Sexualities & Disabilities

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Contributors

Dr. Loree Erickson is a white, queer, femmegimp porn star academic. Based in Toronto, she is the creator of want, an internationally award-winning porn film, and a community organizer. She loves travelling to lecture, making queercrip porn, and facilitating workshops/lecturing on a variety of topics including collective care, disability justice/radical disability politics, and all things related to sex and disability. She is also a fan of sun, sparkly things, and social justice.

Andrea García-Santesmases is a sociologist and anthropologist. She is currently working on a PhD in Sociology at the University of Barcelona about the construction of gender identity in people with physical disability. She is a member of CO-POLIS, an international and interuniversity research group of gender and social control.

Shyamani Hettiarachchi is attached to the Department of Disability Studies, Faculty of Medicine at the University of Kelaniya in Sri Lanka. She is an Adjunct Lecturer at School of Psychology and Speech Pathology, Faculty of Health Sciences, Curtin University, Australia. She works both as a Speech and Language Therapist and Dramatherapist in Sri Lanka. Her research interests include phonological disorders in children, dysphagia and gender and disability.

Omolola A Ladele holds a PhD in English. She is currently a Senior Lecturer in the Department of English, Lagos State University Ojoo, Lagos, Nigeria where she teaches several graduate and undergraduate level courses including, Postcolonial literature, Women and Gender Studies, Feminist Literature, Literary theory. She has presented papers in international and local conferences and these have appeared in peer-reviewed local and international journals.

Andrea McCarthy obtained a BA in Sociology and Cultural Studies from the University of Sussex and an MSc in Social Research Methods at the University of Surrey. Prior to starting her MSc, Andrea worked within the charity sector, undertaking research in the fields of disability, education and the experiences of the care

system for children and young people. Her research interests include sexuality, disability and the impact of informal care on both caregivers and the people receiving care. Andrea is particularly interested in the use of emancipatory research techniques in order to promote inclusive and empowering social research for people with disabilities.

Alessandra Mondin holds a BA in Visual Arts (DAMS - Bologna University) and an Erasmus Mundus MA in Women's and Gender Studies (GEMMA - University of Hull and Utrecht University). She is completing her PhD at the Centre for Research in Media and Cultural Studies at the University of Sunderland. Her doctoral research focuses on feminist pornographies and the aesthetics, ethics and politics of feminist desires.

Heather Tucker is a PhD research student in the Comparative Gender Studies department at Central European University in Budapest. Formerly working as an advocate in the field of intimate partner violence in the U.S.,she has conducted research which focuses on a queer feminist analysis of identity, body politics, and NGO formation within post colonial settings. She is currently carrying out her PhD research project in Accra, Ghana which focuses on body politics, intimacy, and NGOization.

Scott Sheidlower is an Associate Professor and head of circulation and the archivist in the library at York College of the City University of New York [CUNY] in Jamaica, Queens, New York City. He has an M.A. in Art History from NYU; an M.A. in Arts Administration, also from NYU; and an M.L.S. from Queens College/CUNY. He is co-author of Humor and Information Literacy: Practical Techniques for Library Instruction (Libraries Unlimited, 2011). He is working on a second book also to be published by Libraries Unlimited. His e-mail is ssheidlower@york.cuny.edu.

Editorial

Arpita Das & Remi Joseph-Salisbury

Within discourses of sexuality, people with disabilities and their sexual desires are often marginalised; at the same time, sexuality hardly appears as a matter of significance for people with disabilities. Too often, the sexual and reproductive needs, desires, and concerns of people with disabilities remain ignored. People with disabilities are often perceived as 'hypersexual' beings needing to be controlled or, as 'asexual' without any sexual and reproductive needs.

This journal issue attempts to address these under-represented and marginalised voices and aims to advance scholarship at the intersections of disability and sexuality. It has not been an easy process to reach out to scholars and academics for papers for this issue and as editors, we have had to extend the deadline twice in order to be able to collect and present an array of papers. This could be due to a number of reasons. It is possible that the call for papers did not reach scholars who are invested in the intersectionalities of disabilities and sexualities. However, this could also point to factors such as the limited number of scholars working on issues of disability, limited number of people with disabilities in academia working on this issue due to a number of reasons including challenges to access to mobility, higher education etc., and limited number of scholars who may be working on areas of disability and sexuality, which are both marginalised in society. These challenges point to the difficulty of terrain for scholars who are working on these intersectionalities. This issue has therefore taken a longer duration than usual.

At the end of the process however, we have a rich collection of papers from scholars who are geographically well spread out and have been able to bring up very relevant issues that cover a rich array of topics – from people with physical disabilities, people disabled during war, mental disability, 'wannabe people', to caregivers of disabled soldiers from war, from representation in art and culture as well as juxtaposition of issues of people with disabilities with other marginalised communities including people of diverse genders and sexualities, people practis-

ing sexual behaviours that are again ostracized, for example, practises of bondage, domination, sadism and masochism (BDSM) and pornography. We are therefore very proud to present this issue to our readers and we hope it will help enhance dialogues and debates. As our readers will notice, different authors in this issue have used terms like 'people with disabilities' or 'disabled people' and have also used their own definitions of disability. It is interesting to observe the different interpretations and the wide spectrum of definitions that have emerged from the different submissions. We are also happy to note that we have received articles from varied geographical locations including caregivers of people with disabilities from war in Sri Lanka to looking at disability and sexuality in African literature.

People with physical disabilities thus go through different layers of marginalisation in which they are taught early on about the undesirability of their bodies and therefore the need to 'correct' them through procedures which may sometimes last a lifetime. In *Cultures of (Un)desirability: Creating Cultures on Resistance*, Loree Erickson writes about cultures of undesirability through which people with disabilities (like many other marginalised communities) are made to feel "less than" or "too much" loveable or desirable and thus marginalised; societal indoctrination teaches people about how certain bodies do not fit ideas of the 'perfect body' or the 'right body'. Erickson analyses this scenario within pornography with people with disabilities often being invisible as consumers or players and viewed in particular ways. Interestingly however, Erickson presents a reverse narrative and uses queercrip pornography as a tool to resist these cultures and build resilience.

In *Disabling Sexualities: Embodiments of a Colonial Past*, Omolola A. Ladele attempts to advance the critical discourse on sexuality and disability in African literary debates and discusses the interconnections between identity, embodiment, sexuality and oppression. Ladele discusses African identities and embodiment in the context of disability and sexuality locating them in postcolonial Zimbabwe and discusses them through Dangarembga's novels with their preoccupation with the postcolonial. Ladele discusses how these novels discuss women's bodies as tropes in postcolonial African writing and the creation of 'catharsis' to suppress the experience of colonial violence; similarly, Ladele engages with images of male characters as deeply scarred and emerging through the colonial narrative of 'castrated masculinities.' The author also makes interesting observations about definitions of disability and how characters in the novels relate to disability in different ways.

In *Fighting pain with pain: Bob Flanagan /Sheree Rose and Catherine Opie*, Alexandra Mondin writes about three American artists – Bob Flanagan who worked individually and in collaboration with Sheree Rose and Catherine Opie who works with documentary photography; who use physical pain to tackle mental trauma stemming from different disabilities. While for Flanagan it is his physical disability along with his chronic illness, for Opie it is her social disability and stigma attached to her sexual orientation. Mondin discusses how these artists through their work blur the divide between the public and the private and complicate gender and sexuality through the discourse of BDSM thus redefining pain and pleasure. Mondin explores how Opie through her work troubles the representation of the LGBTIQ community, and Flanagan and Rose blur notions of gender.

Authors Hettiarrachchi and McCarthy discuss issues related to caregivers for people with disabilities. In *Of Love, fears and dreams: Narratives of wives of soldiers disabled in war*, Shyamani Hettiarrachchi presents an account of five female partners of military servicemen who were wounded and rendered 'disabled' during the prolonged war in Sri Lanka and discusses the reactions of these intimate caregivers, the sense of abandonment by their native families, and their resilience to forge forward on the task of caregiving to their partners with disability. It is interesting that out of the five women, two had married their partners before the injury and the other three after the injury sustained in the war. In *Effects of informal care on the sexual self: A disability perspective*, Andrea McCarthy discusses the power relationships and dynamics of people receiving informal care by either a family member or a partner. McCarthy highlights the personal experiences, issues of identity and private relationships of people with disabilities with carers and discusses how informal and unpaid care can be disempowering for both carers and for people with disabilities. The difficulties highlighted can range from the feeling of 'inappropriateness' of caring especially when seen in the context of opposite genders in a society which upholds the heterosexual norm as well as the unpredictability and lack of spontaneity in intimate relationships when the lines between caring and intimacy gets blurred. It is also relevant how McCarthy brings up that for care to be empowering, it has to be linked to the rights framework, evolving a better understanding of the impairment for the carers, but also acknowledging the other identities of people with disabilities beyond that of disability alone.

In *Love, sex, disability, coming out and John Travolta in New York and Je-*

rusalem: A twenty year journey, Scott Shieldlower presents a personal narrative of living with disability, sharing his experiences with seeking medical treatment, his love for the movies, his experiences with homophobia and of seeking a partner. This personal narrative gives us an account of the juxtaposition of disability with sexuality and how the intersections between the two levels of marginalisation pose additional difficulties with finding one's own identity.

In *Armless: Wannabe people and the desirability of the disabled body*, Andrea García-Santesmases Fernández reviews the film 'Armless' and discusses societal notions of wannabe people as 'monstrous', highlights the counter narrative of the amputee body as desirable, and questions the stigmatisation of the amputee body, devotee people and pretender people. The author also makes an interesting comparison between wannabe people and their desires for a different body and the need for depathologisation to transsexual people.

In *Neoliberalism and regimes of life and death: A book review of queer necropolitics*, Heather Tucker reviews the book 'Queer Necropolitics', which offers a collection of writings at the intersections of queer politics, gender studies, critical race studies. Tucker makes connections between queer studies with that of disability studies and highlights how biopolitics affect people with disabilities in similar ways.

Editing this volume has been an arduous process; however, it has at the same time been immensely rewarding to receive papers from a variety of fields introspecting and interrogating ideas and notions of disability and the relations with sexuality people with disabilities they share. Although Disability Studies is an emerging field of study and the scholarship on disability is advancing steadily, scholarship on looking at the intersections of disability and sexuality is limited. There is a need to advance knowledge in this field and this journal issue is an attempt to do that. We acknowledge that both disability and sexuality contain vast discourses and this issue is just the tip of the iceberg. Additionally, issues of mental and developmental disabilities remain further marginalised within discourses of disability and we are mindful of the gap within this issue.

We would like to thank all the authors for their submissions and their patience in working and engaging with the feedback received. We are very grateful to our reviewers who have painstakingly read through the papers and provided nuanced feedback for the authors to work on and sharpen their arguments. We are

Transforming Cultures of (Un)Desirability: Creating Cultures of Resistance.

Loree Erickson

ABSTRACT: One of the most insidious and comprehensive ways to marginalize people is to make them question their loveability, their desirability, their collective worth, and establish social organization that reinforces and perpetuates these systemic harms; while internalizing dominance and personalizing oppression. This process is what I am referring to when I say cultures of undesirability. Cultures of undesirability involve the narrowing of dominant western cultural imaginary so that marginalized others come to be so often understood and constructed as both "less than" and "too much," if we are understood as persons at all. As strong as cultures of undesirability are, our resistance is stronger. Queercrip porn, an emerging form of sexual storytelling, shares and fosters queercrip knowledges, pleasures and imaginings. In this essay, I want to share how queercrip porn highlights the multitude of ways marginalized communities navigate and transform cultures of undesirability, acts as a method for fostering resiliency through building and nurturing our collective worth; and finally, how queercrip porn interrupts dominant cultural and structural ways of thinking, being and organizing that contribute to sexual marginalization and cultures of undesirability.

KEYWORDS: queercrip porn; disability; cultures of un/desirability; resistance and resilience.

Cultures of Undesirability

I want to start off with a poem that Masti Khor, a Toronto-based queer brown

femme crip burlesque artist used in a recent phenomenal performance exploring ritual and self-love. I am only using part of it.

> The bud stands for all things, even for those things that don't flower, for every-thing flowers, from within, of self-blessing; though sometimes it is necessary to reteach a thing its loveliness, to put a hand on its brow of the flower and retell it in words and in touch it is lovely until it flowers again from within, of self-blessing (Kinnell, 2001, 94).

Masti Khor and I talk a lot about undoing cultures of undesirability. When I speak or hear the words of this poem I am in my bedroom, she is lying in my bed, I am sitting near her. We hold hands as hours are filled with so much shared laughing, crying and raging. Holding hands in and through the lovely parts and the scary parts. Retelling in words and in touch our collective loveliness.

One of the main reasons I started doing this work was because one of the earli-est truths I ever learned was that no one would ever want me as a partner because of my disability. This message, while often not stated directly, was echoed and confirmed everywhere around me. While my experience is specific it is not unique; many disabled activists speak to the experience of feeling unwanted as a partner and excluded from romantic and sexual cultures (Siebers, 2008). Stacy Milbern writes,

> in fact, this has been my whole life — a string of experiences where I am the friend people are secretly very emotionally intimate with, but the one who is not invited to parties, the friend the person is conflicted about loving … It has been an endless struggle to prove and remember worth in a culture that is relentless in its telling of the wrongness of our bodies (2011, np).

We[1] start learning the wrongness of bodies very early on. I'm sure everyone read-ing this paper learned these lessons. What are the lessons you have learned about bodies/your body/how bodies relate? I am still unlearning these lessons of wrong-ness. It is my go to. It doesn't help that I haven't been asked out on a date in two years. I want to share with you in this space, some of the lessons that I have learned about the supposed wrongness of my body. I would also like to share some of the

lessons I have learned from my wheelchair using body, a body that needs, and is marked by asymmetric curves. These lessons are about resistance and other ways of being in the world. What complex and contradictory lessons is your body teaching you?

From our lived experiences we know that marginalized people are positioned outside the terms of desirability. This often happens through a discourse in which marginalization is seen as the result of isolated personal inferiority rather than a social harm (Waxman, 1994). The frame of personal inferiority, a key component of the medical, charity and eugenic models of disability, perpetuates narratives of asexuality and victimization that dominate mainstream discourses surrounding sexuality and disability (Tepper, 2000). So called "truths" about disabled people[2] are informed by a long history of medical, charity and eugenic models of disability which take up disability, and particular bodies and/or minds, as being in a state of biomedical malfunction (which historically and currently includes many different forms of marginalization) (Withers, 2012). This understanding constructs our needs, lives and desires as outside normativity and therefore unintelligible. According to this hegemonic story, marginalized people will certainly lead a life full of tragedy and/or pathology. We, who are deemed as too little and too much, are also treated as threats and burdens to those around us as well as to the state. We are consistently reminded that there is something wrong with *us*, not the systems of social organization that simultaneously enable some and rule out others (Siebers, 2008). These practices of pathologizing profoundly impact individual bodies, identities, experiences and desires; they also contribute to the creation of categories of difference and distinctions occurring along complex and contradictory points of privilege and marginalization. These dominant western cultural imaginings are part of the institutional and performative cultures of undesirability. The term cultures of undesirability emerges from queercrip, people of color and activist communities to name the multitude of ways that systemic harm manifests in our lived experiences such as sexual oppression, violence, both interpersonal and systemic, and exclusion from community (Erickson, 2010; Mingus, 2011; Gud'buy t'Jane, 2011; and Ndopu, 2012).

We encounter and navigate cultures of undesirability everywhere, *every* time we leave our home, and for many of us even in our homes (if we have secure housing) we are surrounded by understandings of disability, gender, race, sexu-

ality, class and so much more that construct understandings carrying with them so much violence and normativity. Charity ads which line the walls of buses, appear on tv and facebook, are for most people, one of their most common points of encounter with disability. These ads tell us that we have to leave our nonnormative bodies in order to live a good life, that in order to be whole, we cannot be disabled. Disability and race are thrown together to tell a story that disability is not only something to be pitied, but is downright threatening. This is only one site where cultures of undesirability are revealed and constructed. The amount of abuse and violence in marginalized people's lives is simply staggering (Casteel et al., 2008). Cultures of undesirability work in tandem with prisons, psych wards, and group homes to render marginalized people disposable; thus isolate, punish and pathologize them for deviation. Cultures of undesirability are at play in the total lack of regard for accessibility that occurs when community events lack all kinds of access (financial, physical, social, cultural, etc) and thus exclude any number of communities and community members. As Mia Mingus says when speaking to the ways that we must move beyond thinking about access as a bunch of logistics to cross off a list.

The weight of inaccessibility is not logistical. It is not just about ramps, ASL interpreters, straws and elevators. It is a shifting, changing wall—an ocean—between you and I. It is just as much feeling and trauma as it is material and concrete. It is something felt, not just talked about. It is made up of isolation from another night at home while everyone else goes to the party. The fear of being left by the people you love and who are supposed to love you. The pain of staring or passing, the sting of disappointment, the exhaustion of having the same conversations over and over again. The throbbing foolishness of getting your hopes up and the shrinking of yourself in order to maintain (Mingus, 2012, np).

I hear cultures of undesirability in conversations about how sad and hard it would be to have a disabled kid, and in the silence of never being asked on dates. The only thing we can hope for is a cure and to stay alive; certainly we are not supported to expect large-scale structural change, love, community, justice, and hot sex. I am using the concept of cultures of undesirability rather than "disableism" to speak to experiences of sexual oppression and exclusion in an attempt to keep my analysis open to the complexities of identities, bodies, experiences and social locations that are impacted by the wide scope of cultures of undesirability[3]. I have

also chosen this phrase as it has the potential to connect feelings and practices of desiring/being desired to systems of oppression as found in historical and contemporary manifestations of eugenics, economies of desirability as well as practices of cultural production. Where do you feel cultures of undesirability?

Cultures of undesirability are far from accidental. In *Queer Phenomenology: Orientations, Objects, Others*, Sara Ahmed encourages us to not just consider where we are, what we are facing, and what captures our attention, but also the work that brought us to our particular orientations (2006). According to Ahmed, the experience of "feeling at home", or knowing which way we are facing, is about building worlds. This process of building is not casual, accidental or uncomplicated. There is a political economy of attention. We are directed in certain directions more than others. We build with histories and are built from and through histories. Ahmed and Eli Clare name the ways both our bodies and the social body are being pressed in particular directions leaving impressions on the skin (Clare, 2001). Ahmed refers to these as points of pressure as straightening devices. I had to wear a back brace until I got back surgery in the 5th grade to straighten my spine. This was a painful process. Yet, no amount of bracing, internal or external, could bring this unruly body in line. THANK GOODNESS.

We are surrounded by understandings of disability that perpetuate and propagate cultures of undesirability. How often do we encounter images of disability resistance? Resistance images that capture and reflect our lives in all of their complex splendor and hardship. Why don't we see images that refute us as helpless victims of our bodies, highlighting and eliminating our agency and power. What would the world look like if these were the stories of disability we were surrounded by?

The multitude of ways we build worlds amidst these complex exchanges of limitation and possibility reminds us that we don't only inherit oppression, we also live with, draw on and create legacies of resilience and transformation. This practice of obscuring the production and operation of the dominant culture and knowledge is absolutely connected to maintaining systems of privilege as well as to my concept of sites of shame as sites of resistance. Repetition is powerful. We have taken in and internalized so much of this crap that we need to reteach ourselves and each other about our loveliness. If we don't share struggles, passions, and dreams with each other, then we may miss out on powerful imaginings that shift the normative power structure.

Abby Wilkerson's reframing of shame as a part of social control in *Disability, Sex Radicalism and Political Agency* expanded my thinking about shame to include the ways shame is spun to internalize, naturalize and individualize oppression (2002). The idea of sites of shame as sites of resistance asserts that when we visit the very sites where we feel the most shame, we can learn something important because that shame is produced in order to keep us from accessing those very things about ourselves and our communities that may offer us different ways of being, feeling, imagining, and resisting.

Audre Lorde encourages us to resist silencing, ignoring or hiding these sites of shame; for her we need to spend some time with them, get to know them, flaunt them (1984). By doing this work, we can, as bell hooks encourages us, imagine otherwise (2003, 2010). The concept of sites of shame as sites of resistance can be useful in countering the erosion of marginalized people's individual and collective sense of worth. This erasure is absolutely strategic in the ways it only justifies oppression, but also seeks to limit people's capacity to resist as the forces of individualization pre-empt oppressed people from getting together to build community and coalition.

Porn

I make porn from this position of "sites of shame as sites of resistance" as a way of engaging with and understanding disability and desirability differently. In many ways, porn (both mainstream and counterpublic) repeats the current dominant power structures in the stories it tells about bodies and how they are valued. In porn, we are often exposed to a fairly homogeneous representation of desirable subjects. Through everyday encounters and moments, a corporeal, backgrounded know-how emerges that grants to white, settler, cisgender, heterosexual, middle-class, non-disabled, masculinity, an ease of moving through the world with a lack of self-consciousness. When this ease is never interrupted, a higher level of sedimentation occurs, meaning that one is more likely to experience the world as given (Ahmed, 2006). This sedimentation is what enables the naturalization of the operation of the dominant ideology, allowing those who fit in a greater capacity to accept the way things are. What becomes evident in these endeavours is the intertwining of the visual with the creation of truth, reality, storytelling and desire.

Stories emerge in the flow of power, and that power flows simultaneously in what Plummer calls positive (i.e., creative, and productive) and negative (i.e., oppressive and restrictive) ways (2007). Power moves through and within lives, situations, "habitual networks of social activity" and the "whole negotiated social order" (Plummer, 2007, 26). When wrestling with questions of what stories are heard, tellable, felt, and believable, and so on, we see power operating on both a personal level and a social level. Some paths are less followed, some stories are not heard as believable, and some expressions of embodiment are not readable through dominant frames. Certain stories, ones that tend to affirm the way things are and reinforce dominant ideologies, are heard and are easier to understand because they are familiar. We have been surrounded by them our whole lives. It may be frustrating, but it certainly is not surprising that students who have never encountered queercrip porn are left disoriented. Similarly, nondisabled queer communities' standards of desirability are reflected and nurtured by queer porn that has yet to re-imagine disability, and a lot of other identities that are excluded from the queer porn scene (people of colour/trans women/fat people, and so many more). These stories are in need of some queercrip porn disruption. Queer porn expands the relational fabric in ways specific to the communities engaged in their enactment, but still falls short of re-imagining ways of life that speak to the complexities of an expansive relational fabric.

When marginalized characters are present in porn, we are often only able to be desirable in particular ways. We are regularly hypersexualized, tokenized, and/ or segregated into fetish markets. At the same time, our sexual labour is often undervalued (Miller-Young, 2010). We must also question otherness in porn as imagined through disableist, colonialist, patriarchal, nationalist, racist, capitalist and heteronormative frames to reflect dominant imaginings and maintain privilege. Yet, if we stop the engagement there and dismiss porn as simply oppressive or "bad," we miss out on the creative potential of porn. Reframing porn as a technology or as a socially emergent, interactive, dynamic, situated, embodied discursive storytelling practice enables us also to recognize the ways that porn acts as a "fictive discursive practice that produces different conditions of possibility" (Champagne, 1991, 205). This framing means that porn is also a part of power, not somehow outside of it.

I want to use porn's role in producing, sharing, and acquiring sexual knowledge and know-how. Often this knowledge and know-how reflects that which supports

the cultural norms of those in positions of privilege. The skills, knowledge and ex-periences of marginalized communities are often left out of mainstream culture (hooks, 1992). This exclusion means there is a lack of representation and resourc-es that speak to and supplement marginalized people experiences and skills. We have to develop skills and specific forms of know-how, sexual and otherwise, in or-der to navigate and survive in a world that functions through the simultaneous ex-ploitation and systemic erasure of bodies determined as either undesirable and/or hypersexual (Miller-Young, 2010). Sexual stories give us access to languages to articulate feelings, desires, and so on (Plummer, 2007). Storytelling and sharing al-low marginalized communities to enter into community, to cultivate and circulate possibility and tactics, and to foster community building (Creative Interventions, nd). In order for stories to be successful; they need strong communities to hear them. Susie Bright, talking about her life as a lesbian sexpert and co-creator of *On Our Backs,* a lesbian porn magazine started in the mid 1980s, speaks to this inter-relatedness of stories and community. She says,

> the satisfaction of introducing women to the words that describe our sexual lives, to the pictures of our bodies and desires, to the confidence of hearing other women's common and kinky sexual experiences – well, there's been no turning back (Bright, 1998, 15).

As Foucault states, "When we pay attention to the social and cultural history of knowledge, the supposed stability of these conventions and norms is challenged allowing for the production of different or new subjugated knowledges" (1980, 82). I engage with the ways that queercrip porn can be useful as a strategy of survival in the sharing and cultivating of queercrip knowledge, pleasure and imaginings among queercrip communites.

Stories that practice disidentifications and world-making (Munoz, 1999), use arts of life and ways of life to combat our ever shrinking relational fabric (Cham-pagne, 1991), and reframe ideologies to disrupt normative ideologies and systems of oppression and leave us disoriented. These disorienting acts not only challenge our individual sense of comfort and familiarity, but also question the mechanisms that enable these feelings in the first place. These examples stress that it is critical to focus on systems rather than identities in positing a vision of transformation

and resistance that doesn't just benefit those with relative privilege. This emphasis enables us to attend to the ways that marginalized people can unite in differences, as well as in specific and often shared experiences, creating ample opportunity for coalition and collaboration (Cohen, 1997).

As Powerful as the Culture of Undesirability is, We are Stronger.

