Potential Motivations For and Perceived Risks In Research Participation: Ethics in Health Research

Yandisa Sikweyiya[1] and Rachel Jewkes[1]

Abstract

In a South African urban-township-based ethnographic study with adult 19 women and 7 men, we explored people's motivations for and experiences of research participation and perceptions of being asked about sensitive experiences, including gender-based violence. We also explored the implications of participation. Several informants were motivated by self-interest to participate in research, whereas others were more altruistic; yet with many there was a complex overlap. We found 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 wherein individuals assess the potential benefits and risks to themselves and the potential contribution to others.

All research with human participants carries a degree of risk. Research regulatory bodies, including research ethics committees 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. Participant enrollment is critical for research, so it is important to learn and understand what motivates people to enroll in research, what the barriers are, and how research participation is experienced (DePrince & Freyd, 2004; Jefferson et al., 2011; Kneipp, Lutz, & Means, 2009; Rosenbaum et al., 2005).

To date, few researchers have investigated the factors that influence participation and nonparticipation in research from the perspectives of actual participants (Kneipp et al., 2009; Sharp et al., 2006). Available research suggests that research participants' motivations are multifaceted and complex (Hallowell et al., 2010). Scholars 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, the chance to help their community and contribute to the furthering of scientific knowledge (Jewkes, Sikweyiya,

Nduna, Jama Shai, & Dunkle, 2012; McCann, Campbell, & Entwistle, 2010; Sharp et al., 2006; Sikweyiya & Jewkes, 2012).

In some studies, individuals' reasons for participating were given when they perceived some benefit to themselves (Jefferson et al., 2011; McCann et al., 2010). For example, in an HIV behavioral intervention trial with young men and women (aged 15 to 26 years) 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 the 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

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[1]Medical Research Council, Pretoria, South Africa

Corresponding Author:
Yandisa Sikweyiya, Gender & Health Research Unit, Medical Research Council, Private Bag X385, Pretoria 0001, South Africa.
Email: ysikweyiya@mrc.ac.za

example, Viens (2001) argued that factors such as 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 incentives, without considering the risks involved in such studies (see Sharp et al., 2006). This might be so because of having their judgment compromised by the amount of money being offered as an incentive (Viens).

In the Jewkes et al. (2012) study, at the last evaluation phase, participants who had been retained in the trial were asked what had motivated them to participate; the majority indicated that the R20 (approximately 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. 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 also mentioned altruistic reasons (Jewkes et al., 2012). This highlights the multiplicity and complexity of people's motivations to participate in studies (Hallowell et al., 2010).

Researchers have mainly investigated people's reasons for participation in clinical trials, and have included both participants and potential participants (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 to obtain clinical benefit from participating in such trials (Hallowell et al., 2010). In contrast, participants in social scientific and epidemiological studies are less likely to gain direct clinical benefits from research participation, because the researchers use observational designs that are nontherapeutic. 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.).

To date, not many researchers have explored reasons for participation in social science or epidemiological research, in particular on the topic of violence against women (VAW; Edwards, Kearns, Calhourn, & Gidycz, 2009). Several authors have emphasized the importance of investigating the motivations for and barriers to the participation of women 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 husband or boyfriend as a punishment for participating without their partner's 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 of how participants (women and men) perceive discussing experiences of victimization and perpetration of GBV 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 the understanding of how people living in an urban South African township perceive discussing sensitive experiences, including gender-based violence in a research context. We explored their perceptions of the risks and benefits of participating in research on GBV. We also explored their motivations to participate in research.

Setting

Using multiple methods of data collection, we conducted this research in a township in the Gauteng province of South Africa. In 2010, a South African nongovernmental organization called GenderLinks, 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. This GBV survey collected data in face-to-face interviews with men and women age 18 years and above who completed a structured questionnaire in 75 randomly sampled enumeration areas (EA's) in the province. Two of the EAs sampled (for purposes of this article referred to as "Thate Block" and "Siyakhula Extension," which are pseudonyms) were in the study township. We conducted the qualitative interviews 2 to 3 months before the GBV survey interviews were conducted in this community; at this stage, community members were not aware that there was an upcoming survey.

The Thate Block was a fairly established section of the township. It was predominantly a low-income area with few middle-class families. Siyakhula Extension was a relatively new residential area which had originally been a squatter camp—mainly a poor area with a number of shack dwellings built of corrugated iron. These two sections (blocks) were approximately 5 kilometers apart.

