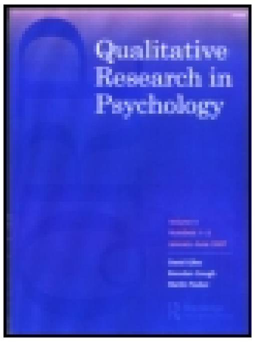

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Creative collaboration on a disability and sexuality participatory action research project: A reflective diary account

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Abstract

This paper presents a team's engagement with a creative collaborative project challenging the myths about the sexuality of people with physical disabilities in South Africa. The paper is presented in the form of a reflective diary account, which has been constructed from minutes of meetings, email correspondences and personal reflections of the activities undertaken. We reflect on the work we have done and what we have learnt, as well as the decisions and dilemmas we had along the way, and the increasingly creative process we embarked on. We reflect on our work with reference to participatory action research and the use of arts-based methods for generating and disseminating knowledge. We believe that this can provide a useful and practical resource for researchers who are new to participatory research methods.

Sexuality, for people with disabilities, has been an area of distress and exclusion (Shakespeare, 2000). For the sexual rights of people with disabilities to be recognised, the private lives of people with disabilities needs to be brought into the public arena, so as to facilitate belonging as sexual citizens (Weeks, 1998; Shakespeare, 2000). Research on disability and sexuality cannot be done without the participation of people with disabilities themselves. In this paper, we reflect, as a core research team, on a creative collaborative research project which aimed to explore and challenge the misconceptions about the sexual lives of people with physical disabilities in South Africa. We have written this paper at the end of two and a half years of working on this project, in the form of a reflective diary account. Four of us [*names removed for peer review]* were the initial core team who developed and proposed the initial project. The remaining two authors were recruited at an early stage to join the initial core team. This account is co-constructed as one voice, the team's voice, based on minutes of meetings, email correspondences and personal reflections of the activities undertaken. We reflect back on the work we have undertaken, the decisions and dilemmas we had along the way, and the increasingly creative process we embarked on. We reflect on our work with reference to participatory action research and the use of arts-based methods for generating and disseminating knowledge. Our intention in writing a reflective account is to explore the evolving nature of research, the dilemmas and challenges, as well as unintended opportunities that arise and how we as a research team worked through them. We hope that this may provide a useful resource for researchers who are new to participatory research methods.

Year 1, March: Background

There was a new funding call out from the *International Foundation of Applied Disability Research*[1], for projects related to disability issues that are participatory in nature, and have a dissemination strategy which includes materials made for a wide audience. This presented us with a chance to do something exciting and creative that builds on our previous work and collaboration on disability and sexual health in southern Africa.

Research has indicated that people with disabilities are often excluded from being able to live fully sexual, and sexually healthy, lives (WHO, 2011). They have lower levels of sexual health knowledge (Eide et al., 2011), and experience a higher prevalence of sexual abuse and exploitation (Hanass-Hancock, 2009; Kvam & Braathen, 2008). It is suggested that in South

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[1] http://www.firah.org/

Africa and elsewhere, this seems to place people with disabilities at greater risk for HIV infection (Groce et al., 2013; De Beaudrap et al, 2017). The myth that people with disabilities are asexual needs to be challenged. People with disabilities are often assumed to be asexual, regardless of whether or not they are; either because they are assumed to lack capacity for or interest in sex (Milligan & Neufeldt, 2001; Esmail et al., 2010). A review of the literature (***, 2017) indicates that there is a lack of focus on sexual and reproductive health care issues for people with disabilities in low and middle-income countries, despite this being the region of the world where the majority of the global population of people with disabilities live (WHO, 2011).

All of us had worked together before in different capacities, and this allowed us to have quick, like-minded discussions about what to do. We decided to do a project that explores and challenges the myth of asexuality among people with physical disabilities in South Africa. The question for us, was: how do we do this in a manner that is accessible and speaks to the personal experiences of people with disabilities? One of us in this initial core research team is the chief executive officer of an organisation for people with disabilities, so we were approaching the project from a participatory framework. However, we also wanted to use a participatory approach with the team members and research participants that were still to join the project (once funded) subsequent to their recruitment on to the project. We intended to use a participatory approach to research method design, data collection and the development of outputs which we could use to raise public awareness about the issues at hand, as well as contribute to the academic knowledge base.

