



Cuthbert, Karen (2013) *'On the edge of "typical"?' A qualitative exploration of the intersection of asexuality and disability.* [MRes.]

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‘On the edge of “typical”’? A
qualitative exploration of the
intersection of asexuality and
disability

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Abstract

This dissertation explores the intersection of asexuality and disability by means of a qualitative study involving asexual-identified disabled persons. The study is framed in response to Kim's (2010, 2011) claims that asexual-identified disabled persons are at risk of (double) erasure, given attempts by the asexual community to distance themselves from disability, and attempts by the disabled community to distance themselves from asexuality, as *both* attempt to increase their acceptance into the mainstream.

Online interviews (using email, instant-messaging and video conferencing) were conducted with eleven participants. Four key themes emerged from my analysis of these interviews: **(i)** participants discursively constructed the asexual community as open and inclusive with regards to disability, but that a normative construction of asexuality was still at play; **(ii)** participants felt that it was important to challenge the asexual assumption made of disabled persons and did not feel marginalised by attempts to do so - possibly because there is a more nuanced perspective on asexuality developing within disability communities that distinguishes between asexuality as *ascription* and asexuality as *identity*; **(iii)** participants were open to the possibility that their asexuality and their disability might be linked but that this could be recognised in a way that was non-pathologizing; and **(iv)** being disabled mediated how people responded to participants' identities as asexual as well as the process of coming to an asexual identity in the first place, and these were further complicated by issues of gender and 'race'.

The study adds to the very small body of empirical sociological research on asexuality. It is also the first to introduce a consideration of intersectionality into asexuality research, and ultimately argues for the importance of considering asexuality – both how it is constructed and experienced – as a socially situated and relational phenomenon.

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Permission to consult

I hereby grant permission for this dissertation to be consulted by anyone who knows of its existence.

Introduction

This dissertation explores the intersection of asexuality and disability, and how this intersection is both lived and understood by asexual-identified disabled persons¹.

Although the term ‘asexuality’ is far from new (it is commonly used in the biological sciences to refer to self-reproducing organisms) it is only with the formation of the Asexual Visibility and Education Network (AVEN) in 2001 that a number of individuals began to actively claim a distinctively ‘asexual’ self-identity. AVEN defines an asexual individual as ‘someone who does not experience sexual attraction’ (AVEN, n.d.), although not all individuals agree with, or use, this definition (Scherrer, 2008: 627). Asexuality might also be thought of as an ‘umbrella’ term encompassing a wide range of nuanced identities and orientations (see Appendix A).

Crucially, within the asexual community², and in much of the research literature (Przybylo, 2012), asexuality is understood not as a dysfunction in need of correction, but as a variation in sexual subjectivity. This is in the context of a wider pathologisation of low or no sexual attraction or desire: for example, male hypoactive desire disorder’ and ‘female sexual interest/desire disorder’ are listed in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, DSM-5, 2013). Although the DSM stipulates that for a diagnosis to be made, the individual must experience ‘distress’ relating to their low sexual desire (and the focus is on ‘desire’ rather than ‘attraction’ which would further exclude many – but not all – asexual-identified persons³), asexual activists have been critical of these diagnostic categories for the pathologising consequences they might have for asexuality.

¹ Throughout this dissertation, I use the term ‘disabled persons’ rather than ‘persons with disabilities’. Oliver (1990: xiii) argues that the latter term suggests that disability is a mere add-on, whereas the former more adequately denotes the centrality of disability to people’s lived experiences.

² For practical ease (although perhaps at the risk of ‘flattening out’ what is otherwise a diverse group) I use the term ‘asexual community’ to refer to all asexual spaces, both online and off.

³ A distinction is often made in asexuality discourse between ‘desire’ (or ‘sex drive’ or ‘libido’) and ‘attraction’. Asexuality is generally defined by a lack of sexual *attraction* (referring to the (sexually-driven) desire to engage in sexual activity with other persons) rather than a lack of sexual desire *per se* (which can be experienced independently of other persons). However, some asexual-identified persons may *also* lack sexual desire.

Given this, Eunjung Kim (2010) discusses what she sees as the ‘health discourses’ deployed by the asexual community. She suggests that asexual activists have tended to emphasise the healthiness of asexual individuals in order to resist pathologisation – for example, stating that ‘the plumbing works fine’ or ‘we are not sick’ - although Kim also acknowledges that these claims might be strategically deployed depending on the audience (i.e. they may be emphasized more when dealing with the media, or with the medical community). However, Kim argues that claiming legitimacy on the grounds of good health and bodily normalcy could have the effect of marginalising disabled or chronically ill persons who identify as asexual. Within some sections of the asexual community, a degree of critical reflexivity regarding these issues has also begun to develop – for example, the asexual blogger Gaia discusses the concept of the ‘Unassailable Asexual’, which refers to:

‘...a political approach towards visibility and community life in the asexual community that we should come off as the most normal, likable, appreciated members of society as possible, besides this one difference.’
(The Queer Ace, 2013)

Kim (2011) has also argued that within the disabled people’s movement, a similar attempt to distance disability from *asexuality* (particularly the assumption that all disabled persons are asexual) is occurring. Kim argues that while this is an important endeavour, much of the rhetoric deployed – e.g. denying the existence of asexuality; positioning sexuality as natural and universal – has the potential to (re)stigmatize disabled persons who do actively claim an asexual identity.

The idea for this dissertation arose after reading Kim’s work. I found these texts to be thought-provoking, but problematic in their lack of empirical analysis. Kim fails to engage with any of the persons she suggests are vulnerable to erasure, and it is this shortcoming that my research attempts to address. I thus set out to explore the personal experiences of asexual-identified disabled persons in light of Kim’s assertions about marginalization and erasure. I was interested in how participants, as disabled persons, made sense of identifying as asexual in light of the connections commonly made between the two, and of the attempts by both asexual and disabled activists to ‘distance’ each from the other (and if they felt that this was indeed the case). I also wished to explore the ‘difference’ that disability might make to the

experience of asexuality, and how this might intersect with other factors such as gender and 'race'. I use the concept of 'intersectionality' to refer to the idea – developed by Kimberlé Crenshaw (1989, 1991) out of the work of Black feminists such as bell hooks (1981) and Audre Lorde (1984) - that 'sexuality', 'gender' 'race' 'disability' 'class' etc. are inherently interconnected (even mutually constitutive) and therefore cannot be analysed separately.

Although my dissertation can be positioned as a response to Kim, it is not so much an attempt to 'test' Kim's claims, but rather a wider exploration of the themes prompted by her work.

Chapter One: Literature review

In the introduction, I framed my dissertation as a response to Eunjung Kim's work on asexuality and disability. In this chapter I will review the wider literature situated within what I have termed the 'discursive field of asexuality', a field which has been growing steadily throughout the past decade. While other texts also deploy the term 'asexual', it is usually done so somewhat functionally: for example, as a term to describe a position within a sexological typology characterised by low scores on measures of both homosexual and heterosexual attraction (e.g. Storms, 1980; Nurius, 1983; Berkey *et al.*, 1990) or as a subset of homosexuality (Masters *et al.*, 1986). It has also been used to describe patterns of relationships – for example, romantic but non-sexual relationships between lesbians (Rothblum and Brehony, 1993), or as a synonym for celibacy (Fahs, 2010). There are also several texts that discuss (and challenge) the ascription of asexuality to particular marginalised groups – for example, older persons (Minichiello *et al.*, 1996; Gott and Hinchliff, 2003), older lesbians (Fullmer *et al.*, 1999), Asian men (Kong, 2012; Park, 2013) and disabled persons (O'Toole and Bregante, 1992; Milligan and Neufeldt, 2001). In contrast, work within the discursive field of asexuality can generally be distinguished by its focus on asexuality as an emerging identity and/or sexual orientation, and has largely arisen in response to, and with awareness of, asexuality as a social movement (although as will be seen, there is considerable diversity within this field). The bulk of this chapter will be concerned with surveying this literature, and I conclude by discussing some key gaps and oversights, and situate my own research within this context. I begin, however, by considering how disability and *sexuality* have been approached in the academic literature, in light of my specific research topic.

Disability and sexuality

Until the 1990s, sexuality had been a peripheral issue in both disabled activism and academic writings on disability. It tended to be viewed as an individual, personal matter and therefore less amenable to social change (Shuttleworth, 2007). When sexuality *was* discussed, this tended to be in terms of rehabilitating lost sexual functioning. However, in the past two decades or so, disability and sexuality have come to be increasingly framed in socio-political terms, particularly as an issue of

social justice. As mentioned above, the assumed asexuality of disabled persons has been challenged, as well as the parallel assumption that those with intellectual disabilities exhibit a deviant *hypersexuality* (Chappell, 1998). The reproductive control of disabled bodies, particularly women's bodies, has also been subject to sustained critique (e.g. Waxman, 1994; Kallianes and Rubinfeld, 1997). The barriers that prevent disabled persons from being sexual have also been explored extensively: institutional barriers (Trudel and Desjardins, 1992; Bernert, 2011); educational barriers (Mona and Gardos, 2000; Wade, 2002); social, economic and environmental barriers (Shakespeare *et al.*, 1996; Bonnie, 2004) and cultural barriers (Shuttleworth, 2000).

However, in recent years there has also been a shift in disability studies towards recognising the *embodied* aspect of disabled sexuality. This reflects the impact of feminist disability scholars such as Sally French (1992), Liz Crow (1996) and Carol Thomas (1999), who have argued that we must also take into account the 'effects' of impairment itself, since we live our lives *through* our bodies. While this has brought about some consideration of the role of impairment in limiting sexual activity (e.g. Wiwanikit, 2008), it has also facilitated recognition of the sexual *potentiality* of the disabled body. This has been especially so in what has come to be known as 'crip theory', which aims to reclaim the derogatory connotations of 'crippled'. Developing from the confluence of feminism, disability studies and queer theory, crip theory re-imagines sexual experience and the erotic body beyond the heteronormative focus on genitals, penetration and conventional erogenous zones. Here, the disabled body is not a defect that needs to be overcome but represents expanded possibilities for pleasure and experimentation (McRuer, 2006). Heteronormativity and ablebodiedness are theorized not as separate strands of domination, but as mutually imbricated in matrices of domination and control (Kafer, 2003).

Having offered this brief overview, I now turn my attention to the discursive field of asexuality.

The discursive field of asexuality

Academic literature within the discursive field of asexuality can be usefully categorized into **i)** empirical studies of asexuality (which can be further broken down

into a) psychological and sexological research and b) sociological research and **ii**) literature that primarily offers theoretical or conceptual reflections on asexuality.