Method

We designed this research as an ethnographic study, borrowing methods and techniques for data collection and analysis from the disciplines of anthropology and sociology (Silverman, 2002). At the start of the research the

first author introduced himself to the community and sought permission to conduct the study. He spent approximately 3 months (March to May) in 2010 collecting data. For these months, he rented a room in the Thate Block and lived full time 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. During his stay in the community, the first author also participated in community activities, attending community meetings and visiting nearby houses and sometimes taverns with young men and women in the community. Following suggestions from community members, the first author identified a man and a woman to be his research assistants, and he explained that duties would include him following them around the community and for them to identify potential participants.

Sampling

We conveniently and purposefully sampled women and men who were above the age 18 years. Community members, community leaders, 2 officials of local victim-empowerment centers dealing with cases of abuse, 3 officials of a community police forum, and other key informants were interviewed. All of these 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.

We approached participant recruitment and data collection fully aware that we were aiming for varying and diverse perspectives (Hennink, Hutter, & Bailey, 2011) in terms of participants' experiences and perceptions about research participation. As such, during fieldwork we employed theoretical sampling, because we intentionally sought people with different characteristics (age, gender, and so forth; Hennink et al.). Although we were aware that educational level might be important information in this study, it was difficult to identify and target people using education as a criterion. We approached this issue with sensitivity, because we felt people might be offended if we directly asked them about their schooling. However, within the categories above, we attempted to interview as many people as we could until the first author believed the data in each category began to repeat itself in subsequent interviews (Silverman, 2002).

Procedures

All interviews were conducted by the first author, mainly in Zulu, although a few informants spoke in Setswana. He used a thematic guide and, with the permission of the informants, audio-recorded the interviews. In total, he conducted 26 in-depth interviews. Participants included 19 women and 7 men. The first author kept field notes throughout his stay in the community, and these notes were included in the analysis. Furthermore, in his interaction with study informants, he also documented how people spoke about issues and what kind of emotions they displayed (e.g., joy, sadness, worry) when speaking about certain issues and experiences (Hennink et al., 2011). Documenting participants' emotions as data is consistent with the viewpoint of Braithwaite (2006) that a good ethnographer documents how he feels during interaction with others and what he hears or observes occurring as people interact among themselves.

The 26 audio-recorded interviews, together with the field notes, were transcribed verbatim; notes were typed and translated into English by the first author. During transcription and preparation for analysis, the first author anonymized the data, removing all information that could potentially identify the participants. The fact that more women than men were interviewed in this study could be a reflection of gender dynamics in these communities. More women than men were unemployed and stayed at home, and thus were more available during the day for interviews. Men were difficult to find, because they worked in nearby towns and came home only very late at night or during the weekends.

Initially, the interview guide included only a few broad questions, with possible probes drafted. We first asked informants if they had ever been involved in research. If so, we asked for accounts of research participation and thoughts and feelings related to this. If not, we asked them to think hypothetically about what they thought research participation would involve and their general feelings about research. We also asked whether there were any issues they perceived to be sensitive to talk about in research, what those issues were, 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 their concerns would be related to such a research topic; we specifically asked how they perceived being asked about experiences of intimate partner violence 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 we had gathered in the first interview through memoing (Darke, Shanks, & Broadbent, 1998), then added themes that we deemed interesting and worthy of more exploration to the interview guide and probed those issues more in depth in subsequent interviews (Hennink et al., 2011). This process continued throughout data collection and provided us with assurance that we had attained data saturation in each variable of interest in the study (Hennink et al.).

Data Analysis

We employed grounded theory 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. Analysis included data from the 26 in-depth interviews and the first author's field notes (Hennink et al.).

Initial codes generally corresponded with themes as set out in the interview guide. We read and reread 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). Next, we 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.). To label the codes, we interpreted what the text under each code represented and gave each code a name.

We maintained consistency in labeling the codes so 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., we constructed concepts and the theory by finding axes between the codes and categories, and thereafter identified the main category. We then explored what the data meant and interpreted them. In this last stage of the analysis, we compared the findings with the existing literature and made conclusions (Dahlgren et al.; Hennink et al.; 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 such as "sensitivity of the research" and "concerns and risks involved in research participation" were concepts that were derived from published literature; we included these themes in the study interview guide and tested them through interviews to determine 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 participants that the information they shared with him would be held in strict confidence. To guarantee confidentiality and anonymity, the names presented in this article are all pseudonyms.