I am currently working on a dissertation where part of my research method is collaborating in the production of queercrip porn and interviewing a small group of lovely people who identify as, or with the term queercrip. The stories centered in this project are of queercrip flaunting, survival and flourishing. I want to think, feel, talk, create and share these stories. My work is shaped by Mia Mingus and Stacey Milbern who remind me of the importance of building crip solidarity from a perspective that takes sites of shame as sites of resistance to any project of transformation. As Mingus writes, "we will weave need into our relationships like golden, shimmering glimmers of hope—opportunities to build deeper, more whole and practice what our world *could* look like" (2010, np). I am thankful for the culture of resistance and desirability that marginalized people create every day. I want us to revel in the Sins Invalid clips on youtube and the excellent and moving queer and trans people of color centered performance nights we have in Toronto where folks are vulnerable, fierce and fabulous. I want us to embody cultures of resistance and resilience by blockading inaccessible public transit when yet again they raise transit fares, or as we occupy government offices when they cut necessary social support, or as we cuddle with a partners and friends. I want us to feel our loveliness in the power, vulnerability, and resilience we express in tears of joy, laughter, and rage.

We need stories that capture what Leah Lakshmi Piepzna-Samarashina and ET Russian call the lust of recognition (2010). Recognizing the hotness in each other's cripness. As we reteach each other of our loveliness with a glance or a squeeze. We need to avoid simply reversing the narratives speaking only to the "positive" side, presenting simplistic purely celebratory narratives of success. Together we can create space for and tell stories that reflect the multifaceted nature of our experiences.

Endnotes

[1]   My somewhat fluid and ambiguous usage of "we" and "us" is intentional. It is meant to allow the reader to situate themselves and think about the practices and processes of inclusion and exclusion.

[2]   I use the term disabled person/people/activists through out this paper. While all language brings with it its own historical cultural baggage, I prefer the term disabled as it highlights and emphasizes the social process which occurs on and through bodies. Also, while I respect "person-first" language as being empowering and important in many communities, for me it still feels like something that you add on to an already established idea of personhood. This notion of personhood often unintentionally and intentionally assumes supposedly neutral social locations, which in fact are often privileged identities made invisible through the processes of naturalization. Therefore I choose to make evident the social meaning making that is occurring on and through bodies.

[3]   For a strategic call to use "disableism" rather than "ableism," please see AJ Withers' website http://still.my.revolution.tao.ca/node/68

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Disabling Sexualities:
Embodiments of a Colonial Past
Omolola A. Ladele

ABSTRACT: Disability studies in postcolonial Africa appear circumscribed by two significant paradoxes. First, there is the abysmally low legislative, political and infrastructural support for persons living with disabilities. The second paradox which seems to amplify the first is that there is a palpable silence on disability discourses in African literary debates; a possible indication of some of the prejudices that underwrite the positions of persons with disabilities.

In addition, African identities have been inexorably altered by the imbalances in the power relations of the colonial experience and some fictional representations of the disequilibrium of the Empire/colony interface illustrate how people can be differently constructed and disabled by privileged and normative discourses.

Thus, the emergent patterns of bodily dismemberment in African subjects are, in this essay, read as thematic and, in a paradoxical sense as aesthetic motifs of Empire's systemic deconstruction and disarticulation of the colonised. This essay examines the twin subjects of disability and sexuality as both culturally defined yet individually embodied semiotic representations of postcolonial subjects. Giving examples from the novels of Tsitsi Dangarembga, which are set within the socio-political context of postcolonial Zimbabwe, this essay critically examines the novelist's character portraitures. In our analyses, we largely deploy critical tools from disability studies in an attempt to demonstrate how the political resonances of their lived experiences are inscribed into African bodies and how these historically differentiated bodies become fractured and simultaneously reconstructed.

KEYWORDS: Sexuality, disability, African fiction, reconstructing bodies, Tsitsi Dangarembga

The victimization, I saw, was universal. It didn't depend on poverty, on lack of education or on tradition. It didn't depend on any of the things I had thought it depended on. Men took it everywhere with them. Even heroes like Babamukuru did it. And that was the problem. (Tsitsi Dangarembga, 1988, 118)

This study originates from an observable dearth of critical discourse on the twin problematic of African sexuality and disability in African literary debates. So far, critical debates on these twin issues have been visibly dominated by international research/studies thus, mostly excluding the critical voices of African scholars. Yet, even in a cursory, most rudimentary examination of African literary representations, there is indisputable evidence that complex issues pertaining to disability, sexuality, gender roles and functions are often foregrounded in the midst of other profoundly engaging thematic preoccupations. For instance, Soyinka's depiction of Eleshin Oba's piquant sexual appetites just before his ominous encounter with death in the play, *Death and the King's Horseman* (1975) has portentous personal and communal reverberations. Similarly, Aminata Sow-Fall, in her slim but revolutionary novel: *The Beggars' Strike or the Dregs of Society* (1981) foregrounds profound conflicts between the talibés or the dregs of the society: the disabled beggars who in a neoliberal capitalist state eager to attract foreign tourists, now constitute a public nuisance. Although that novel interrogates disability issues as it intersects with foundational aspects of the ethics and theology of Islam on the one hand, as well as environmental health issues on the other, it has often been traditionally viewed as a vigorous engagement with Feminist or Marxist ideologies.[1] Also, numerous other African writers imaginatively create disability and sexuality as intertwined discourses yet, in spite of their centrality in both human existence and experience; these discourses are only beginning to emerge from shrouds of superstition and mythology in need of theorisation from the perspectives of African realities, histories, and imaginaries.

In following Bolt (2012, 287) this article attempts to negotiate the palpable 'critical avoidance' that appear to dodge the issues of disability and sexuality in African literary debates. Also, by centralising a specific African locus in a temporal postcolonial moment, the essay calls attention to the disabling politics of particular African, historical and cultural experiences and their impact on the construction of African subjectivities in literary representations. Therefore, in the subsequent

conflation of bodies emerging from such experiences, it becomes pertinent to investigate how the varied interactions of bodies—white/black/brown, male/female, and able/disabled (visible/invisible) are counterpoised and constructed. This then helps us to reconsider the interconnections between identity, embodiment, sexuality and oppression. Moreover, it corroborates Garland-Thomson's position in an early yet important study on disability studies, in which she submits that 'disability is a culturally fabricated narrative of the body: a system that produces subjects by differentiating and marking bodies' (2001, 1). And an important critical question that evolves from this position is: what are the indices for differentiation and how are these powerfully inscribed into people's anatomy within and across cultures? In an attempt to understand these issues, it is instructive to expand the base understanding of disability which extends beyond the mere personal/individual, medical pathologies of human incapacities and limitations. Indeed, there is every indication that suggests that African identities and their embodiments have been inexorably altered by the imbalances in the power relations of the colonial experience. And the fictional representations of some African writers, including Tsitsi Dangarembga, who capture the disequilibrium of the Empire/colony interaction, illustrate how people can be differently constructed and disabled by privileged and normative discourses.

Consequently, this essay calls attention to the intense processes of exclusionary and oppressive marginalisation endemic in colonised societies which are significantly relevant to the processes of creating disabled bodies within the African experience. Thus, the inclusion of conversations or perspectives from other cultural locations of the world invites us to more profound and incisive ways of understanding disability issues. Such cultural narratives underscore the call of cultural theorists such as Whyte and Ingstad (1995) who emphasize the need to culturally localise perceptions of disability. Thus, disability studies helps in understanding our cultures and vice-versa.

In the animated discourses of both sexuality and disability, the body remains the central focal point and this is starkly stated in Snyder and Mitchell's (2011, 10) argument that 'embodiment is a potentially meaningful materiality, a locus of identification'. Following this position in the context of the present discussion means that various bodies depending on which side of the power divide they belong, can be read as scripts which articulate different stories because underlying

the Snyder/Mitchell argument are assumptive paradigms implicit in the definitions of personhood, the politics of identity formation and construction, and the valuational bases of appearances. How then are certain bodies constructed as normative and others which fall outside this norm are the 'Other' and how do disabled bodies navigate normativity? Also, how is sexuality redefined by disability and vice-versa? The example of several homophobic African societies and their pervasive normative masculinist ideologies, which have often been used to police and oppress aspects of women's lives and sexuality are culpable in this regard. Essentially, such societies use the male-equals-power logic in which hegemonic masculinity authorises, transcends and significantly sign-posts all others. Thus, while female African bodies and sexuality are often, sites for the contestation, articulation and negotiation of power, male bodies are politically, socially, and culturally authorised by their ascendant position as the defining powers evolving into what has been profoundly described as 'a national-masculine tradition which provided the pivotal signposts of identity formation …' (Jeyifo, 2004, xvii).

However, In spite of this masculine ethos, African women signal their agency by exploiting various aspects of their sexuality to their advantage and this is expressed in the counter-narratives they produce in which they challenge and destabilise social and sexual stereotypes especially about women. This has been most powerfully inscribed into the growing corpus of writings by female African writers since the close of the twentieth century and continuing into the present time. As journalists, activists, novelists, poets, playwrights, short story writers, children's literature writers from all over the continent, these women poignantly narrate their agency as illustrated in the prose fiction tradition of female Nigerian writers including Lola Shoneyin and Chika Unigwe, Cameroonian, Calixthe Beyala, Zimbabwean writers Petina Gappah and Tsitsi Dangarembga among several others.

Framing the African experience

Although several studies already subsist on Dangarembga's novels and her preoccupation with postcolonial (Boehmer, 2005, 222) and gender debates, it is only recently that disability discourse in her work began to gain ground. One of the most recent studies in this regard is Barker's (2011) seminal study which examines the concept of the 'exceptional' child-protagonist in several postcolonial fictive narra-

tions including *Nervous Conditions*. And whereas Barker's study concentrates on the important element of the child-protagonist, this essay takes a more expansive critical standpoint by centralising both disability and sexuality issues in the young and adult characters in Dangarembga's novels. Also, applying one of Quayson's (2007) nine typologies in his landmark work to their study, Gorman and Udegbe forcibly argue that through the use of disabled women's' bodies as tropes in post-colonial African writing, there is the creation of 'catharsis' which serves to 'erase' or 'suppress' the knowledge of the violence of (neo) colonial relations (Gorman and Udegbe, 2010, 310). However, the trajectory of this essay pays critical attention to both male and female characters in the novels in an attempt to come to a fuller understanding of African identities as altered/reconstructed by colonialism. Also, rather than erasure or suppression as seen in the Gorman-Udegbe work, this paper further demonstrates the graphic foregrounding of the violence engendered by the coloniser/colonised relations and as the bodies of the characters are systematically dismembered, their sense of wholeness and wellness become proportionally diminished. This furthers Quayson's position as he observes in his study that, "it is the body itself in its naked corporeality that is at the heart of social and political nervousness in real life" (Quayson, 2007, 204). In other words, the body is a central or critical nodal point in the wide spectrum of discourses on disability. However, people do not exist in isolation. Disability issues within the coloniser/colonised structure also provoke profound ethical contestations some of which Meekosha (2008) in a materialist reading of these relations calls attention to. Meekosha notes for instance, the fact that the processes of colonialism, neo-colonialism, postcolonialism evoked by the north (metropole) have resulted in vast numbers of impaired people in the global south. She insists that the material figuration of this disjuncture are directly or indirectly the aftermath of the struggle for resource control; mineral, oil and economic resources therefore, calling for a paradigmatic shift in the discourses emanating from the north in order to arrest the form of "scholarly colonialism" it is provoking (Meekosha, 2008, 3). Thus, disability seems accentuated in both novels considered in this essay as they are read within the material figuration of skewed power structures.

All of these taken together inform our considerations of *Nervous Conditions* (1988), and *The Book of Not* (2006). The first novel is a young girl's story, Tambudzai's – of the adult world she keenly observes. From the sensibilities of the

child protagonist, we encounter a plurality of experiences of several other kins-women and their struggles to redefine themselves within the context of the over-whelming masculinist Shona culture. As the plot unfolds, the colonial experience seems to disrupt and remap all the characters—male and female—in economic, material and psychological terms. In the sequel, *The Book of Not*, Tambu begins to confront, first-hand, the complexities of life in post-independent Rhodesia. As a young student in the prestigious Young Ladies College of the Sacred Heart, she begins to feel more acutely the contradictions she had always felt in the first novel, but which she learns to suppress in order not to incur the ire of her uncle and ben-efactor, Babamukuru. Taken together both novels engage with the destabilising resonances in the body and psyche of colonised people as the author interrogates the problematic constructions of bodily and psychological disabilities and sexuali-ties in a racialised situation.

Idioms figuring sexuality and disability in Dangarembga's novels

As noted earlier, disability is not necessarily, Dangarembga's immediate or direct preoccupation in both novels. Yet, her novels convulse with characters who suf-fer various physical, material, emotional and psychological trauma. Immediately striking in the titles of both novels is the highly suggestive, overriding tropes of ill-ness, dis-ease, amputation or disfigurement in physical as well as in psychological terms through which the author creates the tableau for reading disability in the novels. For instance, the title, *Nervous Conditions,* seem to conjure the dis-ease and discomfiture that overrides the experiences of most of the characters in that novel, while *The Book of Not* point to the material and physical deficits encoun-tered as the novel opens.

　　More than in her first novel, the author situates her second story within even more nightmarish, bloodcurdling violence of a newly independent Rhodesia caught in the vicious struggles of decolonisation. Not only does the second novel open with the bloody dismembering of bodies, Netsai, Tambu's younger sister, in particular, bears in her body the pernicious inscriptions of the guerilla wars that plagued her country as she searches for a national ethos. Much like the first novel, *The Book of Not* opens with a subtraction, this time, the bloody dismembering of

Netsai's leg. With the blowing away of one of her limbs, Netsai is not only disabled, she becomes sexually undesirable. Thus, in spite of her inspiring participation in the freedom effort, Netsai's beautiful and youthful body is sadly misshapen by the violence of the *Chimurenga*. With a body misshapen, Netsai's sexuality is deconstructed and she suffers emotional rejection by her lover, the un-named soldier. At this point of disillusion and with her star-spangled dreams completely evaporated, Netsai finally seeks the reconstruction of her body, perhaps hopeful it may become once again attractive. Dangarembga thus, deftly locks Netsai's experience as thematic and aesthetic trope with that of her nation as both limp on in a delusionary walk to freedom.

The Chimurenga wars of Zimbabwe tragically interrupt and deeply wound other characters and as Tambu recalls in *The Book of Not:* 'To the scars of war were added the complications of Independence', (2006, 198). Caught in the traumas of these bloody armed conflicts, Tambu is forced to pick her way through the human debris of her family members in an attempt to make a head way with her own life. The memories of their twisted bodies causes deep psychological trauma for her and she keeps perseverating on this scene not only as she returns to the second year at the Convent, but also later in her adult life. For Tambu, her own disability is both intellectual and emotional; and ultimately material. Unable to surpass the initial brilliance and potential of her O-level grades, she is not able to distinguish herself in any career path, a position she finds both disturbing and disconcerting.

Both novels demonstrate the abject disfigurement of the characters and readers are confronted with an acute sense of the profoundly enervating political processes that alter the identities and sexualities of once colonised people. Thus, disability is not only centralised as thematic motif, it works also as paradoxical aesthetic motif in Dangarembga's novels. These motifs then become counter-normative dialectic which animates the thematisation, symbolisation and setting of the two novels. In very subtle but clear terms, Dangarembga points to the physical and psychological boundaries as well as to the inherent politics embedded within the expropriatory processes of colonialism. Thus, while the lives of her characters seem to be confined to the dusty, rustic village of Umtali, they all experience in varying degrees of intensity, the divisive spatial and racial nuances of the colonial experience. This creates several forms of mutilation or fragmentation, and as the bodies and minds of her characters are scarred and maimed, their sexuali-

ties and identities are irrevocably altered. And the incisive studies of Fanon (1965)[2] and Scarry (1985) provide incontrovertible evidence of the systematic processes of disabling African subjects in the colonial project. The novels thus illustrate the links that exist between the scarred bodies of colonised people and their sexuality, which result from the characters' perilous navigations of the backdrop between colonial domination, Shona patriarchy and other socio-economic burdens of the newly-independent Zimbabwean nation. This is particularly so when situated within the 2004 World Health Organization's definition that sexuality 'is influenced by the interaction of biological, psychological, social economic, political, historical factors' (quoted in IIkkaracan and Jolly, 2007, 3) .

Scholars, in particular—Dunton (1989), Nfah-Abbenyi (1997), and Chanter (2006)—remark that African women's sexuality has been under-researched and therefore poorly understood, especially because it is under-textualised. Chanter observes, for instance, that following the perpetuation of hyperbolic Eurocentric myths about African women's sexuality, the latter have responded with marked reticence. However, the more recent insightful studies on African sexuality by Azodo and Eke (2007), Falola and House-Soremekun (2011) Tamale (2011) clearly indicate scholarly progression on the subject. Arnfred's (2005) seminal study on African sexualities announce the need to rethink African sexualities beyond the imperium of European/Western racialised imaginaries, which have constructed African sexuality as the curiously 'exotic', the noble and the depraved savage' (Arnfred, 2005, 7) . While these images are consistent with the colonialist identification of the African as the 'other', there are other diverse factors including socio-cultural institutions, economic structures, and religious ideologies, which invariably imbricate the expression of intimacy as exemplified in Dangarembga's novels.

For instance, Dangarembga's characters seem to relentlessly embody conflictual tensions as they tentatively embrace a newly independent nation state at the initial stages of defining a new national ethos on one hand, and on the other, a significantly different traditional life defined by prejudicial Shona practices. With bodies seemingly torn between these two defining poles, all the characters; male and female, young or old, educated or not are compelled to negotiate these conflicts. In this process, their bodies and psyche become marked and even if they appear mundanely concerned with the routinised exegeses of daily living, their private individual lives connect with larger political, economic and social burdens

as they live in a bind of domination or subordination, presence or absence, escape or entrapment. This corroborates Willey and Treiber's (2002) observations that:

> Dangarembga not only demonstrates that nationalism and colonialism collude with patriarchy in particularly damaging ways for women, but also insists that African theories of nationalism need to be rethought from the perspective of gender (Willey and Treiber, 2002, xiii).

It is precisely within the framework of their interactions within socially prescribed gender roles and functions that we encounter the process of disabling sexualities in Dangarembga's characters which informs Tambu's innermost turmoil captured in the reflective statement in the epitaph to this essay.

Tambudzai embarks on telling several interconnected stories that imbricate with her own personal life-story in the two novels. Thus, the reader encounters a collage of stories of several individual life stories of women, often set in contrastive relief to accentuate the oppositional differences they embody. This often results in a plurality of standpoints which is *de rigueur* in postmodern feminist narrative tradition. For example, the lives of all the women seem to oscillate around the central figure of Babamukuru, the embodiment of Shona tradition and patriarchy. As the central unifying figure in the novels, Baba totally conforms to the image of the 'good boy' that the colonisers have of him (*Nervous Conditions* 19). But Dangarembga parodies Baba's complete, unquestioning acceptance of the missionaries' teachings. In his total conformity, Baba's mind seems disabled. He becomes robotic, not challenging the racist ideology of the colonisers thus, remaining benign even when he perceives their oppression. Take, for instance, his insistence that his brother, Jeremiah, should 'properly' marry Mainini in the Christian tradition of the missionaries, a proposition that not only draws the fatal ire of Mainini; it also sends her health spiraling downwards.

In her narrations, except for the visibly, physically marked bodies of Nyasha and Netsai ,all the other characters seem (at least, initially) able-bodied yet, they all seem to be crucially disabled at defining points in their development. In *Nervous Conditions*, for instance, Tambudzai's existence, education, destiny and even sexuality are predetermined and almost entirely contingent upon Nhamo's, her privileged brother's life within Shona cultural mores. No wonder as Yvonne Vera

notes, Tambu opens the narration with a taboo in her mouth because right from the onset, Tambu's life seems to be disabled by Nhamo's existence. This somewhat substantiates Garland-Thomson's (2001) observation that previous conceptual traditions see the woman's body in terms of a negation or subtraction of the man's. Thus the author's two novels dramatise the various experiences of different women in a society in which women's 'needs and sensibilities' are neither a 'priority nor even legitimate' (*NC*: 12). Therefore, beyond the sexism that circumscribes the lives of the women, there is, additionally, the ontological contestation for legitimation and recognition by Dangarembga's women which graphically unfolds in Tambu's mind.

All the female characters in both novels suffer various kinds of sexual mutilations. Thus, unable to find full sexual expression and satisfaction in their relationships; they seem to live incomplete lives. For example, Mainini appears sex-less, unable to shed the enervating threefold yoke of poverty, racism and gender discrimination throughout her life. Mainini's portraiture contrasts with that of Maiguru, her educated and sophisticated sister-in-law, who, despite the advantage of her education and sophistication, is unable to sexually attract and sustain the attention of her husband, Babamukuru, who is now enraptured in a banal, routinised life of head at the mission school in Umtali. Her education does not elevate Maiguru beyond the dilapidated confines of Mainini's decrepit kitchen where she laboriously ensures that the food her husband provides last throughout the festive season in Umtali. Maiguru sacrifices everything she has worked for to satisfy sexist cultural traditions, taking the back seat where her society expects her to be. In a complexly sustained relationship with her husband, Maiguru's self-erasure is substantial; possibly leading to her atrophic existence. It is therefore little wonder that she often finds herself at the edge of collapse, but rather than collapse as Mainini does, she walks away.

Set in contrast to these older women is Aunt Lucia, Mainini's younger sister, who seems to have a lusty sensuality and sexuality that notoriously oscillates between Jeremiah and Tekesure. Lucia remains one of the bravest women in the *Nervous Conditions* by openly confronting patriarchy. This occurs at the *dare*, the council of men [which include Aunty Gladys on account of her age][1] who gather to discuss their concerns for Lucia's rambunctious flirtations with two men in the family. However, underlying the surreptitious agenda of the *dare* is an attempt to

control or police what they consider as Lucia's transgressive sexual appetites from their own normative perspective. Unlike the other *maininis* who keep a safe distance from the *dare*, Lucia singularly and openly confronts and defies the authority and diktat of the patriarchs who seek to restrain and therefore 'normalize' her sexuality precisely because Lucia's sexual agency is seen as potentially disruptive. But by disrupting the normalising script of traditionalism the *dare* seeks to impose on her sexuality, Lucia is able to negotiate for herself liberation. Lucia's constestatory disposition connects her with her niece, Tambu, whose posture sets her in sharp contrast with her uncle. Unlike Babamukuru who is a conformist, Tambu and Aunt Lucia are both deviants; they reject the fatal atavism of their foremothers and defy the cultural structures and ideologies which privilege maleness and proscribe women's lives to minimalist spaces. In their relationships and interactions, both the protagonist and Aunt Lucia are distinctively, thematically and symbolically, in opposition to the other women who appear resigned to the prescriptions of an overbearing patriarchal society.

The riveting story of *The Book of Not* is on the boarding house experiences of young African girls at the prestigious Convent. At the Convent, the physical separation of the dormitories as well as the unspoken actions and attitudes of the nuns; their benign generosity clearly delimits the boundaries of the young black girls. In this atmosphere, Tambu is unable to distinguish herself. She is disturbed that in spite of the opportunity and the promise of her brilliant O-level results, she fails, dismally, to surpass that initial potential. The overwhelming experience of racism is for the young Tambu too profound, almost surreal. She therefore survives by recalling and trying to abide by the *Unhu* philosophy as a personal strategy to cope with life on the fringes. The agonizing experience with the white, elderly matron-in-charge at the Twiss Hotel, Mrs. May, is another example. Curiously misnaming Tambu, persistently calling her Isabel poignantly signals for Tambu, a negation of her personal identity which is unbearable. It seems that in the imagination of Mrs. May, Tambu is no more than 'an undifferentiated lump of flesh' (a non-being) which is perhaps more grievous to Tambu than the misnaming. Mrs. May's thoughts about Tambu, therefore, force a voyeuristic contemplation of the young girl's vibrant adolescent body as a site of negation and embarrassment. And this is bizarre as it incredulously signals Tambu's inferiorisation and defeminisation on account of her race, class and gender. At this point in her young adolescence,

Tambu experiences the intensity of a life at the centre of exclusion in which she becomes soldered to scenarios, a part of undistinguished humanity. Like sister Emanuel at the Convent, Mrs. May completely erases Tambu's humanity and personhood as she is considered no more than a piece of flesh; pointing to the devaluation and dehumanisation of the colonised female subject.

Castrated masculinities

Possibly because of her woman-centered agenda, in her two novels, Dangarembga's portraiture of her male characters is not as elaborate as those of her female characters. Rather, the author presents images of men who are deeply scarred and this is possibly, symptomatic of the crises of the strong autochthonous masculinist tradition that pervades African culture and literary texts. Dangarembga's male characters appear ineffectual and ultimately incapacitated in the face of compelling socio-political and sometimes economic forces they have to contend with. Other female African writers including Emecheta, Darko, and El Saadawi, create tropes of disabled masculinities to represent their radical, ideological and aesthetic departure from a failed masculine ethos. These authors therefore repeatedly represent images of men as weaklings, often emasculated caricatures. The import of this representation is, thus, more clearly understood when considered within a conceptual milieu where men's bodily or physical performance is crucial. Thus, while disability may point up one's vulnerability and dependence, masculinity is associated with power, prowess and being in control. Dangarembga's portrayal of disabled masculinities illustrates a contradiction that creates what Shakespeare (1999, 57) describes as "symbolic castration" both a lived and embodied dilemma for disabled men.