Participatory Research

We wanted to make the project as participatory as possible. This was in keeping with a participatory action research approach that aims to generate research that is of use to the participants involved and that can be used for social change (Kagan, Burton & Siddiquee, 2017). Participatory action research is influenced in part by the work of Paulo Freire (1972) who encouraged an approach to research that included the "subjects" of research as active members in the process of inquiry. One of the main aims, is not doing research for the sake of research, but rather to effect social change. The research process, from this approach, is seen as a cyclical process (Kagan et al., 2017; Vaughan, 2015), moving back and forth between collecting data, reflecting upon it and taking action (which may involve collecting more data).

For the disability rights movement, one of the key mottos has been "*nothing about us, without us"*, challenging the predominance of research *on* or *about* people with disabilities, and rather advocating for research *with* people with disabilities. However, there are many ways in which participation can be conceptualised. In community psychology, Kagan and colleagues (2011) describe various forms of participation ranging along axes of passive and proactive participation, and low to high commitment. Participation can take the form of just sharing information with research participants; to consulting with experts by experience; to collaboratively deciding on and agreeing to action steps; to doing activities collaboratively; and supporting independent initiatives. We wanted to do a project where we can maximize participation. Full and meaningful participation of persons with disabilities on issues that affect them, including those related to sexuality, is very important. Kagan and colleagues (2017) summarize a participatory approach as involving cyclical movements between generating ideas, planning, action, evaluating and reflecting. While a cyclical process is emphasised, some have argued that this aspect is less important than the principle of working *with* participants to address issues being researched (Chevalier & Buckles, 2013). In our project, having participation of people with disabilities from the outset, we adopted Kagan et al's model of participation in the generating of research ideas, planning, taking action in data collection, and reflecting on the activities and process.

In reflecting on our own positions as a team, we acknowledge that we were not neutral in our interests on this topic. We all advocate for inclusivity and social justice. However, not being neutral is in keeping with embracing subjectivity in qualitative research (Parker, 2004). In the project, we were not attempting to do an objective experimental study where we were interested in "truth". We were adopting a social constructionist epistemology, and we wanted to use methods where knowledge is constructed collaboratively, which participatory research allowed us to do (Vaughan, 2015). We knew what we wanted to focus on and act upon – challenging the myths about the sexuality of people with disabilities – and this was grounded in existing research (Parker, 2004), but we did not know how things were going to go, what we were going to learn, or what we were going to produce. This was a voyage of discovery. We planned to use tried and tested methods for collecting and analysing data, such as scaled attitude measures with open questions for the survey of societal attitudes, and individual narrative interviews with participants using photovoice. One of the struggles and tensions in participatory action research is balancing the needs and requirements of funding bodies and the research institutions, with the goal of social transformation and active participation (Boydell et al., 2016). We planned to report results for a non-academic audience, making findings accessible so as to raise public awareness of issues of disability and sexuality. But we also planned to publish papers in academic journals, so that this affords the project "academic legitimacy" (Boydell et al., 2016). However, we also considered this as a form of action for change, in that publishing on matters related to disability and sexuality in academic journals, brings attention to the limited publications in sexuality research (Rohleder & Swartz, 2012). Thus in our project we drew on some of the principles of emancipatory research (Kagan et al., 2017), in that part of our goals of dissemination was towards social transformation.

Working together

It was quite tricky trying to organise and work together across four countries. We were all reliant on the South African team somewhat. We also quickly realised that it was going to be quite a challenge to manage the budget of the project when we were working across various currencies (Euro, Botswana Pula, Norwegian Kroner, Pound Sterling, and South African Rand). It helped to have the administrative support of our respective institutions. However, we believe that much of the success in being able to work effectively across these barriers, resulted from our amiable pre-existing collaborative relationship. We were used to working with each other and knew each other's styles. This was an important foundation for creative collaboration. We also relied on technology to enhance our communication and collaboration. We maintained regular contact with each other through email correspondence, and a monthly conference call (via Skype). We resorted to sharing documentation via a password-protected shared online folder. Having such clearly defined means and channels of communication was important for this to work.

Year 1, March-April: Initial planning and proposal

After some discussion of ideas as a core research team, we made some preliminary decisions as to key methods we proposed using. These decisions were for the purposes of providing a methodological framework for the proposal, but the actual data collection methods were to be developed further through a participatory process, after the recruitment of participants. We outlined three broad methods:

Method 1: Photovoice study of personal experiences:

The use of Photovoice (Wang & Burris, 1997) techniques to gather narrative data from people with physical disabilities seemed to us like a good possibility. None of us had used Photovoice as a method before. It is an arts-based participatory research method which has been successfully used in health research previously (Catalani & Minkler, 2010). It is especially effective for use with participants where personal stories are being elicited, often about sensitive topics. Using arts-based research methods allowed for the collaborative construction of data (Boydell et al., 2016). In order to use Photovoice, we understood that we would need to train the interview participants in the project as co-researchers and photographers. Interview participants would be asked to take photographs that represented their everyday experience, and would then be invited to provide narrative discussion in relation to these photographs during an individual interview (Vaughan, 2014). We felt that the use of Photovoice would allow interview participants to set their own agenda and focus of discussion for the interviews.