We did not provide incentives to the informants to participate in this research. After conducting the 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 assist participants who might have strong emotional responses to the interview discussion (SAMRC, 2001). The study township and Pretoria, the nearest town, are well resourced in terms of psychological services and 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 interview discussions.

Findings

In the interviews we learned that 13 informants had not previously participated in research. Nine informants had completed surveys. A number of women had participated in clinic- or hospital-based pregnancy-related interviews, and 1 woman, Ntombi, had participated in a vaginal microbicide trial. The remaining 3 had either participated in interviews about their social services needs or levels of crime in their communities.

Expectations in Research Participation

The 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 would be benefits for the whole community. Our analysis revealed interesting distinctions between the informants who mentioned this and those who did not. The 9 informants with prior research participation and the 1 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 group that did not have prior research participation experience was the majority, and had generally demonstrated a lack of understanding of research; our analysis revealed no differences according to informants' gender in having this perception.

In terms of sociodemographic 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, who was clearly struggling financially, explained her expectations:

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 [corn] 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."

These informants were more likely to also report that they were sole breadwinners 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," or might receive help with their "ill health and other economic problems." The following narrative, from Nomusa, explains this expectation:

You [researcher] come and say you are going to do research in the community. Like after you have interviewed them, 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 socioeconomic challenges prevalent in the community; however, not all informants expected to benefit materially from research participation. Some reported hoping that having disclosed their personal problems, prompt interventions would be made to remedy their respective situation; women were more likely to mention this. Furthermore, these women were more likely to be those who had reported being the victim of interpersonal violence or who had witnessed it in their home. For example, Angelina had reported a long history of partner abuse within different relationships, including the current one, and she mentioned that she disclosed abuse hoping that an intervention would follow:

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 to 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 burned by water thrown by her mother, and the divorce that ensued." Her narrative suggests that she would disclose partner violence in research expecting that an intervention to her situation would be made: "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 of 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 the feared consequences of breach of confidentiality were prominent. A number of women mentioned that research participation might cause or exacerbate violence in their home or relationship. They said that if their partner came to know that they had discussed their relationship in the interview, there was a potential for suffering physical harm or other forms of punishment from their partner.

To illustrate this more fully, during the interview with Angelina, her boyfriend arrived. Angelina panicked and asked to stop the interview and talk about something else. When her boyfriend left, she was able to continue with the interview. She did not explain at the time that the man was her boyfriend; rather, she 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 partner should there be a breach; however, neither of these women had mentioned a history of partner abuse. Bulelwa said,

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.

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.

We did not set out to collect informants' accounts of partner violence, so we are not sure if the two women quoted above had experienced violence, and do not know

why they were worried about possible violent reprisals from their respective partner. However, in this setting the 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; rather, the men were principally concerned that their integrity might be tarnished and that they would suffer embarrassment in the community if their personal information (including their identity) was exposed. They were particularly worried that they might be perceived as weak, and that they might be 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 individuals stated that they would freely discuss personal issues. They included both women and men, and there was no distinction according to age or personal experience between those who were cautious and those who were not. Nevertheless, a number of both men and women reported that there were particular experiences in their lives they would be embarrassed or uncomfortable talking 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 a confidentiality breach were to occur, they feared being judged by 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 to be sensitive by these informants. Broadly, informants mentioned that disclosing abuse or partner violence, either as a perpetrator or a victim, was potentially stigmatizing. They were not comfortable with this because of the shame and blame normally attached to experiencing abuse, either as a victim or a perpetrator. Thus, informants mentioned they feared being labeled negatively and stigmatized.

Some informants stated that it would be difficult to talk about experiences they deemed painful, degrading,

or traumatic, and on this topic 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 and intimate relationships, and being a victim of sexual abuse would be embarrassing and difficult to talk about:

> 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 socioeconomic 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 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 that she did not see any benefit, that she was suspicious of research, and that she was 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 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 was keen to do so, and who did not intend to judge them. They explained that through research participation they derived a rare opportunity to talk about the issues that were bothering them, issues about which they normally would not have people to talk to:

> 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 reported experiencing partner abuse by 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:

> 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 with a willing, nonjudgmental, and empathic listener to be therapeutic. As such, many equated research interviews with therapy, and used such terms as *spiritual relieving* and *healing* to describe this emotional reaction to being interviewed.

What Motivates Participation?

There was an element of altruism that served for 9 informants as a motivation to participate in research. We viewed statements such as the following as altruistic: "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." We noted no particular differential characteristics in informants who reported altruistic motives in terms of gender, age, and personal experiences.