Empirical Studies: psychological and sexological research

To date, empirical studies of asexuality have largely been conducted from within the terrains of psychology and sexology. These studies have coalesced around the following themes:

Prevalence

Bogaert (2004), Poston and Baumle (2010) and Aicken *et al.* (2013) query the prevalence of asexuality within the British and US populations. Undertaking secondary analysis of national probability surveys, and using various ‘indicators’ of asexuality, a variety of estimates have been put forth. Using data from a 1990 British survey, Bogaert (2004) suggested that 1% or more of the population might be reasonably considered asexual given the number of participants who chose the option of “I have never felt sexually attracted to anyone at all” in a question regarding sexual attraction. However, Aicken *et al.* (2013) report that only 0.4% of respondents selected this option in the 2000 version of this survey. Poston and Baumle (2010) examined data from an American survey undertaken in 2002, and compared prevalence rates for what they consider to be three different indicators of asexuality. They found that 6.1% of men and 4.8% of women reported never having oral, vaginal or anal sex with either a man or a woman (the behavioural indicator); 1.8% of men and 1.8% of women selected ‘not sure’ when presented with a set of statements regarding the relative ‘weight’ of sexual attraction in particular directions (the attraction indicator); and 0.7% of men and 0.8% of women selected ‘something else’ when asked about their sexual identity (the identity indicator).

These studies, however, are of limited utility. The authors’ conclusions are drawn from (what they consider to be) proxy indicators of asexuality since none of the surveys provided respondents with the option of ‘asexual’ as a term to identify with. The measures used are both over and under inclusive – for example, Hinderliter (2009) argues that the criteria used in Bogaert’s analysis of “never” having felt sexual attraction might exclude some asexual-identified persons who have felt, or do feel, low amounts of sexual attraction, but this statement can also encompass those who have never felt sexual attraction but do not identify as asexual. This last point is, I

suggest, indicative of an underlying assumption of sexological research on asexuality: that asexuality is not limited to those self-identifying as asexual, but can be also ‘read’ off a person by the responses they exhibit on various researcher-defined ‘measures’. This is epitomized by Bogaert’s (2012: 22-23) claim that a lack of sexual attraction rather than self-identification should be considered *the* definition of asexuality, since the former, he argues, is a more objectively ‘true’ indicator. However, this seems to me to have ethically disturbing implications: it suggests that we as researchers are in a privileged epistemological position and can therefore adjudicate who is ‘really’ asexual, even if this contradicts an individual’s sense of self.

Characteristics of asexual persons

This positivist impulse of sexological research on asexuality can also be seen in the attempt to identify unique ‘characteristics’ of asexual persons. Studies such as this generally involve a comparison against some sort of ‘sexual’ yardstick. For example, using a survey to measure different aspects of sexual response, Prause and Graham (2007) compared the data from self-identified asexual persons to a larger ‘sexual’ sample, concluding that asexual-identified individuals were not more anxious or fearful about sex, but did have lower scores on scales of sexual desire and arousability. Brotto and Yule (2011) went so far as to ‘test’ the genital and subjective sexual responses of asexual-identified women in a laboratory setting, comparing them against a ‘sexual’ sample of heterosexual, homosexual and bisexual women. The authors found no significant difference in physiological or subjective arousal, leading to the assertion that ‘asexuals’ exhibited a ‘normal sexual response’ (p708). While conclusions such as this might be seen to contribute to the depathologisation of asexuality, I suggest that the very act of holding the ‘asexual’ data up against some kind of ‘normal sexual response’ (and failing to interrogate what that might be) itself implies that asexual persons occupy some sort of ontological space apart from ‘sexual’ people. Similar comparisons have been carried out with regards to mental health, finding that asexual-identified persons tended to have higher scores on indicators of mental health problems than (hetero)sexual persons (Brotto *et al.*, 2010; Yule *et al.*, 2013).

Accounting for asexuality

A desire to ‘account for’ asexuality – usually by seeking some sort of biological or psychological base - also characterizes much of this literature. For example, Bogaert

(2004) suggests that pre-natal exposure to different levels of hormones might play a part in ‘determining’ asexuality. Similarly, Brotto *et al.* (2010) and Yule *et al.* (2013) both posit that some kind of deviant developmental factor underlies asexuality: either with regards to adrenal maturation (Brotto *et al.*, 2010) or in the ‘avoidant’ attachment styles asexual-identified individuals might have had as children leading to ‘problems developing intimate relationships later in life’⁴ (Yule *et al.*, 2013: 13). Przybylo (2012) argues that this concern with aetiology has an ambiguous effect with regards to depathologising asexuality: if asexuality can be located in the body, then it may lend asexuality a kind of legitimacy (we can see parallels in the search for the ‘gay gene or the ‘gay brain’), but at the same time, asexuality is also accounted for in terms of something having gone *wrong*; as a deviation from – or at least a difference from – what is considered ‘normal’.

Qualitative research

Researchers working within the sexological/psychological paradigm have also conducted some qualitative studies of asexuality. Prause and Graham (2007) interviewed four self-identified asexual persons as a precursor to their larger quantitative study. Their analysis of this data is, however, somewhat perfunctory despite the tantalising sociological implications it may have – for example, participants actively reconstructing masturbation as a non-sexual activity, participants engaging in sexual activities for a range of social and relational reasons and participants negotiating a set of normative social expectations about sexual attraction and desire. They conclude their paper, however, by calling for more ‘psychophysiological’ research (p354). Brotto *et al.* (2010) also conducted telephone interviews with fifteen asexual-identified persons as a component of their mixed-methods study. Although the analysis is again somewhat cursory, some interesting themes emerge from these interviews. Related to my own research, participants brought up the possibility of a connection between asexuality and Asperger’s, although they were also resistant to the idea that asexuality itself was symptomatic of any kind of disorder. Other interesting themes to emerge included the need for negotiation regarding sex when in a relationship with a ‘sexual’ person, and participants’ tendency to conceptualise infidelity in terms of emotional betrayal rather

⁴ This rather offensive claim fails to recognise that asexual-identified persons *can* and *do* have intimate relationships – with romantic partners, with family, with friends etc.

than sexual activity outside the relationship. However, despite the richness of this data and the potential for sociological analysis it represents, the authors lament in the conclusion that ‘the study did not address the true nature of asexuality’ and recommend further research using presumably more ‘scientific’ methods such as ‘digital ratio, handedness and birth order mapping’ (p615). Again, these sentiments are indicative of impulse underlying this literature to ‘know’ and encapsulate the ‘real’ phenomenon of asexuality.

Empirical studies: sociological research

Empirical sociological research on asexuality has been much scarcer, with only the work of Scherrer (2008, 2010[a], 2010[b]) and Carrigan (2011, 2012) to really speak of. Both are critical of sexological and psychological research for its focus on aetiology, causal explanation and for its comparison of ‘sexuals’ and ‘asexuals’. I describe Scherrer and Carrigan’s work as sociological because of their attempt to engage with subjective insights and with what asexuality *means* in people’s lives; they also recognise the need to set asexuality against a wider socio-cultural backdrop rather than studying it in isolation as the studies above have done.

Based upon data from an open-ended survey, Scherrer (2008) describes the process of asexual identity formation, including the centrality of AVEN (especially AVEN’s definitions of asexuality) to this process. She also discusses how participants redefined some behaviours conventionally thought as sexual (namely masturbation) as non-sexual. Scherrer suggests that this throws into the relief the socially constructed character of ‘sex’, and opens up space for dialogue regarding how we designate and demarcate certain acts and behaviours. Participants also tended to frame their asexuality in essentialist terms– for example, describing it as ‘natural’ or just ‘who they are’. However, participants simultaneously challenged essentialist discourses of sexuality by questioning the idea that sexuality is a universally-shared natural drive. Scherrer (2010[a], 2010[b]) has also explored the relationships of asexual-identified persons. She describes participants articulating desires for a wide variety of relational forms – from close friendships, to intimate but non-sexual dyadic partnerships, to polyamorous configurations that blur the boundaries between friends and partners. She argues that the practice of asexual relationships thus has the potential to expand our constructions of relationships and intimacy that go beyond the absence or presence

of sex. This point is taken up by Carrigan (2012): drawing on data from qualitative interviews and another open-ended survey, he discusses the creative ways in which asexual-identified participants and their non-asexual partners attempted to make their relationships mutually satisfying - although these attempts were not always successful, and necessitated much negotiation and 'emotion work'. Carrigan also discusses the negotiations involved in relationships with friends and family, such as in the coming-out process and navigating certain social situations. Drawing on Archer's work on reflexivity, Carrigan frames these negotiations as part of the wider way in which we are all required to negotiate the social world in late modernity. In doing so, he both emphasises the agency of asexual-identified persons, and refuses to see asexuality as any kind of phenomenon 'apart'. In his 2011 paper, Carrigan outlines the diversity subsumed beneath the 'asexual' umbrella, but points out that this diversity is facilitated by an underlying communal identity, borne from a shared experience of feeling different before 'discovering' asexuality, and recognising oneself in its definition.

Two other studies, although conducted by psychologists, might also be included under the broad rubric of sociological research given their focus on the *social* context of asexuality rather than on individual 'asexuals'. MacInnis and Hodson (2012) surveyed a general population sample on attitudes towards asexual-identified persons and found that they were perceived more negatively than those from other sexual minorities, and were more systematically dehumanized (attributed less 'human' qualities) than any other group. This led the authors to conclude that sexuality and 'humanness' are inextricably intertwined. Gazzola and Morrison's (2012) research concerned those who are the potential *targets* of such prejudice, surveying self-identified asexuals on their experiences of discrimination. The authors found that participants had experienced little in the way of physical violence or economic sanctions, but verbal abuse, gossip and social distancing were commonly experienced. However, the authors concede that the scales used in this survey had been developed for use with other sexual minorities, and therefore may not adequately capture the potentially unique experiences of discrimination faced by asexual-identified persons – for example, the sense of disbelief that is frequently expressed when asexual-identified persons come out.

Theoretical/conceptual literature

Texts that are primarily theoretical or conceptual constitute a large part of the asexuality literature (although some of the above empirical studies also advance some sort of theoretical or conceptual discussion). I have identified three broad themes to emerge in these texts.

Asexuality and medicalization

The differences between asexuality and psychiatric/medical diagnoses such as Hypoactive Sexual Desire Disorder (HSDD) have been discussed in the literature. Bogaert (2006) outlines what he sees as key differences between asexuality and HSDD – namely that asexual individuals often experience sexual desire or arousal (only do not feel the need to ‘direct’ it to other people), tend not to be distressed about their situation and have generally felt the way they do as far as can be remembered. This leads Bogaert to conclude that asexuality should be considered a sexual orientation rather than a disorder. Hinderliter (2013) expands this discussion by outlining what he sees as the differences in ideologies and conceptual origins of asexuality and HSDD. He argues that HSDD is rooted in therapeutic understanding, and is diagnosed by medical professionals (‘from above’), whereas asexuality is an identity largely constructed ‘from below’ and one that individuals can choose to apply to themselves. They also differ in their normative outlook: HSDD sees a lack of sexual interest as something problematic to be corrected, whereas asexuality discourse views it positively, or at least neutrally, and encourages self-acceptance. Kim’s (2010, 2011) work, as discussed in the introduction, might also fit into this category, given her discussion of the attempts by asexual activists to affirm their good health status in order to resist the pathologisation of asexuality.

