(Re)presenting the self: Questions raised by a photovoice project concerning sexuality conducted with people with physical disabilities in South Africa

Xanthe Hunt[1][5], Leslie Swartz[2], Stine Hellum Braathen[3], Cleone Jordan, & Poul Rohleder[4]

[1] Corresponding author: Wilcox Building, cnr Ryneveld and Victoria Streets, Department of Psychology, Stellenbosch University, +27 82 084 0939, xanthehuntwrites@gmail.com

[2] Department of Psychology, Stellenbosch University

[3] Department of Health, SINTEF Science and Technology

[4] Department of Psychology, University of East London

[5] Phodiso Trauma Research Network, University of California, Los Angeles

This article may not exactly replicate the final version published in the journal

(Re)Presenting the self: Questions raised by a photovoice project concerning sexuality conducted with disabled people in South Africa

Abstract

Photovoice is presented here as an emancipatory, participatory research method with the potential to put minority subjects in charge of their own representation. Drawing on research with disabled people conducted in South Africa, we argue that the meaning of images is often hostage to interpretations which reify untruths about the subject. We consider how photovoice projects may give rise to images that perpetuate the subjugation of their subjects, but could also facilitate an emancipatory politics of self-representation through photography, constituting a challenge not only the discursive regimes and ideologies which underlie dominant aesthetics.

Introduction

The way in which something is visually represented both reflects, and sustains, the way in which we – as predominantly visual societies – think about and relate to it (Garland-Thomson 2009). The manner in which the world 'out there' is represented is intertwined with how we represent it in the world 'in here' of our minds. If something is often portrayed problematically in the visual realm, people may be influenced to harbour beliefs of a negative nature, or emotions of a negative valence, about that thing. Equally, if people harbour negative beliefs or emotions about a thing, it is unlikely to be represented visually in a positive manner.

In this paper, we consider the role of images created during a photovoice project, in reflecting and perpetuating problematic beliefs about the minoritised communities which such work hopes to empower. Drawing on a South African project concerning the sexuality of disabled people, we tease apart some of the complex issues engendered by the creation of publicly displayed social objects (i.e., photographs) during the course of research. We argue that attention needs to be paid to the complexities of representing minorities, and the possibilities –positive and negative – of such projects must be considered. Only then might the images generated cleave open a space for a truly emancipatory politics of self-representation through photography, as the method is proposed to provide (Wang 2006; Wang et al. 2004).

Background

The visual representation of any subject is closely aligned with how that subject is understood in a given zeitgeist (in news photographs, for instance), or the attitude of the given representer to their subject (in, say, artistic renderings). This dynamic of beliefs-determining-aesthetics works in the reverse too, and so representations may come to influence the manner in which their subject is understood.

In light of this, activist artists have striven to find new, alternative ways of representing subjects traditionally hostage to problematic representational tropes. With the rise of socially conscious activist work in the social sciences, such self-representation has come to be used in participatory action research, often in the form of photovoice (Wang et al. 2004). Photovoice is a participatory methodology in which participants (hereafter co-researcher-photographers) produce photographs as data through which to represent, visually, their experiences of a given topic. Photovoice and its variants are established methods in

anthropology and in other disciplines, particularly where co-researcher-photographers are 'silenced' minorities – people who are structurally vulnerable.

The idea in such self-representation work is that communities under the thumb of certain social and/or visual representations at odds with their political ends, may use self-representation as a mode of activism: 'the world out there sees and reads us in this way, and this is not to our benefit, so this is how we choose to present and understand ourselves'. The process of coming to speak for oneself is central to the development of one's own political agenda. If a picture speaks a thousand words, then representation – particularly self-representation – can help people to achieve their desired political ends (Rice et al. 2015).

One group of people who have too often been the subject of extremely troublesome visual representations by others, are disabled people, including people with physical impairments (the subjects of this paper). Both the origins and outcomes of this state of affairs are complex (for further reading, see Dawn 2014; Garland-Thomson 2009; Rice et al. 2015).

Briefly, it has been theorised that problematic images originate in problematic social attitudes towards physical difference (origins), and that problematic images of disabled people sustain social representations of physical difference which are problematic (outcomes) (Cohen-Rottenberg 2012; Garland-Thomson 2009). For instance, in the case of inspiration porn-type aesthetics, disabled people might be represented as superhuman and 'compensating' for their disability, by achieving superhuman feats. Inspiration porn is the term coined by Stella Young to describe the portrayal of disabled people as inspirational solely or in part on the basis of being disabled (Young, 2014). Images which draw on this trope, portray disabled people as being exceptional because they live with (what is framed as) an unliveable impairment. This could originate in society's perception that disabled people need to compensate for some inherent lack (origin) (Grue 2016). The result of these sorts of images, however, is the imposing onto disabled people of a grand narrative which demands of

them excessive levels of achievement not required of non-disabled people (outcome). These relationships are bidirectional and synergistic and the above example is simplified. However, it serves to illustrate the possibility of experiential sequelae of visual representations, for disabled people.

With this in mind, we turn, albeit briefly, to the kinds of representational tropes used to represent disabled people, and the implications which these have for thinking about atypical embodiment and one other facet of human experience – sexuality.

As a necessary backdrop to our discussion of photovoice as an emancipatory research methodology, we will briefly outline the following:

1. The research project on which the present work is based.

2. The relationship between social representations and visual representations.

3. Popular visual representational tropes concerning disabled people, and the implications of such for thinking about sexuality and different-than-average embodiment.

4. The promise of photovoice for inverting problematic past representational dynamics, and the reason for its employment in the case study on which the rest of this paper reflects.

The context of the present study

Our photovoice project concerned physical disability and sexuality. The project itself set out to explore the experiences of sexuality (particularly experiences of desexualisation) amongst a group of 13 adults with physical disabilities in the Western Cape province of South Africa, between 2015 and 2016.

In our study, volunteer co-researcher-photographers were recruited through disability networks. In the final sample, there were five male and eight female co-researcher-

photographers. Five of the co-researcher-photographers were Black African, four were Coloured[1], and four were White; three had congenital disabilities and eight had acquired disabilities.

Following photovoice training (during a one-day seminar held in Cape Town), all co-researcher-photographers were provided with Nikon *Coolpix* automatic cameras, and were asked to contribute images which expressed some facet of their experiences of sexuality as disabled people, including parenthood, gender, sexual experiences, dating, and anything in between. The topic was wide-ranging because, during the Cape Town seminar, it had emerged that different aspects of sexual experience were perceived by different individuals, to intersect most profoundly with experiences of disability, and the research team did not want to limit the content produced or experiences shared. Co-researcher-photographers were given at least three months to collect photographs and other materials. These materials were mostly photographs, although one respondent contributed drawings because she was uncomfortable with photographs, because of negative experiences of being photographed as a person who is of short stature.

The co-researcher-photographers were then asked to take part in an individual interview with one of the authors. During this interview, co-researcher-photographers were invited to choose up to five photographs which they felt most represented their experiences. These photographs were used as discussion prompts during the interview.