After some discussion, we decided to just focus on physical disabilities. We had thought about whether we should focus on other disabilities too. However, different disabilities involve different barriers and experiences, which we felt would be too wide for us to capture in what could only be a relatively small project, due to limited funding. In keeping with the visual aspect of the methodology, we decided to focus on visible, physical disabilities only.

Method 2: Survey study of societal attitudes:

We also decided we would conduct a survey of societal attitudes towards people with physical disabilities. No other such survey study could be found, so we believed this would be a novel study. Much of the evidence on the myth of asexuality is anecdotal (Milligan & Neufeldt, 2001), so we thought it would be important to evidence this empirically. We talked about focusing on sexuality beliefs, and beliefs about sexual and reproductive health care and rights. Article 25 of the *Convention on the Rights of Persons with Disabilities* (CRPD, United Nations, 2006) emphasizes the need for States Parties to recognize the rights of persons with disabilities to enjoy the highest attainable standard of health. Thus, we thought it was important that our focus of sexuality included these health aspects.

Method 3: Dissemination of research:

We wanted to use our findings to disseminate to a non-academic, general audience, so that we could raise public awareness about the sexual lives of people with physical disabilities. Alongside academic outputs, we discussed producing a book, written for a non-academic audience, featuring personal stories and photographs of participants, written in collaboration with participants. What this would look like would evolve as the project progressed. In order to increase the accessibility of the book, we planned to approach a publisher that, if we covered the publication fees, would publish the book as a free e-book.

We submitted an outline proposal for a project which aimed to:

1. Investigate the attitudes of the general population towards the sexuality of people with disabilities in South Africa;

2. Explore the experiences of stigma and barriers to fulfilling sexual relationships among people with disabilities in South Africa;

3. Raise public awareness about the intersection between disability stigma and sexuality.

Year 1, September: Phase 2 of proposal development

We were told in June that our outline proposal was shortlisted, and we were invited to prepare a full proposal for submission in September. The funders seemed to like our project idea, and encouraged us to expand on the range of outputs and material that we could produce, including perhaps a video. We thought this was an excellent idea, and so we incorporated into our plans the production of a short video involving brief interviews with one female and one male participant. However, while this seemed like an exciting idea, we felt we needed to be cautious with this, as making a video would have to depend on whether people consented to be filmed for this. It would mean they were not anonymous (although we could anonymise them in the filming). We did not want to promise the funders an output that we might not have the necessary consent from participants to be able to do, so we had to be clear about this as a hoped-for plan.

For the full proposal, we needed to provide more details about methods. We wanted to maintain a participatory approach, so while we needed to articulate some of the methods to be used, we made clear that we were intending to follow an evolving, creative process, while still maintaining research rigour. We needed to make clear in the proposal that we did not know at that stage what the survey would look like. Although the core research team included the participation of persons with disabilities, we wanted to design the survey with input from the interview participants, once recruited. In the proposal, we could, however, be clear that the survey intended to measure societal attitudes, using both quantitative measures drawn from existing scaled measures that were still to be identified, as well as qualitative exploration through open questions. We also did not know what the book would look like, as it was to be written collaboratively, but we could state what the intended focus would be.

In the proposal, we stated that we would aim to recruit sixteen individuals (eight men and eight women) through disability organisations in South Africa. We would invite interested individuals to attend a training workshop held at the start of the project to discuss what their involvement would entail, the use of Photovoice, and where we planned to also get their input on what the societal attitudes survey should include. Further to our initial decision to use Photovoice, we considered that not everyone would want to take photographs, and some participants might have impairments that made it difficult for them to use a digital camera, without assistance. We recognised that we needed to be more flexible with the use of Photovoice as a methodology, and so we made clear that this would be a choice, and that participants would be invited to use other creative media, like drawing or writing. They could also get friends to help with taking photographs.

The analysis of the data from the survey and the interviews would be conducted by the core research team only, but we proposed sharing and discussing the preliminary findings at an end-of project stakeholders' conference. This would allow for some participation in data analysis, but more so, in thinking about the implications of the findings.

