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Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study

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ABSTRACT

Globally, women with disabilities experience heightened and unique forms of violence compared to men with disabilities and women without disabilities. Yet formalised guidelines for their inclusion in gender-based violence (GBV) research is lacking. This paper draws on ethical guidelines for researching violence against women, and studies on the ethicality of including people with disabilities in research, to advocate for women with disabilities' inclusion and safety in GBV research. Reflecting on lessons from a qualitative study on violence against women living with disabilities in South Africa, the paper considers what could be of value for GBV researchers and ethics review committees in low-middle income countries (LMICs). It aims to stimulate debate around the integration of reasonable accommodation, accessibility, and equal participation of women with disabilities in planning and conducting ethical GBV research. The paper recommends that considerations are practically applied and tested in other LMICs, and thereafter critiqued in consultation with a range of stakeholders *and* women with disabilities, to enhance best practice and form a basis for developing guidelines for undertaking ethical and inclusive GBV research in LMICs.

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Ethics; inclusive research; disability; gender-based violence; violence against women

Background

Eighty per cent of the world's disabled population are living in low-middle income countries (LMICs), humanitarian and conflict settings, and various institutions (WHO, 2007; WHO & World Bank, 2011). Vulnerability is heightened by these contexts, and people living with disabilities are more likely to experience violence during their lifetime than their non-disabled counterparts (Hughes et al., 2012). On top of disability-related violence (Lund, 2011), women with disabilities experience gender-based violence (GBV), i.e. the spectrum of gender inequality and psychological, physical, economic and sexual abuse experienced disproportionately by women and perpetrated predominantly by male intimate partners and non-partners (WHO, 2013). Focus on women with disabilities and GBV research in South Africa and other LMICs is emerging (Astbury & Walji, 2014; Kvam & Braathen, 2008; Meer & Combrinck, 2015, 2017; Neille & Penn, 2015; Puri, Misra, & Hawkes, 2015; van der Heijden, Abrahams, & Harries, 2016; van der Heijden & Dunkle, 2017). However, a central ethical dilemma remains unattended; how to include women with disabilities in GBV research and protect them from harm.

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Scholars have developed a set of ethical guidelines for GBV and primary violence prevention studies (Ellsberg & Heise, 2002, 2005; Hartmann & Krishnan, 2016). Ethical recommendations have also been produced for studies on perpetrators of violence (Jewkes, Dartnall, & Sikweyiya, 2012), trafficked women (Zimmerman & Watts, 2003), women in conflict settings (WHO, 2007) and violence against children (CP MERG, 2012). These guidelines try to ensure quality data collection and protection of participants. Guidelines address privacy and confidentiality, safety of participants and research staff, researcher training, and informed consent procedures. However, attention to the unique ethical complexities of research with women with disabilities who may have experienced GBV is missing.

Ethical guidelines tell us that vulnerable research participants should receive special attention as they experience heightened stigmatisation, limited power, lower education, increased poverty, limited resources, live in settings of conflict, and have inadequate physical strength and/or other necessary attributes to protect and defend their own interests; i.e. they may be at risk of being exploited or harmed during research (WHO, 2016). Notwithstanding, there are ethical contradictions for including vulnerable groups, particularly in violence-related research. Moreover, disability scholars acknowledge how ethics relates to weighing the agency and vulnerability of disabled participants, and consider how ethics can be both a tool for both protection and exclusion in research. Disability studies largely focus on the susceptibility of people with intellectual disabilities to coercion and on their capacity to give consent, while also considering the benefits of their inclusion in research (Capri & Coetzee, 2012; Iacono, 2006; Iacono & Murray, 2003; McDonald & Kidney, 2012; Nind, 2008; Northway, Howarth, & Evans, 2015).

For people with intellectual disabilities, disclosure of violence is not easy, given communication and comprehension difficulties; disclosure is not always taken seriously, and inadequate psychological support for the impact of violence is not always available or timely (Northway et al., 2015). Benefits of inclusion are typically de-emphasised or undermined when participants remain in abusive scenarios, when perpetrators are not prosecuted, or when participants find that they are not empowered through self-defense strategies or prevention intervention (McDonald & Kidney, 2012; Northway et al., 2015). While there is widespread contention over the conservative and over-protectionist ethics surrounding disability-inclusive research, there are increasing calls for the direct participation of people with disabilities in *all* research that affects their lives (Barnes, 2003, 2008; Capri & Coetzee, 2012; McDonald & Kidney, 2012).