All co-researcher-photographers were volunteers, and so likely had some interest in exploring questions of sexuality and disability. Prior to the beginning of the project, they were all involved in a photovoice workshop. During this workshop, the idea that non-disabled people desexualise disabled people was brought up and discussed. The co-researcher-

---

[1] The term Coloured refers to a South African census racial group. Historically of mixed European, African, and Asian ancestry, self-identifying Coloured people constitute about 8.9% of the population (StatsSA 2011).

photographers were also later involved in the making of a documentary video which sought to challenge desexualising assumptions about disabled people. As such, all co-researcher-photographers both entered the photovoice work being most concerned with the idea of challenging problematic attitudes which they had encountered, the most prominent of which was desexualisation by non-disabled people.

Following the completion of the project, all co-researcher-photographers were invited to an exhibition which displayed their photos; the awareness-raising part of the photovoice process. About 50 members of the public, disability activists, and health policy makers attended, and the event featured a display of images from the project, captioned by the co-researcher-photographers. Attendees and co-researcher-photographers mingled, discussing the photographs on display, and the authors presented preliminary findings from the broader project.

The topic of this study arose out of the investigators' interest in the so-called myth of asexuality amongst disabled people: the popular belief in and imperative for asexuality amongst disabled people (for a detailed review, please see Carew et al. 2017; Kulick and Rydström 2015). Photovoice was deemed an appropriate tool for three reasons: Firstly, because the topic at hand was sensitive, images serve as a neutral segue into co-researcher-photographers' narratives concerning sexuality; secondly, due to the cumbersome representational baggage sketched above, to which disabled people inevitably find themselves tethered; finally, because of the awareness-raising component of the process (the exhibition for stakeholders and change-agents).

The representation of disabled people in the visual realm has seldom been affirming of their personhood, let alone their sexuality (as the following section will discuss in some depth). Thus, one of the implicit projects of the investigators was to explore how self-representation could be used as a vehicle to re-present the sexuality of disabled people

(Russinova et al. 2014). However, this question was not explicit in the research project, and so the discussion presented in this paper is the product of the authors' reflections on the project, rather than on participant data. One of the authors of the present paper is one of the co-researcher-photographers whose data were analysed and is presented here. The inclusion of co-researcher-photographers as co-authors and co-investigators in participatory research is important, where emic perspectives – hitherto concealed – need to be given space. As will be apparent in the sections which follows – this co-researcher-photographers' critical self-reflexivity and candidness positioned her optimally to contribute to this particular work, as she was willing and able to discuss her choice of aesthetics, on completion of the project, in relation to different ways of representing the self as a disabled person.

On representation, disability, and sexuality

Social representations are societal stocks of shared values, ideas, metaphors, beliefs, and practices through which groups make meaning of the social world (de Rosa 1992; Wagner et al. 1999). Described as the collective elaboration 'of a social object by the community for the purpose of behaving and communicating' (Moscovici 1963, 251), social representations guide thinking about and behaviour towards social objects. The given meaning of a social object (for instance, physical disability) within a society has implications for how that social object is expected to behave, attributes it is expected to have, and which possibilities for engagement with it are appropriate and desired, and which are not.

Stereotypes, myths, and other modes of cultural diffusion share certain characteristics with social representations, predominantly that they guide behaviour towards and promote certain thinking about social objects. Social representations of disabled people tend to characterise them as dependent, de-gendered and less sexual than non-disabled people (Hunt, Swartz, Rohleder, Carew, and Hellum Braathen, 2018; Milligan and Neufeldt 2001).

Disabled people are also commonly characterised as insecure, dependant, weak, asexual, or somehow superhuman (more on this below).

These ways of conceiving of disability in the mind's eye mirror popular ways of visually representing disabled people. We will review popular visual representational tropes concerning disabled people, and the implications of such for thinking about sexuality and different-than-average embodiment, and then discuss recent work by the authors which provides empirical evidence of the tropes which prevail in South Africa, the context of the present work.

Historically, disabled people have often been marginalised from their communities, pathologised by medical professionals, and been the object of the pity or disdain of non-disabled others. As Goodley (2011) notes, societal discourses have positioned disability either as a personal tragedy or a scientific anomaly. Sexuality, on the other hand, is conceived of in contemporary discourse as the purview of the able-bodied and nubile.

Mostly, there is a dearth of images of different than average embodiment in our visual landscape. That representation which does happen, though, often relies on outdated, stereotypical, and de-gendering portrayals of different embodiment. Almost all of these foreclose on the possibilities of the portrayed subject (disabled people) being conceived of as a normal sexual subject (instead, they are portrayed as asexual, hypersexual, or presexual).

For instance, Freakshow-type aesthetics depend on accentuating and displaying bodily difference. Freakshows – mass exhibitions of anatomically unusual bodies – Garland-Thomson (1996, 2) writes, relies on a 'cultural logic [which] construct[s] certain corporeal variations as deviant'. Clinical or medicalised depictions of disability frame it as pathology. Inspiration porn images employ disabled people as exemplary of different virtues, particularly determination.

We offer some of our own interpretations, based on our work and past theorisations, of the implications which these ways of visually representing disability have for thinking about sexuality.

When disabled people are objectified in the manner of the Freakshow, it can be argued, based on the work of scholars who have explored the implications of objectification of this nature for interpersonal relating (Shakespeare 1994), that it becomes near impossible to see them as sexual subjects. As viewers of disability spectacle, non-disabled individuals know that there is something intrusive about their looking. But if that looking is sanctioned as curiosity, then they may be able to rationalise it. If the non-disabled viewer were to acknowledge the human subject behind the objectifying image, they would have to divorce this pretence, and in so doing confront their complicity in another's subjugation. Subjugation in the context of sexualised looking takes on the tone of perversion, and so it may be more comfortable to efface the sexuality of disabled people-as-spectacle.

In the case of clinical objectification and subjugation, we learn to pathologise difference: to conflate physical impairment with illness and contamination, and physical with moral difference. Under the clinical gaze, the humanity of the examined subject is compromised, and their social and sexual desirability tarnished. The objectified, pathologised, sick person with a physical disability is not a suitable sexual subject.

With images which implore non-disabled people to pity disabled people, non-disabled people assume (another) position of power – this time as the fortunate 'normal' person pitying the unfortunate other. They may feel admiration, but they are also grateful for their distance from difference. Feminist critics such as Simone de Beauvoir (1943, 2011) have taught us why pity prohibits mutuality: it is the obverse of aggression, and confers a sort of sadistic might on the viewer, under the guise of sympathy. In representing disabled people as

pitiful, the viewer's eyes are invited to look down on the disabled body. Again, there is no room for sexualised or romantic looking: pity prohibits sexualisation.

Finally, and relatedly, the relative absence of disabled people in popular culture, except as ciphers of the type we have been discussing, serves to exclude them from sexual society. We cannot conceive of – in nuanced, personalising ways – that which we do not see. By withholding disabled people from our daily visual life, we are not challenged to think inclusively about sex and sexuality.