The transgressive potential of asexuality

Several authors also outline the ways in which asexuality might be thought to be transgressive with regards to sexual politics. Przybylo (2011), via Butler’s notion of performativity, argues that asexuality can potentially resist the established sex-gender system by ‘repeating differently’ and thus ‘exposing...the contingency of the entire sexusociety project’ (p456). Also drawing on Butler, Gressgård (2013), suggests that asexuality can disrupt assumptions about what it means ‘to be’ by challenging the ways in which sexuality and personhood are bound together. Gressgård also reiterates the point made by others (such as Scherrer, above) that asexuality prompts a

reimagining of relationships and intimacy, and it is this potential, both disruptive and creative, that the author considers queer. Cerankowski and Milks (2010) suggest that asexuality could make sex-positive feminism and queer politics even more transgressive by challenging normative assumptions about the universality of sexuality that underlie these movements, and by expanding understandings of sexual liberation beyond transgressive sexual acts (which may, ironically, be non-transgressive due to the exclusions and hierarchies they perpetrate).

However, these authors also share the view that asexuality, as it *currently* stands, is not fulfilling this potential. Gressgård makes the point that dominant asexuality discourse, including previous asexuality research, has a ‘consolidating’ effect by perpetuating essentialist understandings and attempting to get at the ‘truth’ of asexuality through naturalist-objectivist knowledge paradigms. Turning to Foucault, Gressgård also suggests that asexuality has made the transition from pathology to identity, but this has been within the terms of neoliberal governance, and is predicated on the production of a self-regulating subject. Przybylo suggests that asexuality can be seen as an attempt to create a ‘safe space’ in response to the uncertainty and confusion of postmodernity, and has involved the shoring up of bodily boundaries and attempts to preserve bodily integrity – something the author views as decidedly *unqueer*. And, referring to the dominant essentialist understanding of asexuality (which they view as a kind of fly in the ointment), Cerankowski and Milks argue that asexual discourse might be enriched by the radical feminist view of abstinence/celibacy/virginity as a politicised act of resistance.

While these texts open up new discursive spaces, they are also problematic. Each of them assumes a kind of normative goal for asexuality, and frames asexuality in political terms, but without considering if asexual-identified persons themselves share this same vision of asexuality. These authors take a somewhat top-down perspective on these issues, and fail to acknowledge the already complex debates regarding feminism, queerness and politicisation that take place within the asexuality community itself, as well as the fact that many asexuals are *already* a part of the queer or feminist communities.

Methodological issues and future research

The issue of how best to go about studying asexuality has also been discussed in the literature (this also includes questions of how to define asexuality, as discussed in the ‘Prevalence’ section above). Hinderliter (2009) argues that adapting existing survey measures to study asexuality is inadequate given that they often contain implicit normative assumptions about sexual desire and attraction. He thus suggests developing an entirely new set of measures that would themselves be based on empirical research with asexual participants. Regarding qualitative asexuality research, Carrigan *et al.* (2013) argue that there is a need to go beyond interviews and incorporate methods such as focus groups and ethnographies. Chasin (2011) suggests that it is problematic to think of single ‘asexual’ population, and also warns against conceptualising ‘asexuals’ as a distinct category of people, preferring instead the notion of an asexuality --- sexuality continuum. Chasin also argues that asexuality research should not be treated as an isolated field, but should be incorporated into the mainstream study of sexualities, given the unique perspectives and insights that it may offer. Similarly Przybylo (2013) suggest that we use asexuality as a *method*, or a lens, to afford us a fresh perspective on norms and assumptions that might otherwise go unquestioned both within sexualities research, but also more broadly.

Literature Gaps and Oversights

Despite this proliferation of literature in the past decade, gaps nevertheless remain. There is a particular gap with regards to the macro-level study of asexuality: for example, looking at the asexual community as a social movement embedded in broader material and discursive networks; in terms of the socio-historical circumstances that facilitated the development of asexuality in Western liberal democracies (Carrigan *et al.*, 2013) and in terms of (sexual) citizenship and sexual rights, particularly in light of recent moves in some US States to include asexuals in sexual orientation discrimination legislature (e.g. New York State Attorney General, 2010). There is also a need for researchers to consider how asexuality intersects with other identities, attributes and relations of power, such as class, ‘race’, gender, age, (dis)ability etc., and the social, cultural and economic capital required to be able to adopt an asexual identity. The reviewed literature – even the more sociologically oriented literature – tends to assume a disembodied (and disembedded) subject free to

lay claim to an asexual identity, without consideration of material relations of power that affect people's experiences and agency in very real ways. Doing so would represent an important 'sociologizing' of asexuality, and move the focus beyond asexuality as a property or inclination of individuals. My own research is a modest attempt to begin to address some of these themes, particularly asexuality's intersection with disability, and also with how the asexual community and asexual activism are experienced and made sense of. In the next chapter, I discuss how I went about conducting this research.

Chapter Two: Research paradigm and methods

In this chapter I describe the research paradigm within which my study is located, as well as the specific methods of data collection and analysis that were employed.

Research paradigm

Guba and Lincoln (1994: 107) use the term ‘research paradigm’ to describe a:

‘[...] set of *basic beliefs* (or metaphysics) that deals with ultimates or first principles. It represents a *worldview* that represents, for its holder, the nature of the “world,” the individuals place in it and the range of possible relationships to the world and its parts.’

They go on to identify four key paradigms in social research: positivism, post-positivism, critical theories and constructivism. Given this, I would position my own research broadly within the constructivist paradigm. My ontological stance is of reality as both multiple and situated; there is no foundational reality ‘out there’ independent of social actors, but is the *process* and *product* of social interaction - including the process of social research itself (Guba and Lincoln, 1994: 110-111). Therefore, I envisage my research not as an act of gazing through a clear-glass window onto the phenomena of ‘asexuality’ or ‘disability’, but as co-constituting those very things through looking and talking about them. As such, my epistemological position is one where researchers are not disinterested scientists who can unproblematically ‘know’ the world, but are always socially positioned, embedded *in* the world, and inextricably imbricated in the production of knowledge, which consists of collective meanings and ‘re-constructions’ (ibid.: 112).

However, my worldview is also strongly influenced by critical theories such as feminism and critical race theory where the social world is characterised by a struggle for power, and by relations of privilege and oppression. Lincoln and Guba’s (Lincoln and Guba, 2013) vision of constructivism acknowledges a place for this kind of critical perspective: they argue that certain social constructions (or ‘discourses’ - of ‘race’, gender, disability, neoliberalism etc.) become reified which serve to maintain the status quo and shore up unequal relations of power. As Fairclough and Wodak (1997: 25) argue, ‘discursive practices have major ideological effects through the

ways in which they represent things and position people'. Therefore, I see my role as researcher as not only exploring how social constructions and discourse emerge through intersubjective processes of interaction, but also with how these maintain oppressive and exploitative power relations – and in doing so, be better positioned to demystify and challenge these. My understanding of sociological research is therefore also an inherently critical one.

Researcher positionality

Given my constructivist worldview, critically reflecting on my own position as a researcher becomes a necessary part of the research process. I do not identify as asexual. This has led me, at times, to question my legitimacy in conducting research on asexuality. While my interest in asexuality stems from an academic and personal interest in the study of sexualities more generally, particularly those considered 'non-normative', I have worried that my interest might (also) be exploitative or parasitic (i.e. am I capitalising on this under-researched and marginalised group in order to further my academic career?). The issue is complicated by the fact that the study focuses on the intersection of asexuality with *disability* - and here I have a history of mental health problems which have been incredibly disabling at times, but I am not visibly disabled, and therefore have 'passing' privilege (and thus do not feel entirely comfortable about claiming a disabled identity). Some authors within disability studies such as Barnes (1992) have argued that non-disabled persons could not and *should not* do disability research because they could not fully understand the nature of disabled oppression; similar arguments might be made with regards to other marginalised groups. However, this suggests an overly simplistic insider/outsider dichotomy and I would argue instead that our identities and our experiences are rather more multi-layered and complex. Feminist theorists of intersectionality (e.g. Crenshaw, 1991; Brah and Phoenix, 2004) have alerted us to the fact that we are all multiply situated along various axes of privilege and oppression. This applies to participants as much as researchers –so while participants may be asexual and disabled, these may only constitute a (small?) part of how participants define themselves; therefore to set 'asexuality' or 'disability' as the criteria for 'insider' status ignores the cross-cutting social relations of gender, 'race', class, nationality, citizenship status etc. that structure all of our experiences and identities, and which come into play in the research relationship (Edwards, 1990; Song and Parker, 1995).

Additionally, Corbin Dwyer and Buckle (2009) also argue that we cannot ever be fully ‘outsiders’ since we will generally have an in-depth familiarity with the research topic (or certainly the literature surrounding it) but we cannot ever be fully ‘insiders’ either, since the role of ‘researcher’ invites a category of its own.

However, I recognise that having a multiplicity of identities does not necessarily mean having a subjugated identity, or that my particular experiences of marginalisation (for example, because of being working class, queer, fat, being perceived as a woman) can somehow ‘make up’ for not knowing what marginalisation on the grounds of disability or asexuality feels like. Therefore, I approached my research with a keen awareness of the politics of representation, and how my own biography may have shaped each stage of the research. I also found Hale’s (1997) guidelines for non-transgender people working on transgender to be useful (such as not assuming expert status, being mindful of one’s use of definite articles and plurals etc.) and tried to adapt them to my own research context.

Methods

Methods used

My research involved online semi-structured interviews. Participants were given a choice of formats for taking part: they could be interviewed asynchronously (via email) or synchronously (via instant-messaging (IM) or through video-conferencing software⁵). I felt that offering a choice of format was particularly important in this context, given Ison’s (2009: 161) contention that researchers interested in the stories of people with disabilities have tended to ‘restrict the way in which these stories can be told’ by privileging verbal forms of communication over others. While the formats on offer to participants still privileged linguistic forms of communication, this was an attempt to reduce barriers to participation to at least some degree (Harris and Roberts, 2003).