While not particularly addressing GBV studies, the positions and arguments pertaining to the ethics of disability-inclusive research are worth considering. Drawing from disability and GBV ethics literature and lessons from a South African qualitative study, this paper considers what could be of value for GBV researchers and ethics review committees in LMICs. It aims to stimulate debate around the integration of reasonable accommodation, accessibility, and equal participation in planning and conducting ethical and disability-inclusive GBV research. The paper recommends that considerations should be practically applied and tested in other LMICs, and reviewed in consultation with a range of stakeholders *and* women with disabilities, to enhance best practice. The idea is thus to form a basis for developing guidelines for undertaking ethical and inclusive GBV research.

The case study

A qualitative study undertaken in Cape Town, South Africa, between 2013 and 2015 revealed the precursors to recommendations made in this paper. The study protocol attempted to be inclusive and applied an emancipatory disability research stance (Barnes, 2003, 2008). The South African Medical Research Council and the University of Cape Town ethics committees approved the research. The study included 30 adult women with a range of physical and sensory disabilities, who participated in in-depth interviews about their lifetime experiences of violence and interpersonal relationships.

Participants' impairments ranged from immobility caused by cerebral palsy, spina bifida, para- and quadriplegia, amputation, deformity, muscular dystrophy, and transverse myelitis. Some participants were wheelchair-users, and others used alternative assistive mobility devices such as prostheses, or moved independently. Hearing and visual impairments were either genetic, congenital or resulting from trauma, autoimmune conditions, cataracts, glaucoma, or chronic conditions associated with Albinism or diabetes. Assistive devices for participants with sensory disabilities included hearing aids or a white cane. However, participants generally had limited access to assistive devices or prostheses.

Participants were recruited from disabled persons organisations (DPOs) such as protective workshops and residential rehabilitation facilities,¹ and were mostly poor Black and Coloured individuals living in informal settlements in Cape Town, and were eligible to receive a monthly disability support grant.² It is important to note that ethical considerations in the paper are specific to participants who reported no cognitive or intellectual impairments, and whose contexts are comparable to women with disabilities living in other LMICs (Table 1).

While the study's protocol stipulated additional sensitivity in undertaking GBV research with women with disabilities, the research process provided a further opportunity to identify lessons learned from the field, and debate the limitations in existing GBV research ethics guidelines that may undermine the protection and equal participation of women with disabilities.

The research process revealed several additional ethical considerations to foster inclusivity: defining disability and inclusive recruitment, facilitating reasonable accommodation and accessibility of informed consent and referral services, the limits of confidentiality and the use of disability intermediaries, acknowledging power hierarchies and disabled researcher positionality, the need for additional researcher training and skills, the benefits and compensation for marginalised participants, promoting positive social change for participants with disabilities, and ensuring accessibility of knowledge, research translation and uptake.

Table 1. Sociodemographic characteristics of participants with disabilities.

<i>N</i> =30	<i>n</i> (%)
<i>Age</i>	
19–25	10 (33%)
26–35	12 (40%)
36–45	5 (17%)
46–54	3 (10%)
<i>Race</i>	
Coloured	9 (30%)
Black African	21 (70%)
<i>Living arrangements</i>	
Living with partner	14 (47%)
Residential care	9 (30%)
Living with family	7 (23%)
<i>Ever partnered</i>	15 (50%)
Married	7 (23%)
Boyfriend	5 (17%)
Divorced	2 (7%)
Widower	1 (3%)
<i>Children</i>	12 (40%)
<i>Education</i>	
Special needs	11 (37%)
Mainstream	19 (63%)
Secondary	8 (27%)
Tertiary	2 (7%)
<i>Employment</i>	
Formal	5 (17%)
Informal	4 (13%)
Protective workshop	21 (70%)
<i>Impairments</i>	
Congenital	19 (63%)
Acquired	11 (37%)

Considerations for disability-inclusive GBV research

Defining disability and inclusive recruitment

How disability and (gender-based) violence are defined depicts how inclusive GBV research can be. Endorsed by the World Health Organization, the International Classification of Functioning, Disability, and Health (ICF) framework recognises that disability is not defined or measured by personal impairment or level of functioning. Rather, disability is socially constructed, i.e. social factors and environmental barriers hinder an individual's full participation in society on an equal basis with others (WHO, 2001). The ICF recognises that impairment severity, age, gender, race, sexual orientation, ethnicity, socioeconomic status, refugee status, etc. interact and marginalise people with disabilities (Haegele & Hodge, 2016; Oliver, 2013). Social and biopsychosocial models of disability concur that if barriers are removed, and people with disabilities are given suitable accommodations, equivalent rights, and access to equal opportunities and resources, they can participate in and contribute to society (WHO, 2001). That said, models of disability are evolving. To dissuade the use of static conceptualisations of disability, ethical guidelines can recommend the incorporation of the WHO's definition of disability and measurement tools (WHO, 2001) to ensure that inclusive GBV studies are comparable.

