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

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Potential Research Participants' Motivations for and Perceived Risks in Research Participation: Ethics in Health Research.

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Abstract

A greater understanding on people's motivations and experiences of research participation; how people perceive discussing sensitive experiences, including interpersonal violence and what implications of participating in such research has for the participants and community is very important for unpacking the ethics of gender-based violence research. 29 in-depth interviews were conducted with 19 women and 07 men (over 18) in a South African urban Township. Field notes were kept and included in the analysis. While many informants were motivated by self-interest, some gave altruistic reasons as a motivation for research participation. Whilst this study did not specifically ask informants to provide accounts of violence, many female informants provided detailed accounts of violence in their relationships; however few of them mentioned they would not discuss their relationships with a stranger [researcher]. If beach of confidentiality occurs, the possibility of violent reprisals from partners was a great worry for majority of women. Yet, some women, including those with abuse history, mentioned that they would disclose violence in a research. Similarly, male informants stated they would report about perpetrating violence in research, with a few of them reporting having beaten their intimate partners. Many women perceived partner abuse as generally a sensitive issue to report in research interviews. Notwithstanding, for some informants, there were other experiences they deemed equally sensitive to report in interviews that were not violence related. Findings highlight that while partner violence and other personal experiences might be difficult to discuss in a research, participants see a need to talk about these issues in research and perceive benefit in doing so.

Keywords: Research participation, sensitive information, Research Risks, South Africa

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, In press ; 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., in press). 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). For example, in the Jewkes et al. (in press) 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., in press). 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.

Methods

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 people who were professionals 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; Mouton & Marais, 1990). This process continued throughout data collection (Hennink, et al., 2011; Mouton & Marais, 1990) 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; Glaser & Strauss, 1967; 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 (Mouton &

Marais, 1990). 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.

Results

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 young woman, Ntombi (28 year old woman) 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 (a woman in mid 40s) 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 a young woman who was well known in the community because of her active involvement in community issues, 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. (Nomusa a 27 year old woman)

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 a young woman (in mid 20's), had reported a long history of partner abuse from different relationships including the current one, 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, a young woman (in mid 20's), 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 in mid 20's)

As well, Matlakala, a woman in mid 60's 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, a man in mid 40's 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 in mid 40's) 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.' (Bulelwa)

Similarly, Yvonne a woman in mid 40's 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, a 29 year old woman, 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, a 49 year old man, 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) 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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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Bibliography

Abrahams, N., Jewkes, R., Laubscher, R., & Hoffman, M. (2006). Intimate partner violence: prevalence and risk factors for men in Cape Town, South Africa. *Violence and Victims, 21*(2), 247-264. doi: 10.1891/088667006780644271

Ajuwon, A. J., & Adegbite, O. (2008). Ethical and methodological challenges involved in research on sexual violence. *Research Ethics Review, 4*(1), 3-9. doi: doi:10.1177/174701610800400102

Black, M. C., Kresnow, M., Simon, T. R., Arias, I., & Shelley, G. (2006). Telephone Survey Respondents' Reactions to Questions Regarding Interpersonal Violence. *Violence and Victims, 21*(4), 445-459. [PubMed: 16897912]

Braithwaite, J. (2006). [Rape, Shame and Pride]. http://www.anu.edu.au/fellows/jbraithwaite/_documents/Stockholm_Prize_Address.pdf

Braunack-Mayer, A. (2002). The ethics of participating in research. *The Medical Journal of Australia, 177*(9), 471-472. http://digital.library.adelaide.edu.au/dspace/bitstream/2440/32634/1/hdl_32634.pdf

CIOMS. (2002). International Ethical Guidelines for Biomedical Research Involving Human Subjects. Geneva: Council for International Organizations of Medical Science.

Dahlgren, L., Emmelin, M., & Winkvist, M. (2004). *Qualitative Methodology for International Public Health*. Umea, Sweden: Print and Media, Umea University.

Darke, P., Shanks, G., & Broadbent, M. (1998). Succesfully completing case study research: combining rigour, relevance and pragmatism. *Journal of Information Systems, 8*, 273-289. doi: 10.1046/j.1365-2575.1998.00040.x

DePrince, A. P., & Freyd, J. J. (2004). Costs and benefits of being asked about trauma history. *Journal of Trauma Practice, 3*(4), 23-35. doi: 10.1300/J189v03n04_02

Dunkle, K. L., Jewkes, R. K., Brown, H. C., Yoshihama, M., Gray, G. E., McIntyre, J. A., & Harlow, S. D. (2004). Prevalence and patterns of gender-based violence and revictimazation among women attending antenatal clinics in Soweto, South Africa. *American Journal of Epidemiology, 160*, 230-239. doi: doi:10.1093/aje/kwh194

Edwards, K. M., Kearns, M. C., Calhourn, K. S., & Gidycz, C. A. (2009). College women's reactions to sexual assualt research participation: Is it distressing? *Psychology of Women Quarterly, 33*, 225-234. doi: 10.1111/j.1471-6402.2009.01492.x