Both visual and social representations act in synchrony (and cyclically) to pathologise or negate the sexuality of disabled people (Cohen-Rottenberg 2012). As many authors have noted (Chivers and Mathieson 2000; Karlen 2002; Lamb 2002; Lemieux, Cohen-Schneider, and Holzapfel 2001; Milligan and Neufeldt 2001), the sexuality of disabled people is particularly poorly understood and attended to, despite the fact that society as a whole is increasingly sexualised in the public sphere (D'emilio and Freedman 1988; Fine 2005; Kulick and Rydström 2015; Payne et al. 2016; Tolman and Tolman 2009). The social desexualisation of disabled people, Payne et al. (2016, 1031) write, 'further makes invisible an already marginalised and pathologised population'.[2]

Contemporary artistic and media representational efforts have changed the status quo in some respects, as concerns disability representation. Indeed, in the Global North particularly, there has been a proliferation of scholarship as well as artistic and other aesthetic endeavours to insert disability into public spaces. For instance, in a 2012 interview, Robert McRuer commented on such work hailing from the United States:

… like Leroy Moore and Krip Hop Nation, or Sins Invalid out of San Francisco.

---

[3] An exception to this general desexualisation of disabled people in the popular imaginary, is its opposite: the fetishisation of disability and bodily difference. Think, for instance, of Lady Gaga in her music video for the song 'Paparazzi', or Michael Stokes' photographic series 'Always Loyal'. In both instances, a very specific type of bodily difference – the merging of body and prosthetic – is eroticised. Whilst such images undoubtedly speak back to desexualising imagery of disabled people, they do so within a very specific and potentially problematic grammar (see Hickey-Moody 2015).

These are performing artists and groups who centralize the work of disabled people of color, in particular, and Sins Invalid (2010) definitely reaches across borders for what they call their 'unashamed claim to beauty in the face of invisibility.' Even the painting of Riva Lehrer, as she puts forward beautiful and enigmatic portraits of individual disabled activists and artists, often has this sort of queer-crip, moving-across-borders valence to it. (Peers, Brittain, and McRuer 2012, 152)

Indeed, Sins Invalid (2010), a 'performance project on disability and sexuality that incubates and celebrates artists with disabilities', have gained prominence in disability and performing arts circles for their reimagining of disability aesthetics, and disavowal of conventional disability representational tropes. Other popular portrayals of disability in nuanced forms, include novels (such as Kenzaburo Oe's *A Healing Family,* and reflected on in the article 'Enabling disability: Rewriting kinship, reimagining citizenship' by Rapp and Ginsburg (2001)) as well as television series (such as *Speechless*, which features Micah Fowler, an actor with cerebral palsy). These are exemplary of what Matt Fraser called 'the precipice of a cultural turnaround in the way that the mainstream media deal with disability' (Hay 2016).

However, the degree to which such representations have penetrated the popular imagining, and the popular imagining in a global Southern context such as South Africa, is questionable. Recent research by the authors (Hunt, Swartz, Carew, Braathen, Chiwaula, & Rohleder, 2018; Hunt, Carew, Braathen, Swartz, Chiwaula, & Rohleder, 2017) found that archaic disability stereotypes still abound in South Africa. A large community sample of South Africans still often seemed to mentally represent disability as precluding sexuality, limiting agency, engendering dependence, or necessitating overcompensation. This research showed that amongst a sample of nearly 2000 non-disabled South Africans, attitudes towards

the sexuality of disabled people were problematic and often desexualising (see Hunt et al, 2018).

As such, in this specific context, efforts at self-representation by disabled people, with a view to developing a positive visual grammar to portray diverse embodiments, seems a fruitful avenue for research and activist praxis. This might give rise to alternative social representations to those which have been found to be prominent.

The promise of photovoice for inverting problematic past representational dynamics is twofold. Firstly, it promises to alter the problematic dynamic which may manifest between a majority photographer, and a minority subject, and in so doing alter the nature of representations of minoritised subjects. Secondly, visuals of something as steeped in representational trouble as the sexuality of disabled people, should best be done by (or at the behest of) those in the know – disabled people themselves – if thinking around that topic is to begin to represent the interests of those portrayed.[3]

Activist images: Photovoice as emancipatory research method

Although we have used the term in passing before in this piece, it is appropriate that we now clarify what we mean by 'emancipatory' practice. What we are gesturing at, with this term, is a way of doing research – of finding out about subjects' lives – which is interesting and empowering for the subjects themselves. Further, what makes a practice (in this case a research practice) emancipatory, is that it serves the ends of those researched in quite direct and experiential ways. What would make photovoice an emancipatory practice is its reliance on the input of the subject at every point in the research process, and the generation, through the project, of engagement of the subject with the research topic, in a manner which is

---

[3] In the case of disabled people who may have difficulty using a camera, the assistance of another may be employed in photovoice work, an individual who then captures images upon instruction from the participant.

engaging for them, and allows for experiential engagement with the topic. More on this in due course.

Until the 1950s, photography generally played a role in the social sciences only when researchers took photographs as mnemonics for later scholarly reflection (Denzin and Lincoln 2011; Lal, Jarus, and Suto 2012; Prosser and Schwartz 1998). However, since then, and particularly in light of the work of Hubbard (1991) and Wang and Burris (1997), researchers have transferred the activity of photography to co-researcher-photographers. The result is that contemporary photography in research involves a means to generate an 'emic' (insider) perspective on a research question, as co-researcher-photographers are requested to collect photographs as data (Lal et al. 2012). In participatory action research, particularly, co-researcher-photographers have proven useful to facilitate cooperation and understanding in research teams with members of varied expertise (Boxall and Ralph 2009; Prosser 1998).

Among the many forms of participatory photographic research, photovoice is perhaps the most clearly operationalized (Wang and Burris 1997). Moreover, photovoice is touted, by scholars from various fields (Prosser 1998), to be an *emancipatory* participatory research method which has the potential to put minoritised subjects in charge of their own representation in the visual realm, mobilise communities, and pave the way for policy change, cleaving open a space for counter-narratives through representation (Allotey et al. 2003; Luttrell 2010; Mitchell et al. 2005; Packard 2008; Pink 2013; Strack, Magill, and McDonagh 2004; Wang 2006; Wang and Burris 1994; Wang et al. 2004).

Photovoice projects require that co-researcher-photographers use photography to express – or aid in the expression of – their sentiments regarding a given topic. Where other forms of qualitative work are dialogue-driven, photovoice pairs co-researcher-photographers' narrative accounts of the phenomenon with their photographic depictions of it (Streng et al. 2004). These products – co-researcher-photographers' images and accompanying narratives –

not only constitute the data for the project in question, but can also be used as social objects for political action: activist images. That is, in addition to their value as social objects, photographs as an artistic medium allow for increased visibility in the public sector (Fleming et al. 2009; Wang and Burris 1994; Wang et al. 2004). As is implied, the 'voice' part of photovoice speaks to the impetus behind this method: that, through their creation of images which carry their meaning, co-researcher-photographers might be able to have their political voices heard.

Photovoice has become increasingly popular in qualitative research with disabled people (Allotey 2003; Balcazar et al. 1998; Dassah, Aldersey, and Norman 2017; Mirza et al. 2008; Oden, Hernandez, and Hidalgo 2010). This is perhaps unsurprising given that photovoice has its roots in participatory action research, which is also a favoured way of working in disability studies (Bhagwanjee and Stewart 1999; Hammel et al. 2008; Kehayia et al. 2014; Kitchin 2000; Minkler et al. 2002). The reasons for the use of photovoice in past projects with disabled people are varied, but centre on the utility of the images generated for activism, and their proposed capacity to combat stigma (Fleming et al. 2009).