The severity of impairments and extent of barriers women face are varied and subjective; and in Southern Africa, scholars agree that disability is not a homogenous concept (McKenzie, Mji, & Gcaza, 2014). Methodologies and research processes therefore should be flexible and responsive to a broad spectrum of impairments, but more importantly they should reveal the disabling and enabling factors that impact on inclusive research participation.

The qualitative and flexible nature of the South Africa case study meant that stringent sampling processes and representivity issues did not apply. Purposive sampling occurred whereby women with disabilities were recruited from a range of protective workshops and residential rehabilitation facilities that work directly with women with disabilities in disadvantaged communities in Cape Town. Gatekeepers at DPOs were contacted to gain permission to introduce the study to participants. Managers and social workers at these establishments helped identify those women they knew or expected had experienced violence, and helped identify participants' mental state or readiness to participate in a study of this nature. A research assistant also helped facilitate recruitment as she had experience in the disability sector and was familiar with the contexts of the workshops and care centres, and lived in one of the communities these organisations served.

Like GBV researchers, some disability researchers suggest placing recruitment in the hands of service providers working directly with women with disabilities and whose interest is in the protection of and benefit of participants (Nind, 2008). Others argue that this kind of gatekeeping or use of intermediaries can be selective and biased (Iacono & Murray, 2003). During the study, it was suspected that one participant had a severe cognitive or learning difficulty. This incident revealed the challenge of relying on gatekeepers to access suitability of participants to inclusion criteria. It further highlights how some service providers in South Africa may have little knowledge or awareness of clients' capacity to participate, or may be complicit in coercing their participation. Other possibilities to understanding this recruitment dilemma is acknowledging that women with cognitive disabilities are at higher risk for violence than those with other impairments (Hughes et al., 2012), and perhaps service providers were less focused on cognitive capacity than increased vulnerability to GBV.

The study recognised that women with disabilities are frequently excluded from research or are spoken for by other stakeholders. Further, understanding that many people with disabilities are isolated and have no contact with service providers or researchers, recruitment strategies needed to focus on finding those most hidden or at risk of marginalisation and abuse. Recruiting from workshops and residential rehabilitation facilities captured participants that were unemployed and had little access to resources, but were accessing disability-related services. Additionally, participants who volunteered were encouraged to act as informants to help identify women with disabilities

they knew had experienced violence. Some of these participants, who were identified by snowballing, were isolated, and had no contact with service providers, thus their recruitment facilitated the study's inclusivity. We argue that in future GBV inclusive studies, inclusion and exclusion criteria must be justified and compensate for the isolation of women with disabilities, especially those who are home-bound, institutionalised or lack communication faculties to reveal experiences of violence.

Reasonable accommodation and accessibility of consent and referrals

Reasonable accommodation is a tenant of the Convention on the Rights of People with Disabilities and refers to any action, behaviour or modification to the immediate environment that has been made to eliminate barriers or increase access, and encourage the equal participation or advancement of a person with a disability in society and in research (UN, 2006). It encompasses the principle of accessibility. The protocol of this study anticipated additional and unintended obstacles to inclusion, and planned to consult with managers and social workers of DPOs to facilitate disability-specific needs and minimise barriers before commencing research. Further to this, participants were given opportunities at the beginning of the study to self-identify supports required to facilitate their participation.

This paper argues that letting participants define their needs improves the quality of inclusive GBV research. That said, reasonable accommodations may be dependent on specific cases and the resources available. In the study, provisions were made for specialised transport and interpreters, and included both oral and written informed consent procedures to facilitate equal participation. Participants were encouraged to nominate an interpreter with whom they had established rapport. It was anticipated that having a trusted interpreter may facilitate disclosure, and help put participants at ease that their stories would be correctly translated. Further, it was anticipated that the length of the qualitative interviews might cause some participants discomfort, as they may tire due to impairments, potentially affecting the quality of the data collected. Accordingly, data collection was put on hold if participants were fatigued, uncomfortable or distressed, and interviews resumed at a later stage (Ellsberg & Heise, 2005).