Year 2, January-August: Getting started

We found out in December of that first year that we were successfully funded, which was excellent news indeed. The project itself was to be funded for two years from 1 June, 2015 to 31 May, 2017. We had so many exciting ideas for what to do, and with the funding, we were given the opportunity to do them. In getting started, we needed to recruit research assistants to complete the core research team, we needed to seek ethical approval, and we needed to recruit research participants.

After successfully recruiting a research assistant and a doctoral student, the core research team (the authors of this paper) consisted of: four men and two women; two persons with physical disabilities and four non-disabled persons. One is a professor, two are mid-career academics, one is a post-doctoral researcher, one is a doctoral student, and one is executive director of a regional disability organisation. We are located in different countries, and have experience of working in different contexts on disability studies and disability rights. Four of us come from a psychology background, one from anthropology and one from rural and community development studies. It is a diverse team, bringing in different perspectives and expertise.

We sought and received ethical approval from [name removed for peer review] first, as the project location was the Western Cape, South Africa. Once ethical approval had been granted there, we sought and received ethical approval from [name removed for peer review]. Ethical approval from each committee were sought in two stages, with approval for the Photovoice study being granted first. Approvals for the survey study was sought later, once the design of the survey was finalised with the collaboration of participants of the Photovoice study.

We wanted to recruit participants to the project as soon as possible. We agreed that [name removed for peer review] would lead the recruit for potential participants by writing to various disability organisations in South Africa, as well as other known contacts, advertising the project to potential participants with our contact details for interested individuals. This advertisement emphasised that this was a project co-led by a disability organisation. After two months, we still had not been approached by any potential participants, and so we renewed our efforts to advertise the project to potential participants through disability organisations and other known networks. The first planned activity with recruited participants was to attend a training workshop which was to be held in December of that year, so we were anxious to recruit participants in a timely manner.

Year 2, November: Recruitment of participants and the process of gaining consent

Recruiting participants was slow at first, but we eventually had recruited a group of persons with physical disabilities who expressed an interest in taking part. At first we had more men than women volunteering, which we were surprised about. We were also concerned that some of the men were very highly educated (university level), and thus not representative of the majority of people with physical disabilities in South Africa. To try and address this, we made a more targeted recruitment drive to specific disability organisations and known contacts to recruit more women and men who had lower levels of education. In the end we recruited twenty potential participants (eleven men and nine women), consisting of various ages and ethnicities.

In our proposal, we had budgeted to pay participants for their time and cover the cost of their transport to attend the initial training workshop, and then again for their later participation in the Photovoice interviews. We considered carefully the payment of an incentive that would facilitate participation, rather than be potentially coercive for participants who may be socially-economically vulnerable (Ensign, 2003; Nama & Swartz, 2002). Participatory research methods require a considerable amount of involvement from people than non-participatory methods. For our project, we were expecting participants to take part in a day long workshop at the start of the project, to take time to generate photographs or other artistic material, and to take part in an interview. People with physical disabilities in South Africa are often reliant on accessible private transport, and this added an extra expense to participation.

Twenty participants would be more than we had planned and budgeted for. However, at this stage, the twenty potential participants had only expressed an interest in taking part, and, after receiving an information sheet about the project, had agreed to attend the initial training workshop. Only after attending the first part of the workshop where the project plans were presented and the nature of their participation fully discussed, would their signed consent to participate in the research be recorded. At this stage we expected that some participants would later decide to withdraw, so it was probably better to start with a higher number. We were also cognizant of the fact that consent is not a once-off decision at the start of the project, but rather an ongoing process of consent given throughout the project (Rohleder & Smith, 2015), and so we intended to revisit consent and the consequences of participation as we progressed with the project. This was especially important in participatory research, where ideas develop as the project progresses, and we were also asking people to create materials for public use.

One female participant who expressed an interest in taking part in the project, indicated that she writes poetry about her experiences and asked whether she could contribute poetry that she had already written prior to the project. We thought this was a wonderful idea, and invited her to perform one of her poems at the training workshop in December, which she agreed to do.

Year 2, December; Participant training workshop

The training workshop was a success. It was very productive, and there was a lot of participation from everyone. Eighteen of the twenty potential participants came in the end (nine men and nine women). Two communicated ahead of time to say they could no longer commit to taking part in the project. We did have an unexpected challenge in that we had deliberately chosen a hotel, partly owned by a disability organisation, as the location for the workshop. We were assured that the venue was accessible for people who use wheelchairs. When we arrived, we realised that there was only one accessible toilet available, which meant that during breaks there was a long queue of participants waiting to use this facility. This was something of an embarrassment to us, and we had to apologise for this oversight.

