers working in the South African setting acknowledge the potential for this risk being realised and the presence of more vulnerable women in communities and ensure their protection in studies (CIOMS 2002). Additionally, I suggest that in light of evidence that some participants were temporarily distressed and had been anxious about threatening reactions from their husbands or boyfriends when they told them about survey participation, research protocols need to put in place safeguards to maximise the protection of these participants.

In Paper 5, I discussed the limitations of the confidentiality principle in the conduct of research with human subjects. I did this by exploring a real life case study that emanated from an unsolicited report by a research participant where she confessed to killing her own child and stating that no one knows about this except her. In this thesis I have shown that, in South Africa, confidentiality in research is clearly not absolute. I thereafter argued that when conducting studies in particular on sensitive topics, research participants should be made aware of the limitations of confidentiality on the information they shared in the studies. Additional to this, I have mentioned that researchers who conduct research on sensitive topics should familiarise themselves with laws that may be interpreted to enforce the reporting of participants' information to authorities.

The findings of this thesis are valuable in this field and may be particularly useful in future for researchers who plan to conduct GBV work in South Africa, and IRB's who review GBV research protocols as they may assist in their deliberations on risk-benefit ratios of protocols and how to maximise the protection of research participants (Rojas and Kinder 2007).

Below I highlight the implications of my findings to the existing ethical guidelines. Thereafter, I offer suggestions for future studies on the ethics of GBV research.

5.13 Directions for future research in South Africa

This thesis presents unique data that contributes to our knowledge on risks and benefits perceived by women and men when participating in research that explores sensitive topics in community based studies in South Africa. A great deal of research is needed to explore GBV research participation risk-benefit ratio in other settings like conflict situations, refugee camps,

abused women's shelters and other institutions or clinic based studies. Such data will broaden our understanding of ethics of sensitive research and enable us to devise context specific effective measures to maximise the safety of women and men in research, if evidence suggests a need for this.

While the findings of this research may be transferable to similar settings and contexts elsewhere (Dahlgren, Emmelin, and Winkvist 2004), there may have been specific context issues that influenced the data generated in this research. As such, further studies are needed to be conducted in other cross-cultural settings to explore adult and young women's autonomy in giving informed consent and their safety in participating in research studies (Osamor and Kass 2012).

In order to ensure ethically engaged GBV research is conducted in South Africa, it is important to investigate empirically and understand how ethics committees evaluate GBV studies in South Africa. We need to understand their consistency in reviewing the protocols, the standards they use; the sources of bias and the values committee members bring to the decision-making process; and the roles the views on gender and paternalism (or a desire to avoid it) play.

The findings of this thesis have shown that a particular group of women in South Africa may be put at risk of physical harm by their research participation in community based studies. This thesis has shown that some women perceive that if their abusive and controlling partners learn that they discussed their relationship or abusive behaviour in the research, partners may retaliate violently. This thesis thus recommends that researchers should be aware of this aspect

of risk to women in this setting and put in place safeguards and other special measures in their research projects to protect women from potential harm (CIOMS 2002).

Furthermore, this thesis recommends that future community-based research in South Africa should adhere to the WHO Guidelines (2001) and safety recommendations (WHO 2001) including concealing the violence focus of the research and to continuously advise women participants not to disclose the focus of the research to third parties, in particular their partners. This should be practiced in all community-based research involving women as it is currently not well understood which men may react violently and what may specifically make them to react violently.

Moreover, because this thesis could not find evidence that the GBV focus of the research specifically put or would put participants in risk of harm, it thus supports the notion that it is good practice in all community-based studies for interviews to be conducted in privacy and for that to mean that children over two years should not to be present during interviews in order to allow respondents to feel free and be candid with their answers.

More research is needed to adequately understand the characteristics of participants who are more vulnerable to physical harm and the circumstances under which this harm could occur.

Fieldworkers rather than senior researchers often are the ones who have contact with research participants and conduct interviews with them. As such, fieldworkers should be trained to be aware that during an interaction with a research participant, possibilities exist that the latter may disclose information that the fieldwork might be legally compelled to disclose to senior researchers and authorities (Paper 5).

The findings presented in this thesis, although they were studied from a GBV perspective, they may cut across many other research areas, in particular those research sensitive topics like alcohol and drug abuse, prostitution, criminal behaviour and homosexuality. However, more research is needed to ascertain whether ethical issues that pertain to these different sensitive research topics are the same.