Ellis, P. M., Butow, P. N., Tattersall, M. H. N., Dunn, S. M., & Houssammi, N. (2001). Randomized Clinical Trials in Oncology: Understanding and Attitudes Predict Willingness to Participate. *Journal of Clinical Oncology, 19*(15), 3554-3561. http://jco.ascopubs.org/content/19/15/3554.full

Ellsberg, M., & Heise, L. (2002). Bearing witness: ethics in domestics violence research. *Lancet, 359(9317)*, 1559-1604. doi: 10.1111/j.1471-6402.2009.01492.x

Ellsberg, M., & Heise, L. (2005). Researching Violence Against Women: A Practical Guide for Researchers and Activists. Washington DC, United States: World Health Organisation, Path.

Ellsberg, M., Heise, L., Pena, R., Agurto, S., & Winkvist, A. (2001). Researching domestic violence against women: methodological and ethical considerations. *Studies of Family Planning, 32*(1), 1-16. http://www.jstor.org/stable/2696292

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing.

Grady, C. (2001). Money for research participation: Does it jeopardize informed consent? *American Journal of Bioethics, 1*(2), 40-44. doi: 10.1162/152651601300169031

Griffin, M. G., Resick, P. A., Waldrop, A. E., & Mechanic, M. B. (2003). Participation in trauma research: Is there evidence of harm? *Journal of Traumatic Stress, 16*(3), 221-227. doi: 10.1023/A:1023735821900

Hallowell, N., Cooke, S., Crawford, G., Lucassen, A., Parker, M., & Snowdon, C. (2010). An investigation of patients' motivations for their participation in genetics-related research. *Journal of Medical Ethics, 36*, 37-45. doi: 10.1136/jme.2009.029264

Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. Los Angeles: Sage Publications Ltd.

Jefferson, A. L., Lambe, S., Chaisson, C., Palmisano, J., Horvath, K. J., & Karlawish, J. (2011). Clinical Research Participation among Aging Adults Enrolled in an Alzheimer's Disease Centre Research Registry. *Journal of Alzheimer's Disease, 23*, 443-452. doi: 10.3233/JAD-2010-101536

Jewkes, R., Nduna, M., Levin, J., Jama, N., Dunkle, K., Khuzwayo, N., . . . Duvurry, N. (2006). A cluster randomised controlled trial to determine the effectiveness of Stepping Stones in preventing HIV infections and promoting safer sexual behaviour amongst youth in rural Eastern Cape, South Africa: trial design, methods and baseline findings. *Tropical Medicine and International Health, 11*, 3-16. doi: 10.1111/j.1365-3156.2005.01530.x

Jewkes, R., Sikweyiya, Y., Morrell, R., & Dunkle, K. (2010). Why, when, and how men rape: Understanding rape perpetration in South Africa. *SA Crime Quarterly, 34*, 23-31. doi: 10.1080/10130950.2007.9674875

Jewkes, R., Sikweyiya, Y., Nduna, M., Jama Shai, N., & Dunkle, K. (In press). Young People's Motivations, Perceptions, and Experiences with Participating in a Cluster Randomized Controlled Trial of a HIV Behaviour-change Intervention in Rural South Africa. *Culture, Health & Sexuality*.

Jewkes, R., & Wagman, J. (2007). Generating needed evidence while protecting women research participants in a study of domestic violence in South Africa: A fine balance. In J. V. Lavery, E. R. Wahl, C. Grady & E. J. Emanuel (Eds.), *Ethical Issues in International Biomedical Research: A Case Book* (pp. 350-355). New York: Oxford University Press.

Jewkes, R., Watts, C., Abrahams, N., Penn-Kekana, L., & Garcia-Moreno, C. (2000). Ethical and methodological issues in conducting research on gender-based violence in Southern Africa. *Reproductive Health Matters, 8*(15), 93-103. doi: 10.1016/j.bbr.2011.03.031

Johnson, L. E., & Benight, C. C. (2003). Effects of trauma-focused research on recent domestics violence survivors. *Journal of Traumatic Stress, 16*(6), 567-571. doi: 10.1023/B:JOTS.0000004080.50361.f3

Jorm, A. F., Kelly, C. M., & Morgan, A. M. (2007). Participant distress in psychiatric research: a systematic review. *Psychological Medicine, 37*, 917-926. doi: 10.1017/S0033291706009779

Kim, S. Y. M., Millard, R. W., Nisbet, P., & Caine, E. D. (2004). Potential research participants' views regarding researcher and institutional financial conflicts of interest. *Journal of Medical Ethics, 30*, 73-79. doi: 10.1136/jme.2002.001461

Kneipp, S. M., Lutz, B. J., & Means, D. (2009). Reasons for enrollment, the informed consent process, and trust among low-income women participating in a community-based

participatory research study. *Public Health Nursing, 26*(4), 362-369. doi: 10.1136/jme.2002.001461

Kuyper, L., de Wit, J., Adam, P., & Woertman, L. (2012). Doing more good than harm? The effects of participation in sex research on young people in the Netherlands. *Arch Sex Behav, 4*(2), 497-506. doi: 10.1007/s10508-011-9780

Machisa, M., Jewkes, R., Morna, C., & Rama, K. (2011). THE WAR AT HOME: Gender Based Violence Indicators Project. Gauteng Research Report. Johannesburg, South Africa: Gender Links & South African Medical Research Council.