Representing the over-determined self: Problems and possible solutions

The following section presents the authors' reflections on the products and process of the photovoice project outlined above. It represents our attempt to think through some of the theoretical and ethical complexities of photovoice work. If one thinks through the project of photovoice work in relation to the visual representation of minoritised subjects, especially disabled people, three central problematics arise: the development of a visual grammar by which to represent the hitherto misrepresented; the inevitability of drawing on (often troublesome) representational tropes in order to frame the self, and the consequences of this for photovoice images and activism. Below, we draw on images from our project to think

through these two challenges, and interrogate possible ways of responding to them – to think about photovoice with representation in mind.

A new aesthetic

Plato wrote that all art is an imitation of an imitation. Certainly, whenever one represents something – say on canvas or film – one must necessarily look to, and draw on, past representations of that thing. As children, we learn to draw trees not by looking at trees, but by looking at how trees have been drawn in the past. This poses a problem for creating images of disabled people: how to develop a new way of 'drawing' a person with a disability when almost all past images of them are somehow troublesome or perpetuate problematic beliefs?

[Figure 1 near here]

Disabled women work against two strong visual tropes. The first infantilises them, conflating some given lack of 'normative ability' with passiveness and dependence (see, for instance, pity porn images in Hadley 2016). The second, reflected in devoteeism and amputee porn, views them as sexual fetish objects (although not everyone agrees with this reading of devoteeism, see Aguilera 2000). Now, given that the present project was concerned with desexualisation more than hypersexualisation (as this was what co-researcher-photographers highlighted as being the more prevalent attitude which they encountered from non-disabled others), the fourth author, J, took her photos with this grand narrative in mind (as evidenced by the narrative which accompanies the picture, and her reflections in this paper). This is clear in the statements, 'I wanted to depict disability as being sexy in a way', and 'What I

wanted was to just like show that people with disabilities [sic] are just normal. We flippen do things, you know, if you can and if it's possible'.

Her images (including the one above) actively speak back to the desexualisation of disabled women. However, in the process of re-inscribing sexuality into a body which society might desexualise, J employs aesthetics which may invite a certain type of (acquisitive) male gaze. In choosing a visual grammar through which to positively encode the femininity and sexuality of the disabled female body, J needed to draw on tropes which are not unproblematic. They are not problematic by any fault of hers. Instead, the ways in which women, including disabled women, might be able to represent themselves as sexy and sexual, are in many ways predetermined by sexual scripts and aesthetics of a patriarchal society.

If her choice lies at one end of a continuum of possibilities when confronted with representing the overdetermined subject (explicitly presenting the body in a manner opposing the tropes), then the choice of the majority of our co-researcher-photographers (as exemplified in the image below) at the other: the absence of the disabled subject.

[Figure 2 about here]

Many of our co-researcher-photographers drew heavily on metaphor, and the images of the built environment, to represent their experiences of sexuality as disabled people. There is nothing sexual about Ian's picture unless it is read in conjunction with Ian's narrative. None of the co-researcher-photographers discussed why they removed the self from the pictures, and why their images were often devoid of sexual imagery as one might popularly conceive of such. One manner of reading this reliance on signs (a picture of a bench) which are divorced from the signified (sexual relationships as a disabled man), is nervousness regarding representing the disabled body. In an attempt not to re-perpetuate problematic

looking dynamics regarding the disabled body, these respondents chose not to represent it at all.

This representational tactic, however, has its own host of implications, the main being that – in a project concerned with disability and sexuality – the disabled body itself is absent from many of the images. This is exemplified in the image above, where Ian employs a disability-void image to represent his experiences of relationship inequality.

However, the presence of a disabled person in an image is not the only means by which disability can be visually represented. Several of the co-researcher-photographers chose to keep themselves out of their images, instead focussing on motifs and metaphors, places and spaces. This could be due to a reluctance to self-display – bordering on concealment – due to the vulnerability which such an act entails – a vulnerability which is amplified in the context of disability, due to history of problematic representation. However, it could also be due to the co-researcher-photographers' conceptions of their own sexuality which are relational, dependent on accommodations and access, and reflected in their daily realities (which was supported, in the interview data, by a focus on these issues). Regardless, however, of the intention of these images – even if they were taken, without the desire to conceal the body – the result of drawing heavily on metaphor was an absence of disability imagery in a project which intended to add to the cannon of disability imagery.

Where dominant systems of visual and social representations objectify and medicalise disability, many co-researcher-photographers produced images which altogether lack the carnivalesque aesthetics of this cannon. While this does not make for photography which stands alone in obvious conversation with the cannon, it reveals certain facets of sexuality in the context of physical disability which the stereotypical or limiting representations of the past elide. So, while we could read this photovoice aesthetic as thwarting the development of

a visual grammar to portray the disabled body, it may also represent a new grammar, one devoid of the problematics of the past.

The meaning of a picture

The second issue inherent in visually representing minoritised subjects in the context of a photovoice project stems from the limits of control over the meaning of an image. Briefly:

a. Once created, an image is not hostage to its intended meaning. Any meaning can be read from it; it is a social object in its own right.

b. As noted, it is difficult not to represent disabled people without potentially drawing on some ways of representing which might be problematic, even if the creator-subject does not intend the meanings which these ways of representing evoke.

c. Once 'out in the world', it is possible that an image will be interpellated with a host of meanings which subjugate the creator-subject.

To briefly expand on the above – once a social object is in the world, its meaning is determined by its viewer. As Roland Barthes (1977) wrote about 'the death of the author', so in photovoice we might find ourselves confronted with a death of another kind – the death, as it were, of the photographer. What Barthes (1977) meant, as intended here, is that readers and viewers have agency, and they use that agency to read and make meaning from the social objects they encounter. This meaning may be at odds with that intended by the creator. Central to photovoice is the idea that narrative should accompany image, and co-researcher-photographers provide captions which are distributed with their images. These captions convey what they as photographers intended the image to 'say' and 'do'. As evident from the above discussion, these meanings might be at odds with what the image seems to 'do' or

represent. However, it is very difficult to guarantee that, once the images are distributed across various platforms as tools for activism, this meaning will remain alongside them.

Consider, as discussed above, that it is extremely difficult to represent the self in a manner which does not harbour the ghosts of past representational tropes. When within a project, a photographer who does draw on a problematic representational trope may still be able to mitigate any damage which such a portrayal might cause, with the use of a caption which carries their intended meaning (as in the case of, say, J, above, where her narrative works against fetishist interpretations of her photograph).

The intended meaning might very well be at odds with the trope employed. This might be particularly the case for disabled people because social and visual representations as social products play a substantial role in the structuring of identities and self-representations (Dassah et al. 2017). As it is a common belief that disabled people make sense of their experiences in light of the existing meanings and practices prevalent in a predominantly nondisabled society, the narrative and visual coding of social objects created by disabled people might very well reflect meanings attached to them by the majority.

Thus, when representing the self during the course of a photovoice project, it is entirely possible that a disabled person might draw on a trope which is problematic. The image, when displayed after the completion of the project, might go on to evoke negative reactions, or perpetuate troublesome viewing dynamics between non-disabled and disabled subjects, despite this not being the photographer-subjects' intention.