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APPENDICES

Appendix 1

PARTICIPANT'S INFORMATION LEAFLET AND INFORMED CONSENT FOR THE FIRST INTERVIEW



COMMUNITIES AND RESEARCH

Introduction

Good day, my name is Yandisa Sikweyiya. I am a researcher at the South African Medical Research Council. You are invited to participate in a research project. You should not agree to participate in this study unless you fully understand what is required of you and you are happy about all the things that are involved in the study. This information leaflet is to help you decide if you want to participate. If you do not understand the information or have any other questions, do not hesitate to ask the researcher.

What is the nature and purpose of this study?

This study is done to understand the thoughts and responses of community members about research being done in a community, where people are asked about their health and life experiences. This type of research is becoming common in South Africa and it is important that we understand more about communities' views about and experiences of being involved in such research. The information collected from this study will be used to help us understand how we may ensure that research in future is more sensitive to the concerns and realities of men and women's lives.

Explanation of Procedures to be followed

I would like to interview you about your thoughts about research, any concerns you may have and any experiences you have of being interviewed. I want to ask you about experiences you have had as a research participant, if you have been one and about what you imagine research would involve, if you have not yet been involved yourself. I also want to ask you about how you would feel about being asked about sensitive questions in research such as how you raise your children or relations with your partner. Because I cannot remember everything that you say in the interview, I will ask to use a recorder (MP4) to record the talk that we will have (see consent form below). You do not have to agree to this if it makes you feel uncomfortable. The interview will last for an hour.

Risk and Discomfort involved.

You might not be comfortable with some questions and other things that we will talk about in the interview. If that happens, please feel free not to answer or talk about things that you are not comfortable with.

Possible Benefits of this study.

As a person, you will not get anything from participating in this study. But the information I am collecting in this study may be helpful in finding better ways of doing studies that ask people about their health and life in general. Getting this information will help researchers in future as they will understand how to do this type of research in South African communities. And it will also help in finding better ways of protecting people and communities from possible harm resulting from a research, if any.

What are your rights as a participant?

Your participation in this study is entirely voluntary. You may refuse to participate or stop at any time without giving any reason.

Has the study received ethical approval?

This study has been approved by the University of Witwatersrand, Health Sciences Committee for Research on Human Subjects (medical). The ethics committee will continue to see if this study is being done in a safe way until the study is completed. I have copies of a letter from the ethics committee that show that the study was approved by them. I may give it you to if you wish to have one.

If you have any questions about the study or something that you are not happy about, please feel free to contact the chairperson of the University of Witwatersrand, Health Sciences Committee for Research on Human subjects (medical), Prof. Peter Cleaton-Jones at this number: 011 717 2229.

Compensation

Your participation in this study is voluntary; there is no reward to be given to you for participating in this study.

Confidentiality

Interview will be between the researcher and you; this will be held in a private place, this will help to ensure that there is no other person who hears what we are talking about in the interview. All the information that you give to the research will be kept secretly. Only the

researcher will know it is you who gave that information. Before we write the results of this study, we will ensure that your names and any other thing that would identify you as participant in this study are removed.

Information and contact person

The contact person for this research is Yandisa Sikweyiya. If you have any questions regarding the research, during and after the interview, feel free to contact him on telephone number 076 365 6169 and 012 339 8619 or my supervisor Prof Rachel Jewkes at 012 339 8525. Yandisa Sikweyiya will be in the community during the course of this study, you may also see him personally.

Useful numbers:

Stop AIDS helpline 0800 012 322

Stop Women Abuse Helpline 0800 150 150

Childline 0800 055 555

INFORMED CONSENT FORM

I hereby confirm that the person asking me to participate in this has given me information to my satisfaction. He explained to me the purpose, things that are involved, risk and benefits and my rights as a participant in the study. I have also received the information leaflet for the study and have had enough time to read it on my own, ask questions and I am happy with the answers I have been given regarding participation in the study. I have been told that the information I give to the study will together with other information gathered from other people, be written into a report and scientific publications. This will be done without my name and any other thing that you identify me as a participant in the study.

I am aware that it is my right to refuse participation in this study without experiencing any harm. I hereby, freely and voluntary give my consent to participate in the study.

Participant's name…….. (Please print)

Participant's signature……Date……

Researcher's name…….. (Please print)

Researcher's signature……..Date……

Witness's name…….. (Please print)

Witness's signature……Date……

Appendix 2

PARTICIPANT'S INFORMATION LEAFLET AND INFORMED CONSENT FOR THE SECOND SET OF INTERVIEWS

COMMUNITIES AND RESEARCH

Introduction

Good day, my name is Yandisa Sikweyiya. I am a researcher at the South African Medical Research Council. You are invited to participate in a research project. You should not agree to participate in this study unless you fully understand what is required of you and you are happy about all the things that are involved in the study. This information leaflet is to help you decide if you want to participate. If you do not understand the information or have any other questions, do not hesitate to ask the researcher.