It is important, however, to note Barrett's (2014, 39) suggestion that it has become orthodoxy to decenter a single, static masculinity in which there is no fixed, essential masculine identity. This suggests that there are varied forms of masculinities and that men would generally variously negotiate their gendered identities in an intensely personal/individual and private level. For instance, the young boys, Nhamo and Chido, in the novels, appear only very briefly in Dangarembga's narration; appearing as mere silhouettes in contrast to the strong character representation of their sisters. Nhamo, for instance, is quickly deleted from the first

narrative while Chido, Nyasha's older brother, appears completely overshadowed by his father's strong mien and high aspirations for his son who is expected to carry on family (or perhaps more accurately, Shona traditions. Chido's pallor is further accentuated as he is intellectually unable to engage with the strong currents of his sister, Nyasha's vibrant mind. Thus, the early textual absence of these young boys signals their inability to generate an alternative discourse to counter the failed, masculinist master-narrative of contemporary African societies of the older generation represented by their father or uncle..

The other men in the novels also appear to reinforce the slight portraitures of the young boys. For instance, there is the insignificant, un-named soldier, Netsai's lover in *The Book of Not*. There is also Jeremiah, and his brigand companion, Tekesure, who are both pitiable caricatures. Their image is structured as thematic and aesthetic opposition to Babamukuru's, the avatar of Shona values and patriarchal culture. The ableist script Baba represents and his normalising symbol and image of resilience, strength, achievement and staid demeanor is however completely overturned by the end of the second novel.

In a final twist of irony, Babamukuru is charged with being a "collaborator" at the *morari*—a village political rally. This takes place in the full glare of his entire family to drive home the humiliation. Here, Baba is physically assaulted and publicly stripped of his revered invincibility. In this scene, Mainini seizes the opportunity of the debacle and vents her seething anger and suspicion on the family head who represents to her the image of the colonial oppressor. In its figural sense, this experience is for Babamukuru, a process of castration from which he never fully recovers physically and psychologically. His personal, tragic emasculation suggestively occurs on the eve of Rhodesia's political independence. Baba's subsequent confinement to the wheelchair, in a supine position operates symbolically to effectively disable him from emerging as a new national icon in the new Zimbabwe.

Conclusion

The above discussions demonstrate that disability inevitably cuts across the many boundaries of gender, sex, class, race, and age as illustrated in the two novels considered here. Particularly in African postcolonial literature, there are discursive links between gender, disability and national identity. It is therefore important to

read disability as integral to the theorisation of the colonised body. Within this conceptual frame, we see how the veridical processes of the event differently mark postcolonial subjectivities. Dangarembga's African characters irredeemably embody various vulnerabilities and disabilities as a result of the virulent interracial relations inflicted upon them by the event of colonialism and in their national and familial relations, these characters are left with transmogrified bodies. Interestingly, Dangarembga does not merely explore the pathologization of colonial subjectivities; she explores in and through them the psycho-emotional impact of various disabilities resulting from that experience as most virulently seen in the deformed bodies of Netsai, Nyasha, Maiguru and Babamukuru.

Also, in centralising the politics of their existence and politicizing the physical and psychological disfigurement of her characters, Dangarembga translates their nightmarish experience of the colonial past into their present, equally traumatic state. In other words, inscribed into the physical bodies of the characters are the ghoulish scars as memorabilia of the colonial experience and its narrative tropes of violence. Additionally, by focusing on the sexualities of her characters, we see how their lives are materially and psychologically inscribed with negations or fragmentations often resulting in the loss of their sexual appetites and identities.

As consistently depicted in her two novels, Dangarembga's African women appear defeminised by severe socio-cultural, political, economic and patriarchal prejudices. To this extent, as they lose their sexuality they also lose their self-defining potential and they are a in constant struggle between self-effacement and self-definition. It however seems that Aunt Lucia is the one exception who does not allow Shona traditional prejudices redefine her. Lucia thus embodies a free spirit and is able to finally make some progression however marginal. She emerges unscathed; insulated from the problematics of a nascent, post-independence life in a tottering nation. Appearing as a beacon on the horizon having gained at least a basic education, it would seem that the author points to the latent potential in Lucia as key to the process of recovery at both national and individual levels.

Endnotes

[1]　　See for instance Nwabueze Joe Obianuju in 'Human Rights Echoes in Aminata Sow Fall's *The Beggars Strike* 1995 *Neohelican.*22:1, 295–310 And more recently, Chioma C Opara 'Drama of Power: Aminata Sow Fall's *The Beggars Strike* in (Eds.) Chikwenye Okonjo

Ogunyemi and Tuzyline Jita Allan *Twelve Best Books by African women: critical readings* (Athens: Ohio UP, 2009) 161–176.

[2] Fanon's well documented treatise on the subject of the disorders in the psyche of the colonised subject as the victim of colonialism especially in his Chapter 5 of *The Wretched of the Earth* provides substantial evidence of crippling monstrosities of that tragic event.

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Fighting Pain with Pain: Bob Flanagan/Sheree Rose and Catherine Opie

Alessandra Mondin

ABSTRACT: This article focuses on a sample of the artworks created by three American artists: Bob Flanagan and Sheree Rose, whose collaboration also generated several performance pieces, and Catherine Opie, who mainly works with documentary photography. In the works analysed here, Flanagan/Rose and Opie use physical pain to tackle mental pain stemming from their different disabilities: for Flanagan it is the physical disability of his chronic illness, for Opie it is the "social disability" of the stigma attached to her sexual orientation. Their works and their lives are strongly interconnected and the divide between private and public is blurred: the personal becomes political. Flanagan and Rose are able to complexify gender and sexuality through the use of BDSM and the redefinition of pain and pleasure. The outcome of their work focuses on the dynamics of their 24/7 sadomasochistic relationship and is the questioning of hegemonic masculinity and normative femininity. The reappropriation and exploitation of medical and cultural discourses about illness and sexual deviance questions heteronormative sexuality and problematises the obliteration of the sexuality of the disabled.[1] Troubling and expanding representational regimes in their work, Flanagan and Rose put forward the corporeality of disability to show pain, which is invisible and escapes language (Scarry 1985; Aydede 2009). As well as Flanagan and Rose, Opie troubles the representation of the LGBTQ community in Western society and uses pain to fight the pain that comes from the minority stress provoked by discrimination and oppression (Meyer 2003). Also, she contrasts through reappropriation the stereotype that conflates sexual deviance, homosexuality, and BDSM. In order to achieve all this, the triptych-like self-portraits that are in dialogue with one another deploy, aside from the influence of the history of photography, the formal qualities of the official portraiture of Renaissance paintings. Moreover, she opposes and problematises the normalising currents in the gay and lesbian community

– marriage and kinship – and expands the idea and the representation of lesbian sexuality and identity – especially lesbian motherhood. Thus, through representational strategies that are entangled with the use of her embodiment and her lived experience, Opie is able to address mental pain through her work.

KEYWORDS: disability, pain, BDSM, performance art, body art, photography, LGBTQ

This article considers the lives and works of Bob Flanagan/Sheree Rose and Catherine Opie in order to show how body art has the potentiality of communicating mental pain through the bodies of the performers, defying its invisibility and challenging its unsharability. Such unsharability is posited by theorists of pain studies, like Scarry (1985), who argue that pain has this characteristic since it escapes language. These works also have the potential to escape society's oppressive stereotypical imagery of disability, mental distress, gender and sexuality and resignify their representations. To quote Flanagan,[2] these artists both 'fight sickness with sickness', they try to cure 'pain with pain,' with different nuances, aims, and for different reasons. Some of their works enable 'encounters with pain' (Ahmed 2002) with the deployment of their lived experience through artistic representation that activate a relationship with the viewer. I borrow the term "encounter" from Ahmed because, as she states, it has the characteristic of 'a meeting, but a meeting which involves surprise and conflict' (Ahmed 2000, 6) and we are confronted with these types of meetings in our everyday lives. Encounters with pain are also possible because the "improper" non-normative bodies of these artists are not 'closed and invulnerable,' characteristics attributed to the white male body by modernist discourses (Shildrick 2000, 217). What emerges from Flanagan is the need to fight the pain of a physical disability and the mental pain it implicates, while for Opie there are at stake different types of disability and pain that are caused by the social environment. Following their lived experiences and their works, the engagement with disability, mental distress and pain will be explored through more than one perspective in order to take into account social and material causes. I will proceed to

analyse some of the work and lived experiences of Bob Flanagan and Sheree Rose, while in the second part of the paper I will discuss some of Catherine Opie's works.

Bob Flanagan/Sheree Rose: Supermasochist Challenges

Bob Flanagan (1952–1996) and Sheree Rose (*n.d.) worked together from 1980 until the 1996 death of Flanagan from cystic fibrosis. Their work consists of performance, text, and video: all of them investigates sensitive issues like illness, sex and death. Flanagan and Rose's work is shaped by Flanagan's lived experience of disability and by the lived experience of their 24/7 S/M relationship.[3] Originally Flanagan has a background as a poet and he works with stand-up comedy and folk music as well, incorporating some of their elements in his performances and visual artworks. Rose is a photographer, video artist, and performance artist; since 1980 she has photographed the underground communities involved with piercing and S/M. Rose is not only Flanagan's partner and pain-giver dominatrix, but she plays an important part in his artistic and political development and in their artistic activity since the moment they met (Jones 1998, 325–326). Public/private spheres are hybridised, and gender roles and sexualities challenged through a poetic of BDSM.[4] In day to day life as well as in their work, Flanagan is slave to Rose practicing, in his own words, a 'gender demolition' (Flanagan quoted in Jones 1998, 233). While he is in full control[5] of every action of the performances through the pre-scene negotiations that render the practice consensual, in their works 'the S/M confusion of passive and active positions becomes a confusion of gender polarities as well' (Jones 1998, 233).

Flanagan and Rose play with masculinity and femininity, questioning them through their S/M. Pain is used by the artists to interrogate these normative gender roles, and normative sexuality in daily life and in sadomasochistic practices. Flanagan's male body is at the centre of the artistic practice, at the same time as a supermasochist superhero and a disabled man. The poem *Why* (presented also during some performances) explains:

> *because it flies in the face of all that's normal (whatever that is);*
> *because I'm not normal;*

(…)

because, as somebody once said, HE'S GOT MORE BALLS THAN I DO;

because it is an act of courage;

because it does take guts;

because I'm proud of it;

because I can't climb mountains;

because I'm terrible at sports (Flanagan and Rose 1997, 59).

Normative masculinity is contradicted: at the same time he can take the pain of disability and of S/M "like a man", but he cannot play sports or do other hegemonically masculine activities. It must be noted that 'in mainstream literature, film, and theatre, disability often serves as a metonym for emasculation' (Sandahl 2000, 97). Usually, this emasculation could lead to a deficit of masculinity and power, but also could invest the protagonist as a temporary painful rite of passage: both feature male disability as 'powerlessness, asexuality, masochism, medicalization, and infantilization' (Sandahl 2000, 97). Flanagan openly confronts this scheme of disabled masculinity by showing the power and sexuality of the disabled, when society and studies on disabilities/sexualities/gender tend to neglect the issue and/or consider it as absence for different reasons (Shakespeare, Gillespie-Sells and Davies 1996). The poem, thus, highlights the contradictions that Flanagan embodies with his mixture of stereotypically stoic masculinity and a body that is far from the one ascribed to hegemonic masculinity.

Hegemonic masculinity, along with patriarchy and heteronormative pleasure, are challenged through pain. Hegemonic masculinity 'embeds physical strength, endurance, youthfulness, and an absence of messy bodily functions' (Hladki 2005, 275), qualities that are overall contradicted by Flanagan. Performances like *YOU ALWAYS HURT THE ONE YOU LOVE* (1991) where he nails his penis to the stool he is sitting on while telling jokes, or *Nailed* (1989), where he sews his penis inside his scrotum and then he nails it to a wooden board (amongst other self-inflicted mutilations) illustrate how Flanagan sees castration as 'the ultimate extreme of everything I do or fantasize about. It's the ultimate way to go' (Flanagan quoted in Jones 1998, 234). His economy of pain and pleasure shatters the penis/phallus with the metaphors of normative masculinity, promoting the recognition that other embodiments of – joyful – masculinity exist and are lived within complex dynamics.

Moreover, the ultimate consequences of using the lived experience of disability, corporeality, and desires are not just the questioning of hegemonic masculinity, but also of the stereotype of the male artist.

Flanagan's artistic practice involves his illness through-and-through. Cystic fibrosis is a highly disabling chronic disease. In 1995, when the illness manifests itself in a more and more severe way, Flanagan writes his *Pain Journal*. In it, he records also the medicine he has to take to manage his illness and his depression, along with his response to them. For example, in February he annotates: 'I don't know when the last time was that we had sex. I say that because I'm watching two people fuck on TV. Sheree and I are close, yeah-closer than ever, in some ways-but physically we don't know where to start. Anti-depressants? Maybe. Good excuse. But I still can't shake my depression' (Flanagan 1995a). These responses are entangled with his reactions and reflections on the inability to engage with sadomasochism anymore. Both the diary entries and some parts of the documentary *Sick: The Life and Death of Bob Flanagan, Supermasochist* (1996), directed by Kirby Dick (with footage by Sheree Rose) highlight the distress of not being able to take sadomasochist pain anymore because of mental (depression) and physical pain (from the terminal stage of cystic fibrosis). In March he writes:

> [I] found myself mulling over why it is I don't like pain anymore. I have this performance to do on April 1st, and I'm shying away from doing or having S/M stuff done to me because pain and the thought of pain mostly just irritates and annoys me rather than turns me on. But I miss my masochistic self. I hate this person I've become (Flanagan 1995b).

He is not able to identify with the person who has lost the grip on pain because of illness and depression and cannot perform sadomasochism to engage with pleasure through pain. Having control over one's own body is central in this excerpt of the entry written in April:

> Felt disoriented and depressed through most of it [a performance he did], as I feel disoriented and depressed through most everything these days.(…) I want her [Sheree Rose] to put dozens of alligator clips on my dick and balls, but I don't know if I'd freak out or not. I can put a couple on myself. It hurts like hell

but most of the time I can hold on until the pain subsides and I get kind of a rush. But can I take it when she's [Sheree Rose] in control? The ultimate question (Flanagan 1995c).

As he said, 'the masochist has to know his/her own body perfectly well and being in full control of their body in order to give it to control to somebody else or to give control to pain, so the masochist is actually a very strong person and I think some of that strength is what I use to combat the illness' (Dick 1996). All his performances are, in one way or another, driven by the urge of coping with the physical and mental pain caused by disability. In *Superman* (a piece written in 1990 that echoes his epithet of supermasochist) he writes as, through the role of slave, in reality in S/M performances he is playing the master with his disease: 'in a never-ending battle not just to survive but to subdue my stubborn disease, I've learned to fight sickness with sickness' (Flanagan 1990). It might seem a discourse tainted with the overcoming narrative of disability, but instead one may see Flanagan using pain against pain in order to function, a word that he uses himself in Dick's film. Siebers too uses tentatively the verb "to function" as pivotal for the life of disabled people (Siebers 2001, 750), which entails knowing their/our disabilities and bodies in order to be able to live their/our lives. Losing the knowledge/control of his own body and disability, Flanagan is questioning (along with Rose in the last part of the film) his masochism.

The last part of Dick's documentary shows Flanagan dying. In a particular sequence he suffers unbearable pain and confusion caused by the imminent reality of his own death and he is saying, sitting on his hospital bed and barely breathing, 'Am I dying? I don't understand it. What is going on? This is the weirdest damn thing' (Dick 1996). This is one of the most unsettling moments of all Flanagan's *oeuvre*, along with the film sequence where Flanagan painfully coughs and with the diary entries. These moments are even more transgressive than the S/M performances *per se*. This is because the corporeality of disability and pain confronts everybody's lived experience. Siebers reports that 'only 15% of people with disabilities are born with their impairments. Most people become disabled over the course of their life' (Siebers 2001, 742). In fact, non-disabled people could be referred to as TABS, which means Temporarily Able-Bodieds (Wendell 1996, 61). Flanagan belongs in this 15% because of the genetic condition he was born with.

He confronts the viewer with his own pain, with his own disability and the ways he represents them as his lived experience. He addresses the viewer with illness, disability, pain, death: there are not many things as uncomfortable as the reality of pain, disability and the social stigma attached to the disabled body. As Siebers says 'the prospect is too frightening, the disabled body, too disturbing', but 'the cycle of life runs in actuality from disability to temporary ability back to disability' (Siebers 2001, 742). Following Siebers' problematisation of social constructivism and new realism in disability studies (2001), I agree that the corporealities of disability can provocatively question that 'the disabled body represents the image of the Other. In fact, the able body is the true image of the Other' (Siebers 2001, 742) because of the immanent and material reality of illness, pain, and disability of the body-mind. With the documentary and with the journal, Flanagan, Rose and Dick produce works about disability with the use of methods that are 'deliberate and detailed, as if they are trying to get people to see something that is right before their eyes and yet invisible to most. The testimony of sufferers of disability includes gritty accounts of their pain and daily humiliations – a sure sign of the rhetoric of realism' (Siebers 2001, 747).

In a metaphorical sense, Flanagan is also part of the other 85%, because of the "acquired sickness" (the "perversion" and pain of S/M). The normative discourses (e.g. American Psychiatric Association 2013) on sexuality stigmatise and pathologise BDSM. He reclaims it as a way to cope with his sickness (the disabling chronic illness). He embodies the questioning of the boundaries between ability and disability, pleasure and pain, the inescapable materiality of the body, the consequences of biopower on the body and the resisting practices against biopower. Rose and Flanagan play with and question the social stigma attached to sexual practices and the stigma attached to illness and disability. The tool used to question stigma is pain: the performances with S/M that deploy pain and the representation (through Dick's documentary film, video, photos and texts) of physical and mental pain.

Flanagan shows the sexuality of the disabled through the reappropriation of the discourse of illness and the medical and cultural discourses of sexual deviance. Reverse discourses are also practiced through the reappropriations of words used in derogative ways. Flanagan reclaims the words "sick" and "sickness" both from the angle of the chronic illness-induced disability and the one of the BDSM com-

munity. These reappropriations carry socio-political value and counter-normative purposes. With these reverse discourses, disability and sadomasochism, as Foucault would argue, start to 'speak in [their] own behalf, to demand that [their] legitimacy or "naturality" be acknowledged, often in the same vocabulary, using the same categories by which [they were] medically disqualified' (Foucault 1978, 101).

In *Sick*, there is a telling conversation between Flanagan and his brother, where the latter states how in shock the whole family was when they discovered Bob's S/M practices, which made his brother's homosexuality seem conventional. The shock was mainly caused by the disabled Flanagan playing with harmful and potential deadly practices. Since 'representation itself [is] a primary ideological force' (Siebers 2001, 739), the reappropriation of the representation of the freak, the sick, the strange is a conscious political move. Flanagan shows the life and death and pain and joy of the disabled. He shows his lived experience, he wants the viewer to deal with it. Garland-Thomson argues that 'disability is the unorthodox made flesh' because it refuses 'to be normalized, neutralized, or homogenized' (Garland-Thomson 1997, 23). Therefore the reappropriation of the discourse of the sexual minority practices like BDSM as "sickness" has a political and cultural implication of confronting (in a way, more than his brother's homosexuality) the supposedly normative, penetrative, genital sexuality of heterosexuals, the obliterated sexuality of the disabled, and the representation through reappropriation of the sexuality of the disabled seen as deviant.

Another performance troubles the boundaries between sickness and health, private and personal realms, putting at the centre Flanagan's lived experience. *Visiting Hours* is a one-person museum show, first exhibited at the Santa Monica Museum of Art in 1992. It was presented again in 1994 at the New Museum of Contemporary Art in New York and in 1995 at the Museum of the School of Fine Arts in Boston. In the documentary there are some excerpts filmed at one of these exhibitions, where Flanagan is in a real hospital bed, dressed with a hospital dressing gown. The public enters the museum-made-hospital in the visiting hours to be part of the exhibition/performance. Flanagan can be approached by the viewers/visitors: he answers questions and chats amiably with the journalists and the public alike. The artist positions himself as a sick relative or friend that you visit because he is unwell. The viewers, in turn, become like relatives or friends of the artist. The reaction of the public is varied and, at the end, unpredictable. A woman,

for example, is seen on screen as struggling to maintain her composure and to find the words to express her dislike in front of Flanagan, before rushing away with what one assumes is a sense of aversion. The effect of realism is uncanny because Flanagan does not simply stage a performance about illness and death, but he lives it with his disabled body. Once again, he transgresses the boundaries of what is supposed to be lived in private and what is apt to be lived in public: the feminist anthem of the "personal is political" resonates with his *oeuvre*. His representation forwards the idea of the pain of the disabled as eminently political, and not just as individual and private. There is the need to pinpoint first that not all disabled people are in pain; second, as studies on pain report, 'pains are said to be *private* to their owners in the strong sense that no one else can epistemically access one's pain in the way one has access to one's own pain, namely by feeling it and coming to know one is feeling it on that basis' (Aydede 2009); and third, that there is no two people with the same kind of disability that 'have the same medical problem or political interests' (Siebers 2001, 743). As Siebers says,

> The struggle for civil rights is completely different from the usual process for people with disabilities because they must fight against their individuality rather than to establish it – unlike political action groups based on race and gender. Consequently, the greatest stake in disability studies at the present moment is to find ways to represent pain (Siebers 2001, 744).

Flanagan is representing his pain through his lived experience of a man with cystic fibrosis, whose life has been subjected to recurrent hospitalisation, medicalisation of his body and his mind, and several threats of imminent death. This confronts the audience openly, not asking for compassion, but asking to question their own lived experiences of pain and illness, or lack thereof.

As stated earlier in the analysis of Flanagan's masculinity, Flanagan and Rose destabilize the conventions of heteronormative masculinity and femininity. Rose does not embody the stereotype of femininity as carer/caring, submission, fragility neither in the performances nor in the day-to-day life with Flanagan. She embraces the role of dominatrix in the S/M relation, challenging the conflation of emphasized femininity with submissive behaviour. In the documentary *Sick: The Life and Death of Bob Flanagan, Supermasochist* (1996) Flanagan is overwhelmed by

the pain of the illness and does not want to engage with sadomasochism with her, and they are both aware of the toll that disability is taking upon their relationship. Flanagan, for example in the *Pain Journal*'s excerpts quoted above, acknowledges Sheree's distress. In the documentary, Rose's reaction might seem rather uncommon when she says to him: 'if you still love me you'll submit to me.' However, she is performing properly her role by trying to stimulate the masochist to engage with pain. It could be seen as a sort of "ethic of care of the dom/me" by helping the partner regaining his submissive role that has been crucial for dealing with his pain. Originally, the ethic of care (Gilligan 1982) has been praised, for instance, for stressing the human reality of interdependence, but it has been criticised for essentialising womanhood, for being heteronormative (as the site of care is assumed to be the heterosexual nuclear family), and oppressive for carers (paid and unpaid) and cared for (disabled and elderly) (Lister 2003). In this particular case, this reading against the grain of the ethic of care might be suitable to see how it is possible to regain agency, control, and independence through interdependence. Rose does not grasp nor share her partner's physical and mental pain, but she is willing to come in his direction, she is willing to take on again the role that makes him feel alive and in control through S/M's pain. It is undeniable that their relationship is made stronger by S/M.[6] She is seeking an encounter with his pain, the unbearable pain of the cystic fibrosis that is killing him, through the pain of S/M. Ahmed says 'pain encounters, or encounters with pain, are crucial to how we inhabit the world in relationship to others; pain encounters involve the animation of the surfaces that both separate us from others, and connect us to others' (Ahmed 2002, 25). She wants to help him to get away from the solitary confinement of his disabling pain and the way she does it troubles the normative prescriptions of femininity.

Moreover, Flanagan and Rose trouble and expand representational regimes. Siebers argues that 'the disabled body changes the process of representation itself. Blind hands envision the faces of old acquaintances. Deaf eyes listen to public television. Tongues touchtype letters home to Mom and Dad. Feet wash the breakfast dishes. Mouths sign autographs' (Siebers 2001, 738). Flanagan and Rose might add to this linguistic and representational challenge that supermasochists with cystic fibrosis and their dominatrixes "pleasure" pain and 'FUCK THE SICKNESS' (Flanagan and Rose 1997, 58).

Garland-Thomson questions Flanagan's self-representations as appropriative of the exotic (or transgressive) mode of representation (Garland-Thomson 2001, 358). It is one of the four modes of representation (along with the sentimental, the realistic and the wondrous) that she highlights as being used in the visual rhetoric of disability in photography and popular culture by modern capitalism for various purposes (Garland-Thomson 2001). The exotic mode to Garland-Thomson serves to 'counter unequivocally the rhetoric of sentimentality and renounce even the admiration of wondrous' (Garland-Thomson 2001, 358). Sentimentality is seen as the 'manifestation of suffering' (Garland-Thomson 2001, 341), and it is made to inspire fine, 19th century's bourgeois feelings that lead to the infantilisation of the disabled (Garland-Thomson 2001, 341–342). The wondrous mode, instead, displays the 'extraordinariness of the disabled body in order to secure the ordinariness of the viewer' (Garland-Thomson 2001, 341), for example through the tropes of the monster or the prodigy.