As Higgins (2016, 672) writes, one of the major ethical problematics of photovoice-type work is that co-researcher-photographers may actively participate in the appropriation of their images, 'reproducing the oppressive relations of power that it aims to work against, albeit differently'. For instance, returning to the image of J above, the disabled subject is caught between two problematical tropes. The first is that of the asexual disabled female

body; the second is that of the disabled female body as fetish object. Working against the former, what Heiss (2011, 2) argues is the 'media's frequent situate[ion] of the "normal" female body as the … absence of fat, wrinkles, physical disabilities, and deformities', J represents herself in a manner which could not only invoke a particularly acquisitive male gaze, but also evoke fetishising looking characteristic of devotee porn. So, while the image was intended (as stated in the accompanying narrative) to be an affirmation of her sexuality, it could be read in a manner which perpetuates a troublesome way of relating to the disabled female body. This has nothing to do with how she represents herself, and everything to do with the way in which images are read; against a cannon of other images of a similar nature. J' image could be read as problematic only because there is a cannon of representation of disabled women, and of women more generally, which is abounding in problematic tropes.

Writing about the representation of disabled people in Indian cinema, Dawn (2014, 517) recommends that 'the film-maker [must] be deliberately mindful of the structures and conventions that permits film to communicate effectively to the mass audience, be conscious of how this language works, how the screen communicates to people and effects their emotions'. In a similar manner, co-researcher-photographers in photovoice projects might be engaged in a session outlining historical changes in disability representations across the world, and involved in a group discussion that can include personal experiences and thoughts about representation and what these mean. However, to do this, without limiting or constraining co-researcher-photographers capacity to convey their sentiments in a congruent way, is a fine line to tread.

Does the risk of producing an image which might be misread by some, outweigh the promise of self-representation as a liberatory end in itself? Past work by Mji, Schneider, Vergunst and Swartz (2014) has shown that the sheer fact of seeing the self represented may hold benefits regardless of the purpose, or later readings, of the image. Thus, it might be

necessary to tolerate the possibilities of later misreadings of a given visual, if the production of that visual is of benefit to the co-researcher-photographers, *and their communities*. The emphasis here is a difficult one to untangle: do the benefits of an individual representing themselves in a way which feels liberatory in the moment take precedence over the possibility that the image could lead to the subjugation of members of the community with which they identify?

Due to the importance of exploration (developing a new visual grammar) in photovoice work of this kind, it may be necessary to not overly mediate the production of images – constraining co-researcher-photographers to be responsible for the way in which their communities are portrayed (this simply reinforces the notion that members of a given social group must 'represent' that group, which deindividualises members). Equally, however, it may not be a bad thing for co-researcher-photographers to be cognisant of past visual traditions, and their implications. This is not to say that their choice of images should be shaped by future audiences, but rather that they should be put in a position to make informed decisions regarding the types of visuals which they produce. Although this may well stifle some of the spontaneity of image-taking, we would argue that researchers have the responsibility not to place co-researcher-photographers in a position where they unknowingly produce images of themselves which are undoubtedly problematic or could have negative consequences for them or their communities (Wang et al. 2004; Wang and Redwood-Jones 2001).

Photographs are just as capable of carrying discernable messages as the narratives which accompany them, and this is both a strength and a weakness of photovoice as methodology. However, if the weaknesses/risks outlined above are borne in mind, it is possible that self-representation can offer a process through which disabled people may challenge problematic assumptions about their sexual selves: images-challenging-ideology.

Below, we outline the manner in which photovoice may cleave open a space for a truly emancipatory politics of self-representation through photography, one which offers a process through which other minoritised populations may challenge problematic assumptions about their selves by presenting their self in the manner in which they would like to be seen. We argue that images of subjects generated by those subjects could constitute a challenge not only to dominant aesthetics, but also to the discursive regimes and ideologies which underlie them.

Creation as resistance: Photovoice as participatory communication for the minoritised subject

At a prior point in this paper, we stopped in order to clarify our intention with the phrase 'emancipatory practice'. We do the same here for the idea of 'creation as resistance'. Emancipatory practice, as noted, refers to participation in research which serves the subjects' ends, by the subjects themselves. Photovoice is an example of this. The idea of creation as resistance points to the part of the photovoice project, in our example, where subjects are able to create social objects – photographs – which further serve their ends as a community, or individuals, or both. Particularly, this is relevant when the creation of social objects (here, visual representations) of the subject or group of subjects, has, in the past, been done at the behest of others, to the detriment of the subject. Simply put, creation is resistance when past pictures of disabled people are negative, and disabled people are given the opportunity to create new types of representations which are not negative.

Adopting a participatory action approach in disability research does more than foreground the importance of accessibility and the effective inclusion of disabled people in research *about* disabled people. It also promises to make an important methodological contribution to disability and sexuality research in the Global South. The contribution of

photovoice is unique in this regard. If the visual representation of disabled people is often problematic, mirroring negative social representations concerning their sexuality, then novel visual representation might equally play a role in challenging such social representations.

Creating an archive from below: Re-visioning disability imagery

In response to this burdensome representational and ideological baggage, Shildrick (2005, 2007, 2015) has argued that there is a need to urgently foreground the aesthetic and intellectual value of disability. Shildrick (2005, 2007, 2009, 2015) proposes a reconceptualisation of the disabled subject as sexual subject. That is, critical reflections on disability should not merely oppose the devaluing of disability but actively value it as an identity (a perspective which has been echoed by McRuer 2006). Photovoice not only holds the potential for this radical reconceptualisation to be a radical re-representation tool, but also that it is done at the behest of disabled people themselves. The necessity of doing needs- and rights-based work of a very fundamental kind in settings in which the resources with which to intervene are scarce (such as inquiry into issues of access) is clear. However, this does not negate the relevance of creative, participatory work regarding 'softer' issues of, say, representation. Self-representation, or taking charge of the dominant other's gaze is an act of resistance, but also an act of self-definition which inscribes into disabled bodies new, generative meanings. As a methodology, then, photovoice seems extremely well-suited for use in application to disability and sexuality.

This suitability is perhaps amplified in global Southern contexts, as illuminated by a reflection of postcolonial critique. Like disability theory, postcolonial critique is concerned with examining the relations of domination between and within groups. However, where disability studies is concerned with the able/disabled dichotomy, postcolonial critique attends to relations amongst countries, 'races', or cultures. Both disability and postcolonialism are

central discourses in the social construction of personhood (Barker and Murray 2010). Both have been used to determine which bodies are deemed worthy of citizenship and rights.

As with disability, the visual representation of persons deemed racially Other – people of colour – has a fraught history. Stereotypical, flattened, problematic renderings of racial 'alterity' have overlain societal anxiety regarding miscegenation and contamination. When it comes to conceiving of the sexuality of the racial Other, a similar process is noted – theirs is all that white sexuality is not, and the racial and sexual Other is feared or fetishised. In social representations, myths and fears about the deviant or hypersexuality of disabled people are very similar to anxieties about people of colour (Frawley 2012; Hook 2012).