After initial introductions and an overview of the project, one of the participants performed one of her poems to set the focus of the discussion on disability and sexuality:

JUST LET ME BE ME[2]

The image that you see is but a shell

Did you stop to think what therein dwells?

Preconceived ideas so hard to change

Should I be the one to have it re-arranged?

My challenge in life is myself to prove

Is it so difficult to get out of your groove?

I breathe, soak up the sun, I have a name

Yet I have to partake in an acceptance game

This attachment I have is to help me succeed

To help me cope and strive for my needs

My desires and needs are similar to yours

I bear the brunt when it comes to the scores

My triumphs, my joys and all its sequels

Should I hasten to tell you? Aren't we equals?

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[2] Written by 'Rosabelle'; used here with permission.

And yet in my quest for acceptance this way

I unwillingly succumb to the things that I say

The mountains I climb are so much higher

In my conquests and fights I need stronger fire

My battles remain hidden from view

Don't be condescending, I will see through you

My appreciation for life is overgrown

If you haven't felt it, it will never be known

Do not make me feel like a lesser being

Your worth I will question and then I'll be fleeing

The gift of friendship that we choose

Transforms us to heights where no one should lose

Let's meet in a garden of equality and grace

Forget our differences, but the smile on my face

Do not judge me by what you see

I am who I am, just let me be me

Thinking back on the day, having this honest and personal sharing from the one participant, encouraged everyone to share in an honest and open way. We had a day's worth of interesting and important discussions at the workshop. The first part of the workshop involved detailed presentation and discussion about the project and what was expected in terms of participation. After this discussion, all participants gave their consent to take part in the project. We also made clear that consent for their photographs and other materials to be used as data, would be sought after the material were produced.

The workshop also included a discussion session about the proposed survey of societal attitudes towards the sexuality of persons with disability. Prior to the workshop, we as a core research team, considered various possibilities for how we should facilitate this. While we felt input on the survey from participants was important, as researchers we also needed to use our expertise to ensure each set of questions were reliable (i.e. consistent with each other) and valid (i.e. measured what they were supposed to measure). We also wanted a survey that captured narratives, and not just scale measures. The intention was to co-create a survey, but within the framework of sound research practice. So, we decided to make a presentation about the survey, our initial ideas and examples of how questions can be framed and asked (e.g. likert scales, invited responses to case vignettes). Following this initial presentation, there was some very rich discussion about some of the issues participants had experienced, and ideas about what sorts of questions should be asked. While our initial intention was to have a survey of non-disabled persons' attitudes towards persons with disabilities, participants felt that it would be important and interesting to make the survey available to all (including persons with disabilities). There is a difficulty, however, in how to account for or 'measure' disability in a survey questionnaire.

There are many models for understanding ‘disability’ (see Goodley, 2011). Two of the most dominant are the medical model and the social model. The medical model understands disability as resulting from an underlying physical or medical impairment, whereas the social model (which we were primarily informed by) understands disability as resulting from an environment that excludes people who may have impairments or some perceived bodily or behavioural difference (Goodley, 2011). In a survey questionnaire, we needed to ask about participants’ experience of disability in an efficient manner, and where we could use the data for statistical analysis and comparing responses according to population groups. A useful tool for including a ‘measure’ of disability in survey questionnaires, that takes into account participation and exclusion are the questions developed by the Washington Group on Disability Statistics (they have a useful website with various resources here: http://www.washingtongroup-disability.com/). These set of questions was developed by an international task group with participation from organisations for people with disabilities. From the discussions, we concluded as researchers and participants, that key areas to ask about in the survey included: Attractiveness; Dating; Sex; Sexual Health; Reproductive health; and Sexual Orientation. This was very helpful input which we were to use in compiling the survey questionnaire. We agreed that we would pilot the questionnaire with the participants first, to get their further input, before we opened the survey for general responses.

The participants were very excited about the project and the use of Photovoice. When explaining this method with participants, we (the research team) made clear that we were asking for photographs of images that were symbolic of or represented their experiences; we were not asking them to take explicit photographs of a sexual nature. One participant called out, “but why not?” This generated some laughter, but led on to a very interesting discussion about disability and sex and the absence of explicit discussion about this, highlighting what a silenced topic this is. It was agreed that we did not want to silence such discussions, but we confirmed that the photos were also intended for general public use, so it would be best for them to not be sexually explicit.