What is the nature and purpose of this study?

This study is done to understand the thoughts and responses of community members about research being done in a community, where people are asked about their health and life experiences. There has recently been a survey in this community which I understand you (or a family member) completed and you agree to be interviewed about this experience. Thank you for this. The reason why I want to interview you now is to find out how you feel about having done that interview and what sorts of thoughts you have had since then. If it was a family member doing the interview I really want to know whether they have discussed concerns with you and whether you have had concerns about them.

Explanation of Procedures to be followed

I would like to interview you about your thoughts about the research, any concerns you may have and any experiences or conversations you had afterwards that may have been connected to the interview. Because I cannot remember everything that you say in the interview, I will ask to use a recorder (MP4) to record the talk that we will have (see consent form below). You do not have to agree to this if it makes you feel uncomfortable. The interview will last for an hour.

Risk and Discomfort involved.

You might not be comfortable with some questions and other things that we will talk about in the interview. In that happens, please feel free not to answer or talk about things that you are not comfortable with.

Possible Benefits of this study.

As a person, you will not get anything from participating in this study. But the information I am collecting in this study may be helpful in finding better ways of doing studies that ask people about their health and life in general. Getting this information will help researchers in future as they will understand how to do this type of research in South African communities. And it will also help in finding better ways of protecting people and communities from possible harm resulting from a research, if any.

What are your rights as a participant?

Your participation in this study is entirely voluntary. You may refuse to participate or stop at any time without giving any reason.

Has the study received ethical approval?

This study has been approved by the University of Witwatersrand's Committee for Research on Human Subjects (medical). The committee will continue to see if this study is being done in a safe way until the study is completed. I have copies of a letter from the ethics committee that show that the study was approved by them. I may give it you to if you wish to have one.

If you have any questions about the study or something that you are not happy about, please feel free to contact the chairperson of the University of Witwatersrand Committee for Research on Human Subjects, Prof Peter Cleaton-Jones at this number: 011 717 2229.

Compensation

Your participation in this study is voluntary; there is no reward to be given to you for participating in this study.

Confidentiality

Interview will be between the researcher and you; this will be held in a private place, this will help to ensure that there is no other person who hears what we are talking about in the interview. All the information that you give to the research will be kept secretly. Only the researcher will know it is you who gave that information. Before we write the results of this

study, we will ensure that your names and any other thing that would identify you as participant in this study are removed.

Information and contact person

The contact person for this research is Yandisa Sikweyiya. If you have any questions regarding the research, during and after the interview, feel free to contact him on telephone number 076 365 6169 and 012 339 8619 or his supervisor Prof Rachel Jewkes at 012 339 8525. Yandisa Sikweyiya will be in the community during the course of this study, you may also see him personally.

Useful numbers:

Stop AIDS helpline 0800 012 322

Stop Women Abuse Helpline 0800 150 150

Childline 0800 055 555

INFORMED CONSENT FORM

I hereby confirm that the person asking me to participate in this has given me information to my satisfaction. He explained to me the purpose, things that are involved, risk and benefits and my rights as a participant in the study. I have also received the information leaflet for the study and have had enough time to read it on my own, ask questions and I am happy with the answers I have been given regarding participation in the study. I have been told that the information I give to the study will together with other information gathered from other people, be written into a report and scientific publications. This will be done without my name and any other thing that you identify me as a participant in the study.

I am aware that it is my right to refuse participation in this study without experiencing any harm. I hereby, freely and voluntary give my consent to participate in the study.

Participant's name…….. (Please print)

Participant's signature……Date……

Researcher's name……. (Please print)

Researcher's signature……..Date……

Witness's name…….. (Please print)

Witness's signature……Date……

Appendix 3: Informed consent for audio-taping of interview.



I hereby confirm that the researcher, Yandisa Sikweyiya has requested my consent to audio-tape the interview. The researcher has informed me that the information I give on the interview will not be known by other people except the researchers and that only people who form part of the research will have access to the audio-tapes.

I am aware that my name including personal details will not appear in the transcripts resulting from the interview. I understand that I may refuse my interview being audio-recorded and that I will not suffer any negative consequences for that.

I voluntarily give consent that my interview be audio-recorded.

I have received a signed copy of this informed consent agreement.

Participant's name……..

(Please print)

Participant's signature……Date……

(Please print)

Researcher's name…….

Investigator's signature……..Date……

Appendix 4: Interview Guide for Part 1 interviews.

This interview guide is for conducting individual interviews with men and women (over 18 years old) in the community.