Given the history of national and international race relations, any image of a person of colour carries with it a host or interpellated meanings. Whilst these meanings today include sexuality, that sexuality often skirts the edges of the 'normal' (socially desirable, sanctioned), and, if a genuine portrayal is offered, it is hard-pressed to not fall into stereotypical patterns of representing race (see, for instance, discussions surrounding Black persons in pornography; Dines 1998; Miller-Young 2007; Royalle 1993).

Mapping the interstice between visual representations of two types of visual 'difference', racial Otherness and disability, then, reveals a number of areas of commonality. Dossa (2006), for instance, notes that racialised women with disabilities draw our attention to the normative and restrictive criteria of personhood, exclude markers of difference based on race, gender, class and disability which characterise contemporary society. An exercise in shooting back at representations of sexual otherness amongst disabled people in a postcolonial global Southern setting, is an intersectional enterprise, and has the potential to explode stereotypes of both race and embodiment. It is also a project which echoes calls by postcolonial and Southern theorists for an archive from below (Bandyopadhyay 2009; Jolly 2008). It must be noted, however, that 'analogies between disability and race, gender, and

sexuality tend to obfuscate biopolitical realities' (Puar 2017, xxii), and so those parallels highlighted here are theoretical, and acknowledge the lived differences of minoritised identities.

Marcus (1996, 6) draws our attention to the 'the activist imaginary', the means by which media, including photographs and film, can be used by minority groups to 'pursue traditional goals of broad-based social change through a politics of identity and representation'. It is possible that the types of representation – and the types of identities – revealed by creators with disabilities during the course of photovoice work, may indeed be vastly different from those imposed on them by dominant meaning systems. This holds, we would suggest, for co-researcher-photographers who accidentally draw on problematic representational tropes, encountering the two challenges outlined above. Given that photovoice accompanies each image with a co-researcher-photographers generated narrative, it might allow for these problematic visuals to begin to evoke new meanings (for instance, if images such as J's are repeatedly displayed alongside narratives such as hers, which speak an affirming meaning into the sexualised disabled female body, then eventually images of that body may come to evoke more liberatory meanings).

This is important. Spectators' responses to disability are often determined by ready-made or pre-determined response options – for every disability trope there is a limited way of viewing disability. If new ways of representing disability *or* viewing disability are explored, the greater the possible range of readings and meanings disability imagery may have (Hadley 2014). New ways of viewing disability, encouraged either by new aesthetics or by new meanings accompanying old aesthetics, may provide a space for consensus-building negotiations about disability, the body, and representation (Hadley 2014).

Through self-representation, our co-researcher-photographers challenged our conceptions of what disability and sexuality in South Africa, one instance of a global

Southern context, might look like. Where dominant systems of visual and social representations objectify and medicalise disability, playing up impairment to suit one or another grand metaphorical narrative, our respondents produced images which altogether lack the aesthetics of this canon. Instead, they used their photographs to highlight the relational nature of sexuality and intimacy, and employed the built environment and issues of physical access to shed light on the importance of accommodation, power dynamics, and social representations in determining their sexual self-esteem, and development.

Yet, there is ambivalence here – the absence of the disabled body from the images, and the gaze anticipated by the disabled woman representing sexual selfhood – in these images: is absence concealment? Is the desire for the gaze problematic? Perhaps, and perhaps not at all. However, if the very making of the image is a political action, and a departure from past enforced inaction, then such work constitutes a first step, regardless of how uncertain, or how rocky the terrain.

Putting custody of the camera with these co-researcher-photographers enabled them to act as thought leaders, drawing on the immediacy of the visual image to stimulate discussion, and a revisioning of the intersection between geopolitics, sexuality, and bodily difference (Wang and Burris 1997). Pribram (2004), reading Foucault, suggests that representation is a site for cultural struggles over meaning formation. In the process of photovoice, we see that meaning production occurs regarding the visual image; social structures, ideologies, and contested identities are played out within the frame. It is possible that the harm of an unintended meaning being read from an image is outweighed by the value of the production of that image as an end in its own right.

Perhaps one of the greatest contributions of photovoice for working with disabled people is the potential for such work to create an archive from below – an archive of disability self-representation. Such cultural products, and their creation and public display,

can foster audience's engagement with a credible and authentic cultural counter-narrative (Sandell 2013).

Finally, as already noted, if we harbour beliefs of a negative nature, or emotions of a negative valence about a thing, we are unlikely to represent it visually in a positive manner. This works on the intrapersonal level too, and we are as unlikely to visually represent ourselves in a positive light if we feel badly about who we are. Working within the bounds of projects aimed at re-imagining how the self can be portrayed, using different visual grammars, could allow for a positive re-definition of the self. These images invert the usual dynamics of looking characteristic of the cannon of representations of different bodies. The enforced passivity of viewing offers a reversal of the usual habits of looking at disabled people. The photographer-subject is empowered and accorded status because of their power as creator (Povee, Bishop, and Roberts 2014; Wang and Burris 1997). In the case of photovoice, that power can be used to take pictures which do not conform to a societal stereotype or social expectations for the subject or their visual representation. However, before such a re-imagining of disability aesthetics can take place, greater attention must be paid to issues of visual representation: we must think photovoice with representation in mind.

References

Aguilera, R. J. 2000. "Disability and Delight: Staring Back at the Devotee Community."
Sexuality and Disability 18 (4): 255–261.

Allotey, P., D. Reidpath, A. Kouamé, and R. Cummins. 2003. "The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon." *Social Science & Medicine* 57 (5): 949–958.

Balcazar, F. E., C. B. Keys, D. L. Kaplan, and Y. Suarez-Balcazar. 1998. "Participatory action research and people with disabilities: Principles and challenges." *Canadian Journal of Rehabilitation* 12: 105–112.

Bandyopadhyay, R. 2009. "Archiving from below: The case of the Mobilised Hawkers in Calcutta." *Sociological Research Online* 14 (5): 7.

Barker, C., and S. Murray. 2010. "Disabling postcolonialism: Global disability cultures and democratic criticism." *Journal of Literary & Cultural Disability Studies* 4 (3): 219–236.

Barthes, R. 1977. *The Death of the Author.* UbuWeb Papers. http://www.tbook.constantvzw.org/wp-content/death_authorbarthes.pdf

Bhagwanjee, A., and R. Stewart. 1999. "Promoting group empowerment and self-reliance through participatory research: a case study of people with physical disability." *Disability and Rehabilitation* 21 (7): 338–345.

Boxall, K., and S. Ralph. 2009. "Research ethics and the use of visual images in research with people with intellectual disability." *Journal of Intellectual and Developmental Disability* 34 (1): 45–54.

Chivers, J., and S. Mathieson. 2000. "Training in sexuality and relationships: An Australian model." *Sexuality and Disability* 18 (1): 73–80.

Cohen-Rottenberg, R. 2012. "Caught inside a paradox: How cultural representations perpetuate disability stigma." *Disability and Representation: Changing the Cultural Conversation.* http://www.disabilityandrepresentation.com/caught-inside-a-paradox-how-cultural-representations-perpetuate-disability-stigma/

Dassah, E., H. M. Aldersey, and K. E. Norman. 2017. "Photovoice and persons with physical disabilities: A scoping review of the literature." *Qualitative Health Research* 27 (9): 1412–1422. doi:10.1177/1049732316687731.

Dawn, R. 2014. "The politics of cinematic representation of disability: "the psychiatric gaze"." *Disability and Rehabilitation* 36 (6): 515–520.