Unlike Garland-Thomson, I find this exotic and transgressive mode of self-representation as functional for political purposes through the reappropriation of the body of the disabled as freak. His self-representation is akin to grotesque realism, where the grotesque body is 'open, protruding, extended, secreting body, the body of becoming, process, and change' (Russo 1997, 325). Flanagan's image of his body is ultimately grotesque as it 'displays not only the outward but also the inner features of the body: blood, bowels, heart and other organs. The outward and inward features are often merged into one' (Bakhtin 1984, 318). As Garland-Thomson argues, Flanagan 'fuses the cultural figures of the invincible superman, the porn star, and the sick person, he combines cape, chains, piercing, and the oxygen mask characteristic of cystic fibrosis to discomfort his viewers' (Garland-Thomson 2001, 358).[7] Moreover, his performances augment, through their conflation, the excesses of the disabled body and non-normative sexuality through the grotesque body. A body, his lived body, that secretes mucus, desires cuts, spill blood, oppose the asphyxiation of the disease by desiring it for pleasure, laughs and lets you laugh at his own death, disease and pain. Or is it your own death, disease, and pain you are laughing at? The discomfort is functional for Flanagan's embodiment and lived experience because, as Siebers says, 'different bodies require and create new modes of representation' (Siebers 2001, 738). There is the need to engage with different representations of Other and many bodies in order to contest the "rhetoric of the One."

Garland-Thomson also finds that the main outcome of the exotic mode of the photographic representation of disability is distance (Garland-Thomson 2001, 358). However, I find that Flanagan's performances have, instead, complex effects, because if the visual characteristic of the performance could be a strange spectacle – both fascinating and repulsive – for the normate viewer, the humour (in the jokes, the facial expressions, the songs and so on) he uses in some of his performances does not distance the public, but draws it closer. The humorous effect is augmented as well by the contrast that is created from the union of the tragic and the joyful, like in the diddle he sings on the notes of Mary Poppin's *Supercalifragilisticexpialidocious* (1964) in a performance:

Supermasochistic Bob has Cystic Fibrosis
He should've died young but he was too precocious
How much longer he will live is anyone's prognosis
Supermasochistic Bob has Cystic Fibrosis

I'm dili-dili, I'm gonna die
I'm dili-dili, I'm gonna die

When he was born the doctors said he had this bad disease
That gave him awful stomach aches and made him cough and wheeze
Any normal person would've buckled from the pain
But SuperBob got twisted now, he's into whips and chains

I'm dili-dili, I'm gonna die
I'm dili-dili, I'm gonna die

Years have come and gone and Bob is still around
He's tied up by his ankles and he's hanging upside down
A lifetime of infection and his lungs all filled with phlegm
The CF would've killed him if it weren't for S&M!

Supermasochistic Bob has Cystic Fibrosis
Supermasochistic Bob has Cystic Fibrosis
Supermasochistic Bob has Cystic Fibrosis (Dick 1996).

The dark humour of the lyrics about illness and death is mitigated – but also enhanced – by the catchiness of the song, which transports immediately to the elated, innocent, positive, encouraging mood of the original. This atmosphere might help to keep the audience closer in order for disability, pain and non-normative sexual practices not to be overlooked because they are perceived to be too intimidating or disturbing. It also might draw the public closer to the complex lived experience of the artist, to function as an encounter with the pain of the Other through humour. Thus the involvement in comedy by the disabled is also important because humour has been historically negatively extracted from impairments (Clarke 2003). Therefore, the supermasochist's humour has a political potential: 'an important part of the [disability] movement has been to reclaim humour – to laugh at disabled people not as victims but as role models' (Hasler 1993, 2). This type of humour has a moral character and thus it is in accord with the grotesque since 'the object of mockery is a specific negative phenomenon, something that "should not exist"' (Bakhtin 1984, 306). The value of his comedy is similar to the one of other Others (e.g. women, poc, and LGBTQ individuals) as Barnes (1992, 15) argues, because it is able to 'makes sense of the senseless and, most importantly, satirises without rubbishing individuals.' Moreover, Flanagan as Other asserts something that seems to escape to the symbolism assigned to the disabled. Wendell brilliantly states: 'I have concluded that I am always sick and often happy, and that this seems very peculiar in my culture' (Wendell 1996, 63). Therefore, establishing such representations might help reconfigure the discourses on the disabled and the lived experience of disability.

Flanagan exploits the pain of BDSM in order to fight the mental and physical pain coming from his chronic illness. His own body, embodiment and live experience are deployed in his performances that defy the stereotypical representations of the disabled, reconfigure the representation of the sexuality of the disabled and resist the medical discourse of non-heteronormative sexuality. In addition, Flanagan and Rose are able to question normative heterosexuality and normative masculinity and femininity with their lived experience of BDSM that their performances highlight. Ultimately, the representational techniques used by Flanagan activate the viewer for an encounter with pain and confront pain's unsharability.

In the following part of the article, I will look at how Opie is able to use the pain of sadomasochism to fight mental pain and produce a series of interrelations that question the disabling patriarchal society which causes such pain.

Catherine Opie: Perverting Tensions

I would like to go from Flanagan's lived experienced of pain to the one of Catherine Opie's, shifting from physical disability to social disability and analysing how she uses pain to fight pain. Catherine Opie is a lesbian photographer, born in Ohio in 1961, and currently living and working in California. She has been working for three decades, becoming one of the most influential artists of her time photographing America's social and geographical configurations. She explores the concepts of identity and community, how they interconnect and how they influence each other. One of her most popular works is the series *Girlfriends*, shot from the mid 1980s throughout the 2010s. Friends and lovers are the subjects for her camera, through which she documents LGBTQ, BDSM, and artistic subcultures in a profoundly intimate and honest way. The settings and the compositions are informal and spontaneous, revealing how much Opie is a part of those cultures.

In 2008–2009 the *Catherine Opie. American Photographer* solo mid-career survey has been exhibited at the Solomon R. Guggenheim Museum in New York. The specification of the title as American photographer recalls some of her great American predecessors and influences, like 'Walker Evans' 1938 *American Photographs* exhibition at MoMA and Robert Frank's 1958 book *The Americans*' (Zellen 2009, 76). The portraits' series of communities and individuals (which are not limited to the queer scene but they comprise also, for instance, football players and surfers) remind of photographers like Walker Evans (for the attention at the American subcultures), August Sander and Bernd and Hilla Becher for the approach of the typological catalogue (present also in her landscapes, freeways and minimalls series). Her photography has always been informed by the need to document, describe, catalogue: 'since a very young age I've had this drive to describe…to document. (…) It's just this intense desire to catalogue and archive the people and the places around me' (Opie in Reilly 2001, 87). In addition, she brings into play art history with mastery: 'there's a seduction that happens, (…) I use all of the classical tropes of art. They allow people to enter the work, and to look at something they might not otherwise look at' (Opie quoted in Dykstra 2008, 132). This strategy is particularly evident in three self-portraits that in the exhibition are set in a small space of the Guggenheim, an 'alcove' as Dykstra reports (Dykstra 2008, 132), and that are in dialogue with one another. She deliberately adopts Hans Holbein's visual strategies in order to give authority and formal decorum to unconventional sub-

jects through the saturated monochrome backgrounds and stylized formality. The purpose is to shift towards a more traditional portraiture (compared to the *Girl-friends* series, for example), and, in order to achieve this, she resorts to Holbein as an 'influence behind the color and the gaze' (Opie in Reilly 2001, 90). Recalling her own lived experience, she says 'my own experience of being bald, tattooed, and pierced was that people were scared of me' (Opie in Reilly 2001, 90). Therefore, she tries to represent the Other – e.g. the SM community, transsexuals, transgenders, gays, lesbians, transvestites – differently in order to defy stereotypes and regain a certain representation that gives the respect and dignity that have been missing in culture and society at large. Thus, to do so, she resorts to some strategies adopted by Renaissance painters, while, in the meantime, she highlights the identities of her sitters. This representational strategy is present also in her self-portraits.

In *Self-Portrait/Cutting* (1993), for example, there is a reminiscence of the tradition of the female nude seen from the back, and, through the rich damask background and the solidity of the figure, the great sixteenth century painters of official portraits of royals and eminent personalities. On Opie's bare back blood is still dripping from the cuts that draw the simple, stick-figures pictures of two women holding hands, with, in the background, a house with a smoky chimney, and sun, a cloud and birds in the sky. It reminds the children's pictures of a happy family portrait and its sweetness and innocence. Opie's head is positioned at the joint of two of the festoon of fruit and flowers waved on the fabric of the background: this expedient establishes symmetrical rigor that leads to a calm and firm sensation of the composition; this choice of sombre coloured background with the abundance of such fruit and flower decoration symbolically mirrors the subject's frustrated desire for a prosperous union. The emptiness of the composition of the photography is a stylistic device used by Opie in various series in order to symbolize loss with different purposes (Opie in Reilly 2001, 94). The desire for kinship and the pain for the loss of it emerge on the skin of the subject through the use of physical pain. In fact the picture has been shot when the relationship with her former girlfriend ended and Opie questioned herself and her longing for a family and for marriage (Dykstra 2008, 132).

I would like to elaborate on the personal, lived experience of Opie's pain and distress, in order to embrace the communitarian and identitarian sense that all Opie's series intimately possess. The lived experience of the LGBTQ community

have been affected and shaped by the difficulties, the distress and the struggles of fulfilling also intimate desires such as kinship, marriage, family, and children. The picture reminds viewers vividly of the lack of the legal rights to form a non-heterosexual family in most parts of the world. In this sense, patriarchal society is disabling, it causes pain, a pain that is borne by the body of whoever does not fit the heteronormative prescriptions not merely virtually – everyone is not coherently able to embody the heterosexual norm without any contradiction – but critically – the queer embodiments that critically fail to approximate such norms (McRuer 2006, 30). Rich points out how 'social relations of the sexes are disordered and extremely problematic, if not disabling, for women' (Rich 1980, 632–633). Moreover, the scholar states that compulsory heterosexuality is a system 'through which lesbian experience is perceived on a scale ranging from deviant to abhorrent, or simply rendered invisible' (Rich 1980, 632). Homosexuality, until 1973, has been classified in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 1973) as a mental disorder. The legacy of this classification still continues: as Meyer says 'this heritage has tainted discussion on mental health of lesbians and gay men by associating – even equating – claims that LGB[8] people have higher prevalence of mental disorders than heterosexual people with the historical antigay stance and the stigmatization of LGB persons' (Meyer 2003, 674). Then the pathologisation of homosexuality continues both in the medical field and in the social imaginary. Meyer (2003) elaborates a variant of the social stress theory through many sociological and social psychological theories, called minority stress. This model illustrates 'the excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often a minority, position such as the LGB population' (Meyer 2003, 676). The conclusion of Meyer's study is that the LGB population has a higher rate of mental disorders and distress than the heterosexual one because of social stress (e.g. discrimination, prejudice, stigma, internalized homophobia).

The picture carved on Opie's back could lead in different directions towards different positions in the LGBTQ community itself, not just in society at large, on the issues of marriage and parenting. McRuer highlights how 'indeed, many people considering LGBT rights at the turn of the century (including many LGBT people themselves) are still surprised to learn that queer communities have actually been deeply divided over the issue of gay marriage' (McRuer 2006, 79). There are

mainly at stakes the "equality" discourse, embarked through the politics of assimilation; and the "diversity" discourse, that rejects the assimilationist stance. Therefore there are other threads at stakes in the lines dripping bloods on Opie's skin: the pain stemming from the disabled condition of not having equal rights, the pain rising from the divisions inside her own LGBTQ community, the pain and distress of struggling for other configurations of kinship and society, the pain of sacrificing live experiences and embodiments by entering the normalizing mould of marriage in order to advocate for equal rights and equal treatment. Normalisation is one of the weapons of power (Foucault 1979, p. 184), therefore same-sex marriage for the LGBT community portrays, not just the fulfilment of a human right, but the risks connected to endorsing forms of social control. Cott (2000) argues how the history of (Christian-modelled monogamous) marriage in U.S.A. is imbricated in the formation of America as a nation and of its values. Cott contends that marriage is both a private and public establishment and the state uses this institution to accomplish its own aims. Historically, the roles of husband and wife have been shaping their citizenship: marriage is a tool 'through which the apparatus of state can shape the gender order' (Cott 2000, 3). The result of this shaping has detrimental and discriminating consequences for women.

Self-Portrait/Cutting is a reflexion in embryo that precedes the later *Domestic* series (1999), where she travels around the U.S.A in a RV to photograph lesbian couples in their homes. It is an experience for Opie to ponder about what a family is. One of the outcomes of the deep learning experience this project gives her, apart from the renewed compelling interest in her own lesbian community, is that 'the lesbian domestic couple doesn't necessarily have to be based on the heterosexual model' (Opie in Reilly 2001, 87). Rich would argue further by saying that 'lesbian existence comprises both the breaking of a taboo and the rejection of a compulsory way of life' (Rich 1980, 649). The breaking with the heterosexual matrix is taken further by other ways of embodying relationships and Opie's representations of that is a powerful one. Another series that progresses the meditation on same-sex couples and parenting and that documents the lived experience of kinship is the autobiographical *In and Around Home* (2004–2005). In these pictures she portrays the day-to-day life of her family (her partner and her two children) in her home, and glimpses of the political election and social and political debates have a part in the representation. In 2006 she comments upon this series:

Should I be complacent at this point because I'm living my American Dream? And I feel that as an artist it's my responsibility not to be completely complacent, to try to create a weave of complexity through images and looking at the world, and ideas of the history of photography as well as the history of culture… and to still stay really aware of that and give that back to an audience (Opie quoted in Guggenheim).

The complexifying intentions and the refusal of complacency are present in *Self-Portrait/Pervert* (1994). In it, Opie is sitting quietly on a chair in front of another rich and finely decorated background. She is wearing leather hood and pants, on her bare chest the word "pervert" is carved with an elegant script that matches the elegance of the backdrop, on her arms are symmetrically inserted forty-six needles. The composition is minimal, but the cure of the lines is controlled and balanced, not dissimilar to the one of an official portrait of a Renaissance master painter and that confers an extreme dignity. *Pervert* recalls the series she shot of the BDSM community and incorporates the formal elements of other more formal portraits like *Cutting*. The solidity, symmetry, and dignity of the subject is reminiscent of Holbein the Younger[9] (1497/8–1543). It especially has consonance with the *Portrait of Charles de Solier, Lord of Morette* (1534–1535) for the frontal disposition and the sultry quality of the blacks, but also the solidity and strange calm displayed by the portraits of Henry VIII. The simple draping of the textile on the background reinforces the elegant symmetry of the whole composition. As said before, the references to Holbein reinforce the sense of solemnity and power of the representation.

Opie commented on the making of *Pervert* as 'an anguished reaction to the AIDS epidemic, as well as a cry against the "normalizing" of gay and lesbian communities' (Dykstra 2008, 132). The bareness of the composition that does not include anything other than the subject and the background reinforces the sense of loss – a feeling present in many series – that her community and her generation has experienced from the AIDS epidemic (Opie in Reilly 2001, 94). This is part of the minority stress theorized by Meyer (2003) suffered by the LGBT community and its members. They have been accused, stigmatised and discriminated for the disease. In addition, they have been suffering the pain of losses of family, friends and members of such community, but also the lack of appropriate (medical, social and political) care and support for the sufferers of HIV and AIDS.

The artist reports how the mainstream lesbian community does not fully accept the S/M scene, and that her self-portraits as well as her studio portraits are meant, also, to 'expand the idea of lesbian identity' (Dykstra 2008, 132). The portrait is a statement of identity and a way to counter effects of the distress and the pain of being stigmatised in one's own subculture, and not only in society at large. She regains positive control over the representation of lesbian and S/M sexuality using the efficacy of the reverse discourse, seen also in Flanagan. The word "pervert" is cut on the skin to embody the reappropriation of the word by the BDSM community. As said before, the LGBTQ community has a painful history of medicalisation and discrimination. In addition, the control of sexuality has been exerted also through the medical classification of certain practices as deviant. Practices like sadism and masochism are still defined as paraphilias in the *Sexual and Gender Identity Disorder* chapter of the *DSM-IV-TR* (American Psychiatric Association 2000). This definition as mental pathology is inherited by Freud's and Kraft-Ebbing's views of S/M. While in the *DSM-III* (American Psychiatric Association 1987) they are classified as psychosexual disorders *per se*, the *DSM-IV-TR* defines S/M as pathological when the related 'fantasies, sexual urges, or behaviours cause clinically significant distress or impairment in social, occupational, or other important areas of functioning' (American Psychiatric Association 2000). In the end, with the *DSM-IV-TR* the medical model of those sexual practices does not shift consistently in order to avoid discrimination and stereotyping; moreover, there is no mention of the difference about a consensual and voluntary practice, and a violent and abusive one. The *DSM V* (American Psychiatric Association 2013) asserts again what is supposed to constitute normophilic sexual interests and behaviours. Amongst the many issues that I do not have the space here to discuss, I would like to highlight how it is problematically unclear around the definitions of distress, impairment, psychosocial difficulties, harm, and risk of harm that differentiate paraphilic disorders from paraphilias (*atypical* sexual interests, urges, fantasies, and behaviours – again, despite the attempt to discern between what might be considered pathological and non-pathological, it is a definition set against "normal sexuality"); other issues are related to its gendered nosological approach and how the access to pornography is an associated feature that supports the diagnosis of paraphilic disorders. The *DSM* still overall reinforces normativity through pathologisation.

Through the stylistic and compositional devices of the picture, Opie also tries to give a new legitimate dignity to her own lived experience as lesbian and to BDSM, using pain to reappropriate her own sexuality and her own body on her own terms, away from the heteronormative matrix, and away from the diktats of part of the lesbian community that seems to endorse just one possible embodiment of lesbian identity and sexuality. Some feminists consider masochism a replica and reinforcement of 'major epistemological and behavioural structure of male dominated societies' (Hopkins 1994, 116). Lesbian feminist sadomasochists and other sadomasochism activists defend their sexual activity as an issue of private matter, but also as concerning 'political identity, spirituality, and epistemology' (Hopkins 1994, 117–118). The part of the LGBTQ community that favours assimilationism for political purposes downplays the different lived experiences. I do not claim that BDSM is the absolute and ultimate practice for gender and sexual subversion, but I argue that it is one possibility through which one can interrogate gender, sexuality, and the encounter with the other. For instance, BDSM could teach simple, practical things that could be of benefit of all kinds of sexual practices: 'vanilla sex [conventional sex] is as much about trust as leather folks attribute to S/M. In fact, I use safe words and I keep clear boundaries of do's and don'ts. The vanilla community should get hip to the fact that just because it's vanilla doesn't mean that safe words aren't necessary' (Hopkins 1994, 135–136). Therefore, Opie is able to create a dialogue through the reappropriation of representations of BDSM and lesbian identities.

The self-portrait that might be seen as completing a triptych with the aforementioned two is *Self-Portrait/Nursing* (2004). Opie is sitting on a big chair in front of a bright red damask backdrop, her shoulders and chest naked, and nursing her son Oliver. The lived experience of lesbian maternity is the focus of the composition, which retains the solidity and dignity of the other two portraits. Another distress suffered by the LGBTQ community is the lack of recognition, rights and representation of their parenting. Normative maternity seems instrumental to serve just the heteronormative economy, and the invisibility of lesbian maternity is consistent to this purpose. The Western patriarchal culture is saturated by the representations and the prescriptions of the Christian maternity, the only ones that seem to be valued. Opie reappropriates and exploits the Christian iconography (which has Ancient Egyptian and Byzantine origins) of the *Madonna Lactans*, the nurs-

ing Virgin. Studies show the political and social implication of the development of this iconography in Tuscan Renaissance (Miles 1986 and Holmes 1997). The artist uses such iconography politically to refocus the viewer on the lived experience of the Other. There are some renditions of the *Madonna Lactans* in popular culture imagery and in art photography. For example, in Cindy Sherman's *simulacra* of the series *History Portraits* there are the *Madonna Lactans* of the *Untitled #216* and the *Untitled #223*, which rely on different qualities and have different outcomes from Opie's photograph. In her self-portrait with her son, Opie's lived experience is functional for the expansion of the kinds of representations for the lesbian and queer embodiments. The sweet closeness that this representation of mother and child has opened up the possibilities of kinship. In addition, breastfeeding is still much debated nowadays. Carter's study examines how 'breast feeding is an overwhelmingly heterosexual subject' (Carter 1996, 116). Representing breastfeeding in lesbian maternity is a counter-normative political move. The lack of abundance of representations in popular culture and in the arts of the variety of lived experiences of lesbians augment the minority stress and impinge the political and social processes. Opie is ultimately a political artist in her series that portray the lived experiences of the LGBTQ community.

In the end, she is an American photographer: she documents American's diverse communities, but, moreover, she commits politically to re-representing the diversity on which the nation was founded.

Opie uses her body, her embodiment and lived experience in the triptych-like self-portraits in order to fight the mental pain and minority stress that the LGBTQ community experiences and that stem from the disabling heteronormative society and the medical discourse on homosexuality and BDSM practices. On her flesh and skin, the carving of the reappropriative word 'Pervert' in *Self-Portrait/Pervert* (1994) questions the normative current of the lesbian community, heteronormative sexuality, and representations of lesbian and BDSM sexualities in patriarchal society and in the medical discourse and represent the mental pain that these entail. In *Self-Portrait/Cutting* (1993) the mental pain stemming from the frustrated longing for (non-heteronormative) kinships and the lack of legal rights for marriage same-sex couples comes out on Opie's skin through the cutting of the drawing of a lesbian couple. The triptych is completed with the performance of lesbian maternity in *Self-Portrait/Nursing* (2004), a lived experience painfully unrecognised

by patriarchal society. The formal qualities taken from the style of the official Renaissance portraiture give the photographs dignity, solidity and symmetry, which ultimately render powerful and eloquent the representation. The representational techniques facilitate the sharing of the mental pain because it comes through the body of the performer.

This article has used the work of Rose/Flanagan and Opie in order to show how sexuality and disability are complexly constructed and how subversive strategies are embodied and enacted in a patriarchal and disabling society that creates pain and distress in the Other, the non-normate. To Garland-Thomson, in our society the normate is 'the figure outlined by an array of deviant others whose marked bodies shore up the norm's boundaries' and also the 'the corporeal incarnation of culture's collective, unmarked, normative characteristics' (Garland-Thomson 1997, 8). In this heteronormative framework, Rose/Flanagan and Opie question the norm's boundaries. In the artworks analysed, they question normative prescriptions of gender, sexuality, body and embodiment. At the same time, they question through their art practice and representational techniques the unsharability of pain. They both deploy effectively their non-normate bodies and lived experiences (S/M, disabling chronic illness, relationships, desires, pain, distress, lesbian identity, LGBTQ community, lesbian maternity) in reappropriative and reverse discourse techniques in order to fight pain, mental distress, stigma, and discrimination.

Endnotes

[1]   The use of 'disabled' instead of 'with disability' is in line with the framework adopted here that favours the social model of disability over the medical model, which deploys the latter wording.

[2]   The poster for the installation by Bob Flanagan and Sheree Rose called Visiting Hours (1994) sports the caption 'Fight Sickness With Sickness.'

[3]   In the BDSM jargon, a 24/7 S/M relationship is a "play" that virtually and ideally never ceases and it is carried on twenty-four hours a day, seven days a week.

[4]   BDSM is a compound initialism consisting of the grouping of various erotic practices, where B/D stands for bondage and domination, D/s for domination and submission, and S/M for sadism and masochism.

[5]   In the BDSM community the debate on who possess the control (for example via safewords, pre-scene negotiations, or in the dynamic of the relationship) is still open. For an

example, see in the British online community Informed Consent one of the board post called *Debunking D/S #1 – subs are always in control* (Informed Consent 2012).

[6]   Recent scientific studies have made the claim that positive hormonal changes might occur in couples engaging in consensual sadomasochistic activities and this results in an increased closeness and intimacy of the relationship (Sagarin, Cutler, Cutler, Lawler-Sagarin and Matuszewich 2009).

[7]   See, for instance, the poster for Kirby Dick's film *Sick: The Life and Death of Bob Flanagan, Supermasochist* (1996).

[8]   The diction in Meyer (2003) is "LGB" and not, for instance, "LGBTQ". Transsexuality is still considered nowadays (American Psychiatric Association 2000) a mental disorder and classified as gender dysphoria under *Gender Identity Disorders*. The medical model of trans* is highly contested. Furthermore, I do not intend to elide trans*, queer and questioning individuals by using this study, but only to point out this specific variant of the social stress theory that might also be valid to talk about their experiences.

[9]   Hans Holbein the Younger (1497/8–1543) was an important painter and printer of the Northern Renaissance, best remembered for his religious commissions and the portraits of royalty and prominent figures of his time.

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Of love, fears and dreams: Narratives of wives of soldiers disabled in war

Shyamani Hettirarachchi

ABSTRACT: *Context* The long drawn-out war in Sri Lanka, though now ended, has resulted in a high incidence of war-related injuries and disabilities and an arguably high, yet unaccounted incidence of trauma. There is at present some research, though very limited, documenting the effects of trauma on self-image among soldiers following war-injuries or disabilities in Sri Lanka (Fernando & Jayatunge, 2012; Jayatunge, 2008). There has been no focus on exploring the potential impact of a serviceman's or servicewoman's war-related disabilities on their significant partner within the Sri Lankan context. What is the lived experience of wives of soldiers disabled in war in Sri Lanka?

Methods This study explored the potential emotional and psychological effects of war and disability on relationships post-war in a phenomenological study documenting the lived experience of female partners. It focuses on the narratives of five female partners of military servicemen wounded in war, collecting data through observations, semi-structured-interviews and dramatherapy techniques of image, artwork and letters. To understand the narratives of the participants, the researcher used models of disability and constructions of gender and masculinities to underpin data collection and analysis.

Results Three main themes and five subthemes emerged through an inductive (Data-driven) and deductive (theory-driven) analysis using the principles of Framework Analysis (Ritchie & Spencer, 1994). The main themes were fears, love and dreams, while the subthemes included reaction, abandonment, reliance, resilience and sacrifice and blessing.