My decision to use *online* methods was, in part, pragmatic. Asexual-identified people with a disability are a relatively small group; expecting to recruit locally was therefore unrealistic, and time and monetary constraints meant I would not be able to travel far

⁵ Both IM and video-conferencing interviews were undertaken using Skype (www.skype.com).

to interview participants. By using the internet as a research medium, I was able to overcome this restriction and connect with participants located thousands of miles away (Hunt and McHale, 2006: 1416). Additionally, the use of online methods is particularly apposite in this case given that the development of asexuality as a concept and a marker of identity has been closely tied up with the emergence of online asexuality spaces (Carrigan, 2011).

I chose to use *interviews* because, as Lewis (2003: 56-57) notes, they would allow me to engage with the complex, in-depth subjectivities of participants, including how participants construct their own stories and make sense of their experiences. Other online methods, such as online ethnography or online focus groups would not let me do so to the same extent. This particular strength of interviewing applies to interviews that take place both online and offline, but there are also some key differences between these contexts, which I will explore in the following sections.

Online interviewing

Time and space

One of the key distinguishing features of email interviews is their asynchronicity: exchanges do not occur in 'real time'. By removing the pressures of immediacy found in synchronous forms of communication, both researcher and participant have time to reflect upon and then construct their responses, having the ability to edit as they do so. The resulting data is therefore perhaps more akin to solicited documents such as mass observation directives or diaries (Gibson, 2010: 2). Interviewing via IM shares features of both email and face-to-face interviewing (or video-conferencing) in that it is *synchronous* (or 'near synchronous' given that it is conventionally acceptable to take a moment to respond to a message (Fontes and O'Mahoney, 2003: 3)) but is at the same time also a *written* account.

Interviewing via email, IM and video-conferencing all also involve spatial dislocation. Because interviews can be conducted wherever there is available technology (although this means that in order to take part, participants must also be in possession of that technology, which may have an impact on those who can take part), this also increases the flexibility of the format. However, when parties are located in different time zones, scheduling a mutually convenient time for synchronous interviews can be difficult.

'Authenticity' and deception

Given this asynchronicity and/or spatial displacement, email and IM interviews are often viewed as somehow less 'authentic' than face-to-face interviews. For example, Opendakker (2006: §2.1.) argues that there is a loss of spontaneity in email interviewing due to its asynchronicity, with the implication that spontaneity is more epistemologically valuable, or perhaps more 'revealing', than responses which have been carefully mulled over and edited. Indeed, Bampton and Cowton (2002: §2) argue that the ability to draft and redraft responses allows participants to 'create the desired impression', again with the implication that this is undesirable from the researcher's point of view. However, approaching my research from a constructivist perspective, I reject the notion that there is a 'pure' unmediated truth that can be got at through spontaneous participant responses, and suggest that all forms of interaction involve some kind of management of the self (Goffman, 1990 [1959]).

The idea of 'truth' or 'authenticity' also relates to the charge made by some that deception or misrepresentation is a risk when using email or IM interviewing due to the relative anonymity of these formats (e.g. Mann and Stewart, 2000: 208; Jones, 2005: 80). However, while the idea that deception is rampant on online environments has been challenged empirically (Whitty; 2002; Stieger and Göritz, 2006), others, taking a more constructivist position, have argued that even if misrepresentation does occur, this is still valuable data in itself as it is all part of social interaction (Taylor, 1999). Still others might argue that the notion that we have only one 'body' and one identity is a modernist fallacy, thus rendering the charge of deception itself moot (Bromseth and Sundén, 2011). Given this, I was not overly concerned about 'deception' – save for the issue of age, where ensuring that all participants were over the age of 18 was built into the ethical conditions of this research⁶.

More ethical research?

The asynchronicity of email interviewing may also make for more ethical research since as Meho (2006: 1291) argues, participants have greater control over what they wish to reveal through their ability to edit and redraft; they can also more easily avoid

⁶ I stressed the age requirement in both my recruitment message and information sheet, and, from the complex, reflective and 'insider' accounts offered, was satisfied that all participants were 'competent' adults.

questions they do not wish to answer (McAuliffe, 2003: 65). Email and IM interviews also allow participants a greater degree of anonymity since the researcher need not know what they look like, or how their voice sounds – something which may be particularly important when researching sensitive topics (Liamputtong, 2007: 158-159). However, I feel that it is important to recognise that the potentially democratizing nature of email interviews only goes so far. James and Busher (2006: 414) remind us that email researchers still retain ultimate control over the process by shaping the agenda and setting the rules of engagement. Additionally, email researchers, like those undertaking any other kind of social research, have the ‘final say’ with regards to interpreting, selecting and (re)presenting participant accounts (Stacey, 1988). And despite Chen and Hinton’s (1999: §13.3) contention that the email (and IM) interview would be a ‘great equalizer’ since the gendered, racialised and classed bodies of researcher and participant are not ‘visible’, I would agree with Madge and O’Conner (2005: 85) when they argue that ‘mannered behaviours, pre-interpreted meanings and unstated assumptions are clearly ‘visible’ during online conversations’. We do not shed our habitus like a skin when we ‘go’ online – indeed, the idea of ‘going online’ seems increasingly archaic when the ‘online’ has become such an integral part of our embodied lives.

Time commitment

The amount of time required to conduct interviews was also affected by the use of online methods. While video-conferencing interviews are much the same as face-to-face interviews in this regard, the time commitments of both IM and email interviews are significantly longer. Each of my instant-messaging interviews took over two and a half hours to complete but generated roughly the same amount of words as a transcribed video-conferencing interview lasting 45 minutes. This is a significant time commitment to expect of participants (although the process was punctuated by comfort breaks) and I as the researcher came away from each IM interview feeling very fatigued, both mentally and physically. With regards to email, Cook (2012) estimated that in her research, each email interview took 6-8 hours to complete, albeit spread out over a period of weeks/months. More exhausting than this, however, was the emotional labour resulting from what Egan *et al* (2006) describe as the ‘lack of temporal parameters in email interviewing’, given that email can arrive in one’s inbox at any time. Thus, for the two and a half months during which I conducted interviews,

I felt I was constantly switched on to my inbox, exacerbated by the fact that my smartphone is also linked to this, and notifies me every time I get an email. And while email and IM interviews do not require transcription (see below), Kazmer and Xie (2008: 267) argue that interviewing via IM and email are in no way short cuts since data management (i.e. collating responses, standardizing formats etc.) can be unexpectedly labour intensive.

Transcription

IM and email interviews have the advantage of providing both researcher and participant with an on-going record of the interview, which both parties can look back on to prompt further questions or thoughts (Hinchcliffe and Gavin, 2009: 328). Data also comes already transcribed, which is not only of great practical benefit to the researcher, but also affords the participant more control over how they are represented in the transcription: for example, it is not up to the researcher to decide how a participant's spoken word should be rendered into text, or whether to render into text what *sounded like* a laugh but may have had a different meaning for the participant (Kazmer and Xie, 2008: 271). While video-conferencing interviews must be transcribed in the way that face-to-face interviews do, one can also draw on visual data from the interview since simultaneous audio and video recordings can be easily made, and a camera is already being used to conduct the interview (Bertrand and Bourdeau, 2010: 73).

Recruitment and data collection

I posted a recruitment message (see Appendix B) on the AVEN forums after securing permission from the moderators to do so (who also 'authenticated' my post on the forums). In order to post my recruitment message I had to sign up for a user account/profile and this involved stating my a/sexual orientation which is then displayed publically. After much deliberation, I chose to use the word 'sexual', taking the lead from some other members whom I had seen using this term. I cannot know if this affected recruitment (either positively or negatively) but no-one ever remarked upon it – although, it is not clear if this was because it was irrelevant to prospective participants, or if it went simply unnoticed. The moderation team also reposted my

message on the AVEN Tumblr⁷. I also posted my recruitment message on a popular Livejournal asexuality community⁸, although here I found that certain members were somewhat suspicious of my research and my motives for doing it, possibly due to a lack of a formal ‘moderation’ process for research requests, as is the case on AVEN. Some members expressed concern that by researching asexuality and disability I would further pathologise asexuality. I felt that these concerns were entirely valid, and so attempted to provide a bit more detail about my research aims in the comments section of my post.

Recruitment was on a self-selecting basis⁹. In total, I received 42 emails in response to these recruitment messages, and I emailed an information sheet (see Appendix C) to every person who contacted me expressing interest in the project. If the individual emailed me back affirming their willingness to participate after reading the information sheet, I then emailed them a consent form (see Appendix D) with instructions to complete it electronically and return it to me. Once received, I then began the interview process. In the IM and video-conferencing interviews, questions were asked and answered sequentially, as in a face-to-face interview. However, with the email interviews, I sent around 3-4 questions in each email (see Appendix E for the interview guide). I did not want the interview to feel like a questionnaire, but I was conscious of the fact that sending one question at a time might make participants lose interest and/or make for a protracted interview process. Once the participant replied to my questions, I would respond with some comments, some questions prompted by the participant’s particular responses and some new questions until I felt I had covered everything.

Out of the initial 42, 10 individuals completed the process. If a participant was taking a while to respond to a set of email questions, I sent a gentle ‘reminder’ email as suggested by several sources (McAuliffe, 2003; Meho, 2006; King and Horrocks, 2010). One participant, who had completed around four fifths of the email interview process failed to respond to this reminder, so I sent a second (and final) email expressing my concern that everything was OK on their end and asking them to

⁷ <http://avenpt.tumblr.com/>

⁸ <http://asexuality.livejournal.com/>

⁹ Regarding disability, my criterion for inclusion in the study was only that participants consider themselves to be disabled (see also Appendix C).

confirm if they still wished to take part (and if they did not, if they also wanted to withdraw their previous data), to which I also received no response. This left me with the dilemma of what to do with this participant's data. Given the near-completeness of what had been a very rich interview, as well as the participant's failure to withdraw, I made the decision to include this participant's contributions to the research, although I am aware that this is a somewhat murky ethical area – for example, Hunt and McHale (2006) argue that non-response should be seen as full-withdrawal. I therefore include data from 11 participants in my analysis (see Appendix E for participant demographic information).

Self-disclosure

I began my research with the idea that self-disclosure on the part of the researcher was necessary for a non-exploitative interview (Oakley, 1981) but found that this was much more difficult to put into practice. None of my participants asked any personal information of me, and so at times, I experienced feelings of guilt that I was just 'mining' data. I recognise that power disparities might have made it difficult for participants to ask questions of me, so I might have proactively ventured some information about myself during the 'tentative' phase of the interview (Corbin and Morse, 2003), or perhaps given more of an indication that I was willing to answer any questions they might have about me and my relationship to the topics under discussion. However, I also acknowledge the possibility that participants had *no desire* for this kind of reciprocity. Ribbens, in response to Oakley, makes the important point that reciprocity might be construed as imposition:

'I have also felt sometimes that when I have volunteered information about my own family experiences, that my contribution has been seen as a nuisance, interrupting the woman's own flow of thought. After all, is not part of the research exchange that I have expressed an interest in hearing about the interviewee's life? I have given her permission to do what is normally seen as an indulgence and socially reprehensible: to talk about oneself at length. If I start talking about myself, this may be seen as breaking this research contract, rather than sharing myself with her' (Ribbens, 1989: 414).