There was also a very interesting discussion about confidentiality, which arose when one participant wanted to take a photograph of the group. Some participants felt uncomfortable with this, as they did not want the photograph (with them in) to be uploaded on Facebook or other social media. They felt that it would identify them, and they wanted to remain anonymous. It also led to further discussion about some participants’ experiences of being the object of the public’s gaze, and sometimes having people photograph them without permission, as objects of curiosity (or “freaks” as one participant stated). It is poignant that we were using artistic, mostly visual, research methods as an emancipatory tool, where so often imagery of disability is used in stigmatizing and oppressive ways (Garland-Thomson, 2009).

At the workshop, we also discussed the possibility of producing a video of two interviews. Most participants thought this was an excellent idea, and that we should go further with this to make a short educational film, if possible. Many indicated that they would be very happy indeed to take part. We made it clear that we could only include a small number of participants in the film, and we would approach some individually on the basis of unique stories they may have. Consent to take part in the video would be sought at a later stage, only after their individual Photovoice interviews.

Overall, the workshop and the discussions generated, left us with a very real sense of opportunity to do something different and conduct this research project in an evolving, creative way.

Year 3, April: Starting to collect survey data

We spent some time designing the survey questionnaire on the online platform, Qualtrics. We had it professionally translated so that the survey would be available in four of the twelve most widely spoken official languages of South Africa: English, Xhosa, Zulu and Afrikaans. We piloted the survey with the eighteen participants who attended the workshop, and they had a few minor suggestions for improvement of wording, but on the whole they were happy with it. The survey questionnaire included items to measure such constructs as dating beliefs and social distance (as used in Marini et al., 2011). Furthermore, we generated questions to compare the perceived sexual rights, and access to sexual and reproductive healthcare of people with physical disabilities and the general population. Additionally, we included open-ended questions designed to elicit rich data from respondents.

In order to attract as wide a range of respondents as possible, we advertised the survey on the website pages of two prominent national newspapers. We also used social media and our own social and professional networks for further distribution. We employed and trained three field data collectors to collect paper and pen responses from a large socio-economically deprived area in Cape Town, where many residents do not have internet access. At this stage responses to the online survey were only trickling in. But as is the nature of survey research, we knew that we needed to keep monitoring responses and continue making advertisement drives.

Year 3, May: Collecting Interview data

We completed the in-depth Photovoice interviews. In the end we conducted twelve interviews. Two female participants decided they no longer wanted to be interviewed as in the end they felt uncomfortable about being interviewed on what was for them such a personal and private topic. Three further participants had to withdraw from the project due to change of circumstances. The twelve participants are from diverse ethnic and cultural backgrounds, varying in age; some are married, some are single, others are in a relationship. Four were born with a disability and nine had acquired a disability (most as a result of an accident in their young adult years). Of these two were quadriplegic as a result of the accident, and seven were paraplegic

All participants, however, happened to identify as heterosexual, and so the experiences that were explored were heteronormative. This is unfortunate, as the experiences of people with disabilities who identify as lesbian, gay, bisexual and transgender are under-represented in the literature (Löfgren-Mårtenson, 2009). We would have wanted more diverse sexuality represented, but we had to work with the participants we had.

Twelve interviews were fewer than we had hoped for, so we agreed to make an additional effort to recruit some other potential participants to interview. However, the interviews we did conduct were very interesting and we learnt a lot. A proper thematic analysis (Braun, Clarke & Terry, 2015) of the data would come later. After having completed the interviews, some of the emerging themes that we identified were:

Themes from interviews with the women:

- Sexuality was seen as strongly connected to romantic love, relationships, building a family and being a mother;

o Many women felt that men do not see them as sexual beings, because they think that they will not be able to have children and be good wives due to their disability;

- The women who had children had experienced that many people, including health workers, were surprised that a disabled woman could be pregnant. None of the women saw their disability as a real barrier to becoming pregnant or being a good wife and mother;

- Some of the women had been told from when they were small children (by parents and other family) that they could not expect to ever be girlfriends, wives or mothers because of their disability. Other female participants had been told the opposite, that there was no reason why they could not be sexual and be in romantic relationships like everyone else. This shaped the way they saw themselves as sexual and romantic beings as adults;

- Several of the women had experienced that men misused them; courting them and having sex with them, but with no intention of having a relationship with them or marrying them. However, several of the women also had very good experiences of sexual and romantic relationships, built on love, trust and respect.