Discussion Factors connected to disability and gender which permeated the narratives of the participants represent a tension between female normative traits, roles and responsibilities and the leadership role of primary caregiver and breadwinner assumed by women following their husband's war-related disability. The women

appear to navigate through masculinist spaces while simultaneously facing negative societal reactions to disability. The findings may be useful to be considered in discussions of psychosocial support for soldiers disabled in war and their partners at the level of policy and practice.

KEYWORDS: disability, soldiers, wives, narratives, gender

The end of a thirty year conflict in May 2009 has resulted in a generation of Sri Lankans disabled and arguably traumatized by the experiences of war. Available statistics estimate that between 80, 000 to 100, 000 people were killed during the course of the war (ABC News, n.d.) with the exact number of casualties and those wounded said to be high but unknown. Jayatunge (2008) asserts that the prolonged war has 'changed the psychological landscape' (p. 140) of the country. The incidence of post-traumatic stress disorder (PTSD) remains unknown, although thought to be high (Jayatunge, 2008). There is very limited research on the effects of PTSD and the influence of trauma on self-image among soldiers following war-injuries, or as a result of disabilities in Sri Lanka (Fernando & Jayatunge, 2012; Jayatunge, 2008). That said, there is on-going debate on the relevance and limitations of the PTSD construct as a 'trauma lens' for defining a psychological condition or experience in disparate cultural contexts (Bracken, 2002; Chakraborty, 1991; Kirmayer, 1996; O'Brien, 1998; Marsella, Friedman, Gerrity, & Scurfield, 1996; Pupavac, 2001, 2004; Summerfield, 1999, 2001, 2004) particularly with regard to a 'charity model' response from society (Galappatti, 2003). Trauma (be it war-related or otherwise) does need to take account of the cultural context that influences life experiences (Batista Pinto-Wiese, 2010), given the strong effect of religion and socio-cultural beliefs on how Sri Lankans contend with disabilities.

Disability can be defined as 'the loss or limitation of opportunities to take part in the everyday life of the community on an equal level with others due to physical and social barriers' (Yeo and Moore, 2003, p. 572). In Sri Lanka, disability has been conceptualized primarily within a religio-cultural paradigm, synonymous with explanations of 'karma' or 'god's will'. There is perceived societal stigma attached to

persons with disabilities and their families, particularly with regard to marriage prospects and community participation. It can be argued that these previous negative perceptions of persons with disabilities are, to some extent, changing as a result of the large number of civilians and particularly members of the armed forces who were disabled by war-related injuries. This is evident in the focus on service-provision and medical care for military personnel wounded and disabled in war, during and following the immediate aftermath of the war. Nevertheless, the medical intervention and rehabilitation services may be said to be 'charitable' endeavours rather than viewing disability as a rights issue.

With regard to gender, the statistics reported for the mid-year population in 2012 revealed a population of 48.5 percent male and 51.5 per cent female residents in Sri Lanka in an estimated 20.328 million (Central Bank of Sri Lanka, 2012). However, this advantage is not mirrored in the position of women viz a viz in upper management or in political representation in parliament. In spite of boasting the statistic of the first female Prime Minister, the representation of women in government continues to be at a very low percentage (Kodikara, 2009). The increasing access to education to all children has resulted in a literacy rate of 93.2 percent for male and 90.8 per cent for females respectively in the country (Central Bank of Sri Lanka, 2013), although some have questioned the veracity of this finding. In stark contrast to the number of female students entering local universities which stands at around 55% (Haraldstad, 2012), the current labour force is comprised of just 30% of women in the country; one of the lowest in the region (Daily Mirror, 2014). In 2012, 6.2 per cent of women were said to be unemployed, with conversely only 2.8 per cent of their male counterparts not in employment (Central Bank of Sri Lanka, 2012). Of the factors contributing to this marked discrepancy between the level of education and that of employment are limited child care facilities and a 'culture of masculinity', making the corporate world arguably a 'masculine space'. Although the corporate world and the political arena continues to be dominated by men, the conflict has resulted in an emergence of female-headed households, particularly in the North and East of Sri Lanka (Goonesekere, 2009), with a potential change in traditional roles and power dynamics within relationships. Extending this to men disabled in the war, arguably, this would impact on the roles and responsibilities traditionally imbued by men and women within heterosexual relationships and of notions of power and subordination within a culturally patriarchal society

'Masculinity' is defined as 'simultaneously a place in gender relations, the practices through which men and women engage that place in gender and the effects of these practices in bodily experience, personality and culture.' (Connell, 1995, p. 71). It refers to a stipulated set of social roles and behaviours imbued by men within a particular society at a particular time in history (Kimmel, 2000). These prescribed roles are based on gender rather than biological sex, with a diverse range of masculine identities formed within society reflecting a process of socialisation. A recent report undertaken by CARE (2015) document masculine norms and attributes in Sri Lanka, which impact on and function as risk factors for sexual and gender-based violence. The claim by Connell (1995) is of a pluralist notion of many 'masculinities', with evolving views of masculinity within the social sciences, history and psychoanalysis affected by its associations with colonialism and the global economy.

Disability and gender are intertwined with the socio-economic and cultural context. It is acknowledged that disability requires to be considered as an element of a cultural matrix, influenced by factors such as gender and political and economic status. The notion of 'abelism' (Campbell, 2009) appears to permeate the constructs of disability within Sri Lankan society. Connected to disabilities, in Sri Lanka, sexuality and sexual and reproductive rights of persons with disabilities have not received sufficient acknowledgement or a platform for extensive discussion. It is within this backdrop that this study hopes to document the lived experiences of wives of soldiers disabled in the war. This paper is divided into three sections. Section one briefly details the methodology employed within this study. In section two, I present the themes and subthemes that emerged from the narratives of the participants, reviewing these themes from a lens of culture, constructs of disability and stigma, feminist theories of deconstructing and reconstructing the 'feminine' and ideas on 'masculinities' and with consideration for socio-economic views of poverty and its intersectionality with gender. The paper ends with brief concluding comments in section three.

Methods

This study focused on documenting the experiences of women married to military serviceman wounded and disabled[1] in war. Due to the lack of previous local

research, the three data collection methods of in depth interviews, observations and dramatherapy techniques were selected to collect narratives of five women married to soldiers disabled by war-related injuries. Semi-structured interviews were favoured as the lack of strict structure will enable the narratives to be narrated from the participant's viewpoint, rather than determined completely by the researcher. The researcher is a female speech and language therapist and dramatherapist working with both children and adults with communication difficulties with a growing research interest in the intersection between disability and gender.

Participants

The participants were between 18 to 42 years of age. Two of them had been married prior to their partner's injury and the other three had married subsequent to their partner sustaining an injury in war, which had resulted in a disability. Relevant demographic details are provided in table 1 together with information on the partners in figure 1.

Table 1: Demographic details of the participants

Participant[2]	Age in years	Education	Employment	Years of married life
Inoka	18	O/L*	Unemployed	1 year
Gayani	42	A/L**	Seamstress/owns a little clothes shop	19 years
Lalani	24	O/L	Part-time worker at a clothes factory	1 year
Sarani	21	O/L	Unemployed	4 years
Nilanka	32	A/L	Part-time worker at a clothes factory	10 years

*O/L = Ordinary Level Examination is a National Examination taken by students at 16 years of age.

** A/L = Advanced Level Examination is a National Examination taken by students at 19 years of age and is the entry requirement to local universities.

Partners of soldiers who are residents at a run-stay rehabilitation facility run by the government were invited to take part. Information sheets outlining the purpose of the study and the expectations of the participants were offered. Wives of soldiers at the rehabilitation facility who expressed an interest in taking part in the study were contacted. All participants wishing to be part of the study gave written consent prior to data collection. Ethical approval for the study was gained from the Ethics Review Committee of the Faculty of Medicine, University of Kelaniya, Sri Lanka. The

main ethical consideration of maintaining confidentiality was addressed through the use of pseudonyms in order to protect the identity of the participants.

Figure 1: Information on the participants' partners

Gayani's husband

Deaf, blind

Had been in a coma for 2 years

Poor bladder control

Unable to walk

Communicates by reading letters written on his chest and speaking

Inoka's husband

Poor mobility

Poor bladder control

Uses a wheelchair

Lalani's husband

Poor mobility

Uses a wheelchair

Fingers numb at times

Poor bladder control

Sarani's husband

Poor mobility

Uses a wheelchair

Poor bladder control

Recurrent sores

Nilanka's husband

Poor mobility

Uses a wheelchair

Data collection

The five participants were visited at their homes in the south of the country. Semi-structured interviews were carried out in the participants' first language of Sinhala to uncover the lived experiences of the participants. An interview guide influenced by models of disability and constructs of gender and masculinities was used with each participant. The topics included the perceptions and explanatory models of disabilities; perceived familial and societal views on disability; support structures; impact of the war-related disability of everyday life, and the influence of the disability on gender roles and responsibilities.

The interviews were between 60 to 90 minutes in duration. As an adjunct to the interviews and as the subject under discussion was very sensitive and personal, dramatherapy activities of image work, art and writing were offered, providing a

level of distance, as needed. Two of the participants were open to image work while one requested to write down her thoughts. All the participants were also observed at their homes for between 2–3 hours.

The five participants' husbands stayed at a rehabilitation centre far from their hometown and received visits from their family either weekly or less frequently. The soldiers visited their homes infrequently, once in 2–3 weeks or in one case, once a year. Three of the participants lived with their in-laws. One was hoping to build a house, one was in the process of getting financial support from the government to build her own house while the other was looking to make some renovations to her mother-in-law's house to make it accessible for her husband. One of the houses was on top of a hill making it inaccessible to a wheelchair user. Of the two participants remaining, one had a small house which was incomplete, the building of it has ceased when her husband was wounded. The other participant owned her home, which was a two-stored building, having built it on her own following the injury to her husband.

Data analysis

The interview data was audiotaped and transcribed verbatim. The data was anonymised using pseudonyms prior to analysis. The data was translated as required from Sinhala to English for the purpose of publication. Every effort was made to retain the authenticity and 'voice' of the participants by translating the data into colloquial Sri Lankan English (Gunesekera, 2005).

The interview data were analysed using the key principles of Framework Analysis (Ritchie & Spencer, 1994). Framework analysis was chosen due to the distinct yet interconnected stages of familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation, making it a robust data analysis method. It was deemed appropriate also as it allows for themes to develop from the research questions and from the accounts of the participants without fracturing the individual participant's narrative (Rabiee, 2004). All the available data in the form of the audio recordings, interview transcripts and field notes from the observations and therapy activities were reviewed. The concepts that emerged from the comprehensive reading of the transcripts were used to inform the formation of the thematic framework. The themes that emerged were used as labels for codes.

A matrix chart was compiled using the codes, and applied to the whole data and data from all the transcripts pertaining to each theme transferred to the chart.

One transcript was randomly selected for initial analysis and analysed independently by a linguist and by the researcher. While the researcher was guided by theories of disability and gender within analysis, the linguist adopted an inductive data-driven approach. Following analysis, the two coders met to discuss and determine a coding framework, which was then used to code the rest of the data. An outline of the key findings follows.

Results & Discussion

Three main themes and five subthemes connected to theories of gender and masculinity and to constructs of disability emerged through the data. Three main themes of fears, dreams and love were identified with the latter emerging as the overarching theme (Figure 2). In addition, five subthemes of reliance, reaction, courage and sacrifice, abandonment and blessing were identified within the narratives of the participants.
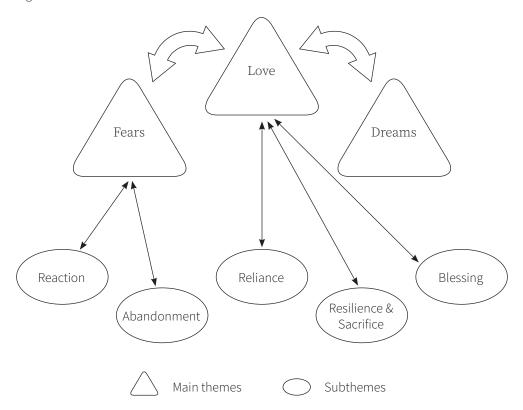
Figure 2: Main themes and subthemes

Love

This theme which permeates all of the narratives refers to the care and devotion of the wife towards her husband in the face of opposition. The participants had made a choice to marry a soldier disabled in the war or to continue their relationship following the injury, in spite of the weight of opposition from family members and deep-rooted societal stigma. Addressing the ubiquitous and primal nature of stigma, Corfield (2011) alleges that 'stigma is the projected and socially-accepted negative interpretation', in this case, of disability.

Lalani, who was in the first year of marriage became very emotional while talking about her family. She narrated the events leading to her decision to run away from home to get married due to objections from her mother and brothers. She explained as follows:

> I was so sad when my mother forbade me from seeing him. She said that he was not an appropriate man for our family, that he is not good enough to be my husband as he cannot look after me. It was very hurtful to hear those words. I know who he is. He is good enough for me. I don't mind that he cannot walk. I decided to run away with him. I got (gained) him… (Crying) but I lost my family.

One factor which fuelled the opposition from families reflected negative perceptions of disability, which was the suggestion that the person with disabilities was 'not an appropriate man' for their daughter or sister as he would be unable to 'look after her'. Viewed through a gender perspective, the soldier now disabled by war-related injuries was seen as lacking in some way or 'less than' a man, incapable of fulfilling his traditional gender role of protector and provider (Corker & Shakespeare, 2002; Shakespeare, 1999; TARSHI, 2010). It disallows for multiple constructs of masculinity as 'a diversity of identities amongst and within different groups of men – leading to the notion of different versions of masculinities' (Kimmel, 2000 in CARE, 2015, p.12).

Lalani continued her narrative of family rejection, explaining her brothers' views, which within disability discourse were of discrimination. Through a disability lens, a soldier wounded and disabled in the war was viewed through a medical paradigm of having a "defect" (Kaplan, n.d., Shakespeare, 1999). This view of dis-

ability as an 'impairment' or 'deficit' or as an aberration from the 'norm' or 'ideal' body intersects with notions of 'abelism' (Campbell, 2009) and masculinity (Addlakha, 2007) as the subtext is of the young soldiers wounded in war being seen as 'less than whole' and therefore unable to match the requirements of a male partner within a heteronormative relationship (Connell, 1995).

Lalani recounted:

> Miss, you don't want to hear what my brothers said. They say that they are worried about what my relatives will think. They think that X has tricked me into marrying him. They have shouted at me to end the relationship saying that I will bring disgrace on the family. But I like X. I wanted to be with him, so I ran away with him.

The notion of being 'tricked' into marriage was also echoed by Inoka whose parents had reported similar objections to her relationship at first as Lalani's mother. Inoka noted that her father forbade her from leaving the house but that she managed to visit her partner, running away with him to get married against her parents' wishes. Explaining this, she said:

> When my father heard about my affair, he was furious. He forbade me from going anywhere. He did not even allow me to go to the temple alone. When X got wounded, I think my father was worried about what the neighbours would say if I got married to a disabled person. He kept saying that X has tricked me into a relationship because I am young. I managed to meet X and I agreed to run away with him.

Another factor influencing the reported negative perceptions of family members, in this instance, in-laws, was the suspicion that the women were willing to live with a man with disabilities due to his state pension or for financial security. The connotation here is an inability to allow for the possibility that a young woman without disabilities would choose to marry or continue to live with a person with disabilities, unless there was some external reward. There appears to be a differential valuing of life based on ability or a devaluing of worth based on perceived ability/disability. As Sarani clarified:

I am not sure why his mother thought that I was after his money. I went against my family to be with him because I care about him. But nobody seemed to believe this.

These factors intersected with the idea that it is inconceivable to accept love as a potential reason for the women choosing to live with their partner with disabilities. All five women talked about how much they 'cared' for their partner and chose to marry or continue to live with their partner. Gayani put this succinctly when she said, 'he is still my husband, even if he can't see or hear or walk. I care about him. I will not leave him.'

Reaction

Family reaction

This theme denotes positive or negative reactions to marrying a person with disabilities, in this event, a soldier with war-related disabilities. The reaction was from family, other men or the general public and includes non-acceptance of the relationship and ambiguous, changing or predatory reactions. The negative response to disability appears to eclipse the arguably 'heroic' status imbued by war veterans reflecting societal stigma towards disability. The participants experienced the reaction of their families to their marriage to a soldier disabled in the war as primarily negative, reiterating notions of 'abelism' (Campbell, 2009) and stereotypes of the 'able-bodied male' and able-bodied privilege. The three participants who got married after their partner became wounded in the war narrated a comparable experience of facing a negative reaction from their families. This resonates with the cultural model of disability through its lens of 'cultural' interpretations and stigmatisation, which in turn informs our notions of self and sexuality. It offers 'a system for interpreting and disciplining bodily variations' and provides 'a set of practices that produce both the able-bodied and the disabled' (Garland-Thomson, 2002, p.5). Lalani who has been married for one year recounted her past, explaining how she disregarded her family's wishes and got married to her husband. Explaining this, she said: 'My family don't like him. I secretly ran away with him. They still don't like it…because he is disabled. My brothers have never visited. My mother has

never seen him…I want to leave that past behind me'. She was resolved to leave what she explained was a 'bitter past' behind her and look to create a 'new' life for herself with her husband. Through her own decision to 'run away' and to 'leave that past behind', Lalani is arguably challenging the notion of ableism and gender stereotypes in her making a life-changing decision about her own life, within a culture of patriarchy.

There were questions raised on the inability of the soldiers to assume expected traditional social roles within a heterosexual relationship. Sharing a somewhat comparable experience to Lalani, though more nuanced, Inoka described how she experienced her family's reaction to her marriage as follows:

> My family did not like him at first. They like him now. I don't think it is because he is disabled. I think it is because they did not know him. But I don't know…they may be concerned about my future.

The 'concern' about Inoka's future may stem from her husband's perceived inability to fulfil his traditional 'masculine' role as 'protector' and 'provider' within marriage. Her husband, experiencing a war-related disability is viewed as 'differently able' or 'not good enough' to be in a partnership with a person without a disability. This may feed into the religio-cultural explanations of disability as due to karma or God's will, with the subtle suggestion of persons with disabilities as 'lacking in' good fortune.

Lalani's and Inoka's narratives reflect a deeply embedded view of disability within Sri Lankan society as innately negative. The reaction of Lalani's family, therefore, is of concern for her, as she is deemed to have married a man unsuitable as he is unable to provide for her as a non-disabled man arguably could, devaluing him as being not on par with a man without disabilities. The perspective of the woman's family is in-line with the religious or moral model of disability, though arguably a diminishing view, which contends that disability is due to misdemeanours or retribution for 'sins' of a previous life, resulting in pity and marginalization (Addlakha, 2007; Anthony, 2009; Ghai, 2002; Kaplan, n.d.).

Sarani's story is also of a negative reaction, but from her husband's family rather than from her own. Explaining this, she recounted that, 'He got wounded 3 months after we started our relationship. I did not tell my mother. He asked me to

go away with him and I did.' She spoke at length of how her in-laws believed that she was 'after his money', reporting that,

> His mother does not like me. She thinks I'm after his money. My parents did not like it at first because he is disabled, but are alright now.

She explained that she was saddened by the reaction of her in-laws and the overall lack of acknowledgement of all that she was doing to take care of her husband. Reinforcing the notion of 'abelism', the reaction to a relationship of a woman with a man with disabilities appears to be to cast the woman in a very stereotypical and derogatory role of a 'gold digger'. The subtext of this narrative is the view that a man with a disability cannot be considered worthy of an adult relationship leading to marriage and that a person with disabilities, in this case the man, would not be able to fulfil the perceived expectations of 'maleness'. Therefore, the compensation or payback is the husband's money or his state pension. Sarani's concern appears to be that her own 'sacrifice' of being her husband's caregiver remains unacknowledged. In this, she imbibes the traditional role of a female as 'caregiver'. Contrasting the experience of women with disabilities to that of men in the Middle East, Abu-Habib (1997) asserts that 'Men with disabilities commonly marry – often an able-bodied woman, who subsequently serves as a lifetime carer' (p. 74), suggesting that men with disabilities are able to lead a 'quasi-normal' life. Inoka's self-proclaimed 'sacrifice' to become the primary caregiver to her husband embodies concepts of a 'lifetime carer'.

Reaction of other men

The women perceived a 'predatory' reaction on the part of other men towards them, epitomizing a sense of male entitlement within a patriarchal society. The younger participants felt a sense of vulnerability, particularly in public spaces due to being married to a person with disabilities together with their age and also possibly due to their youthful appearance. As their husbands were wheelchair-users, these young women felt that other men doubted that they were in a fulfilling sexual relationship, or assumed that they were unhappy and therefore open to an extra-marital relationship. Inoka, the youngest of the five women felt particularly

vulnerable and preyed upon, and shared her thoughts as follows:

> I notice men looking at me. They know my husband is disabled. I am aware of
> my vulnerability…the pressure from others. I tell my husband even if someone
> looks at me. Then he will not distrust me.

This view underscores a particular construct of masculinity speaking to notions of male entitlement. It promotes the view of men as strong and aggressive, with a sense of prerogative and privilege in heteronormative relationships within a patriarchal culture. Due to the fear of being preyed upon and to counter any suspicions harboured by her husband, Inoka does not go to work, to the temple or to visit her family or friends. She spends all her time at her husband's sister's place, looking forward to her husband's visits or to her visits to the residential centre.

Another explanation may be deeply-held constructs on disability and sexuality, in this event, of the soldiers with disabilities incapable of satisfying sexual relations with their partner. The embodiment of masculinity within bodily performance results in the vulnerability of gender in the face of an inability to sustain performance, such as in the case of a physical disability (Connell, 1995, p.54). Historically, persons with disabilities have been portrayed in society in two paradoxical portrayals as asexual, a rejection of their sexuality (Cheausuwantavee, 2002; Mona & Shuttleworth, 2000; Fiduccia, 1999), a sexually disenfranchised group in society (Milligan & Neufeldt, 2001) or as over-sexualised (Albrecht, 2005) with the participant views reflecting the former as held by men in society. As Finger (1992) asserts, 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about – and formulate strategies for changing – discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (p.9). So, while the narratives of the participants suggest society's notion of asexuality in relation to their husbands, it also covertly refers to the sexual agency or lack thereof in connection to these women who are excluded or marginalized from realizing their sexuality and reproductive rights.

That said, Addlakha (2007) argues that sexuality and sexual and reproductive rights have been seldom voiced in the literature in India, which mirrors the situation in Sri Lanka. As she notes, 'Sexuality is an area of distress, exclusion and self-

doubt for persons with disabilities' (Addlakha, 2007 in TARSHI, 2010, p.5). While there is limited available literature on all aspects related to persons with disability, the narratives by these women of how they experienced the comments and dialogues and their interpretation of the discourse reinforces the view of persons with disability as asexual, as lacking a right to sexual wellbeing.

Although there is an acknowledgement of a disenfranchisement among the sexes, women with disabilities are said to be particularly vulnerable due to 'the double burden of ableism and sexism' (Addlakha, 2007 in TARSHI, 2010, p.5). That said, a disability is viewed as impacting on self-perceptions and societal concepts of manhood and masculinity (Addlakha, 2007). The traditional societal expectation or stereotype of a man as aggressive, self-reliant and the breadwinner of the family is at odds with the perceived dependency of men with disabilities (Shakespeare, 1999; Tepper, 1999a, 1999b). It also reinforces the stereotype of the male partner in a heteronormative relationship as dominant, as the 'protector' of the woman's honour; as able to fight and ward off other suitors.

Gayani, the oldest of the five, also explained a sense of vulnerability that she felt. Her husband is unable to walk, and had lost his hearing and vision as a result of the war. The medical authorities are also unable to assess his mental health status. As Gayani reflected, 'Sometimes he shouts and I feel that he thinks he is still at war. In his mind, he is still fighting. He cannot abandon the war'. He visits his home once a year for the New Year celebrations in April. Gayani lives with her 4 children and narrated how she had to become the breadwinner of the family following her husband's injury. 'Men in the neighbourhood compare me to their wives and say how industrious and courageous I am. They try to win my heart but I am careful. They are the very people who sent nasty letters once I got this land because they are jealous'. Her words reflect the vulnerability of a woman even within a strong female-headed household. While the reported higher propensity to sexual abuse and exploitation has been documented (Beck-Massey, 1999; LaBarre, 1998; Nosek, 1996), there is little on the potential vulnerability felt by a woman (particularly a young woman) with a partner with disabilities within a patriarchal society with the double burden of ableism and sexism. Although socialized into portraying a practice of 'desexualized subjectivity' (Shildrick, 1996; Shildrick & Price, 1996), the narratives of these women indicate the points of resistance that enable them to affirm their right to choose and to their sexuality. As an extension of the social

model, which asserts that persons with disabilities are agents of resistance rather than 'victims' (Shakespeare, 2000), these women appear to resist oppression and thereby challenge existing social structures.

Abandonment

The theme of abandonment concerns feelings of neglect, isolation and ostracism experienced by the participants. This sense of feeling let down was said to be from the participant's immediate family and from the wider society. The reason for abandonment from the immediate family appears to be a lack of acceptance of the disability and due to a devaluing of diversity or stigmatisation of variation. Garland-Thomson (2002) contends that understanding of physical variation within the binary of desirable or undesirable undervalues diversity, resulting in the internalisation of a certain idea of the self. The self-worth of the person with disabilities was articulated within terms of what he was unable to do, rather than from a point of ability, resistance and resilience. Therefore, a recurrent concern was the questioning of the motive for a woman without disabilities to choose to marry a soldier with war-related disabilities. The explanation favoured was that the women got into, or continued to be in the relationship for monetary gain. The soldier's family members appeared to hold this view, with the women's families fearing for the quality of life of their daughters.