Have you ever been involved in research?

Probes: if yes, to ask about the experience and thoughts and feelings related to it, and then go to the relevant hypothetical questions below.

If no: continue with hypothetical questions

What do you think research would involve? What do you think happens after an interview to the information given? What concerns do you have about this? Is there anything that worries you about research? Why do you think it is done and who do you think benefits?

Do you think there are issues that would be harder to ask about in research, sensitive issues? What would be a sensitive issue? Why is it sensitive when another issue might not be?

What about how you raise your children and whether they go hungry? Is that a sensitive issue? Why? Would there be any concerns about being asked about that in an interview?

What about gender-based violence? Is that a sensitive issue? Why? Would there be any concerns about being asked about that in an interview?

Possible probes:

- How do you perceive the issues of IPV and rape of women and men?
- On what circumstances would you tell others (who and or when?) or they think others should be told?
- Disclosing experiencing/perpetrating gender-based violence, what issues would you consider before doing that?
- How as individuals (or collectively) within the community have you dealt with issues of gender-based violence happening in the community?

How do you perceive being asked to talk to researchers about your experiences of IPV and sexual violence?

Possible probes:

- What would be your concerns and issues about this?
- What would be your benefits and opportunities about this?
- Please share with me any risks that you think you might run from participating in this study, if any?
- How would you prefer a research talk (interview) about gender-based violence be organised?

- Who would you want involved in such a talk (interview)?

Do you think gender-based violence would be more sensitive than being asked about how you look after your children, or less sensitive? Why?

Appendix 5: Interview Guide for Post-Survey Interviews.

This interview guide is for conducting individual in-depth interviews with men and women who were participants of the Gender Links survey.

What are your views and perceptions of the survey that you were part of?

Possible probes

- Please describe for me how you were asked to participate in the survey?
- Who were involved in the process of requesting your participation and what did they do?
- Who would you have wanted to be involved in that process, and why?
- Please describe for me what the interviewer said to you about the survey?
- Please explain with whom did you discuss your participation in the survey, and was it before your participation or after?
- What do you think the survey was all about?

What were your concerns and feelings about the survey process?

Possible probes

- Were there good things or bad things you found about the survey?
- What were the consequences, violence, trauma and intimidation you experienced from participating in the survey? If yes from who?
- Were there any fears and concerns you heard about the survey after you have participated?
- Can you describe what was going through your mind as you were answering the survey questions?
- How have you been thinking about the issues asked about in the questionnaire
- Are the any issues you would like to talk about that were asked in the survey

Impact of research on participants

- How did answering the questions in the survey made you feel?
- Some people experience bad feelings about thinking and talking about personal things to researchers, some don't, what type of feelings did you experience?
- How would you say the research was helpful or harmful to you?

Issues of referral

Possible Probes

- Did thinking about the issues asked in the survey cause you any discomfort? What happened?
- What kind of support did you feel you needed having thought about the things you were asked in the survey?
- Was an opportunity for support provided to you and by who and how?
- How did you deal with the emotions invoked by your thinking about the survey questions?

Appendix 6: Slip for intention to participate in the qualitative study.

(**Gender Links researchers should introduce the qualitative study and invite participants to consider participating in the qualitative study. This slip will be filled by those who want to be contacted for the study**).



You are invited to participate in a study about your thoughts and experiences of being a participant in a research study. This is a completely separate study from the one you have just been interviewed for. No information will be shared between the two studies, and you are free to refuse to participate in this study. If you agree to participate we will ask you to be interviewed once or twice more and the interview will take the form of a conversation with a researcher, Yandisa Sikweyiya, from the Medical Research Council.

Yandisa stays at no……name of the street……Area……..

His phone no is ……..

****

I as a participant in the survey, I would like to be contacted for the above mentioned study.

My name is……..stay at No……Name of the Street……

Area……..

I would be happy if the researcher could contact me on

…….. (Phone number) ☐

I would be happy if the researcher would visit me on this date…… ☐

At……..

Accept: ☐

Refuse: ☐

[i] Medical Research Council. Guidelines on ethics or medical research: General Principles, 2001. Available from URL **http://www.sahealthinfo.org/ethics/ethicsbook1.pdf** (last accessed 05 August 2010).

Appendix 7:

Example of grounded theory analysis done, from codes to categories

Text	Codes	Categories
"I think if I have given you an important point like the suffering of the people, I think you would do something in order to ensure that people stop suffering. For them to be better and stop suffering; witnessing people suffering is painful, because you don't invite poverty; it comes on its own."	Desire to help Desire to contribute to positive change Expectations from research Impact of research	Conditional Altruism