Indeed, given the fact that participants very easily shared personal stories with me, it may be the case that participants enjoyed having this space to 'author' their own

experiences, especially given the lack of research of this particular topic. Clark (2010) suggests that this is one of the key reasons why people engage in qualitative research, and I would venture that this ‘authorial’ potential is especially heightened in email interviewing, since the nature of the exchange encourages long, reflective responses with minimal interruption.

Data analysis

Following on from my constructivist perspective, I approached my data using a discursive analytical framework. Phillips and Hardy (2002: 6) provide a useful explanation of discourse analysis:

‘Traditional qualitative approaches often assume a social world and then seek to understand the meaning of this world for participants. Discourse analysis on the other hand, tries to explore how the socially produced ideas and objects that populate the world were created in the first place and how they are maintained and held in place over time.’

In discourse analysis, the focus is on ‘discourse as a topic in its own right’ (Potter and Wetherall, 1987: 35) rather than trying to ‘recover events, beliefs and cognitive processes from participants’ discourse’ (ibid.) or to ‘use discourse as a pathway to entities or phenomena lying ‘beyond’ the text’ (ibid.: 49). The researcher might also write themselves into the analysis, such as considering how researcher-participant exchanges contribute to the making of ‘reality’ (Presser, 2005) as well as how the researcher’s social position might affect the interpretation of that reality. However, Holstein and Gubrium (1997: 127) point out that along with looking at the meaning-making process itself, it is important not to lose sight ‘of the meanings that *are* produced’. This does not mean we must reinstate an objective reality, but rather that we recognise that what is being said and the meanings being conveyed ‘relate to the experiences and the lives being studied’ (ibid.). It is with this in mind that I now turn to my findings chapter.

Chapter Three: Discussion and analysis of findings

In this chapter, I discuss the key themes to emerge from my analysis of the eleven interviews. I have grouped them as follows: how the asexual community was constructed in participant accounts; how participants engaged with the ‘myth of asexuality’ and attempts to challenge it within disability communities and organisations; the idea of a link between asexuality and disability and lastly, how disability mediates the experience of asexuality.

Constructing the asexual community

All participants framed the asexual community as generally open to and accepting of disability. Evidence was marshalled in favour of this, for example, Natalie¹⁰ explained how she had “met a lot of aces online that are autistic, physically disabled, depressed, etc.”; others, like Lauren, drew on the positive reception she had received when she discussed her mental health problems on the AVEN forums. Participants went on to account for this openness, most commonly with reference to the idea that those in the asexual community knew what it was like to be ‘different’:

“At AVEN, everyone knows that they are a minority in this world, so, I think that leads to them being more supportive and accepting of people with disabilities, both mental and physical” – Lauren

“We’re all mostly feeling a bit different from society as it is” – Natalie

“Asexuals are on the edge of “typical” and so they would have empathy to those who are atypical in other ways” – Erin

Jo specifically attributes what she sees as the increased empathy and sensitivity of the asexual community to the marginalisation that many asexual-identified persons have experienced in LGBT spaces:

“I think a lot of people report not being received well by LGBT people and so it makes them...because we’re kinda newcomers to that group ummm and so we’re more aware of being perhaps mistreated or misunderstood” – Jo

¹⁰ See Appendix F for demographic data pertaining to participants.

Several other participants also made reference throughout their interviews to the hostility they had faced from LGBT communities: for example, Ryan felt that a kind of ‘Oppression Olympics’ was at play, where LGBT persons would compare what they perceived to be a lack of ‘asexual oppression’ to the assaults, murders and imprisonments suffered by LGBT populations. Erin also suggests that the LGBT community in some respects has more in common with ‘straight’ society - for example, she thinks that both LGBT and straight communities place a premium on sexual attractiveness, whereas ‘asexuals are more likely to see people as having characteristics outside of those that make them sexually desirable’. She suggests that this may lead to the asexual community being more open to those – such as disabled persons – who have been constructed as sexually undesirable by mainstream (sexual) society. This framing of the asexual community/asexuality in general as especially enlightened (since there is no sexual attraction to ‘get in the way’) was also expressed by other participants:

“I kind of like not seeing other people as objects, I mean, just not having that dimension to my thinking is nice – I kind of wish that that were more the case, like if you have that way of thinking then you kind of have to fight against it in a lot of contexts if you want to you know, treat, the person as a human being” - Jo

We might relate these comments to broader scholarship on how social movements construct a collective identity. Taylor and Whittier (1992) suggest that three interrelated processes are involved: drawing boundaries to construct a collective self and a collective other; developing interpretive frameworks through which meaning can be attributed; and deploying strategies to negotiate negative social definitions. We can see these at work in participants’ accounts. Boundaries were clearly drawn between both ‘straight society’ and LGBT communities. Asexuality was very much positioned as a marginalized group against the perceived dominance (and hostility) not only of heterosexuality but also LGBT. This involved re-framing asexuality’s difference not as a deficit or pathology, but as an actual *advantage*: it was seen to afford a clearer view, ‘uncontaminated’ by sexual attraction and resulting in more authentic interpersonal relationships.

Challenging the construction

Given this construction of the asexual community as disability-friendly, I wanted to solicit participants' views on the 'charges' that have been made regarding the potential marginalisation of disabled asexual-identified persons through claims of health and normality (see #16 and #17 of the interview guide, Appendix E). In positing this view, I was explicitly challenging participants' construction of the asexual community. Participants responded to this challenge by skilfully reinterpreting my reading of the situation – for example, Natalie makes the distinction between *asexuality* being presented as 'healthy' (which she believes is what is happening) and asexual *individuals* being presented as 'healthy' (which she does not):

“I have only seen the terms “healthy” and “normal” in regards to sexuality and not to overall health. Asexuality and its subsets *is* normal, as in it's not unhealthy to be asexual. I don't believe this says anything about each individual's personal health. I think it's just a reminder that there's nothing to be afraid of when it comes to sexuality.” – Natalie

Ryan and Helen both argued that the desire to be recognised as 'normal' is in actuality a request for the asexual community to be recognised as *heterogeneous*, like any other cross section of the public. Therefore, it would not follow that disabled persons would be excluded. These accounts, including the ones in the previous section, suggest that participants did not feel any way marginalised or excluded from the asexual community on account of their disability. It is certainly the case that we must take the epistemological context into consideration – having been recruited from asexual online communities, the participants were positioned as 'representatives' of those communities, and were speaking to a researcher about a subject on which little academic research has been conducted. The research relationship was therefore implicitly inscribed with political meaning, and participants' constructions may be read as an attempt to present the asexual community as positively as possible. However, given my own social constructivist position, this does not mean that participants' accounts were true or false, or more or less reflective of 'reality', but rather that these discursive constructions – how participants talk about and frame asexuality and the asexual community - are part of that reality itself. This is perhaps especially so given that the asexual community is still largely constituted by online

discussion rather than by offline meet-ups etc. – it is quite literally a discursive community.

Other exclusions

However, while rejecting my suggestion that disabled persons might be marginalised within the asexual community, some participants spoke of other exclusions. Erin felt that the grey-A orientation was often delegitimised in the asexual community. She likened this to the marginalisation of bisexuals within LGBT spaces:

“It is a little frustrating that people on both sides seem to think that you are either one or the other – no matter what group I’m identifying with (bisexual or gray-A) there are people saying you are either straight or gay or you are either sexual or you aren’t with that ‘stop trying to be special’ kind of insinuation” - Erin

However, Erin also acknowledges that this hostility might be rooted in a fear that the visibility of grey-A will make asexuality seem like it is a choice, or a ‘phase’, with the implication that this will invalidate asexuality. On the other hand, Camille felt that *aromantic*-identified persons were marginalised within the asexual community, but she too suggests that this marginalisation stems from a concern with how asexuality ‘appears’ to broader society:

“I think this is more a reaction to the fact that some sexual people think asexuals can’t feel love. They think about characters like Sheldon from The Big Bang Theory. Some asexuals counterbalance it by saying “no, asexuals are normal, they’re romantically attracted to others the same way as sexual people” and when they say that, they exclude people on the aromantic spectrum from the “normal population”. – Camille

Camille goes on to suggest that this may mean that many disabled people are thus excluded by proxy, since she perceives there to be a tendency for those on the autism spectrum to identify as aromantic. Both Camille and Erin’s accounts highlight how health, or at least, ‘normality’ discourses may work through marginalising *particular* asexual orientations (rather than or in addition to disability), and through the construction of an ‘ideal’ kind of asexuality: asexual (as opposed to grey-A or demisexual) and (hetero?)romantic. It may be that we can see the development of a kind of ‘asexual-normativity’ at work here; after all, Klesse (2007: 2) reminds us that

‘alternative’ or ‘non-normative’ sexual identities or forms of relating can still be structured by hierarchical power relations. This is perhaps another example of boundary work - but this time undertaken *within* the community, and involving the demarcation of the more and the less legitimate (Gamson, 1997: 180). This, along with participants’ constructions of the asexual community, demonstrates that not only is the asexual community diverse, as Carrigan (2011) has argued, but is also a site where ‘meaning work’ is undertaken to ‘affect interpretations of reality among various audiences’ (Benford, 1997: 410). This highlights too how the asexual community should not be viewed as a reified ‘thing’, but rather as a dynamic network of relations and representations.

Challenging the myth of asexuality in disability communities

Kim (2011) suggests that a potential danger of contesting the ‘myth of asexuality’ in disability communities is that it will erase those people who actively identify as asexual. I wanted to explore if participants shared Kim’s reading of the situation, or had experienced erasure themselves (see #21 in interview guide, Appendix E). However, many participants were not involved in any kind of disability community or organising; discussion of these issues was therefore somewhat limited. All of my participants did however acknowledge the asexual assumption made of disabled persons and agreed that it was important that it was challenged - although like Kim, they also expressed reservations about going too far in the other direction. Kate, who *was* active in disability organizing, felt however that it was important to challenge the stereotype ‘even if asexuality gets overlooked from time to time’. She felt that the political priority should be in recognising the sexuality of disabled persons – although if we understand ‘sexuality’ in terms of the recognition of sexual *agency*, this could also mean recognising that some disabled persons might identify as *asexual*. However, as Shildrick (2012) argues, it may be that the legitimisation of disabled sexuality is conditional upon its heteronormativity, or even ‘homonormativity’ (Duggan, 2003). To use Rubin’s (1984) terms, disabled sexuality might be drawn into the ‘charmed circle’, but in this process, the charmed circle itself is reinforced, and non-normative sexualities – conceivably including asexuality – may be further denigrated.