By his or her family

Gayani continued to share her story of abandonment from her husband's family. She explained how she was supported by the army and continued to receive her husband's pension. This money, she said, is in dispute as her mother-in-law too is making a claim for it. 'His mother has not come to see him since the accident. His mother is demanding Rs. 10,000 a month. I can't afford it. I have to send my four children to school, feed them and maintain the house. I also have to pay up my loans. I started a little shop this year and I am managing it.' Contesting this claim to the soldier's pension underlines Gayani's mother-in-law's refusal to acknowledge the legitimacy of Gayani's marriage to her son. It highlights the adage of 'in it for the money', which again unwittingly underscores notions of 'abelism' (Campbell,

2009). In spite of this, Gayani has built a house for her family and a little clothes shop in a single room in front of her house where she sells children's clothes that she has sewn herself. She has also bought herself a motorcycle, which she uses to travel into the city to get her supplies of cloth and thread, with no reliance on others.

By society

Viewed through a disability lens of diverse perspectives over the decades, the religious or moral model explains disability as resulting from retribution for misdemeanours from a past life or bad karma (Addlakha, 2007; Anthony, 2009; Ghai, 2002; Kaplan, n.d.). This has been noted to lead to societal isolation. According to Addlakha (2007 in TARSHI, 2010) '…the law of karma decreed that being disabled was the just retribution for past misdeed. Pity, segregation, discrimination and stigmatisation became normalised in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group, but also leading to the internalisation of such negative stereotypes by disabled persons themselves' (p. 11). Two of the women reported feeling forgotten and neglected by wider society. Nilanka said that, 'No one remembers the wounded soldiers. We are on our own now'. Akin to this, Inoka shared mixed feelings about her husband's involvement in the war, feeling both pride and sadness. 'No one cares for them now. No one remembers the war. People have forgotten. They don't remember if there was a war or what has happened to the soldiers. I feel proud of him and a little sad. If he didn't join the army, this would not have happened isn't it?' A sense of regret, in this case, of their husband joining the army, featured in both Nilanka's and Inoka's explanations of feeling abandoned by society.

Through their response to this reported societal reaction, to leaving their families and breaking family ties to be in a relationship with the soldier with disabilities, these women in fact postulate a social model of disability. Through their resistance of social pressure, with social structures that are oppressive and deny equality and full access of participation in society to persons with disabilities (Shakespeare, 2000). It is society that 'disables' and persons with disabilities, and in this

case partners of persons with disabilities are not 'victims' but agents of resistance, countering oppressive societal structures (Shakespeare, 2000).

Reliance

This theme refers to the participant's perceived need in their partner's life. This was described as unidirectional with the man needing or depending on the female partner. On the one hand, this view dovetails with that of the normative 'feminine' roles of undertaking domestic chores and taking on the role of caring for her partner (Addlakha, 2007). On the other hand, the physical and unfamiliarity with supporting a person with a disability and medical needs and therefore the level of dependency could be argued to challenge traditional constructs of gender identity. Disability has been conventionally viewed as characterised by 'vulnerability, powerlessness and dependence' (TARSHI, 2010, p.54). This image is in stark contrast to characteristics afforded to masculinity such as aggression, being the main wage earner and self-reliant, making it 'doubly stigmatising for men with disabilities' (TARSHI, 2010, p.54). All five women shared stories of their partner's reliance and dependence on them. As Inoka put it, 'everything is difficult for him…going to the toilet is difficult…many things. I help him with everything'. Sarani too conveyed similar thoughts saying, 'I wait at home and do all his work for him…to help him. I lift him to the chair. I clear his catheter'. Lalani extended these thoughts further relaying a sense of pride in being able to support her husband. "I help him get to the chair. I can lift him. I feel proud of myself'. Lalani is a petite woman challenging views of masculinity with regard to courage and strength and her ability to physically support her partner.

Similarly, Nilanka, who subjectively appears physically vulnerable was still able to support her husband as he is a wheelchair-user who experiences poor mobility. She too spoke at length about her husband's level of dependence. Nilanka explained how her husband needs support with all activities of daily living, saying that, 'he needs my help with everything. I help him to the toilet, to have a bath, to get dressed, to eat. I am not complaining. This is my role now. My duties as a wife'. Her view fits in with the normative feminine role of wife and homemaker. Gayani extended this idea of dependency, expanding it to include her children. She explained in much detail how her husband is 'totally reliant on the family'

when he visits home. Given that he has lost his eyesight, hearing and mobility, with some questions about his psychological state and wellbeing as a result of the war, Gayani explained how she and her daughters support her husband during the day as follows:

> When he was first brought home on a visit, I had to help him. I was afraid that I might hurt him. Now my daughters and I have learnt how to help him. It is not easy as he is heavy and he can't see, so he can't help us to lift him, and he can't hear, so it is difficult to know what he is thinking.

Gayani noted how all financial transactions, the building of her home and the establishment of her shop and her new entrepreneurial role as dressmaker and breadwinner had propelled her to take on a more dominant role:

> I have become tough, miss, like a man. I got this house done and the shop constructed all by myself. I bought a motorbike and travelled to the city to get building materials. Some of the men in the village try to flatter me but I take no notice. They think I am vulnerable because my husband is totally disabled and can't protect me. I am tough, miss. I shout at the men. I am protecting my daughters.

The narratives embody the paradigm shift observed with the feminization of poverty within female-headed households as a result of the war (Goonesekere, 2009). This is in contrast to the presumed norm of a male-headed households or "stereotyped roles in society" (Hyndman, 2008, p. 105). The contention within Gayani's discourse is how her experiences have shaped her personality with her being cognisant that she needs to take on the persona or 'masculine characteristics' of aggression, as she says, 'like a man', to be seen to be tough, not as 'vulnerable' as her husband can no longer fulfil his traditional male role of 'protector' (Shakespeare, 1999), which in turn she imbibes in her role of protecting hearth and home, suggestive of self-reliance, a trait usually connected with masculinity (TARSHI, 2010).

Blessing

The theme of blessing denotes elements of good merit that would befall a per-

son who engages in good deeds such as self-sacrifice in looking after someone who is physically and emotionally dependent. Though religious in nature, this explanatory model of disability within a charity or welfare model promotes feelings of sympathy and dependence requiring the 'charity' or assistance of others (Khanna, 2004). Arguably, this philosophy permeates much of the work currently undertaken by civil society organisations in Sri Lanka echoing a 'stigma-collective paradigm' (Cheausuwantavee, 2002). Connected to the theme on reliance, three of the participants also interpreted the opportunity to support their husbands within the framework of religion, Buddhism to be specific. Inoka asked me the following question twice in order to get confirmation for the idea of gaining good karma for caring for someone who is ill or disabled, which was a view she subscribed to: 'It is a blessing for me to care for him, isn't it?' I wondered whether this repeated question carried with it an underlying doubt or if it reflected her need to be validated.

Inoka went on to explain that she learnt on her own how to care for her husband:

> Miss, it is 'ping' (good merit) for me to be able to care for him like this. Nobody showed me how to but I can help him in the bathroom. I am just worried whether I can continue to do this. He may need other help in the future.

Nilanka too spoke in explicit terms, stating clearly her belief in gaining merit for supporting her husband as 'I will gain 'ping' (good merit) for looking after him'.

Resilience and sacrifice

This theme constituted a sense of resilience and sacrifice – in the face of objections and control from partners. This again connects with internalised notions of duty and domesticity for women (Khanna, 2004). The constructs of masculinity as 'protector', 'aggressor', the person offering 'financial security' (Shakespeare, 1999) are challenged in the light of women having independence to work and be financially secure, with opportunities for interpersonal relationships with the opposite sex. This appears to threaten the man's sense of masculinity and self-worth, with possible concerns of not being 'whole' or 'able'. This in turn appears to be masked by aggression in-line with 'masculine' constructs of demanding that women do not work and/or have minimal contact with other men. Viewed within a medical

model of disability that pathologises the body of the person with disabilities, the body is thought of as diseased, broken and not whole in comparison to the norm of an 'able body' or ideal (Khanna et al., 2004). That said, it appears that this 'dominant' role of exerting power over the actions of the woman, which is seen as a traditionally masculine trait is maintained through the disallowing of particular relationships or opportunities.

The younger women talked about how they were not going to work thereby sacrificing a life of potential independence to look after their husband. This is what Inoka had to say:

> I am not working. I don't do anything. It can be difficult to get leave on the days my husband is at home, so I am not working…I wait to support him. He comes home once in 2–3 months for a few days.

However, with time, in conversation, it was revealed that yet another reason for not working was that her husband was unhappy with her having any contact with other men. This dislike or by extension insecurity felt by the husband was also echoed within Lalani's experience as 'He (her husband) does not let me go to work fulltime. He does not like me associating with other men in the village' and that of Sarani as 'He does not let me travel or work'. Unable to talk about this part of her story, Gayani opted to write down her thoughts. I gave her distance and sat a little away from her while she wrote on page after page for approximately 20 minutes. Her written narrative includes the following text:

> Although my husband is there (she has cut out the word 'there'), I cannot put his loss into words. But because of my four beautiful children, I have the strength to face anything. I am a person who has suffered a lot. From the day my husband got shot, we have suffered a lot.

I visited Gayani just after the New Year and her husband had been brought home from the residential facility. While Gayani narrated her story, I could see her husband writhing on the bed, while his daughters dropped by to see if he was alright. Noticing that her husband seemed restless, Gayani left the interview to tend to him. I watched as one of her young daughter's wrote with her finger on her father's

chest, which is the communication system available to them as he has lost both vision and hearing. I saw how he touched his wife's hair and face and then with what appeared to be a mischievous smile touched his wife's body. Gayani managed to calm him down and I felt that I was privy to a very private intimate tender moment. This observation was a counterpoint to the discourse on sacrifice, albeit an incident from a meeting, which occurs once a year.

This incident was a reminder and challenge to the widely prevalent view of the asexuality of persons with disabilities (Addlakha, 2007; Cheausuwantavee, 2002; Mona & Shuttleworth, 2000; Fiduccia, 1999). It highlights the intricate negotiations between disabled masculinity, desire and feminization that Gayani appeared to experience at that moment. In a world where sound and sight are impaired, touch appears to have remained as a powerful medium of communication.

On her return to the table, Gayani went on to document her emotional journey and her resolve to start working and to support her family of four children.

> There are times when I get angry. I want to look after him without him suffering. There were times when I was fed up. All our dreams were shattered…6 months before early retirement. His pay got cut and we became destitute. Some people wait till they get a hand-out. Being a woman does not mean that I cannot (work)…I am the breadwinner now.

Her words echoes the feminization of households and underscores the resilience of young women made to inhabit patriarchal spaces and the changes in the power differential between husbands and wives. Gayani's words and her resolve to be a breadwinner is in contrast to the dependence on hand-outs within a welfare model.

Fears

This theme denotes concerns about the future; about one's physical and financial ability to continue to be the main caregiver to a person with disabilities in the face of increasing dependence. The strong bidirectional link between poverty and disability has been noted in the literature (Elwan, 1999) and have been reinforced by the findings in this study. Disability places people in a vulnerable socio-economic

position, particularly within resource poor countries where persons with disabilities are at the lowest rung of the financial ladder. Although pleased that they are able to care for their partner, these women were concerned about the future and about their ability to continue to be able to support their husbands. Overall, there was an anxiety about what the future holds. Nilanka shared her concerns for the future displaying her commitment for the long haul saying, 'I wonder if there will be a time when I cannot look after him…I am worried'.

Gayani too shared similar fears for the future, even though her husband only visited her at home once a year. She said:

> We cannot look after him at home. He is better off at the centre. He is only brought home once a year for Avurudu[3] (tears in her eyes). … I wonder if I can manage to look after him even once a year as things get worse.

While needing to live in the 'here and now', particularly as a result of the high level of dependency of the soldiers with disabilities, the women all appeared to be burdened by thoughts and concerns about their ability to continue to take care of their partners in the future as presumably, the level of dependence and care required will increase. Again, this concern underlines the shift in the gendered expectation of taking responsibility for the future and of being the main income generator. Connected to this is the lack of financial security expressed by Sarani who appears to be balancing her husband's request of not working with the reality of financial needs:

> I don't work. The money he gets from the army may not be enough in the future. He already has bladder problems and gets sores often. His family is poor. They don't help us.

Dreams

The theme of dreams contain the hopes held onto for the future. This included the desire to start a family, for children to succeed and for the possibility of building one's own home. All three of the younger women mentioned their yearning to start a family. Looking through a series of postcards I had presented to her, Lalani

said that she was drawn to one particular image. Explaining her choice, she said, 'I like this picture…My hope is to start a family (eyes well-up with tears)'. She also discussed her vision of making an accessible home so that her husband could be as independent as possible. 'We are making changes to the toilet so on his next visit, he will not have to use a chair outside. We need to collect money to complete it', she said. There was acknowledgement of the influence of financial constraints on the quality of life of persons with disabilities.

Inoka talked about her desire to build a little home for her family and to start a family. Sharing her dreams, she said, 'I want to see him. If he does not come home, I go to see him. I am waiting to be free to live happily[4]. If I look sad, it is too sad for him…so, I don't show it We want to have a place of our own someday soon; I hope…I would like to have a baby.' Sarani who was spending much time babysitting her two nephews said that she would 'like to have my own'. Like Inoka, she was concerned about not having her own space as well as the lack of an adequate income. She explained: 'We took a loan and bought this property. We have applied for help to the army. We want to build an accessible little home.'

Talking of one of her moments of successes, Gayani related how the support from the army had enabled her to build her home at a time when she had no idea where to go or to whom she could turn to. Communicating this, she said:

> I can face any sadness because they (army) made us a house. We now have a land and house to call our own. One of the fears I had was that my children would not have a place to live. But now we have a place of our own.

The need to own a place of their own and be less dependent on in-laws and to feel like a 'real' family echoed through the narratives of the women. It is suggestive of the potential negative consequences on the sexual and gender identities of the soldiers and their partners post-injury. As one of two participants with children, Sarani articulated this desire clearly saying 'we both want to be a real couple; to have a small house of our own and to start a family'. This need to be a 'real' family expressed by Sarani resonates with the narratives of the others. This need to be viewed as a 'real' or by extension, a 'non-disabled couple' or 'normative couple', may be connected to notions of stigma prevalent within society.

Gayani wrote at length about her dreams of success for her four children. She

said that she lives for them, to support their education and to look after her husband to the best of her ability. Continuing to write in her last page, Gayani states:

> There are a lot of things. But there is not enough time to write everything. My only wish is to be able to teach my children well and to look after my husband well and live the rest of my life well.

As I was leaving, Gayani got her daughters to come and speak to me and worship me, as is the local custom when you meet a teacher or an elder. Gayani's parting words were:

> My daughter drew this picture[5]. She wants to give it to you. She is such a talented artist. I want her to study hard and be successful (tears in her eyes). This is my only wish.

Conclusions

Overall, the narratives of the five participants generated three main themes and five interconnected subthemes. The overarching theme across all the narratives was love. These women have and continue to experience negativity from their families and report feeling a sense of abandonment from society; they live in relative poverty, display extraordinary courage, sacrificing their lives to care for their husband and children; they try to forget an unpleasant past and dare to dream of a future with hope.

The main limitation of this study is the small number of participants. The paper reported on the narratives of five women, which reflected their lived experience as recounted by them. While the researcher was able to make a few observations, these were limited to a few visits and was not in depth documentation across time. Further research studies should include a larger cohort of participants to enable the identification of themes relevant to a larger number of women, which in turn could influence policy-makers to review the psycho-social support offered to partners of soldiers wounded in the war. It is acknowledged that stigma is a complex phenomenon warranting in depth, nuanced representations of stigma and the stigmatisation process. It would also be of benefit to undertake longer

term ethnographic studies, looking at the interaction between and the influence and interplay of hierarchies, gender and socio-economic background on acknowledging and dealing with disability. Such studies have the potential to expand our understanding of the multi-layered nature of disability and gender.

Endnotes

1   It is acknowledged that the servicemen themselves may or may not define themselves as 'disabled'. Four of the five army officers described themselves as 'disabled'; the other had lost his sight and hearing and so, it was not possible to verify this.

2   Pseudonyms are used throughout to safeguard confidentiality.

3   'Avurudu' refers to the Sri Lankan New Year celebrated in April by Sinhala and Tamil-Hindu people.

4   She is living with her in-laws at present.

5   A picture of a monkey on a tree.

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Understanding and Exploring the Effects of Informal Care on the Sexual Self: A Disability Perspective

Andrea McCarthy

ABSTRACT: This journal edition explores the complex relationship between disability and sexuality for people receiving informal care provided from a family member or partner. Rarely does academic literature explore the personal experience, identity and the private relationships of disabled people, particularly within the context of care. As such both scholars and social workers have largely undermined disabled people's ability to control their own lives; including their sexual identity and intimate relationships within care settings. Within this paper I argue that the extent to which sexual agency can be exercised is influenced by intersecting parts of people's lives, such as having independence and supportive social networks. This paper will explore the complexities of personal relationships amongst disabled people receiving informal care, examining the limitations to intimacy and wider social life. Informal care can be extremely disempowering for both carers and those being cared for, often regulating their lives through the imposition of routine and structure, leaving little room for spontaneity. Therefore, for some disabled people and their carers this regulation and control of everyday life can have a significant impact on personal relationships, self-esteem and independence. Using case studies based on face-to-face interviews, this paper will explore the impact of informal care on personal relationships of people with a range of physical, mental and learning impairments. I propose that academia and social care professionals can learn from the personal experiences of the active disabled voice within research, particularly in relation to exploring intersectionality.

KEYWORDS: Disability; Sexuality; Sexual Agency; Informal Care; Intimacy

For many disabled people with complex needs, social care is essential for carrying out everyday tasks such as getting dressed, cooking and washing. Whilst some disabled people receive formal state care, many are still reliant on friends, relatives and often partners to provide essential care for them (Purandare 2003). This type of care is widely referred to as 'informal care' and is predominantly unpaid (Dearden 2001). Welfare provision has often depended on a relationship between both the state and support from social networks such as family members or partners who play a vital role in the both the care system and their loved ones lives.

Much research has shown concern for the impact of caring for both carer and recipient on their wider social lives (Arber and Ginn 1991). Recent studies have shown both formal and informal social care for disabled users have focused on the restrictions of social life, including the effects of isolation and helplessness for carers and recipients (Tarapdar 2007).Social care users often find their everyday routines regulated by rigid care routines and relationships mediated by the provision of care (Beckett 2007). Furthermore there has been increasing research into these issues and recognition within social research itself that care is a complex intersection between public and private spheres (Daly and Lewis 2000). This raises vital questions towards the effects of care on personal relationships.

These studies pose significant academic importance to this under-researched area and begin to draw links between social care and sexuality for disabled people (Beckett 2007). Furthermore, to date, literature has rarely acknowledged disabled people as able to control their own sexual agency and is often heavily focused on abuse and a lack of sexual agency. Tom Shakespeare (1994) suggests that within social research academics have often ignored the personal experiences of disabled people and have spoken on behalf of them. Abberley also recognised that disabled people within social research are often viewed as passive research subjects that fail to question power relations between the researcher and the researched (1987).This has also been a recurrent theme within feminist and more recently Critical Race Theory (CRT) which has critiqued previous forms of literature for not recognising power relations which reinforce colour-blind or sexist points of view. Hylton argues that CRT has enhanced his critical eye and enabled him as a researcher to draw on the theoretical framework to draw on other literature that has critiqued mainstream race research (2012).

This project seeks to draw upon these theories and recognise the importance of the active disabled voice in research. Stone and Priestly suggest that academics working within the dominant paradigms of disability have continued to marginalise disabled people by portraying themselves as the holders of knowledge (1996). Moreover, disabled people's autobiographical accounts are laden with examples of care being given without choice and a lack of consideration to protect the agency of the care user (Beckett 2007). In order to question previous methods of the social analysis of disablement, it is vital as a researcher to engage with an emancipatory form of research that gives participants a platform to voice their experiences. Within this paper I will be discussing the complexities of research into disablement and sexuality by drawing on past literature that rarely challenges the power structures that exist between the researcher and participant. This paper will seek to critique mainstream disability research, questioning these power structures, and instead drawing on perspectives of personal experiences told by the disabled participants.

The structure of this article is as follows. First I will outline some of the academic literature surrounding the topics of disability, sexuality and social care in order to review existing literature within these fields. This is followed by a description of research methods and procedures used during the study, including some of the challenges to conducting research on sensitive topics with potentially vulnerable groups of people. This is followed by a discussion of the several case studies which are divided into a discussion of three themes: independence, social networks and stigmatisation. Finally I will discuss opportunities, limitations and direction for future research in order to contribute to these under-researched fields of study.

Sexuality, disability and care

The disabled body is often perceived negatively by society, overshadowing almost all other aspects of a disabled person's identity. The concept of the disabled body is central to the idea of power and control as it is the social currency in which people signify power and worth (Gershick 2000). Therefore the treatment of people within society depends on how normative the body is perceived. Foucault's concept of the 'monstrous' (1999) describes sexuality as constituted not by otherness of abnormality, but by the offence it offers to the law in transgressing set guidelines

and regulations. However, sexuality is of course expressed through many different forms and has been recognised in social research as an integral part of human life (Weeks 2003; Merleau-Ponty 1962).

The disabled body is conceptualized in many different ways and generally grouped by physical and psychological impairments (Gerschick 2011). These impairments include mental health, deafness, blindness, Asperger's Syndrome, developmental disabilities and Tourette's, some of which I refer to within this paper. However, the category 'disability' has a long history that has focused predominantly on segregation (Shildick 2002). Beer argues that 'disabled people are 'left on the margins of social life', partly integrated and partly not, anomalous for the remainder of their lives' (Beer 2003:66). It is this separation between disabled and non-disabled people within social life that creates a divide not only within society, but also within social research where disabled people are often excluded as active participants.

Research into the personal experiences of disabled people is a relatively recent phenomenon in academic research and has previously surrounded issues such as abuse and lack of sexual agency. Since the 1990s the term 'disability' has been highly contested and the definition of who lies within the category 'disability' has been highly politicised.

Lunsky and Konstantareas (1998) suggest that there is little research in this area due to misconceptions about sexuality and disability. They argue that this has had a significant impact on how researchers view the value of the sexuality of disabled people, particularly those with developmental disabilities. They also suggest that there may be a negative perception of research in this area, resulting in it being perceived as not worthy of researching. This is due to the perception of a dormant sexual life for disabled people. Researchers may be deterred from researching disabled people for fear the participants won't be able to understand questions, or be capable of participating in the study (Lunsky and Konstantareas 1998).

Research has suggested that the categorisation and labelling process used in social research has been a limiting experience for many disabled people, which have ignored other equally important aspects of an individual's identity. McReur and Mollow (2012) claim that for a person to identify as 'disabled' is a complicated process. The marginalisation of people with a physical or learning impairment shows a focus on disability within a medical context, rarely taking into account

multiple and intersecting identities that make up the self.

The marginalisation of disabled people is inherently linked to societal critique of the disabled body, which is often perceived negatively and overshadowing almost all other aspects of the person's identity.

Foucault (2003) analyses the construction of bodily narratives in relation to power structures, relating to the disabled body, and its punitive deviant perception within the power of normal binary. The body is central in social life; people's treatment within society depends on how normative their bodies are: "One's body serves as a type of social currency that signifies ones worth […] people with less-normative bodies, such as people with disabilities are vulnerable to being denied social recognition" (Gerschick 2007: 76). This raises questions as to the perceptions of disabled people in society and whether or not they are controlled by what is socially constructed as 'normal'. Disabled people are considered as either in need of protection, or 'abnormal' and often denied sexuality as a result (Milligan and Neufeldt 2001).

Links can be drawn between the representations of disabled bodies, women and black people each sharing experiences of social prejudice from societies that locate the 'problem' with the body (Stone and Priestly 1997). In contrast to this, Oliver argues the social model of disability locates disability within the values, mode of production, political economy and welfare system of society (1990).

Sexuality is a subject that is rarely spoken about in relation to disability. This is a complex issue which is inherently linked to oppressive representations of the disabled body and subsequent regulation of disabled people's agency to exercise a sexual self that is visible to the public eye. Sexuality itself is still a taboo subject, historically being seen as sinful unless it is for procreation (Tepper 2000). Past literature on sexuality has questioned the definition of sexual identity and the relationship between the sexual and the social (Weeks 1985). It was not until the 20th century that scholars began to (re-)view sexuality as a natural part of human experience (Foucault 1978).

Foucault argues that sexuality is controlled and regulated by organised power structures limiting how sexuality is exercised. It is expressed through many different ways and is recognised as an integral part of human life (Weeks 2003; Merleau-Ponty 1962). Centuries of oppression have resulted in deeply entrenched norms surrounding sexuality. Foucault's work is inherently linked to the oppression and

otherness of disabled people with particular reference to the disabled body which is segregated from the idea of dominant cultural 'normality'.

Research by Lamb and Layzell (1994) also recognise the unspoken taboo surrounding disabled people and their intimate relationships. They argue that disabled people's emotional and sexual needs are rarely discussed in everyday life and views on sexuality and disability have only be challenged as a result of input from disabled people themselves (Oliver 1996; Barnes and Mercer 1996). This is an argument also supported by Bonnie who suggests "society at best finds the thought of a disabled person being sexually repulsive and at worst presumes we are all asexual" (Bonnie 2004: 125).