Macklin, R. (2004). *Double Standards in Medical Research in Developing Countries*. Cambridge, United Kingdom: CAMBRIDGE UNIVERSITY PRESS.

McCann, S. K., Campbell, M. K., & Entwistle, V. A. (2010). Reasons for participating in randomised controlled trials: conditional altruism and considerations for self. *Trials, 11*(31). doi: 10.1136/jme.2002.001461

Mfecane, S. (2008). LIVING WITH HIV AS A MAN: IMPLICATIONS FOR MASCULINITY. *PINS, 36*, 45-59. http://www.pins.org.za/pins36/pins36_article05_Mfecane.pdf

Mouton, J., & Marais, H. C. (1990). *Basic Concepts in the methodology of the social sciences*: Human Sciences Research Council.

Paradis, C., Phelan, M. P., & Brinich, M. (2010). A pilot study to examine research subjects' perception of participating in research in the emergency department. *Journal of Medical Ethics, 36*, 580-587. doi: 10.1136/jme.2002.001461

Rosenbaum, J. R., Wells, C. R., Viscoli, C. M., Brass, L. M., Kernan, W. N., & Horwitz, R. I. (2005). Altruism as a reason for participation in clinical trials was independently

associated with adherence. *Journal of Clincal Epidemiology, 58*(11), 1109-1114. doi: 10.1016/j.jclinepi.2005.03.014

SAMRC. (2001). GUIDELINES ON ETHICS FOR MEDICAL RESEARCH BOOK1: General Principles including research on children, vulnerable groups, international collaboration and epidemiology.

Savell, J. K., Kinder, B. N., & Young, S. M. (2006). Effects of Administering Sexually Explicit Questionnaires on Anger, Anxiety, and Depression in Sexually Abused and Nonabused Females: Implications for Risk Assessment. *Journal of Sex & Marital Therapy, 32*(2), 161-172. doi: 10.1080/00926230500442326

Sharp, L., Cotton, S. C., Alexander, L., Williams, E., Gray, N. M., & Reid, J. M. (2006). Reasons for participation and non-participation in a randomized controlled trial: postal questionnaire surveys of women elgible for TOMBOLA (Trial Of Management and Other Low-grade Abnormal smears. *Clinical Trials, 3*, 431-442. doi: 10.1177/1740774506070812

Sikweyiya, Y., & Jewkes, R. (2012). Perceptions and experiences of research participants on gender-based violence community based survey: Implications for ethical guidelines. *PLoS ONE, 7*(4), 1-9. doi: 10.1371/journal.pone.0035495

Sikweyiya, Y., Jewkes, R., & Morrell, R. (2007). Talking about rape: South African men's responses to questions about rape. *Agenda, 21*(74), 48-57. doi: 10.1080/10130950.2007.9674875

Silverman, D. (2002). *Interpreting Qualitative Data. Methods for Analysing Talk, Text and Interaction* (Second ed.): Sage Publications.

Slack, C., Stobie, M., Milford, C., Lindergger, G., Wassenaar, D., Strode, A., & IJsselmuiden, C. (2004). Provision of HIV treatment in HIV preventive vaccine trials: a developing country perspective. *Soc. Sci. Med., 60*(6), 1197-1208. doi: 10.1016/j.socscimed.2004.06.049

Viens, A. M. (2001). Socio-Economic Status and Inducement to participate. *The American Journal of Bioethics, 1*(2), 1f-2f. doi: 10.1162/152651601300169202

Wasunna, A. (2007). Minimizing the risk to women in a study of domestic violence in South Africa: Easier said than done. In J. V. Lavery, E. R. Wahl, C. Grady & E. J. Emanuel (Eds.), *Ethical Issues in International Biomedical Research: A Case Book* (pp. 355-359). New York: Oxford University Press.

Widom, C. S., & Czaja, S. J. (2005). REACTIONS TO RESEARCH PARTICIPATION IN VULNERABLE SUBGROUPS. *Accountability in Research, 12*, 115-138. doi: 10.1080/08989620590957193

Wood, K., & Jewkes, R. (2001). 'Dangerous' love: reflections on violence among Xhosa township youth. In R. Morrell (Ed.), *Changing Men in Southern Africa* (pp. 317-336). London: Zed Books.

Wood, K., Lambert, H., & Jewkes, R. (2007). 'Showing roughness in a beautiful way': talk about love, coercion and rape in South African youth culture. *Medical Anthropology Quarterly 21*(3), 277-300. doi: 10.1525/maq.2007.21.3.277