WHO guidelines on violence against women research recommend that researchers have an ethical obligation to provide participants with information on services that can respond to their needs (Ellsberg & Heise, 2002, 2005). Thus, accessibility of referral services is an additional recommendation for planning inclusive GBV research. The study envisioned that researchers help facilitate access to protection and justice, given that women with disabilities have been historically marginalised from accessing services, and are often unaware of resources and services that exist in their communities (Baart & Taaka, 2018). It was the responsibility of the researchers to facilitate accessible referrals, in consultation with DPOs and GBV service providers.

Disability scholars acknowledge the mental health effects related to violence against women with disabilities (Astbury & Walji, 2014; Dembo, Mitra, & McKee, 2018; Joseph, Soletti, & Basumatary, 2017). This study focused on sensitive topics relating to stigma, discrimination and violence, which had the potential to invoke embarrassment, fear, sadness, or anxiety for participants. This applied to researchers as well, who could potentially feel distressed after hearing traumatic stories. While researchers were given de-briefing opportunities (Ellsberg & Heise, 2005), it was important that participants experiencing trauma directly from experiencing violence, or through talking about it, be offered accessible services and appropriate professionals for onward referral and assistance. A pamphlet was provided to participants, however, many participants were unaware whether they could utilise these services, and the written text was a barrier for participants with sight impairments, a lesson learnt for future research. Thus, ethical guidelines should endorse using a service access checklist to ensure the accessibility of such services, i.e. guidelines should recommend checking for ramps, lifts, toilet access, and how referrals are shared with participants – collaborative referral processes between GBV services and DPOs can ensure accessibility. In the study, researchers offered to initiate contact with professionals for participants, and it was stipulated that costs

would be covered for transport to these services if needed, taking into consideration the obstacles associated with getting to and receiving health care (Baart & Taaka, 2018).

Accessibility of study information and informed consent is another area that needs special attention and appropriate facilitation if GBV research is to be inclusive. Inclusive communication is a methodology for ensuring that information can reach all participants regardless of the nature or severity of impairment or level of education, such as speaking slowly or using inclusive communication tools such as Braille (Nind, 2008). Furthermore, while it is common practice to request written consent, Silverman (2013) states that highly formalised ways of securing consent should be avoided in favour of fostering relationships in which ongoing ethical regard for participants is sustained.

It was anticipated that participants living in the poorer communities of Cape Town were more likely to have literacy limitations and limited access to communication alternatives, potentially making accessible informed consent problematic. Moreover, GBV research guidelines acknowledge how written consent may be troublesome as it may be viewed as a risk by respondents or may be difficult for illiterate participants. In these cases, verbal consent is an appropriate alternative (Jewkes et al., 2012). What is less agreed upon is how verbal consent should be obtained and documented.

Understanding that people with sight impairments rely heavily on speech communication, an option for verbal explanation of consent was important for the study. Talking one-on-one with participants, sharing study information, and asking participants to state their name, acknowledge comprehension and agreement to participate on audiotape, facilitated verbal consent. For those few participants who used South African Sign Language (SASL), a self-nominated sign language interpreter ensured accessibility and facilitation of either signed or verbal consent.

To date there is little to no research that has been conducted on the power dynamics of including a third party or intermediary in GBV research procedures such as informed consent – an exception being the dynamics on guardianship for minors (CP MERG, 2012), and a brief consideration of including caregivers in consent processes (Hartmann & Krishnan, 2016). The ethicality of using proxies for consent of participants with intellectual disabilities has been covered (Carey & Griffiths, 2017; McDonald & Kidney, 2012). However, while guardian consent is required in the case of minors and those who lack mental capacity to provide consent in South Africa (Republic of South Africa, 2002, 2005), GBV ethical research guidelines should consider diverse and often ambiguous roles and standards of intermediaries used to facilitate inclusivity, for diverse disabilities and across different settings.