Themes from interviews with the men:

- Sexuality was seen as strongly connected to notions of masculinity, and being an "adequate" lover able to "pleasure" their female partner.

o Many emphasised the importance of sexually "pleasing" their partner, because some felt that the risk was that their partner would leave them for a "better" lover;

- Some men spoke about their struggles with being dependent and "passive" in a relationship and how this challenged their traditional, cultural beliefs about masculinity;
- Some men, and one young man in particular, spoke about how when meeting for the first time, women tended to see their disability first rather than who they were as a person. As one man put it "they see the chair; not me".

Eight participants took photographs; two participants made drawings; and two participants chose to just talk. One participant also shared poems and text alongside her photographs. These materials acted as prompts during the interview for eliciting their personal narratives. All participants gave consent for the research team to use the photographs for dissemination purposes[3]. At this stage we still needed to select which ones we would use for the planned book and other outputs. There were so many interesting photographs, some of which were quite beautiful and artistic.

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[3] A selection of photographs with accompanying narratives are available to view on [website removed for peer review]. All photographs are available on the website with participants' express permission.

We invited participants to give pseudonyms to refer to themselves. However, the majority of participants insisted that they were happy for us to use their real names in any reporting of data. We wanted to respect their wishes, but it is important to consider very carefully the consequences of this. Our plans were to co-author a book with participants, which would include educational discussion about the topic matter, and would include personal stories and narratives. Following the strictures of research protocols, we were concerned about preserving their anonymity. However, many wanted to use their real names, they felt they wanted to be open about who they are and to educate others. The request to use their own names may be part of a personal process of empowerment. Some commented on what a positive experience it had been to take part in this project. As one person said in their interview:

"It's been a very good exercise to do some thinking and to sort of prepare for today, because sort of putting [drawings] into this folder has been almost a symbolic action of…you know, there's a whole part of my life that not many people know about and that has got beautiful and ugly sides, and that has got pain and joy, and I'm open to seeing where it takes me next."

We recognised that we needed to continue thinking about this and continue to have ongoing dialogue with the participants about how they wish to share their stories and photographs as we move on to the more public dissemination activities.

Year 3, July: Evolving dissemination plans

We had originally proposed having a stakeholders' conference at the end of the project. We later thought that there was an opportunity to do something more creative here, in keeping with the explorative and artistic nature of the project so far. We had collected some wonderful photographs, poetry and a film. We thought that we should host an interactive event, where we would invite the participants, representatives from disability organisations, health organisations, government, academics and the press. One of us suggested organising an artistic performance as part of the event. We discussed the possibility of a local dance group that features people with disabilities and able-bodied people as performers. We thought that this would enhance the depiction of inclusion and further challenge stereotypes. As discussed earlier, arts-based research has tended to utilize arts-methods as forms of data collection, but increasingly arts-based activities are also starting to form part of dissemination activities, making knowledge dissemination more accessible to a diverse range of stakeholders (Boydell et al., 2016). We had a number of materials that we could use, not just for a book, but to exhibit and showcase alongside the planned traditional research outputs. We proposed this to our funders, requesting additional funds to make this possible, and they agreed. We now had the challenging task of trying to find a suitable venue that was accessible to a group of people with disabilities. The place we used for the workshop was too small for such an event, and not up to acceptable standards as far as accessibility was concerned.

Year 3, December: Working on the survey data and publications

The response rate to the survey had been disappointingly slow over the first few months, so we had to change strategy for attracting responses. We emailed an advert about the survey to the student email list of two large universities from different regions of South Africa, with institutional approval. We had to seek ethical approval from our own ethical panels for this amendment. This made a significant difference, and we ended up with a total of 1990 respondents. However, because of the recruitment from the two universities, our sample is a bit skewed towards people with higher levels of education. This, unfortunately, introduces some bias in to the findings.

We have analysed the quantitative and qualitative data from the survey and have submitted two manuscripts comprising the results to academic journals. In the first paper (*[citation removed for peer review]*), we have found that the non-disabled respondents perceived people with physical disabilities as having fewer sexual and reproductive health rights, and fewer needs for access to services, than non-disabled people. These findings provided some empirical support for the anecdotal account of the prevalence of the myth of asexuality among people with disabilities in South Africa. We have also conducted a thematic analysis (using Braun et al., 2015) of responses to a dating scenario question involving a non-disabled person potentially dating a person with disabilities (*[citation removed for peer review]*). There were some positive views about dating a person with disabilities, but our analysis suggested that many non-disabled people tend to desexualise persons with disabilities, and view them with pity, anxiety and even fear (about dependency) as potential dating partners.