Over recent years a number of key activists and academics have begun to conduct researched into the field of disability and sexuality, challenging the idea that disabled people do not exercise a sexual self (Tepper 2000; Shakespeare 2000; 2002). However, it is important to remember that options for exercising agency are still only empowering a small percentage of disabled people, who are able to explore their sexual desires (Smith 2004). Smith suggests that there are a number of reasons underlying why such a small number of disabled people feel they can exercise a sexual self, relating to social and cultural barriers such as the perception of a lack of agency, stigmatisation of disability and a negative public reaction to disability. It has been recognised by activists and scholars alike that to exercise sexual freedom and happiness is a fundamental human right (Geschick 2011). More recent publications have continued to explore the complexity of disability and sexuality through an interdisciplinary approach (McCarthy 2011; Oliver & Barnes 2012).

However, few scholars have explored these issues within the context of care. The act of care in itself represents uneven power structures in which disabled people are seen as passive, powerless and dependent on others (Silvers 1995). This argument is also shared by Paul Abberley (2002) who highlights the disempowering effect day-to-day exposure to medical interactions can have, which can be problematic for bodily agency and integrity for disabled people. However, the perspective of disabled people receiving care has largely been left out of care research. Lloyd in particular highlights the importance of feminist research on caring that recognises the experience of disabled women in care as doubly disadvantaged as their bodies are scrutinised against traditional notions of femininity and sexuality (2001).

Disabled people within an environment of social care often have very little agency, both in terms of exercising sexuality and having control over the process of care itself. Beckett (2007) argues that for care to become empowering, it must be linked to a framework of rights. This supports a body of literature claiming that care is related to a lack of agency, control, and ability to control basic social functions (Beckett 2007; Hughes 2007; Fine and Glendinning 2005). Both in the context of a care home or for social care users receiving support within their own homes, research has shown that individuals have very little control over their own destiny.

There has been increasing recognition in recent years of non-traditional types of care for disabled people, often carried out by family members or partners (Beckett 2007). This creates a blurred boundary between the relationship between personal lives and care for disabled people. Beckett (2007) argues this lack of clarity on the definition of care is problematic for both carers and care receivers, where both are constrained and have limited choices. This level of constraint may impact on personal relationships between carers and care givers; however, the effect this has on sexuality is largely underexplored.

Intersecting elements of disabled people's lives can affect both dating experiences and levels of sexual behaviour (Kef and Bos 2006). There is a lack of research within social science on the sexual lives of disabled people and the experiences of intimacy and sexual and romantic relationships have been ignored. Having a disability may result in moderate to severe restrictions in the performance of social roles related to work, family, leisure and relationships. Kef and Bos also suggest that dating occurs much less often amongst people with a physical disability (2006).

Research exploring sexuality and disability has acknowledged the profound effect that disability has on sexuality. However, the impact that care has on disabled people's lives is still underexplored and in need of further research to explore how disability and sexuality intersect with elements of care such as personal relationships, marriage and family life. This paper will explore some of these issues in order to draw links between sexuality, disability and social care.

Methods

This paper is based on empirical research using semi-structured interviews. People with a variety of different impairments were interviewed on their experiences

of informal social care and exercising sexuality. In this research project, ten semi-structured interviews were conducted; eight in person and two by phone on the request of the participants. These interviews were conducted between September 2012 and February 2013 in Brighton and Hove, forming the data for my dissertation thesis at the University of Sussex. Recruitment of participants was a particularly challenging process as the majority of respondents were considered a 'hard to reach' group not often not able to access public spaces due to their impairments where advertisements about the research may be displayed. Most respondents were recruited through a gatekeeper who enabled me to gain the trust of participants and reassure them of the legitimacy of the research with relative ease. This approach to recruitment was particularly beneficial for the project due to the sensitive topic and involvement of potential vulnerable respondents. The rest of respondents were recruited online through forums once permission had been granted from the owners of the sites. This enabled respondents who were not so mobile to still be able to partake in the research.

Semi-structured interviews allowed interviewees the freedom to discuss their experiences in detail and at their own time (Bryman 2001).The interviews were made as informal as possible in order to make participants feel comfortable. It was vital to use a more intimate approach to interviews in order to limit embarrassment and make the respondents feel comfortable (Stewart, et al. 2007).

The research focused on personal experiences of disabled people through a qualitative method of data collection. To avoid filtering experiences and gain an accurate wider view, qualitative research into people with disabilities' experiences appeared the most effective way to produce valid data (McCarthy 2000). Thematic analysis was then used in the analysis of the data, resulting in three main: stigmatisation, social networks and relationships.

The decision to use empirical research methods is attributable to both the sensitive topic and the detail that I felt this topic needed to provide any significant understanding of the personal lives of disabled people. Research conducted in the 1990's had previously failed to ground their work within an epistemological framework, often being considered as oppressive to the disabled participants involved (Abberley 1987). Therefore this research sought to firmly locate itself within an emancipatory paradigm that puts profound importance on giving a voice to the personal as political, and endeavouring to focus on personal experiences of participants.

The use of semi-structured interviews gave respondents an opportunity to voice their individual experiences of participants at their own pace, and supported emancipatory research techniques. A longer, less structured interview enabled a practical benefit to the self-empowerment of participants and removal of barriers that may prevent them from taking part in the research. This technique is much more suited to small scale projects to reduce any disabling barriers (Barnes 1991; Fontana and Frey 2005).

Independence

Independence was a key aspect in all the respondents' lives, relating to individual agency and self-esteem. This theme was identified by respondents in reference to the extent to which they could carry out everyday activities without the care of another person, usually a family member or partner. Several respondents felt that receiving both formal and informal types of care affected their ability to structure their day and carry out spontaneous activities or outings with friends and family. Respondents described how care amongst partners or close family members had changed their relationship. Many often struggled to distinguish time spent together intimately or as friends and time within the roles of carer and recipient.

The close relationships respondents had with informal carers often impacted on self-esteem and the ability to separate their disability from the rest of their identity. Several respondents felt their lives had become dominated by structure, routine and often control, as much of their day was spent carrying out essential tasks, with few opportunities for leisure or relaxation. I will illustrate some of these issues using case studies of respondents within the study who experienced physical, mental and learning impairments. In the accounts below issues of the structure, control and unpredictability of the need for care illustrate how personal relationships can be affected by the reliance on informal care.

Impact on the family unit

Alexia has Chronic Fatigue Syndrome and is married with two teenage children. Alexia's impairment can fluctuate from day to day, meaning some days she can carry out everyday tasks with very few symptoms and on other days she may be

unable to leave her bed due to fatigue. Alexia also expressed signs of depression relating to the limiting effects of her impairment, resulting in feelings of worthlessness and lack of self-esteem. This was often due to the unpredictable nature of her impairment which left her unable to make plans or be sure she would able to carry out tasks on certain days. She was heavily reliant on close family and her husband to look after the children on days when she was unable to, which left her with a feeling of helplessness. This was also a contributing factor to excessive strain on both her marriage and family life.

'I'm reliant on my husband and daughter, they have to do everything when I'm confined to my bed, I just feel helpless, completely useless.' Alexia described how the reliance on her husband for care had impacted their sexual relationship as she was often unable to be intimate. 'When I'm really ill I can't even make love to my husband, it's really impacted on my relationship, all he seems to do is care for me it's very un-erotic and can be quite depressing.' The relationship of Alexia's husband as both a partner and carer had impacted upon the marriage not only financially, but upon intimacy in the marriage. The lack of permanence in the severity of her illness meant that she was not eligible for formal social care. Therefore the impact was that both family life and her marriage were regulated by unpredictability and the loss of spontaneity that she felt would benefit her close relationships.

Restrictions of care on everyday life

Jane has Multi Degenerative Disk Disease, the symptoms of which include poor mobility, severe back pain and incontinence. She is a wheelchair user and lives alone. Jane has a formal carer who comes in once a day to help with breakfast and getting dressed which she does not like as the carer often arrives late, restricting her ability to plan the rest of her day. Jane has had a number of partners over a period of time that have come and gone; unable to cope with the role of caring for her. Jane felt as though her disability 'owned her' and this was often the cause of her relationship breakdown and topic of conversation with friends. 'I am fiercely independent, probably trying to prove to me and to other people that the disability doesn't own me'. Despite her determination for independence, Jane had spoken in length about her depression over the limitation of her impairment of both her social and sexual life. She also felt that when talking to friends, people

raised little conversation that was not related to her disability, resulting in loss of self-esteem.

'When I see people I haven't seen for ages and they ask me how I'm getting on and what surgery I've had, it's like there's more to me than that'. Jane indicated that often when she socialised with people she did not see often, her disability was the main topic of conversation leaving her feeling 'othered' amongst her friends. Jane felt the impact of her impairment had not only resulted in a lack of meaning-ful, supportive social networks but had hindered her ability to settle down with a partner.

Age and the complexities of growing up with a parental carer

Zoe is 19 and has Spinal quadriplegia C3–C1[1]. She is a wheelchair user and has a PA (Personal Assistant) with her during the day to help with mobility and day to day tasks. During the evenings and other times when her PA is not with her, she is cared for by her dad who is a single parent. Zoe has a strong relationship with her dad and they often talk openly when talking about Zoe's sexuality. However, the relationship between Zoe and her father had become increasingly complex after she had reached puberty. She felt the caring relationship she had with her dad had become 'inappropriate' and 'uncomfortable', particularly when helping her wash and get dressed. Zoe expressed how the relationship of her dad as a carer had made her feel desexualised and childlike.

The complexity of the parental care relationship had furthermore deepened when Zoe had met her current partner. Her emerging sexual agency had resulted in the role of care being taken over by Zoe's boyfriend. She felt the intimacy of her caring routine such as washing were no longer appropriate for her dad to under-take 'I've had people around me, like my dad and family looking after me. They still make me feel I'm not an attractive person and should be kept in the dark'. Zoe felt the process of care being undertaken by a family member was a desexualising ex-perience that had impacted on her ability to exercise an intimate relationship with her boyfriend. This is a concept that Cole and Cole (1993) argue has desexualising experiences on libido, and self-esteem affecting the disabled person through their sexual lifespan. The clinical process of care carried out by her father had caused

Zoe to feel desexualised. The overall reliance on care had subsequently changed the dynamic of the relationship with her dad and strengthened the intimacy between her and her current partner.

Stigmatisation

Based on personal experience, stigmatisation of the label 'disability' was an issue that all the participants recognised. Mollow and McReur (2012:1) suggest 'rarely are disabled people regarded as either desiring subjects or objects of desire'. Participants had encountered negative comments about their disabilities from a range of different people in their lives, including strangers in the street, co-workers and even family members. Often friends and family would have very little understanding of the importance of sexual agency, showing disapproval when they entered into a relationship. Howard Becker's (1963) theory of deviance argues that individuals can break the rules that are agreed by a group of people, but as a result are labelled as 'outsiders'. Becker's study can be linked to the participants within these case studies, with many experiencing hostility about exercising a sexual self. Participants were often questioned by both members of the public and their own family friends, placing stigma on both their identity as a person with a disability and as someone who exercises a sexual self. Becker's identification of individuals as rule breakers being labelled 'outsiders' by dominant societal norms is inherently linked to society's regulation of disabled people, particularly when exercising sexuality. One respondent named Julie had particularly harboured painful feelings of low self-esteem and lack of self-worth relating to an internalised oppression resulting from her rejection of the label disability. These negative feelings had resulted in a difficulty coming to terms with being diagnosed with a disability later in life.

The stigma of the label

Julie has severe dyslexia, but was not diagnosed until she was in her mid-30s. She had also just recently been diagnosed with depression as a direct result of not being able to cope with her diagnosis of dyslexia. She felt by being diagnosed with both a mental health condition and learning impairment, both labels would dis-

advantage her in her life. 'It took me a long time to get used to having a disability, I felt like it would make me appear incapable to myself and to others'. Julie's struggle to come to terms with the diagnosis of both impairments was founded on her preconceptions of the stigmatisation of the label 'disabled'. The category 'disability' has a long history that has focused predominantly on segregation where people feel that they will become an 'outsider' (Shildrick, 2002).

For Julie, the biggest impact upon her life was the stress of coming to terms with diagnosis, and the label 'disability'. This had impacted on her relationship with her partner due to her acute lack of self-esteem and feelings of worthlessness. Julie described her relationship with her partner being about going out and having fun with their friends. Whereas after her diagnosis with dyslexia, and subsequently depression, she described herself as introverted and lacking self-esteem, which had impacted on her confidence within the relationship. Hahn suggests that the effects of stigmatization may cause powerful psychological barriers that may create obstacles for the disabled men or women in love and marriage (Hahn 1981). The psychological obstacle was founded upon her struggle to connect with the label 'disability' largely due to her diagnosis later in life. When asked how she felt her disability related to her sexual identity she replied 'I think it does, I mean although personally more the transition of accepting that I would have a disability, it's a very big thing for me to accept the sort of label side of it; just the effect on my self-esteem'. Julie clearly identified with stigmatisation through the label of disability which impacted on her self-esteem, 'I felt like it was quite a transformation over a period of time which definitely impacted on my self-esteem'. Becker's (1963) suggestion that minority groups are labelled, creating a self-fulfilling prophecy where the individual internalises and becomes the label. Julie's reluctance to adopt the label 'disability' was due to fear of feeling, and being perceived as incapable if she adopted the label of having a disability.

Goffman (1963) argues that a coping strategy regarding social stigma is withdrawal from society. He suggests that society develop places for stigmatised individuals, which he refers to as 'total institutions' (Goffman 1961). It was evident in this research that the category disability in itself is a form of 'total institution', which is controlled and regulated, limiting the experience of sexuality for many disabled people. Regulation can occur in many different ways including limiting access to locations to meet partners or exercise a sexual self.

Public reaction to disability

Rosie was diagnosed with ME (Myalgic Encephalopathy)[2] when she was 19; she is now a partial wheelchair user. Now age 25, much of the interview had been about comparing her life before and after she was diagnosed. The majority of these comparisons were made in relation to how she is perceived in public by strangers. She explained how people talk to her in the street, often at night when out socialising, asking about intimate details relating to her sex life. 'There's usually questions about 'does it work' [to have sex], you get people saying "can you have sex?" People assume your sex life is going to involve hoists'. Rosie experienced a surprised reaction when she did tell people about her long term partner, 'People come up and are really surprised when I mention I have a boyfriend, and say "oh well done"'. Rosie's experiences indicated a wider public perception of disabled young people as passive, incapable of having a sexual relationship and needing care. She felt that because her disability was not visible unless she was using her wheelchair, she had a duty to inform people about how having a disability should not affect sexual agency.

Rosie also expressed the complexity of online dating as a person with a disability. She had created an online dating profile after being diagnosed with ME as she felt it was an easy and convenient way for her to meet people. Several times she experimented with disclosing that she was disabled, and not listing her disability. 'It's difficult deciding whether you mention your disability or not. When I did, I mainly got disabled people replying. I thought this was weird […] it doesn't mean were going to have anything in common'. When Rosie listed her disability, mainly disabled people replied, indicating that there may still be stigma attached to disability when looking for a sexual partner. Morris argues that "We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to conclude in our own oppression (1991:183). Rosie's experience with the dilemma of whether to disclose her disability on online dating sites was due to past experiences of prejudice towards her disability when meeting potential partners in the past. She felt that when she did disclose her disability, only other people who were also disabled would reply; suggesting that some disabled people may feel that prejudice has limited opportunities of choice to find a potential partner. There-

fore Rosie's experience may evidence that some disabled people feel they may only be able to enter a relationship with someone who has had a shared experience to them, rather than feeling able to choose a partner based on compatibility. The feminist slogan 'the personal is political' is inherently linked to this argument where the personal experience of disabled people is connected to larger political and structural attitudes.

Social networks

The ability to interact with a social network of friends is an important aspect in many people's lives, regardless of whether they have a disability or not. However some respondents within this study indicated that having a close and trusted friendship was a vital aspect of their sexual self. Several respondents felt they had a group of friends who would support them in all aspects of their lives, including sexuality; this was a vital part of reassurance for them. Social networks were expressed by all participants as an important aspect of confidence, independence, being able to meet potential partners and discuss love and relationships amongst friends. However, despite the importance of social networks, it must be acknowledged that several of the case stories previously discussed highlighted examples of friends and family showing a lack of recognition of the respondent's life beyond their disability. This resulted in frustration and resentment from participants and highlights the complexity of the role of social networks and the need for a balance between having someone who is understanding and supportive, but also recognising that disability is only aspect of their identity.

Friendship as positive regulation

Joanne has bipolar disorder[3] and lives with her husband and two young children. Her positive experiences of social networks with friends were vital to providing support for her impairment. Joanne used friends as a support network to identify when her mental health condition was getting, in her words, 'out of her control'. 'People monitor what I'm up to because it sort of relates to where my brain's working and that might be when I'm having a little up time'. Joanne's symptoms are common amongst people with bipolar who often experience ups (known as

mania) and downs where they can feel much less active. During what Joanne defined as a particularly 'high' phase, she experienced risk behaviours such as an uncontrollable libido and recklessness, so she relied on friends to support her to keep her bipolar under control. In the past her high libidos resulted in her having an affair, so she relied on friends to help her rationalise the situation. 'I sort of had a little affair and in which people thought oh she's going a bit loopy because that's not right is it?' Social interaction for Joanne was a direct support for both her disability and sexuality to be regulated and controlled by those around her.

Socialising as a way to meet partners

Christine has Tourette's syndrome[4]. She receives negative attention when out in public from people who do not understand her disability. Christine's 'ticks' cause her to make involuntary physical and vocal movements that are often unusual and alarming to strangers. Christine expressed how she would like to find a partner, but feels people are often deterred by her impairment. She also stressed the importance of a close group of friends to socialise which is vital for her confidence to find a partner. 'It's hard to meet people, when I'm with my friend I'm a lot calmer so my ticks are less frequent and people are more likely to approach me'. Christine's close social networks and supportive group of friends was an important stage in socialising to meet a partner. She suggested that her disability had stopped her from getting a partner in the past and was the cause of several relationship breakdowns. 'I've never had much luck with women, people are fine with it at first but then they seem to not cope if you're down about it [her disability]'. Christine identified that her disability was preventing her from exercising a sexual self and meeting a potential partner due to lack of understanding about her disability.

Conclusion

The findings from the case studies reported in this article represent the importance of examining intersectionality in the lives of disabled people. Past literature on disability, sexuality and informal care has tended to ignore the personal experiences of disabled people, particularly surrounding sexual agency. Three main

themes were uncovered in the data, offering explanations to the links between sexuality and disability; these were independence, stigmatisation and social networks. These themes discussed intersecting sections of respondent's lives, often not directly linked to sexuality, but inherently linked to an overall sense of self-esteem and wellbeing. The range in complexity of different impairment will inevitably bring varied experiences. The findings in this article illustrated the unpredictability of impairments such as Chronic Fatigue Syndrome and the effects of living with a fluctuating impairment on personal relationships. Unpredictability in care routine was often a cause of what some participants described as an 'extra burden' on the care process.

The data collected in this study has found that there are several intersections between elements of social life and sexual agency. This was related directly to impact on sexual agency and the extent to which respondents felt confident exercising a sexual self. Stigmatisation, lack of independence and pressure of informal care on partners all contributed to the limitation of the sexual self. The extent to which care routines allowed participants to be independent impacted on self-esteem, which was a central issue to all of the themes discussed in this paper. Self-esteem was often linked to a feeling that their impairment had overshadowed other parts of their identity. The support, or lack of support from social networks was linked to the need for having both an understanding of their impairment, but equally acknowledge aspects of their identity beyond disability. The importance of recognising these intersecting themes illustrates the complexity that disability and care bring to sexual relationships. For many, this relates to stigmatisation and public perceptions, which were felt to limit participants more than the actual impairment itself. 'The social model of disability identifies systematic and attitudinal barriers for disabled people that contribute to the exclusion of disabled people from society. 'Disability' as a label is a source of oppression which places significance on the limitation of the mind or body. The social model of disability recognises that disabling barriers are socially constructed rather than being organised by a person's impairment itself (Scope 2014)

This article demonstrates the importance of examining the personal experiences of disabled people receiving informal social care. The findings indicate not only complexities surrounding personal relationships with carers, but the impact of public perceptions of disability on sexual agency. It is articulated in this article

how the perspective of personal experience in social research can strengthen understanding of informal care and sexuality. The use of the emancipatory paradigm within the research and the commitment to conducting emancipatory research techniques illustrates my politicised action in challenging past roles of disabled people in social research. Touraine also argues that participant observation may only provide 'light touch' data that does not illustrate a commitment to the historical struggle and movement of research participants (1981). As a researcher interested in disablement, it is vital that the research process itself is challenged and the voices of participants are heard in order for oppressive practices to be challenged. My decision to engage in emancipatory research techniques is used to highlight the importance of research that engages with the personal experiences of disabled people, rather than speaking on their behalf. I have proposed during this article that academia and social care professionals can learn from using emancipatory techniques in order to promote the importance of agency for disabled people and those receiving social care.

The overall negative perception of disabled people in the public eye and its potentially damaging effects was a prominent finding. Recent government welfare cuts have directly impacted on disabled people and undoubtedly had an effect on attitudes toward people with disabilities. This article highlights how participants were scrutinised in the public eye, often being asked to justify different elements of their lives including intimate details of personal relationships. Oliver argues that the social model of disability is located firmly within the political economy and welfare system in society (Oliver 1990). This negative public perception of disabled people has been shown in this research to impact on self-esteem and undoubtedly effecting sexual agency, personal relationships and confidence of disabled people.

Although key debates within the fields of sexuality, disability and social care have touched on issues of sexuality amongst disabled people, rarely does this literature illustrate the experiences of disabled people across all age groups. Research has seldom examined the intersectionality of disability, sexuality and social care and has largely been delayed in response to adopting emancipatory research techniques. The development of research within these fields and careful consideration to personal experience will greatly assist with future understanding of the intersection between disability, sexuality and informal care.

Endnotes

1   Spinal quadriplegia C3–C1 is a spinal cord injury resulting in either complete or incomplete quadriplegia, where voluntary movement and sensation of the limbs is severely limited.

2   Myalgic Encephalopathy (ME) is a term used to describe people who feel that Chronic Fatigue Syndrome is too general and does not reflect the severity and different types of fatigue. It highlights that fatigue is just one of many symptoms that can vary from day to day.

3   Bipolar disorder, formerly known as manic depression, is a condition that affects your moods, which can swing from one extreme to the other.

4   Tourette's syndrome is a neurological condition affecting the brain and nervous system that is characterised by a combination of involuntary noises and movements called 'tics'.

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Love, sex, disability, coming out and John Travolta in New York and Jerusalem: A twenty-year journey

Scott Sheidlower

Personal Narrative

Before getting into the details of my story a little background is important. My disability is both dystonia musculorum deformans and epilepsy. The dystonia is the most visible of my disabilities. When I first developed it, the disease manifested itself as paralysis on the left side of my body. My dystonia was an atypical case in that it affected my arm and wrist more than my leg. My left wrist and fingers were totally paralyzed and when I walked my left foot walked on the heel. The left dimple on my face was not as deep as the right dimple when I smiled. Sitting up required a great deal of energy because I did not know what to do with my left arm. My left arm could not be raised as high as my shoulder.

The dystonia began at age fourteen when I was in ninth grade, during which I applied to and was accepted into the Bronx High School of Science. This happened in 1970. However, my first non-masturbatory erotic experience happened in 1966 when I was ten years old and before my disability. In that year my father took me out for my birthday, just him and me. He was an alcoholic. After dinner we went to a bar that had a belly dancer. My father seemed to know her and he told her that it was my birthday. She made a big fuss over me. It made me uncomfortable. This being before Stonewall[1] and in a more innocent era, I didn't know why. I had to wait until I was twenty to discover why I had felt that way.

The world in which I became disabled and the world in which I came out were very different from the world of the early twenty-first century. This was a period preceding the US television series *Glee.* On *Glee,* as in today's society, both gay

and disabled characters (although they are not the same characters) are accepted. This was not true then and Stonewall was just starting to affect American society.

Stonewall, the event that triggered gay liberation, happened in 1969. I was only thirteen and not yet disabled. Very few people, at the age of thirteen, discussed the event or LGBTQ people (they were all homosexuals then or queers [and queer not in a good way]). I read a short article about it in the *New York Post* and was turned on. Yet I was still so very unconscious of my life, myself, and my desires that I didn't make the connection that reading about gay men excited me because I was one of them.

When I became disabled in 1970 society was also different than it is in the twenty-first century for the disabled and their sexuality. According to my understanding and limited experience as a young teenager, American society at that time had only two role models for the disabled: Dickens's Tiny Tim from *A Christmas Carol* and Helen Keller. Dickens describes Tiny Tim and his attitude towards being disabled as follows:

> And how did little Tim behave?" asked Mrs. Cratchit . . . ." "As good as gold," said Bob, "and better. Somehow he gets thoughtful, sitting by himself so much, and thinks the strangest things you ever heard. He told me, coming home, that he hoped the people saw him in the church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day, who made lame beggars walk, and blind men see." (Dickens, 1988, 52–53)

In other words the disabled were to be an object of pity; a problematic and an asexual one.

The other role model for the disabled then was Helen Keller. Her story was well known and had been reinforced by director Arthur Penn in his 1962 movie adaptation of William Gibson's play *The Miracle Worker*. Not to take anything away from either Annie Sullivan or Helen Keller, but they work miracles! Helen Keller went on to graduate college. She learned to speak although her parents had been told she couldn't do so. She was "Super Crip." Although Sullivan flirts with James Keller, Helen's older brother in the movie, as soon as he sees her disabled eyes he drops her. That's all the disabled could look forward to in 1970.