Confidentiality and intermediaries

Respecting anonymity and protection of vulnerable research participants is fundamental to the ethical principle of ‘do no harm’. International guidelines on GBV research clearly identify privacy and confidentiality as essential to women’s safety and data quality (Ellsberg & Heise, 2002, 2005; Zimmerman & Watts, 2003) and recommend confidentiality be reaffirmed throughout the research process (Hartmann & Krishnan, 2016). Confidentiality requires additional attention in the case of intermediaries who aid women with disabilities. The presence of an intermediary during interviews can severely limit equal participation and confidentiality, and may expose women to disclosure-related violence and other harmful repercussions (Jewkes, Watts, Abrahams, Penn-Kekana, & Garcia-Moreno, 2000). To minimise harm and ensure their safety, confidentiality needs sensitive facilitation.

In cases where assistance was needed, i.e. SASL interpreters for participants with hearing impairments, participants identified intermediaries with whom they had established rapport to ensure their trustworthiness. Where participants were not able to identify an assistant, an alternative was using proxy interpreters or assistants selected by DPOs, and de-briefed by the research team. Sign language interpreters signed a pledge agreement that acknowledged their respect of participants’ confidentiality. Equally, participants had to agree to their assistants’ involvement in the interviews and acknowledge the risks involved. These agreements were dealt with before each interview.

Acknowledge power hierarchies and researcher positionality

The spectrum and diversity of disabilities, and intersections with other social categories, will play a role in creating power differentials between researchers and participants. Regardless of variations in appropriate data collection methodologies, hierarchies between a non-disabled researcher and disabled participants, or the vastly different socioeconomic opportunities between different participants with disabilities, may be amplified (McKenzie et al., 2014; Stone & Priestley, 1996).

Ethical and inclusive approaches to GBV research should reflect on power differentials and researcher positionality, and the impact they have on the collection, interpretation, and representation of data.

In the study, power differentials were made more complex by the interaction of disability status, and socioeconomic and historical racial inequalities entrenched by apartheid. While the advantage of having a Black African female research assistant with a disability from one of the included communities helped facilitate rapport and deeper sociocultural understanding, participants' background contrasted largely from the principal researcher's. The white female principal researcher was from a historically privileged background, with a high level of education and formal employment. She was also a woman living with a congenital physical disability. While disability research does not necessarily require that disabled researchers collect data (Barnes, 1992), the disability statuses of both researchers helped break the 'disability divide', and facilitated rapport with participants. Participants were more likely to include researchers in their narratives by saying 'people like us' or 'you know how difficult it is', despite other differences. That is not to say that other identities such as gender, nationality, age or race (of the research assistant) may have further facilitated rapport.

Researchers in LMICs show how participatory research strategies facilitate reasonable accommodation, alleviate power hierarchies and foster representation of participants and sociocultural interpretation of findings (Capri & Coetzee, 2012; Chappell, Rule, Dlamini, & Nkala, 2014; Harris & Roberts, 2003). To minimise power differentials, South African disability researchers advocate involving participants as co-researchers. Chappell et al. (2014) argued that participants' training and inclusion in research processes reinforced the agency of participants, and allowed them to build identities as co-researchers – other than as passive participants. Chappell et al.'s study particularly helped rural Black South African youth gain self-worth and recognise their potential for inclusion in social and health care opportunities and interventions (2014).

While including people with disabilities as co-researchers can close the gap between researcher and participants, this strategy was deemed unsuitable for an exploratory study on GBV, where survivors with disabilities may experience re-traumatisation by interviewing participants. Furthermore, vicarious trauma may be exaggerated by a disabled researchers' own experience of marginalisation and GBV. While Swartz (2014) advocates training uneducated and unqualified persons with disabilities in research in LMICs, further considerations and evidence of participants' involvement in GBV-specific research is needed.

Additional researcher training and skills

The World Health Organization's ethical recommendations argue that interviewer skills, competence and training are key quality measures for GBV research, and recommends at least two weeks of GBV training to be included in protocols (Ellsberg & Heise, 2005). Similarly, the emancipatory disability paradigm suggests that disability-specific training of research staff should be emphasised and budgeted for (Barnes, 2003). Accordingly, training budgets and needs for inclusive GBV studies will vary across the spectrum of impairments, settings, and socioeconomic status of the research population. Despite living with a disability and having skills in conducting GBV research, the principal researcher required disability awareness and disability sensitisation, as it was her first experience conducting disability-specific research. The research assistant was a trained occupational therapist with experience in working in the disability sector, and could thus provide mentorship on

disability-related issues, inclusive communication, and challenging disability stereotypes during the research process. The research assistant was in turn instructed on GBV ethical mandates, such as respecting confidentiality, ensuring safety during fieldwork, and referring participants after disclosure, by the principal researcher. The mutual learning and facilitation of both disability and GBV sensitivity in the study can be empowering to researchers, and facilitate sensitive and inclusive research.