De Beauvoir, S. 2011. *The Second Sex.* New York: Vintage Books. https://uberty.org/wp-content/uploads/2015/09/1949_simone-de-beauvoir-the-second-sex.pdf

De Beauvoir, S. 1943. *L'Invitee.* Paris: Gallimard.

de Rosa, A. S. 1992. "Social Representations and Attitudes: Problems of Coherence Between the Theoretical Definition and Procedure of Research." Paper presented at the 1st International Conference on Social Representations. Ravello, Italy, October. file:///C:/Users/User/Downloads/deRosaA.S.1992.SocialRepresentationsandAttitudes.Problemsofcoherencebetweenthetheoreticaldefinitionandprocedureofresearch.pdf

D'emilio, J., and E. B. Freedman. 1998. *Intimate Matters: A History of Sexuality in America.* University of Chicago Press.

Denzin, N. K., and Y. S. Lincoln. 2011. *The Sage Handbook of Qualitative Research.* Sage.

Dines, G. 1998. "King Kong and the white woman hustler magazine and the demonization of black masculinity." *Violence Against Women* 4 (3): 291–307.

Dossa, P. 2006. "Disability, marginality and the nation-state–negotiating social markers of difference: Fahimeh's story." *Disability & Society* 21 (4): 345–358.

Fine, M. X. 2005. "Desire: The morning (and 15 years) after." *Feminism & Psychology* 15 (1): 54–60.

Fleming, J., J. Mahoney, E. Carlson, and J. Engebretson. 2009. "An ethnographic approach to interpreting a mental illness photovoice exhibit." *Archives of Psychiatric Nursing* 23 (1): 16–24.

Frawley, P. 2012. *Sex and Disability.* Taylor & Francis.

Garland-Thomson, R., ed. 1996. *Freakery: Cultural Spectacles of the Extraordinary Body.* New York and London. New York University Press.

Garland-Thomson, R. 2009. *Staring: How we Look.* Oxford University Press.

Goodley, D. 2011. "Social psychoanalytic disability studies." *Disability & Society* 26 (6): 715–728.

Grue, J. 2016. "The problem with inspiration porn: a tentative definition and a provisional critique." *Disability & Society* 31 (6): 838–849.

Hadley, B., ed. 2014. "'That you would post such a thing…': Staging spectatorship online." In *Disability, Public Space Performance and Spectatorship*, 109–147. New York: Springer.

Hadley, B. 2016. "Cheats, charity cases and inspirations: disrupting the circulation of disability-based memes online." *Disability & Society* 31 (5): 676–692.

Hammel, J., S. Magasi, A. Heinemann, G. Whiteneck, J. Bogner, and E. Rodriguez. 2008. "What does participation mean? An insider perspective from people with disabilities." *Disability and Rehabilitation* 30 (19): 1445–1460.

Hay, M. 2016. *Mat Fraser on the Future of Disability in the Media.* https://www.good.is/articles/mat-fraser-american-horror-story-freakshow-disability-media-oneofus

Heiss, S. N. 2011. "Locating the bodies of women and disability in definitions of beauty: An analysis of Dove's campaign for real beauty." *Disabilities Studies Quarterly* 31 (1). http://www.dsq-sds.org/article/view/1367/1497

Hickey-Moody, A. 2015. "CARBON FIBRE MASCULINITY: disability and surfaces of homosociality." *Angelaki: Journal of Theoretical Humanities* 20 (1): 139–153.

Higgins, M. 2016. "Placing photovoice under erasure: A critical and complicit engagement with what it theoretically is (not)." *International Journal of Qualitative Studies in Education* 29 (5): 670–685.

Hook, D. 2012. *A Critical Psychology of the Postcolonial: The Mind of Apartheid.* Routledge.

Hubbard, J. 1991. *Shooting Back: A Photographic View of Life by Homeless Children.* San Francisco: Chronicle Books.

Hunt, X., Carew, M.T., Braathen, S.H., Swartz, L., Chiwaula, M. and Rohleder, P., 2017. "The sexual and reproductive rights and benefit derived from sexual and reproductive health services of people with physical disabilities in South Africa: beliefs of non-disabled people". *Reproductive health matters*, 25 (50): 66-79.

Hunt, X., Swartz, L., Carew, M.T., Braathen, S.H., Chiwaula, M. and Rohleder, P., 2018. "Dating persons with physical disabilities: The perceptions of South Africans without disabilities". *Culture, health & sexuality*, 20 (2): 141-155.

Hunt, X., Swartz, L., Rohleder, P., Carew, M. and Hellum Braathen, S., 2018. "Withdrawn, strong, kind, but de-gendered: non-disabled South Africans' stereotypes concerning persons with physical disabilities". *Disability & Society*, 1-22.

Invalid, S. 2010. *Sins Invalid: An Unashamed Claim to Beauty in the Face of Invisibility.* www.sinsinvalid.org.

Jolly, M. 2008. "The south in southern theory: Antipodean reflections on the pacific." *Australian Humanities Review.* http://australianhumanitiesreview.org/2008/03/01/the-south-in-southern-theory-antipodean-reflections-on-the-pacific/

Karlen, A. 2002. "Positive sexual effects of chronic illness: case studies of women with lupus (SLE)." *Sexuality and Disability* 20 (3): 191–208.

Kehayia, E., Swaine, B., Longo, C., Labbé, D., Ahmed, S., Archambault, P., J. Fung et al. 2014. "Creating a rehabilitation living lab to optimize participation and inclusion for persons with physical disabilities." *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap* 8 (3): 151–157.

Kitchin, R. 2000. "The researched opinions on research: Disabled people and disability research." *Disability & Society* 15 (1): 25–47.

Kulick, D., and J. Rydström. 2015. *Loneliness and its Opposite: Sex, Disability, and the Ethics of Engagement.* Durham, NC: Duke University Press.

Lal, S., T. Jarus, and M. J. Suto. 2012. "A scoping review of the photovoice method: Implications for occupational therapy research." *Canadian Journal of Occupational Therapy* 79 (3): 181–190.

Lamb, S. 2002. *The Secret Lives of Girls: What Good Girls Really Do--Sex Play, Aggression, and their Guilt.* Simon and Schuster.

Lemieux, L., R. Cohen-Schneider, and S. Holzapfel. 2001. "Aphasia and sexuality." *Sexuality and Disability* 19 (4): 253–266.

Luttrell, W. 2010. "'A camera is a big responsibility': a lens for analysing children's visual voices." *Visual Studies* 25 (3): 224–237.

Marcus, G. E. 1996. *Connected: Engagements with Media.* University of Chicago Press.

McRuer, R. 2006. *Crip Theory: Cultural Signs of Queerness and Disability.* NYU Press.

Miller-Young, M. 2007. "Hip-hop honeys and da hustlaz: Black sexualities in the new hip-hop pornography." *Meridians: Feminism, Race, Transnationalism* 8 (1): 261–292.

Milligan, M. S., and A. H. Neufeldt. 2001. "The myth of asexuality: A survey of social and empirical evidence." *Sexuality and Disability* 19 (2): 91–109.