We managed to interview another man, increasing the total number of participants interviewed to thirteen. This male participant took photographs that did not depict issues of sexuality specifically, but more generally issues of environmental barriers. Interestingly, many of the participants took photos of environmental barriers, emphasising the primacy of the experience of social exclusion in sexuality and relationships (Shakespeare, 2000; Shakespeare & Richardson, 2018). This is echoed in some of the themes that were emerging from our analysis of the interviews – the experience of exclusion from being able to live fully sexual lives. Some people described relationships as a 'no-entry' possibility.

Year 4, February: Working on a book and film

Our funded project was to come to an end in May, but the creative collaboration would continue beyond this. We initiated the process of writing the book. We identified particular participants to co-author specific chapters with us, and we will invite other participants to write personal stories for the book. We made these authorship proposals on the basis of: practicalities (it is more manageable to have small groups of authors per chapter); levels of confidence in writing expressed by participant;; and the uniqueness of their personal stories. For example, one participant had considerable experience of engagement with reproductive technologies and services, and so had the experience to bring in co-authoring a chapter on this topic. Many had not written before, so in order to facilitate this we invited them to a life-writing workshop which was to be held prior to the planned interactive event marking the end of the project. By this stage, preparations for this event were well under way, and we were very excited about it. We booked a venue and had invited a number of guests. We planned to have an exhibition of some of the photographs with accompanying narratives from the interviews. We were busy co-producing these with the respective participants. Once again, we reviewed consent and the use of pseudonyms, but many still wanted to use their real names.

We were particularly excited about screening the short documentary film that we had made. We hired a videographer who recorded brief interviews with four participants (two men and two women). A fifth participant who was uncomfortable about being filmed, but still wanted to be involved, recorded a voice over narrative for the film. The videographer was using snippets from the four interviews, other bits of filming and the narration, to make a short film. The process of constructing a story board was a learning experience and really highlighted what it means to co-construct a narrative. We only had the budget and time resource to make a short (15-minute) film, and by necessity we had to edit what to include and what to leave out from the four interviews. We had to decide how to depict stories of exclusion, as well as stories of inclusion. Inevitably we could only tell a selected story, from a range of possibilities. This was a new venture for all of us, and something that we could only do collaboratively. We co-produced interview schedules with the four people involved. We co-wrote the narration with the person who recorded the voice over. We also agreed on what would be edited and included for the film.

Year 3, June: Bringing things to an end

The stakeholders' event in March was a real success, and a very rewarding day of sharing. The day included an exhibition of some of the photographs and the screening of the film. It was very well received, and there was a lot of discussion afterwards about disability and sexuality issues and how the film and photographs could be used. The heteronormative focus of the film was quite rightly pointed out by some in the audience, and we had some discussion about the need for further work looking at intersectionality in relation to disability and sexuality.

In the lead up to the event, we developed a website, and consulted with an expert on making the website as accessible as possible to individuals with varying disabilities. The website (*website address removed for peer review*) includes the film available also as a subtitled version, and some of the photographs and narratives of participants.

At the writing workshop, participants were invited to write about their personal experience of taking part in the project. Their writing indicated that it was a positive and rewarding experience, as it was for us all. As one person commented:

"In this study I often forgot that I was a participant because of the learning / benefit / blessing for myself. The immediate value of the project to me, as a participant during the study was tremendous. Even just identifying under-solved issues in my own life – even without starting a formal therapeutic intervention, has been therapeutic. Participation in the project has encouraged / strengthened my resolve to be an advocate – albeit in an area that does not feel comfortable."

Our project had now formally come to an end, in terms of funding, but there was still so much to do. We have had one big disappointment. The book proposal we submitted to the book publisher was rejected, as they felt that the proposed book was not academic enough. This came as a big disappointment to everyone, because we had made it clear that we intended a book to be accessible and which connects to personal narratives. We have already initiated the process of co-authoring the book with some of the participants, and so we do not want to give up on our plans. We will pursue the submission of a proposal to a different publisher. It is not often that we get the chance to do research that is so creative and evolves in this way. We have extended ourselves to doing things in novel ways, and have learnt so much. It feels like we have only started.

Participatory research is in many ways a voyage of discovery. It can be a challenge to balance the needs and requirements of formalised research institutions and funders, with making research that is useful to the people it purports to benefit. Undertaking such research requires careful preparation and a framework within which to work from (some ideas to start off with), but an open and flexible approach that allows one to go in unexpected directions. We benefitted from having previous experience of working together, so we could trust each other in this process. Important too was building trust among all involved. We could achieve this through frequent dialogue and holding workshops where issues could be discussed and ideas generated. It was not always an easy process, but it was certainly exciting.

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