Benefits and compensation

The emancipatory disability paradigm stipulates that all research must benefit participants (Barnes, 2003, 2008). Gestures of reciprocity and the provision of feedback to the study population should serve as measures to enact beneficence, a universal ethical research requirement (Beauchamp, 2003). Scholars define reciprocity as the act of presenting participants with a token of appreciation for participating in research; it may also act as a form of coercing vulnerable participants to take part in research studies (Marshall & Rossman, 2011).

Considering that poverty is a contextual factor hindering women with disabilities' equal participation in life (Mitra, Posarac, & Vick, 2013), the contentious issue of compensation being coercive should be suspended, as involving women with disabilities in research may provide relief from abject poverty and social isolation, especially where access to resources and services is limited, as in South Africa and other LMICs. Considering the socioeconomic demographics of the study sample, fiscal payments of R150 (USD 10) to participants were likely to have compensated for time and energy spent participating in interviews, but also complemented disability cash transfers, assisted in family financial obligations, or have gone towards rehabilitation and care needs, or purchasing assistive devices. In the study, participants asked for more money than had been originally stipulated, because of disability-related financial exploitation and theft of their personal monies from family members and other caregivers (van der Heijden et al., 2016). Moreover, women with disabilities may have differing needs in terms of benefits and compensation. The length of the research and contribution expected from participants, as well as the variation in participants' socio-economic needs and assistance requirements, can determine the argument for how much monetary compensation should be given.

While monetary compensation can make women feel like valuable contributors to knowledge generation (Kruger, Ndebele, & Horn, 2014), participants can also benefit from intangible compensation (Fontes, 2004). Participants' involvement inadvertently raised self-awareness of their own trauma and problems, and awareness of their rights to freedom from violence, and their right to be included in research. Raising awareness is also likely to increase access to existing health and violence prevention services and interventions, and should be a central tenant to disability-inclusive research.

Overall, compensation and the potential benefits of the research should be a thoughtful process in the protocol, guided by input from local DPOs who are aware of and advocate for participants' needs and rights. Both compensation and benefits should be discussed during recruitment and informed consent processes. Some disability scholars argue that the benefits of inclusion in research must extend beyond compensation for it to be emancipatory (Barnes, 2003, 2008), i.e. inclusion in research must facilitate social change, and better the lives of participants with disabilities.

Emancipatory research for positive social change?

From an ethical perspective, it is important to consider why and how we include women with disabilities in GBV research. One of the reasons for qualitative disability research is that it allows participants' expectations, perceptions and experiences of social change to be explicated (O'Day & Killeen, 2002). For GBV research, disability-specific risks and forms of violence, as well as unique contexts of violence can be elicited, to inform appropriate prevention programmes and interventions that are inclusive of disability experiences. Emancipatory research that puts participants with

disabilities in control of the research process can suspend stigma and assumptions that women are passive victims of violence. South African disability scholars agree that participants must have some measure of control over studies that affect them directly (Capri & Coetzee, 2012). Moreover, existent gaps and accessibility issues in GBV service delivery can be uncovered, and provide opportunities to dismantle disability-related barriers to GBV care and support. Engaging women with disabilities in their perspectives on their inclusion in GBV research, and its risks and benefits, will also ensure autonomy and participant perspectives that can guide future inclusive GBV research that does no harm.

Violence against women research should only be collected if done correctly and used for violence prevention and social change (Ellsberg & Heise, 2002, 2005). Similarly, the premise of emancipatory disability research is that research be used for social change and findings should include policy or practical implications (Barnes, 2003, 2008; Stevenson, 2010). The politics of research, and who it serves, has elicited much scholarly debate, particularly when including participants with disabilities. There is often an implicit paternalism around the inclusion of disabled participants, and this is even more so where issues of sexuality or violence are included. Both vulnerability and resilience of participants should be considered in relation to what the study offers or is perceived to offer. The belief that participation will mitigate violence and/or improve lives may be especially likely in contexts where the perpetration of violence is often left unaddressed, as is so often the case with women with disabilities.