Minkler, M., P. Fadem, M. Perry, K. Blum, L. Moore, and J. Rogers. 2002. "Ethical dilemmas in participatory action research: a case study from the disability community." *Health Education & Behavior* 29 (1): 14–29.

Mirza, M., A. Gossett, N. K. C. Chan, L. Burford, and J. Hammel. 2008. "Community reintegration for people with psychiatric disabilities: challenging systemic barriers to

service provision and public policy through participatory action research." *Disability & Society* 23 (4): 323–336.

Mitchell, C., N. DeLange, R. Moletsane, and T. Buthelezi. 2005. "Giving a face to HIV and AIDS: On the uses of photo-voice by teachers and community health care workers working with youth in rural South Africa." *Qualitative Research in Psychology* 2 (3): 257–270.

Mji, G., Schneider, M., Vergunst, R. and Swartz, L., 2014. "On the ethics of being photographed in research in rural South Africa: views of people with disabilities". *Disability & Society*, 29 (5): 714-723.

Moscovici, S. 1963. "Attitudes and opinions." *Annual Review of Psychology* 14 (1): 231–260.

Oden, K., B. Hernandez, and M. Hidalgo. 2010. "Payoffs of participatory action research: Racial and ethnic minorities with disabilities reflect on their research experiences." *Community Development* 41 (1): 21–31.

Packard, J. 2008. "'I'm gonna show you what it's really like out here': The power and limitation of participatory visual methods." *Visual Studies* 23 (1): 63–77.

Payne, D. A., H. Hickey, A. Nelson, K. Rees, H. Bollinger, and S. Hartley. 2016. "Physically disabled women and sexual identity: a PhotoVoice study." *Disability & Society* 31 (8): 1030–1049.

Peers, D., M. Brittain, and R. McRuer. 2012. "Crip excess, art, and politics: A conversation with Robert McRuer." *Review of Education, Pedagogy, and Cultural Studies* 34 (3–4): 148–155.

Pink, S. 2013. *Doing Visual Ethnography.* Sage.

Povee, K., B. J. Bishop, and L. D. Roberts. 2014. "The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities." *Disability & Society* 29 (6): 893–907.

Pribram, E. D. 2004. "Spectatorship and subjectivity." In *A Companion to Film Theory,* edited by T. Miller and R. Stam, 146–164. London: Blackwell Publishing.

Prosser, J. 1998. *Image-Based Research: A Sourcebook for Qualitative Researchers.* Psychology Press.

Prosser, J., and D. Schwartz. 1998. "Photographs within the sociological research process." In *Image-Based Research: A Sourcebook for Qualitative Researchers,* edited by J. Prosser, 115–130. Psychology Press.

Puar, J. K. 2017. *The Right to Maim: Debility, Capacity, Disability.* Duke University Press.

Rapp, R., and F. D. Ginsburg. 2001. "Enabling disability: Rewriting kinship, reimagining citizenship." *Public Culture* 13 (3): 533–556.

Rice, C., E. Chandler, E. Harrison, K. Liddiard, and M. Ferrari. 2015. "Project Re• Vision: Disability at the edges of representation." *Disability & Society* 30 (4): 513–527.

Royalle, C. 1993. "Porn in the USA." *Social Text* 37: 23–32.

Russinova, Z., E. S. Rogers, C. Gagne, P. Bloch, K. M. Drake, and K. T. A. Mueser. 2014. "A randomized controlled trial of a peer-run antistigma photovoice intervention." *Psychiatric Services* 65 (2): 242–246.

Sandell, R. 2013. *Re-Presenting Disability: Activism and Agency in the Museum.* Routledge.

Shakespeare, T. 1994. "Cultural representation of disabled people: dustbins for disavowal?" *Disability & Society* 9 (3): 283–299.

Shildrick, M. 2005. "Unreformed bodies: Normative anxiety and the denial of pleasure." *Women's Studies* 34 (3–4): 327–344.

Shildrick, M. 2007. "Contested pleasures: The sociopolitical economy of disability and sexuality." *Sexuality Research & Social Policy* 4 (1): 53.

Shildrick, M. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality.* Springer.

Shildrick, M. 2015. *Leaky Bodies and Boundaries: Feminism, Postmodernism and (Bio) Ethics.* Routledge.

Statistics South Africa. 2011. *Census 2011. Census in Brief.* http://www.statssa.gov.za/census/census_2011/census_products/Census_2011_Censu s_in_brief.pdf

Strack, R. W., C. Magill, and K. McDonagh. 2004. "Engaging youth through photovoice." *Health Promotion Practice* 5 (1): 49–58.

Streng, J. M., S. Rhodes, G. Ayala, and S. Phipps. 2004. "Realidad Latina: Latino adolescents, their school, and a university use photovoice to examine and address the influence of immigration." *Journal of Interprofessional Care* 18 (4): 403–415.

Tolman, D. L., and D. L. Tolman. 2009. *Dilemmas of Desire: Teenage Girls Talk About Sexuality.* Harvard University Press.

Wagner, W., R. Farr, S. Jovchelovitch, F. Lorenzi-Cioldi, I. Marková, G. Duveen, and D. Rose. 1999. *Theory and Method of Social Representations [online].* London: LSE Research Online. http://eprints.lse.ac.uk/2640/1/Theoryandmethod.pdf

Wang, C. C. 2006. "Youth participation in photovoice as a strategy for community change." *Journal of Community Practice* 14 (1–2): 147–161.

Wang, C., and M. A. Burris. 1994. "Empowerment through photo novella: Portraits of participation." *Health Education Quarterly* 21 (2): 171–186.

Wang, C., and M. A. Burris. 1997. "Photovoice: Concept, methodology, and use for participatory needs assessment." *Health Education & Behavior* 24 (3): 369–387.

Wang, C. C., S. Morrel-Samuels, P. M. Hutchison, L. Bell, and R. M. Pestronk. 2004. "Flint photovoice: Community building among youths, adults, and policymakers." *American Journal of Public Health* 94 (6): 911–913.

Wang, C. C., and Y. A. Redwood-Jones. 2001. "Photovoice ethics: Perspectives from Flint

    photovoice." *Health Education & Behavior* 28 (5): 560–572.

Young, S. (2014). I'm not your inspiration, thank you very much. TEDxSydney. April.

Figure 1 legend

Caption:

'I wanted to depict disability as being sexy in a way. I can't hide my flaws and imperfections like other people can. Mine is there for the world to see. In the process of rediscovering my sexuality, I have learned to use what I have to seduce and entice. The silent battles I have fought of self-acceptance and validation has left me with the realisation that I no longer have to hide the naked beautiful truth of who I am … a woman in every essence of the word.'

'A friend of mine [took this]. He was really cool. I mean, I have known him for years. I said, look, this is what I want, can you do it very discretely? I don't want it to be sleazy or shit or anything, but just like real.'

'What I wanted was to just like show that people with disabilities are just normal [sic]. We flippen do things, you know, if you can and if it's possible.'

(J)

Figure 2 legend

Caption:

'I actually wanted a picture of a seesaw. One can't really enjoy the full benefits of the seesaw unless there's another person on the other side. So you might be in a park full of people with very high spirits and all of that [and] you might go and sit on the seesaw, but it's almost entirely useless until someone sees you as worthy of joining you.' (Ian)