None of my participants felt as if they had been excluded or erased within disability communities, or by dominant disability rights discourse. Kate went on to suggest that in actual fact, the disabled activists in the communities she was a part of were quite conscious of their use of terminology:

“When I’ve seen asexuality mentioned by disability activists, it’s mainly been in one or two contexts: One, complaints about disabled fictional characters being portrayed as ‘asexual’, meaning ‘without sexuality’, in the media. Two, people talking about why using ‘asexual’ in that context might be a problem.” - Kate

She went on to describe a post written by a disabled woman on a lesbian-feminist blog that reflected on these issues:

“Her argument was essentially that ‘asexualised’ disabled characters weren’t actually being depicted as asexual, in the sense that they’d thought about their sexual orientation and realised they weren’t attracted to anyone. Instead, they were being depicted as *non*-sexual in the way a child or robot is – they didn’t feel sexual attraction because they were too ‘innocent’ or ‘emotionally cold’ to understand sex’. – Kate

So while many did rail against the depiction of disabled persons as asexual, there also existed voices (presumably who were aware of the existence of asexuality as an identity category) to counteract this reading and provide a more nuanced view. Kate’s experiences suggest that there may not be a blanket rejection of ‘asexuality’ within disability communities, as Kim fears, but that members may engage with discourse in more complex and sophisticated ways. This may be increasingly the case as asexuality gains more positive media coverage (such as in the recent six-part series in the Huffington Post (Mosbergen, 2013)) and the visibility of asexuality as an identity grows. Kate’s account also highlights the importance of distinguishing the societal ascription of asexuality from the agentic sense of being asexual. I suggest that disability scholar Tom Shakespeare’s (2006) distinction between ‘labels’ and ‘badges’ might be useful here. We can differentiate between asexuality as a *label* that is *stuck* on certain people, and asexuality as a *badge* that some people feel describes their sense of self, and is *worn* (with the agency that this implies). This distinction might help to increase conceptual clarity.

Links between disability and asexuality

I was keen to understand how participants understood their own asexual-identification or orientation in light of also having a disability, given the connections commonly made between the two. Perhaps surprisingly, many were willing to consider the possibility that their disability/illness and their asexuality might be connected in some way (although a couple of participants also rejected this outright). A variety of possible links were expressed: for example, Kate mused that her lack of confidence resulting from her mental health problems may have led to her repressing her sexuality as a young teenager. Similarly, Dawn suggested:

“ME is still a mystery condition in many ways, as is clinical depression, my other diagnosis. A sudden loss of interest in all things (including sex) is characteristic of some mental problems, so I can't say for sure that there is no connection.” - Dawn

Erin and Jo both suggested that there may be a connection between their embodiment and their asexual identification:

“I do have some kind of a vague theory as to where it all comes from, that like, ummm, you know, being in constant pain from a young age that maybe I didn't have the same connection to my body that other people do and maybe that had something to do with how I view other people's bodies or physical interaction in general, so I think that might be part of it.” – Jo

“Learning about my particular condition and that part of it – joint hypermobility – has a lot to do with lack of proprioception and weird sensory issues – well, sometimes I wonder if I have a simple disconnect between my mind and body, and that is why I don't feel like my body wants to engage with anyone sexually” - Erin

Erin and Jo's accounts point to the role that the bodily experience of being impaired has played in their lives (Thomas, 1999) and how living in a particular body may have shaped their (sexual) subjectivity. However, this view was held in tension with the awareness that the asexual community was hostile to any links being made:

“I think there can be a sticking point with the asexual community at large. They are frustrated with always having asexuality be “something

wrong with them” – whether it’s doctors or peers or partners, people are always presuming there is some kind of defect that makes a person asexual. So there is a bit of friction there.” – Erin

Ryan also felt that the asexual community was hostile towards the suggestion of a link:

“I think the view that asexuality is not related to physiological, hormonal or psychological problems is very deeply ingrained in the asexual community. One of the most common dismissals we get from non-asexual people is the assumption that we are ‘repressing’ something, that it was caused by since-forgotten childhood trauma or abuse, that it is a hormonal deficiency or a neurological problem, or otherwise caused by some sort of deformity or deficiency. Given our struggle to get people to accept that asexuality exists and is a valid sexual orientation, these kinds of dismissive arguments are very much not welcome.” – Ryan

So while the asexual community might be open to members with a disability, this is perhaps conditional on not making *connections* between one’s asexuality and disability. Making such a connection would seem to undermine the strategy of the ‘unassailable asexual’ - as blogger Gaia puts it: ‘no-one can tell the unassailable asexual they are asexual *because* of something’ (The Queer Ace, 2013).

‘Cause’ is irrelevant

However, some participants challenged the idea that linking disability and asexuality *had* to be seen as dismissive or invalidating. As Kate put it:

“I don’t think a link between asexuality and ASD would make anyone’s asexuality not ‘valid’. ASD asexuals would still be asexual, it just wouldn’t be for the same reasons as other asexuals.”- Kate

Jo expressed a similar sentiment:

“I think that, umm, the idea that your orientation umm doesn’t have any kind of cause has been like created as a kind of like the test of legitimacy – you know, the reason why being gay is legitimate is because you’re born that way and can’t do anything about it – not, you know, maybe something caused you to be a certain way which might be the case for some people but you know, why should you be any other way? I mean,

it's legitimate, it's however you feel, it doesn't matter how that came about so, umm, no it wouldn't matter to me personally, wouldn't make it any less legitimate if it had a cause...I'm sure a lot of people are born that way and maybe some of them aren't and have reasons for becoming that way...either way it's legitimate.” - Jo

Recognising that asexuality might have a biological or neurological or psychological ‘basis’ for some people, or may be rooted in a particular experience of embodiment, did not mean that asexuality was therefore seen as something to be ‘cured’. This was similar to Brotto *et al.*'s (2010) finding that although their participants discussed a possible connection between asexuality and Asperger's, they were also reluctant to see asexuality as a disorder. Participants thus simultaneously resisted the *medicalization* of asexuality by embracing asexuality as one more way of being-in-the-world, regardless of ‘cause’. What was important was that ‘asexual’ was a term that an individual felt they could identify with. In these accounts, the idea of what constitutes a ‘legitimate’ sexuality (not ‘caused’ by anything but equally not freely chosen) was challenged, but the sexological search for aetiology was also rendered irrelevant, since ‘cause’ was only something that had a place in personal narratives, and did not hold wider significance. These accounts also remind us that while the dominant framing may be to resist the connection between disability/illness and asexuality, community members are not passive dupes buffeted around by discourse, but are capable of a much more active engagement, and have a repertoire of frames that they are able to deploy (Hull, 2001).

Disability mediating the experience of asexuality

All participants felt that disability mediated the experience of asexuality in some way. This was mostly expressed in terms of how other people have responded, or might respond, to their asexuality as a disabled person. Most asexual-identified persons have to deal with their asexuality being attributed to some kind of pathology (as discussed above), but Ryan very eloquently argued that a disabled person's embodied existence could be used as ‘proof’:

“As an asexual person with a disability, I definitely think I get the dismissal that it must be caused by some other factor, rather than being a

genuine, pervasive and enduring sexual orientation, because people have clear ‘evidence’ to draw from. They believe that asexuality is caused by some deformity or physiological issue, they see that I have some kind of physiological issue, so they see a causal relationship... Although non-disabled asexual people still get that argument, it’s easier for them to argue against it because the “causal link” is missing one of the major components” - Ryan

Bobby also suggests that scepticism, or dismissal, is exacerbated by the presence of disability:

“there might be...a bit more of a scepticism there, a bit more of – “well you already have this”...for a disabled person, you go “it’s a disabled person” and you might think that asexuality just comes along with that or something, or maybe their medication, you know what I mean? Yeah, I think there would be a bit more scepticism toward a disabled person saying that they were asexual” – Bobby

Here Bobby points to how disability often comes to define the totality of a person’s existence (“it’s a disabled person”), so that all their actions come to be read through the prism of disability, including sexual identity. As O’Toole (2000: 210) puts it: ‘[for disabled people] it is presumed that any sexual expression is an expression of illness or disability’. Interestingly, in Bobby’s account, even though disabled persons are assumed to be asexual by default, this perhaps counter-intuitively increases scepticism towards disabled persons self-identifying as asexual because *actively* claiming an asexual self-identity would seem to contradict prevailing ableist norms of passivity and dependence. Appleby (1994: 24) explores this in relation to lesbianism and disability; she quotes one participant who suggests that you have to ‘be normal to be abnormal’, referring to how an ‘alternative’ self-identification only tends to be considered legitimate or ‘real’ if the subject is able-bodied. Here the previously discussed concept of ‘labels’ and ‘badges’ might also be useful – perhaps you cannot wear asexuality as a *badge* if you are already wearing it as a *label*. More broadly, this also links into debates around individualization and claims of how we are now all able to craft our own biographies (Giddens, 1991). Bobby’s account would seem to challenge this: the right to be an individual is perhaps provisional on one’s able-bodiedness.

In Steff's case, she felt that her disability impacted upon her journey towards claiming an asexual identity:

“I think my experience has been different and more difficult from non-disabled asexuals because I assumed my lack of interest in sex was because of my disability...I blamed my lack of interest in intimacy on my Aspergers. If I did not have Aspergers I think I would have suspected I was asexual a lot sooner.” – Steff, email interview

Steff also describes how her mother had talked to her as a teenager about how many people with Asperger's do not have, or are not interested in sexual relationships. Shakespeare *et al.* (1996) identify socialization and the 'management of expectations' as a barrier to disabled people being sexual; here we might also see it as a barrier to disabled people being *asexual*, in the sense of claiming asexuality as a positive identity. Kim's (2011: 483) concern that the assumption of asexuality leaves little room for *agentic* asexual existence may be seen to be reflected in Steff's account, as in Bobby's. Steff also brings our attention to the fact that when negotiating an asexual identity, not everyone is subject to the same kind of pressures and expectations to be a sexual being. This challenges Scherrer's (2008: 632) argument that coming to identify as asexual involves rejecting the ubiquity of sexuality: for some marginalized groups, sexuality has *not* been considered ubiquitous. It also complicates Carrigan's (2011) account of the formation of an asexual identity: he suggests that common to this process is a feeling of individual difference (which is ultimately resolved through discovery of the asexuality community), but I would argue that this is dependent on an able-bodied (perhaps even white and male) subject for whom asexuality has not already been ascribed.