In the study, participants were informed they would not directly benefit from participating, but that their contributions may help to define the needs and priorities for women living with disabilities in similar contexts. Participants were also told that data may benefit the future lives of women living with disabilities, and that their inclusion might help dismantle barriers to services and social stigma around disability (Iacono, 2006; McDonald & Kidney, 2012). Despite no tangible benefit, participants expressed positivity about being invited to participate in research related to disability and GBV, and found it a rare or first opportunity to talk about their lives and violence experiences.

Furthermore, there is advantage for disability inclusion in GBV research in that it alters the ways in which agency is expressed and stimulated through the research process. Women with disabilities in the study were not passive participants; they demanded societal change, asked for assistance and referrals to GBV services, and requested research incentives and study feedback. A mainstay of emancipatory disability research echoes GBV research ethical guidelines, in that it calls for empowering participants through research processes. A robust argument is that to achieve empowerment, disability should be eradicated; meaning research must impact on the non-disabled society too (Barnes, 2003). Using research to stimulate change in societal perceptions of women with disabilities, and raising awareness of their situations, especially their experiences of GBV, requires action from both disability and non-disability sectors.

Research for who? Accessibility of knowledge and research uptake

For ethical and inclusive GBV research, contributions from research should be disseminated for beneficence and impact (Barnes, 2008). However, there is great paucity of data on the accessibility and inclusivity of knowledge uptake and research translation in GBV research protocols and agendas. Expertise in augmenting and disseminating disability-friendly research materials and findings, particularly findings that can be integrated into policy and violence prevention measures, is lacking. Involving disabled participants and the disability sector in knowledge translation and uptake can ensure that findings are appropriately disseminated, and that research uptake strategies help to prevent violence against women with disabilities. While publishing of academic papers exposes the inaccessibility of the majority disability and GBV knowledge generation, it can lead to wider awareness of violence against women with disabilities, and provide an impetus for further research, research translation and uptake, which will benefit both disability and GBV sectors.

Limitations

The formative nature of the study has potential to stimulate future ethical and inclusive GBV studies, contributing to knowledge on violence against women with disabilities. However, it is not without limitations. The qualitative nature of the study, and small sample, means recommendations in this paper may require modifications for larger quantitative or population-based GBV research. Furthermore, inclusive GBV research undertaken with women with cognitive or severe communication impairments will require additional considerations. Moreover, conflict and institutional settings will need specific recommendations extrapolated where violence against women with disabilities is exaggerated (Kett & van Ommeren, 2009), and additional ethical issues may apply to violence-related studies including men and children with disabilities.

Conclusion

Ethics committees are notorious in promoting over-protectionist or paternalistic frameworks for research with vulnerable populations, especially concerning children and people with disabilities; more so when violence or sexuality topics are covered. However, the CRPD (UN, 2006) underlines the importance of mainstreaming disability in all spheres - it is the right of women with disabilities to be included in research that may protect them from violence. Inclusive ethical research recommendations may be diverse, and may be characterised by a lack of consensus, divisive value orientations, and gaps in knowledge and practice. The heterogeneity of disability in research populations also dictates the diverse accommodations required for achieving inclusive GBV research. Proposing and approving GBV inclusive research in a wide range of settings where women with disabilities are at higher risk of violence will encompass multi-stakeholder collaboration and additional ethical precautions.

The study formed the groundwork for thinking about the mediating factors which undermine inclusivity, and which may pose ethical dilemmas for GBV research involving women with disabilities. In looking toward formalising ethically strong guidelines, inclusive GBV research should not be constrained; it must be conducted with sensitivity and expertise, with ongoing reasonable accommodations and safeguards put in place. The extrapolation of these and future inclusive ethical issues should be tested, with reflections from the field, and include contributions and advice from disability experts, GBV researchers, ethics committees and stringent peer review processes. In doing so, we can encourage higher quality GBV studies that leave no one behind.

Notes

1. Protective workshops are day-programme facilities set up in urban and rural communities by the Department of Social Development. The aim of the workshops is to provide skills building and income-generating opportunities to persons with disabilities whose functionality does not necessitate institutional care but is too severe to qualify for employment. Protective workshops are safe, disability-friendly environments set up in local communities that provide skills building and income-generating opportunities to supplement disability grants. The care facilities were community-based entities providing residential accommodation to disabled adults.
2. The South African governmental disability grant is available to those with certified impairments who are medically unfit to work. At the time of the study participants were receiving US\$103 monthly.

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