Granted President Franklin Delano Roosevelt was disabled and had married, but his disability was hidden and not spoken about at the time. Things didn't change in

larger society until 1978. That year a film, *Coming Home*, was released. That film told the story of the wife of an American soldier in Vietnam, played by that year's Oscar-winner Jane Fonda who had an affair with a paralyzed returned soldier, played by John Voight. The film was a topic of general conversation both around "water coolers" and in the media. Not because Fonda's character and Voight's character had an affair! No, they were shocked and surprised that Voight's disabled character was sexual (Fonda has oral sex with him in the movie). The shock of finding out that the disabled were sexual beings started to change society and eventually my life too.

In 1971 when I was fifteen, I was lucky and was taken by my mother to upper Manhattan to Columbia Presbyterian Hospital's [now known as New York-Presbyterian/Columbia University Medical Centre] emergency room. They were not sure what was causing the paralysis and so admitted me. Columbia Presbyterian and now New York-Presbyterian/Columbia University Medical Centre is a teaching hospital. I was eventually seen by a doctor whose father was the head of neurology at Mt. Sinai Hospital in New York City. Because of his father's profession and connection with a Jewish hospital, he recognized my paralysis as Dystonia. I was told it was a rare Jewish disease and that there was no treatment. I took part in a trial for a Parkinson's medication called L-DOPA. The drug did not do an awful lot for me, but it did make it slightly more comfortable to sit up in a chair.

There was one other new Parkinson's treatment that could be tried. It was a brain operation that had been developed by Dr. Alan Cooper at St. Barnabus Hospital in the Bronx. My family had decided we were not going to try this operation until, or unless, the L-DOPA did not work. The reasoning being that whilst you can stop taking medicine, an operation is permanent. The operation is called a cryothalamectomy. Cryo means cold and a thalamectomy is the removal of the thalamus. So the operation destroys part of the thalamus using cold; in this case liquid nitrogen. I had the operation at St. Barnabus, but not by Dr. Cooper. I had it performed by his younger associate, Dr. Waltz, who I called "the dancing doctor." Anyway, the operation was a success. It released my left hand, but not my left wrist. My left foot relaxed to the point where I now walk on the sole of the foot, at least most of the time. My right dimple is still deeper than my left dimple, but I have a beard so you really cannot tell anymore. The operation is done while the patient is awake and uses only a local anaesthetic. The creepiest part of the operation is that while they were drilling through my skull in order to insert a needle into my brain

I heard the drilling going on. Once they had created a hole the size of a nickel in my skull they inserted a needle and stimulated various areas to see what they controlled. When they found the area related to the Dystonia they destroyed it with liquid nitrogen. They then stitched me up and I then went to the recovery room. I slept for two or three days after the operation.

During the time I was disabled I had received home instruction and graduated junior high school. Obviously, since I was disabled and stuck mainly at home I didn't date, nor did I meet people. After the operation, in the fall of 1972, I was able to return to school. Since I had been previously accepted into the Bronx High School of Science, a specialized school that emphasized science, it was arranged that I would start there as a sophomore in tenth grade.

I returned to school with a very pronounced limp and a bald head (my head had been shaved for the operation). My arm was stiff and fairly immobile, as was my left wrist. I was also extremely shy and had a low sense of self-esteem (after all, I was different. Although nobody said that, I felt it). I had almost no friends. I do not know if people dated, but being only four years after Stonewall, there was certainly no gay life at the school. In 1973, I graduated from high school.

In the fall of 1973 I started Hunter College of the City University of New York (CUNY). It was an interesting place. All the stalls or most of the stalls in the men's rooms had holes in their partitions. I was so innocent that I had no idea what these were. They were glory holes. You could make a connection with the guy in the other booth and he could stick his penis through the hole or you could stick yours through to be played with. Once I knew that it explained the many dried stains on the stall's walls. It took me a while at Hunter to learn that this was their use and to use and enjoy them sexually in this manner.

Since my major was in archaeology, I decided in 1975 to go to a school with a better reputation for archaeology, The Hebrew University in Jerusalem, Israel. It was and still is one of the premier schools for biblical archaeology. I applied and was accepted. I have no family in Israel, but I thought it would be like New York only in Hebrew. I was completely wrong.

In fall of 1975 I moved to Israel just to go to school. I was put in an ulpan, an immersive class, to learn Hebrew, and I began to make friends. My best friend had a girlfriend, but I did not yet understand that I was gay. I was very homesick. Jerusalem and Israel are nothing like New York in Hebrew.

As a whole, I did not run into any prejudice against the disabled. Israeli society was very accepting of the disabled since the country had a great many men and women who had become disabled as soldiers during the multiple wars Israelis had been involved in. They were treated very well by the members of society and completely accepted. In this respect, I felt that Israeli society was ahead of American society. But there was a catch! This only applied to the disabled who were disabled due to military actions. Citizens born disabled were seen as second-class citizens because they were unable to go into the army. Nonetheless, my fellow students in my dorm on Mount Scopus accepted me.

To combat my homesickness, I started going to the movies whenever I could. I began going to the movies they showed on campus and eventually started going to the Jerusalem Cinematheque where I commenced watching both old and foreign movies. I became a regular and began speaking with the people who like myself, were waiting for the doors to open both in the street and in the lobby. One of them was an older British Gentleman, L., who was in Jerusalem teaching English as a second language. I found him interesting in that he knew a lot about movies and he had travelled widely teaching. During this time I was spending more on movies than on food so that when he invited me over to his house for a meal, I accepted. That was the night I lost my virginity.

Both American and Israeli societies were still largely homophobic. However, American society was more explicitly sexual in general. The 1970s were the height of the sexual revolution in America. Jerusalem is considered a holy city, so my orientation had to be kept pretty much a secret. The only ones I told were my closest friends from America and they accepted me. In spite of that, Jerusalem and archaeology were not a good fit for me and, in 1976, I returned home. As stated, the 1970s were the height of the sexual revolution in America. I found a New York City full of opportunities for sex. I picked people up on the subway on my way to wherever I was going; I met them in subway men's rooms, in the street, and in Central Park. In spite of being able to find sex easily, I was unable to find a boyfriend. Granted, since sex was so easy to find, gay men were not looking for boyfriends, but because I didn't have the right look, the right clothes or the right style, I found fewer people interested in me as time went on. This got worse after 1977. In that year *Saturday Night Fever* was released and the country went disco crazy with John Travolta's character, Tony Manero, as the model and the ideal, especially in

his dance moves. My disability prevented me from making those dance moves. Hence I was a very poor choice for a date. Finally, in the middle of the 1980s just as AIDS was proliferating, I met someone who didn't care about style or dance moves. I don't know what happened in the dating world again until around 1996 when he and I broke up.

Finally in the mid-1990s I started dating again. The world had changed! It was a change I still see today. People see more of me and less of my disability. Part of the change, in my opinion, has to with several images of the disabled as sexual beings that have been widely communicated throughout American society. Two of the most prominent of these are the character of Luke Martin, the quadriplegic played by Jon Voight, in the 1978 Academy Award winning film, *Coming Home.* Another more contemporary disabled character with a libido is Artie Abrams, the teen in the wheelchair in the television series, *Glee.* Several Glee episodes in the second season show him dating & kissing a girl, Brittany. As stated, it is nearly impossible to find a sexualized disabled character prior to 1978. With gay marriage and gay rights being prominent topics in the United States the stigmatization of LGBTQ people in the U.S. has waned in many states. All of this makes it easier to be a disabled gay man in the United States in the early twenty-first century as opposed to being one in the middle of the twentieth century. When all of these changes are added to the fact that general society has seen more openly gay people since the start of the AIDS crisis, such as Rock Hudson, has meant, in my opinion that, especially in urban areas in the United States, LGBTQ people are more visible and hence have become more acceptable to most people. Pro-gay Supreme Court decisions, such as the June, 2015 decision in *Obergefell v. Hodges* that decided that same-sex marriage was legal in the entire United States or the 2003 decision in *Lawrence v. Texas*, that struck down homosexual sodomy laws, effectively legalizing gay sex, have also helped to make LGBTQ people more visual and more acceptable, although it should be noted that transgendered people are still experiencing a great deal of prejudice and transphobia.

Endnotes

[1]   AKA The Stonewall Rebellion. Stonewall was a riot by gay men against New York City Police that took place in the Stonewall Bar, a gay bar, in Manhattan's West Village on the evening of June 28, 1969. This event is considered the start of the Gay Rights Movement.

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HabibAzar. 2010. *Armless.*

Wannabe people and the desirability of the disabled body: A film review of *Armless* by Andrea García-Santesmases

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What is this film about? The wannabe question.

Armless (directed by HabibAzar in 2010) is the story of John, a wannabe person. Wannabes are people who, despite having a healthy body, feel that they have a disability and wish to change their bodies because of this, for example, through amputations and spinal cord injuries. These people are diagnosed with *body integrity disorder*. This "disorder" has no cure or successful treatment, so wannabe people usually live their condition in a traumatic way, experiencing shame and guilt. Because their stigma is an invisible plight, wannabes are categorised as "discreditable" according to Goffman's Theory of Stigma (1963), unlike those who are "discredited," who have an outward manifestation of the trait that stigmatizes them.

The wannabe question is a reality largely unknown by the general public, and as such, the analysis of the few audiovisual products on the subject that have been produced in the last few years is crucial in order to interpret the first projections of this question into the public sphere. The cultural industry is constructing a "monstrous" image of wannabe people, portraying them as people who should be ashamed of their condition, suffer it secretly and in silence, and expect social and personal rejection. The stigma tends to be the most dominant attribute by which society explains all of the stigmatized individual's actions and behaviours (Goffman, 1963). Consequently, it is unsurprising for wannabe people, in this case, to try to hide their condition.

Armless is a great example of Goffman's theory. The main character of the film feels the need to amputate his own arms. As he is aware of the lack of comprehension of his desire for body alteration, he lives in permanent fear of personal

and social rejection. In *Armless* John often closes himself in his bedroom closet, a metaphorical act symbolizing a hiding of his desire for body alteration.

Another scene that illustrates a wannabe's hardship is when John decides to travel to the capital to contact a surgeon. He leaves a message to his wife, saying merely "You are not going to see me anymore. Sorry. I love you." He prefers her to think that he is having an affair or that he simply doesn't love her anymore, rather than share his painful secret.

Born in the "wrong body": similarities and differences with transsexuality

Usually wannabe people, like John in *Armless*, know exactly which type of amputation they require and which part of the body to start with. Baine and Levy (2005) explain that, "in the case of at least some wannabes, the limb in question is not as healthy as it might appear: in an important sense, a limb that is not experienced as one's own is not in fact one's own." (P. 85) In that sense, wannabe people consider the procedure essential in order to feel "complete." Another important and frequent element is the emergence of the desire in early infancy, after seeing an amputee who intrigued and fascinated the small child. In *Armless*, John refers to an amputee man that captivated him when he was 8 years old.

The wannabe person's body alteration is usually portrayed as a necessity, which if not addressed by regular surgery, may cause him or her to resort to illegal surgical procedures, self-harm, or to provoking accidents, placing their lives at risk. The narration of this reality has a morbidly recreational tone in *Armless*: John goes to a shop in order to buy the most powerful chainsaw to cut off his arms.

The way the wannabe question is presented is reminiscent of transsexuality: people who feel that they have been born into the "wrong body" and who are willing to subject themselves to the necessary medical surgery in order to adapt their physical bodies to their body image ideal. In *Armless* when another character asks John what is wrong with his arms, he simply replies, "They are there." In the case of transsexuality, the body adaptation refers to a sex/gender change, and in the case of wannabe people, from a healthy to disabled body. This analogy is being reinforced by the biomedical discourse in referential documentaries such as *Whole* (2003) and *Complete Obsession* (2000). The surgeon in *Complete Obsession* explains that, after initially feeling disconcerted by the wannabe people's request,

he realised that "they are not that different from transsexuals who amputate a healthy part of their body in order to fulfil their ideal body image". Other authors further this analogy, explaining that these groups of people experience their desire for body alteration involuntarily (since infancy, First, 2005; Barnes, 2011), unchangingly (the desire must have always existed, Barnes, 2011), and incurably (cannot be resolved by psychological or pharmaceutical treatment, Bayne and Levy, 2005).

This interpretation of the wannabe condition is an attempt to normalise it via an analogy with transsexuality and obtain social acceptance. However, the pathologisation of the wannabe condition through psychiatric diagnosis ignores many other important aspects of their reality (Lawrence, 2011).

What about desire?

Armless shows how John believes that the amputee body is desirable, even attractive. He describes the amputated body as "beautiful, as it should be." When he makes love to his wife, he pretends to be amputated, playing a submissive sexual role: "There's nothing here, no arms, do what you want to me, I can't do anything, make me suffer." First (2005) shows the connection between the desire to possess an amputee body and the sexual arousal for amputee people.

Wannabe people demand a body alteration, which in many cases will leave them in a situation of dependency, or at least, a loss of autonomy. From a biomedical point of view, this can only be seen as a problem, an unwanted inconvenience (Bryan, 2012). For instance, when the surgeon's secretary asks him why he doesn't want to operate on John if he cuts people all the time, he answers angry, "But in a normal way! He couldn't do anything without arms!" In contrast, wannabe people do not appear to view this situation of dependency as something totally undesirable (Duncan & Goggin, 2002). John refers to an amputee who had achieved his dream of being amputated as someone who "no longer has fear," and believes that if he also undergoes an amputation procedure, the loss of a body part will lead to a liberation from the fear of loss in general.

Monster of Nowadays

Armless does a wonderful job of analysing the cultural representation of wannabe people. It has all the important elements with regards to this question: the social

stigma, the ethical debate and the psychological pathologisation. John is portrayed as a typical wannabe: stigmatized, guilty, ashamed, but also convinced that he can't change his desire that needs his body to change.

John's wife and John's mother represent the expected behaviour from a "normal" family, which makes it even easier to empathize more with them than with John. His strange, incomprehensible and terrifying desire converts him into the "other one" because, despite the advances of social acceptance that have taken place in this field throughout history, the disabled body continues to be perceived as something monstrous. Thus, the wannabe people's desire to claim disability is considered even more monstrous.

One cannot, and must not, feel sexual desire for a monstrous body. Moreover, one cannot, and must not, desire to be the owner of a monstrous body. Devotee people (people who feel sexual attraction towards disabled bodies) and pretender people (people who simulate disability through the use of prostheses and orthoses due to an aesthetic and/or sexual attraction for these types of bodies) are also socially stigmatized for this reason.

We must keep in mind that we are before an unknown reality that, up until now, has never been seen as more than a psychological disorder. The analogy between wannabes and transsexuals leads us to believe that the psychiatric pathologization is only a first step towards the full realisation of their rights: for years the queer movement has been working on a political level for the depathologization of transsexuality, which makes it reasonable to believe that at some point, wannabe people will also politicise their condition and demand its depathologization.

Nowadays, there are still few cultural products about wannabe-pretender-devotee question. This vacuum fosters isolation, secrecy and fear surrounding the lives of these people. In this sense, *Armless* is a bold gamble that seeks to faithfully portray a hugely unknown phenomenon and, at the same time, meet the formal requirements of fiction. These kinds of films are a very good opportunity, from an academic and activist point of view, to discuss important topics such as disability, dependency, sexual desire or embodiment and to also challenge some views surrounding them.

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Neoliberalism and regimes of Life and Death: A Book Review of *Queer Necropolitics* by Heather Tucker

ABSTRACT: This review is of the newly published *Queer Necropolitics*, edited by Jin Haritaworn, Adi Kuntsman and Silvia Posocco. The collection includes writings about opening up the intersection of queer politics, gender studies, critical race studies, sexuality, anthropology, and colonial studies, offering insight into an array of approaches to a complex reading of contemporary politics. *Queer Necropolitics* adds to existing scholarship on the aforementioned subjects through engaging with scholar Jasbir Puar's conception of 'queer necropolitics,' as an expansion upon Michel Foucault's biopolitics (Puar 2011). This collection explores queer necropolitics as a tool for expanding on understandings of the regimes of life and death and their connection to transnational flows of capital, militarism, and power.

In light of this volume's call to focus attention on the intersection of disabilities and sexualities, the newly published Queer Necropolitics, edited by Jin Haritaworn, Adi Kuntsman and Silvia Posocco, brings insight to the mutual constructiveness

and complex assemblages of sexuality, race, class, ability, and nationality. The volume uses Jaspir Puar's conceptualization of 'queer necropolitics', as a framework that takes into account the ways in which 'queer subjects' are folded into a part of larger society, through transnational discourses and realities. Similarly, disability scholars have made connections between normative notions of the body, society, and economics and the ways in which some populations are viewed as constructive to life, and how some populations are left to socially die. Nirmala Erevelles, for example, urges that disability is an ideology of difference from which race, gender, and sexuality are on an axis in relationship with economic life within transnational capitalism (Erevelles 2011).

Similarly to disability studies, the concept of queer necropolitics owes its theoretical genealogy to Foucault's notion of biopolitics, or biopower, literally the ways in which 'techniques of power' control bodies and populations (Foucault 1978). The concept of biopolitics linked the discipline and control of the state through discourses of the individual body and control over the 'mechanics of life' of the 'species body', through constructing and identifying non-normativities through race, sex, and sexuality (Foucault 1978). Expanding upon Michel Foucault's concept of biopolitics, Puar's queer necropolitics explores how queer subjects are being 'folded (back) into life' or the bio, while also exploring how naming racialized queernesses has become a means to 'discipline and control subjects and populations' (Paur 2007: 35). Jaspir Puar (2007) has taken up the conception of biopolitics, as a queer project, as she considers the ways in which 'non-normative sexualities are rarely centered in efforts elaborating the workings of biopolitics, although non-normative sexualities are always a marked 'perversion and deviance that is a key component of the very establishment of norms that drive biopolitical interests' (Puar 2007:35).

Queer necropolitics also expands on the notion of necropolitics as proposed by postcolonial theorist Achille Mbembe. Mbembe (2003) proposes necropolitics, in order to problematize biopolitics as falling short of providing substantial theorization of the colonial/racialized encounter, but also the contemporary ways in which some populations are 'marked for death'. Mbembe introduces the notion of a necropolitics, which the author proposes more appropriately accounts for 'late-modern colonial occupation' and which includes a conception of death, or the necro (Mbembe 2003). Focusing primarily on the U.S. as an imperial power

in the 'war on terror', the volume is introduced as engaging with necropolitics to challenge transnational makings of the 'West', in opposition to the rest concerning bodies and populations, and thus, issues regarding sexuality, race, and nationality (Hall 1994: 275–320). The usefulness of the combination of queer and necropolitics, the editors argue, is that it provides a tool with which to examine 'unequal regimes of living and dying' in neoliberal times, or rather it provides a tool for expanding upon biopolitical theory, as well as necropolitical theories (Lubheid 2008:169–190). Thus, the various contributions throughout the book challenge the normalizing and deathly regimes of neoliberalism, which position some bodies towards life (bio), and others towards death (necro). In the theme of necropolitics, the book offers explorations into different terminologies, which further conceptualize the necro, such as 'zones of abandonment,' 'deathworlds,' 'social death,' and 'slow death' (Beihl 2001; Hartman 1997; Patterson 1982; Povenelli 2011; and Berlant 2007 in Haritaworn et al 2014). While keeping this queer necropolitics central, a 'reading sideways' of the politics of sexual rights is used throughout the volume as an approach, inspired by Puar to engage with the construction of queer. The use of queer ranges throughout the volume, from defining queer as dislodging conceptions of normality and therefore, systems of reference, which have typically created the connections between gay and lesbian subjects and identities, while also defining queer as 'a point of tension to normativity' where friction occurs (Haritaworn et al 2014: 1–216). This notion of queer is helpful to interrogate normativity intersectionally, an essential frame of thinking for disability studies.

In the first section entitled deathworlds, queer necropolitics is examined through 'war machines' (or Achille Mbembe's notion of contemporary militarized conditions of postcolonial African countries), the criminalization of AIDS, and transnational adoption in the exploration of "queerness as a speculative economy' (Possoco in Haritaworn et al 2014: 1–216). Che Gossett proposes queer and trans abolitionist critiques of prison and psychiatric institutionalization. The author suggests that such institutionalization is used as a solution by mainstream LGBT organizations, and relies on the state as such. The author further suggests that the reliance on law as the end all and be all is an uncritical, unjust solution promoted by LGBT organizations. Furthermore, Gosset provides a fierce analytical tool for examining the intersection of AIDS discourses and structural inequalities. Michelle R. Martin-Baron explores thinking through queer as in affect and ritual,

using necropolitics to analyze 'war machines' or 'segments of armed men that split up or merge with one another depending on the tasks to be carried out or the circumstances', and the ways in which queerness is a part of the 'structures of patriarchy' (Martin-Baron in Haritaworn et al 2014). Queerness is understood here as a ritual of kinship, as 'a point of tension to normativity' where friction occurs (Haritaworn et al 2014:95). Silvia Posocco explores necropolitics through a transnational lens, suggesting that transnational adoption is an assemblage of cultural forms, a form of commodified labour, and as such, is connected to life and death problematics. Posocco explores the ways in which such problematics in transnational adoption flows create racialized conceptions of political rationalities, which construct U.S. based adoption of Guatemalan children as a solution to a history of colonial violence.

The second section of the collection investigates queer necropolitics through the conception of wars and borderlands. This section explores Mbembe's 'topographies of cruelty', Povenelli's 'zones of abandonment', and the ways in which racialized bodies are subjected to such spaces. These spaces, or 'topographies of cruelty,' were, according to Mbembe, spaces of colonial territorialization, which now travel alongside capital in neoliberal regimes. In Sima Shakhsari's piece, the author explores the concept of 'zones of abandonment' in which queer persons are regulated. Exploring such a trans necropolitics, the author explores the 'politics of rightful killing' through representations of queer refugee life and death, and how such are 'inherently connected to the government of the population' (Haritaworn et al 2014:95). The author thus challenges rescue narratives that seek to provoke a victim subject in order to maintain 'binary frames of freedom and oppression' (Haritaworn et al 2014: 95).

Building on the postcolonial insights of Spivak (1988) and Bhaba (1994), Jason Ritchie's contribution analyzes the ways in which racialized queer othering subjects the colonized Palestinian queer to zones of abandonment or necropolitical spaces. Using queer as an interrogation of that which challenges norms, Richie's most interesting insight lies in his challenging of dominant settler colonial gay and lesbian mainstream homonormativity and the supposed logic of 'liberal gay politics of visibility and recognition' and developmental discourses (Ritchie 2014:111–128 in Haritaworn et al 2014). These, according to him, hold power to create the victim/savior dichotomy, which rely on the essentialization of Arab cul-

ture as religiously making queer impossible, while hyper-sexualizing the Palestinian queer other. Aren Z. Aizura explores the notion of precarity and 'queer' or trans necropolitics. Using Butler's definition of precarious life, as the 'erasure of (certain) queer bodies from public discourse,' thereby marking the bodies as 'ungrievable,' Aizura explores trans feminine embodiment (Butler 2006 in Haritworn et al 2014). The author interrogates those processes that produce discourse and knowledge within capitalism, which rather simplify and instrumentalize trans feminine lived experiences on a global scale (Aizura 2014: 131 in Haritaworn et al). Aizura explores these processes as creating categories and identities, which withhold complexity of trans feminine embodiment, for example.

The third and final section of the book further explores Mbembe's concept of the 'topographies of cruelty' through incarceration and prison (Mbembe 2003 in Haritaworn et el). This section reflects on the ways in which topographies of cruelty, or the normalization of spaces and systems such as the prison, travel transnationally and globally as 'social death' through the war on terror and the globalization of the prison industrial complex, using bodies as raw material. This is examined by Sarah Lamble, who explores the ways in which 'affective economies' or the 'circulation and mobilization of feelings of desire, pleasure, fear, and repulsion, are utilized to seclude all of us into the fold of the state' (Lamble 2014:152 in Haritaworn et al). Lamble names queer investments in punishment as 'the material processes that accompany such affective economies' in channeling resources to the prison industrial complex (Lamble 2014:152 in Haritaworn et al). Following along the lines of interrogating the normalizing neoliberal state and criminalization of those who do not follow regulations, obligations, and state rules, Elijah Adiv Edelman looks at the necropolitical regulations of transfeminine bodies of colour as criminal. Edelman explores the ways in which such bodies are regulated through policies such as prostitution free zones (PFZ) in Washington D.C., which Edelman argues, show how necropolitical ideologies are enacted spatially. Similarly, Morgan Bassichis and Dean Spade, engage with the ways in which black bodies are regulated to spaces of social death. Their article particularly engages with the ways in which the 'wounded white gay citizen' must make claims for 'successful reproduction' in the U.S. nation through identifying their non-blackness and/or lack of criminality (Bassichis and Spade 2014:192 in Haritaworn et al). The article exposes how homonormativity relies on anti-blackness, therefore tying the notion of black suf-

fering and black premature death through claims to citizenship as feeding into a 'structuralized bodily terror' (Bassichis and Spade 2014:199 in Haritaworn et al).

In conclusion, the volume proposes useful ways of contextualizing neoliberal regimes and their effects on populations and individual bodies, a concept central to disability studies. Similar to disability scholars approaches to contemporary conceptions of normativities, the queer necropolitics collection connects constructions of such conceptions through transnational discourse, and examines which bodies are positioned in spaces of life (bio), and which of those are positioned in spaces of death (necro) of various means. The authors throughout this book offer critical insights into the many ways in which 'reading sideways'[1] through a queer necropolitical framework can accomplish understanding and contextualizing these contemporary regimes of life and death using queer, post-colonial, and de-colonial feminist tools.

Endnotes

[1] I am referring here to Jaspir Puar's notion of reading sideways, which was proposed in her publication, *Terrorist Assemblages, homonationalism in queer times* (Durham and London, Duke University Press, 2007)

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