For Kate, her main concern was that identifying as asexual as a disabled person would be construed as 'playing up to a stereotype' or confirming the 'link' between asexuality and disability, which people in *both* asexual and disability communities may resent. She describes an incident where she felt particular pressure because of being both asexual and disabled:

“I do worry about having to justify myself – and the other weekend, at Pride, I found myself worrying that I might be making asexuality 'look

bad' if I wasn't appearing sufficiently neurotypical" – Kate, email interview

She goes on to suggest that this has led her to be more attuned to how asexuality 'looks' to the 'outside' world:

"I also caught myself surveying the group I was in, hoping we had a large enough range of personality types, a range of ages, a clear mix of genders and gender presentations etc. I was worried that, if we appeared too homogenous in any way, we might end up accidentally reinforcing a pre-existing negative stereotype. To give some examples: too many disabled people ("asexuality is a medical symptom"), too many geeky people ("asexuality is an excuse for socially awkward people who can't get dates"), too many young women ("silly attention seeking teenage girls") or too many middle class white people ("probably a hipster thing") –
Kate

Although Kate's concern is that asexuality appears diverse enough, it is still a 'normative' and controlled kind of diversity, and might be viewed in terms of constructing the 'Unassailable Asexual' (interestingly, Kate's account suggests that the 'Unassailable Asexual' would not necessarily be middle class or white, as these might also be used as a way of discrediting asexuality). This would seem to chime with Gressgård's (2013) argument that the shift from asexuality-as-pathology to asexuality-as-identity is dependent on the production of a self-regulating subject; and this is something that is perhaps even more so for those positioned at the intersection of asexuality and disability, as Kate's account of micro-managing her behaviour and appearance shows us.

Kate's account is very similar to blogger Gaia's description of the Unassailable Asexual:

'...the best representatives would be considered those who are heteroromantic, have a sex-drive, don't have a history of mental disorders, were never sexually assaulted, grew up in a sex-embracing environment, were always asexual, and are generally positive, friendly, attractive people who enjoy the company of others.' (The Queer Ace, 2013)

However, while Gaia had given up asexual activism because she felt uncomfortable about projecting this image, Kate was anxious that it *was* projected. Contra Cerankowski and Milks (2010), Przybylo (2011) and Gressgård (2013), Kate's account suggests that she does not want asexuality to be seen as transgressive because this might negatively impact on the already precarious status of the asexual community. These writers do not consider the 'costs' of framing asexuality as transgressive - or rather, the costs (i.e. being excluded from the parameters of normativity) are valorised as part of that same transgressive queer project. But, as Sara Ahmed argues, this view might only be available to those who possess the social and economic resources to 'support the 'risk' of maintaining anti-normativity as a permanent orientation' (2004: 152). This links back to the discussion about whether 'abnormality' may only be accessible through a pre-existing 'normality'; for Kate, as a disabled person who may have already been positioned out with the bounds of normativity, transgression is perhaps not only more difficult, but perhaps also a less romanticised prospect.

Dawn also discussed being worried about 'confirming the stereotype', but also how she has come to accept that this is something she cannot control, since her use of mobility aids means she is unable to 'present' as able-bodied. Dawn also suggests a way in which the stereotype may work to her personal advantage:

"On the plus side, nobody tries to play matchmaker, or pesters me about my "biological clock". I'm in a wheelchair - clearly I have neither the desire nor the ability to make babies. It keeps the bulk of "busy-body strangers" off my case"- Dawn

Feminist disability scholars have written about how disabled women have not been perceived as 'real' women in terms of their eligibility as sexual or romantic partners, or as mothers (Begum, 1992; Kallianes and Rubinfeld, 1997), but Dawn's account highlights how this also works to liberate her from oppressive social expectations of femininity (to have children by a certain age; not to be left on the 'shelf) especially as an asexual-identified person who does not want a partner, nor to have children. Here we can see how disability, asexuality and *gender* also intersect in interesting - and perhaps contradictory - ways.

Impact of gender

Other participants also offered thoughtful accounts of how gender, asexuality and disability might intersect. Kate felt that having Asperger's meant that her asexuality was already seen as less valid (because it is assumed to be caused by a neurological 'problem') but was further delegitimised on account of Kate being a *female-bodied person* with Asperger's. While she suggests that all persons on the autistic spectrum are constructed as 'innocent', it is something that she feels is more pervasive for girls and women. She describes how:

“I have, on several occasions, worried that people who know about my ASD will assume that I call myself asexual because I'm too 'innocent' to understand sex, or else frightened of it due to being 'childlike' (and not that, you know, I realised I didn't feel sexually attracted to others, questioned, had sex and found it wasn't a turn-on, questioned again and eventually decided 'asexual' was the closest fitting label).” - Kate

This quote highlights how Kate's identity as asexual arose out of a long process of reflection, experimentation and self-questioning, which is contrasted by the simplistic assumptions that she fears will be made of her because of both her gender and her disability. Natalie also refers to how women in general are perceived as innocent, and while this, for her, meant that people were less surprised when she came out as asexual (“the reaction to women coming out as asexual is sometimes “That's normal for women””), she still felt that this was a damaging assumption because “asexual women are misunderstood and sexual women are berated for being overly sexual”. In discussing her (invisible) disability, Natalie also highlights how as a woman, she felt she was rarely taken seriously, or presumed to be a reliable judge of her bodily state, with her pain often dismissed as menstrual cramps. Natalie's account shows how women are often prevented from 'owning' their own experiences, as other motives or explanations are epistemologically privileged over women's own voices (whether in relation to bodily experience, or experiencing a particular kind of sexual subjectivity). Ryan too was fully aware of his 'masculine privilege' and also reflected on how gender may be used against asexual-identified women to delegitimise, or negate, their identity:

“One response I know a lot of women get is “obviously you’re too ugly to get any, so you make up excuses to console your ugly face while you sob into your pillow” - Ryan

He contrasts this with a typical reaction an asexual-identified man might receive:

“for a male, a non-asexual might say something like “dude, you don’t know what you’re missing!”” - Ryan

Here again we can see how a woman identifying as asexual is not taken seriously (i.e. it must be attributed to some other factor) but a man identity’s as asexual is perhaps more likely to be accepted, or at least ‘heard’, if still lamented. I would also argue that these differing responses may also relate to the fact that although a certain kind of sexual passivity may be expected of women, as Natalie described, they are also expected to be (hetero)sexually *available* – and when they are not, this necessitates some form of patriarchal social censure. However, this second response also hints at the cultural expectation that men in particular *should* want sex, which Ryan also recognises:

“As a male I’m expected to like sex and be wanting to ogle women on the street and so on, and as a disabled male I’m expected to ‘suck it up’ and not complain, and as an asexual feel like there’s this constant juggling game going on” - Ryan

Ryan feels that being (hetero)sexual is necessary to be recognised as properly masculine. He expressed a desire to be recognised as masculine, and he feels that his disability puts extra onus on him to perhaps prove his masculinity (to ‘suck it up’ and ‘be a man’), but that identifying as asexual removes a key resource for doing so. Brown (1994) discusses how becoming sexual is framed as a key part of the ‘normalisation’ process for disabled persons, so Ryan may feel the additional burden of this. Similarly, Bobby felt that there was more pressure on men to be sexual, but interestingly, felt that he was advantaged in being a *heteroromantic* asexual man since he perceives women to be more accepting of an asexual orientation, and more likely to be happy with an asexual partner. His account is useful in that it draws attention to the ways in which romantic orientation might also be of relevance in exploring how gender, disability and asexuality might intersect.

Impact of 'race'

Most participants were silent on the issue of how 'race' might have an impact on their experience of disability and/or asexuality, or could not envision *how* they could have an impact. All of my participants identified as white or white presenting, and so we might see this silence in terms of white privilege: where being white accrues systematic advantages, but this process is simultaneously rendered invisible through the denial of whiteness as a racialised category (McIntosh, 1989).

Jo did however concede that being white and middle-class made it 'easier' to be asexual:

“Well I definitely think that being umm asexual is easier as a middle class white person in the US. There is umm...more cultural acceptance than I think I would necessarily receive in a different circumstance...you have more freedom to think about those things and they're more likely to be understood in those circumstances than they necessarily would be if I were ummm if I were economically disadvantaged then I think that the culture would be more conservative ummm about social issues like that”

– Jo

However, rather than recognising the socio-structural capital afforded her by being both white and middle-class which perhaps reduce the 'costs' of adopting a non-normative sexual identity, Jo instead invokes an image of the liberal, tolerant white middle-class, juxtaposed against the spectre of poor, racialised communities where asexophobia may be more rife. Scholars such as Gúzman (2006) and Puar (2007) have discussed how there has been a racialization and nationalization of gay as 'white' and 'Western', while homophobia becomes sutured to the non-white and the non-Western, and by implication, the 'non-civilised'. It may be the case that similar discursive constructions are at play here, although this would require further investigation (and the asexuality literature thus far has exhibited its own white privilege by its silence on the issue of 'race').

Ryan also reflected on why the asexual community was dominated by white persons, suggesting that this was 'possibly because we aren't also dealing with racism and so can focus on asexual visibility foremost'. While Ryan acknowledges the white privilege he and most of the asexual community have (they don't have to 'deal' with

racism), his account remains problematic. First of all, he sees racism and asexuality as separate, but it may be the case that particular constructions of ‘race’ prevent certain persons from claiming an asexual identity – for example, the hypersexualisation of Black bodies, seen in the cultural tropes of the pimp, or the welfare queen (Amos and Parmar, 1984; Ware, 1992) – and again, this relates to the idea that one must be ‘normal’ to be ‘abnormal’. Secondly, Ryan’s account positions racialised communities as somehow further behind on a teleological trajectory (they have to deal with racism before they can be concerned with something (as trivial as?) asexuality). Although Ryan’s point is that racism is ‘worse’ (or more consequential) than not having your asexuality recognised, this kind of narrative also has the effect of perpetuating an image of racialised communities and persons as one-dimensional, and as situated in a suspended temporal space apart from the present. However these claims are hypothetical, and the fact that they *are* hypothetical is significant – neither Jo nor Ryan could draw on any real-life examples, suggesting that there is either a lack of ‘non-white’ asexual-identified persons in the asexual community, or that they are not visible. Both of these scenarios highlight the need for a critical engagement with ‘race’ in future asexuality research.

Summary

In this chapter, I have discussed four major themes to emerge from my analysis of the interview data. These have been: how participants discursively constructed the asexual community; participants’ engagement with the ‘myth of asexuality’ and attempts to challenge it within disability communities; the possibility of links between asexuality and disability; and how disability mediates the experience of asexuality, including how this intersects with gender and also with ‘race’. In the next, and final, chapter I draw some conclusions about the study as a whole.