Gracia, who had disclosed a history of abuse in her intimate relationship, mentioned that she was motivated to disclose her history because such information might help other women who have been abused: "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:

> 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 socioeconomic hardships, hoped the information he disclosed might be useful to others: "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 society in general) 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. For example, George expressed the desire to contribute to society through his information, but he also expressed the hope to benefit personally: "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 participate—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, whereas for others there was an overlap between altruism and self-interest. This finding supports findings reported from 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 reported that for those participants who had agreed to be randomized into the trial, participation seemed to be "something of a win:win situation" (p. 7) in which they could contribute to the betterment of others while also self-benefiting.

In the present study, we did not collect enough data on the educational background of informants to allow us to interrogate data through making comparisons by education level, yet we found that the informants who had prior experience of research participation were younger, had reported some tertiary education, and 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. 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 gained 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), but without unpacking what altruism might mean in the research context (Braunack-Mayer; Hallowell et al., 2010). Our analysis reveals that altruism is not a straightforward phenomenon. We have learned that in many cases altruism and self-interest as motives for research participation were inextricably linked (Braunack-Mayer). A number of informants reported that they would be or were motivated by a desire to help unknown others while at the same time anticipating benefits directly to themselves or to their family or community (McCann et al.). Thus, we concur with Hallowell et al. that because research participants are "social actors who exist within a network of social relations" (p. 44), their motivations for research participation might be moderated by other factors in their lives.

Various factors, including socioeconomic needs, education level, previous research exposure, and other social factors that pertain in individuals' situations, circumstances, and contexts might serve to influence their decisions to participate or not participate 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 ends.

In this study, some women—especially those who had been or were currently in abusive relationships—participated carrying hopes that an immediate intervention would 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—specifically 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 their partners, or aggravate an already violent situation (Council for International Organizations of Medical Science [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). As such, we suggest that researchers should consider this risk and that special precautions should 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 involves women, because it is currently not well understood what might trigger reprisal, and under what circumstances. Some authors have commented that asking participants about their personal, sensitive, or painful experiences carries the potential to emotionally and psychologically damage respondents (Black et al., 2006; Savell, Kinder, & Young, 2006; Widom & Czaja, 2005). In this study we 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 so without reporting becoming emotionally damaged by it.

These findings suggest that discomfort and pain from answering sensitive questions do not equate to 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, are not psychologically or emotionally damaged from talking about their traumatic histories in the research context (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 recognized (Macklin, 2004). In the present study a number of informants said that should they become uncomfortable with a research question or think the question was invasive or sensitive, they would inform the researcher that they were unwilling to answer the question or would end the interview. Some reported that they would not answer the question factually; indeed, we learned that 2 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 the 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 recent

traumatic experiences in their life (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. Only 1 informant perceived no benefit in research participation, and viewed it as burdensome.

In the present study we enrolled two groups of informants. Some had participated in research before, whereas some had not (cf. Kim, Millard, Nisbet, & Caine, 2004). Thus, we collected real-life accounts from one group and hypothetical accounts from the other. This opens the possibility that some informants, in particular those who gave hypothetical accounts, might have reported what they thought the researcher wanted to hear. However, we concur with Hallowell et al. (2010) 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" (p. 45).

Living in the community full time allowed the first author to capture data that was unspoken, that was acted out as people interacted with one another. He was able to overhear and/or observe events and incidents as they unfolded, 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, or 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 at in informal talks with or among people, the first author was able to probe for those issues in subsequent interviews, leading to a deeper understanding (Mfecane; Wood & Jewkes; Wood et al., 2007). For example, the manner in which men and women communicated with each other, how they resolved conflicts when they arose, and relationship dynamics were captured through observations. Interviews in this study were conducted by a male; thus, a possibility exists that this might have influenced the data collected in interviews with women, because they might have been uncomfortable sharing intimate information with a man.

Conclusion

We have shown that the decision to participate in research is mostly a balanced and conditional process (Hallowell et al., 2010) in which people assess the potential individual benefits to themselves alongside the potential 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 the study, they did not view discussing such experiences as emotionally harmful. Furthermore, the vast majority not only appreciated the opportunity to talk about such experiences, but perceived benefit in doing so in the safe environment provided by the research.

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Author Biographies

Yandisa Sikweyiya, MPH, is a senior scientist at the Medical Research Council in Pretoria, South Africa.

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