Conclusion

The aim of this dissertation was to explore the experiences and understandings of asexual-identified disabled persons. This was prompted by Kim's (2010, 2011) claims that these individuals might experience marginalisation or erasure due to dominant discourses within both asexual and disability communities. While these claims were explored, I also looked at the intersection of asexuality and disability more generally.

Summary of findings

A variety of themes emerged from my analysis of eleven qualitative online interviews. Participants constructed the asexual community as open, inclusive and accepting of disability; indeed, the asexual community was framed as *especially* inclusive because lacking sexual attraction meant one *gained* an 'enlightened' perspective on interpersonal relationships. Participants also rejected the notion that activist claims of health and normality were marginalising by suggesting an alternative (and 'corrected') reading of them. However, participants spoke of other exclusions (concerning grey-A, demisexual and aromantic identified persons), which suggested that an asexual-normativity (if not a specifically able-bodied asexuality) was in operation, designed to bolster the 'unassailability' of asexuality. I therefore argued that we should view the asexual community as a site where meaning is constantly being made and contested.

With regards to disability communities, none of the participants felt erased by attempts to challenge the asexual assumption made of disabled persons. I suggested that 'asexuality' is perhaps increasingly being understood as an identity/orientation within disability communities, and that using Shakespeare's distinction between labels and badges might allow us to continue to challenge the *ascription* of asexuality whilst also recognising that asexuality is a term some people choose to identify with.

I also discussed how participants were willing to consider links between their disability and asexuality, and how for some, such a link was important in their own narratives. At the same time, participants were aware that making such a link would not be well received within much of the asexual community since this might undermine the cultivation of 'unassailability'. However, some participants attempted to resolve this tension by positing an alternative way of looking at the situation. They challenged the view that to have one's sexuality be considered legitimate, it must be

endogenous – that is, *of itself*, without anything other than ‘normal’ developmental patterns causing it. Participants thus suggested that acknowledging links need not be invalidating, because what *matters* is that one identifies as asexual now.

Participants also felt that disability impacted on the experience of asexuality in a few different ways. Some participants felt that the visibility of disability gave detractors extra ‘ammunition’ to dismiss their asexuality. Disability was also seen to impact the process of coming to an asexual identity. I suggested that reflexive identity construction might be conditional on being recognised as able-bodied, making it perhaps more difficult for those already wearing an asexual label to also wear an asexual badge. I therefore also argued that the process of coming to an asexual identity described by existing asexuality literature might be based on the implicit universalization of an able-bodied (perhaps also male, white and middle-class) subject, who has had a particular relationship to the ‘sexual assumption’. Other participants felt a particular responsibility to monitor themselves so as to ‘present’ asexuality in the best possible light, again; I also suggested that the positioning of asexuality as ‘transgressive’ by some writers was also dependent on a certain kind of privilege.

Participants also felt that their gender intersected with asexuality and disability to create particular experiences – some argued that women were less likely to have their a/sexual agency respected because of the imperative for women to be (hetero)sexually available, and because women are often prevented from authoring their own experiences. This was also something that was compounded by certain disabilities, where there is a presumption of ‘innocence’. However, being disabled and asexual as a man also brought certain challenges, particularly in being able to be ‘successful’ in one’s masculinity, although I also suggested that this might be mediated by one’s romantic orientation. Conversely, participants were largely silent on the impact of ‘race’, perhaps because being white meant that participants did not *have to* think about ‘race’. Some participants ventured that being ‘non-white’ would make identifying as asexual more difficult for a few different reasons, but this was based on hypothetical scenarios, which in itself highlighted the need to interrogate the silences regarding ‘race’ both within asexual communities and also in asexuality research.

Contribution

This dissertation has complicated and multiplied the existing picture of asexuality by considering how asexuality intersects with disability (and to a lesser extent, with gender and 'race'). As such, it has made the first steps in bringing a consideration of intersectionality to bear upon asexuality: it has shown how social relations and constructions of ablebodiedness, gender and 'race' complicate understandings and meanings of asexuality, and also work to constrain (and enable) persons in distinct ways. This dissertation has also shown how the asexual community and asexual-identified persons do not exist in a vacuum, nor are they a pre-given static phenomenon that can be objectively 'known' as is assumed in much of the existing literature, but rather that they are constantly *constituted* and *constituting* through processes of meaning-making that work dialectically with wider social norms, expectations and relationships. I have therefore advanced an understanding of asexuality as a thoroughly *social* phenomenon.

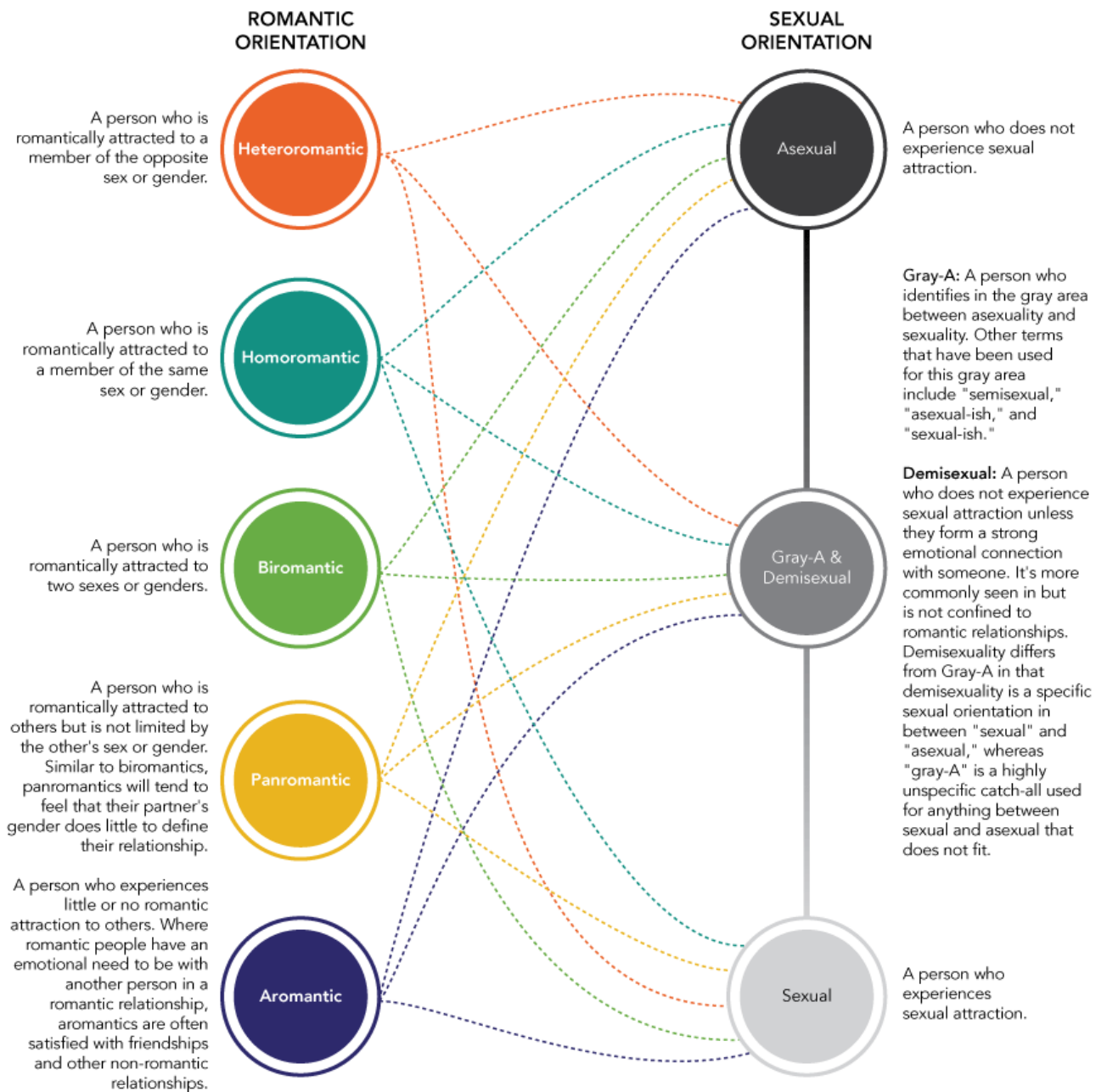
Much scope remains for further sociological research on asexuality. It is my hope that my dissertation will prompt future researchers to recognise the importance of intersectionality in researching asexuality, as well as take into account more broadly the ableist, racist and sexist, as well as classist, homophobic and transphobic context in which we all negotiate our a/sexual subjectivities. It is my hope that these researchers will interrogate their own work for the ableist, gendered, racialised etc. assumptions they make, and thus the exclusions they might perpetuate. They should also be critically aware of how (and by whom) meanings and constructions of asexuality might be made, and how the social membership of asexuality is constituted. This is an exciting time for asexuality research, but going forward, it is important that we begin to develop a less individualized, less disembodied perspective, and instead one that is more engaged with issues of power, and the *social relations of asexuality*.

APPENDIX A: Identities/orientations in the asexual community

Infographic reproduced from The Huffington Post, 19th June 2013. Available from: http://www.huffingtonpost.com/2013/06/19/asexual-spectrum_n_3428710.html

The Asexual Spectrum

Many asexuals identify with two orientations: a romantic and a sexual one. According to the Asexual Visibility and Education Network (AVEN), an asexual's romantic orientation determines "which gender(s), if any, they are inclined to form romantic relationships with." There are also individuals in the asexual community who identify in the gray area between asexuality and sexuality.*



*Note that this infographic is a limited and not definitive model of the asexual spectrum. Not all asexuals will identify or agree with the definitions in this graphic.

Source: AVENwiki (asexuality.org/wiki/)

APPENDIX B: Recruitment message

Hi everyone,

My name is [REDACTED] and I'm a sociology postgraduate student at the University of Glasgow, Scotland. For my Masters dissertation, I am conducting research on the topic of asexuality and disability: specifically exploring the experiences of people who self-identify as asexual and have a disability, and looking at the ways in which asexuality and disability might 'intersect'. I'm recruiting people to take part in an online (individual) interview with myself – and I was hoping that some of you might be interested in taking part!

I am interesting in hearing from folks all along the asexuality spectrum, and of all genders, relationship orientations, nationalities etc. I am also working with a broad definition of 'disability' – what is important is that you consider yourself to be a disabled person, or that you consider yourself to be disabled in some way.

It's also really really important that you are over the age of 18!

If you think you might be interested, you can send me an email at 0705067c@student.gla.ac.uk and I'll then send you a plain language information sheet which will give you a lot more details about the study (as well as my full name, contact details for my supervisor and University ethics committee). Once you have read that you can decide whether or not you want to take part. By contacting me you are in no way committing yourself to taking part - and if after reading the information sheet and decide that it is not for you, then that's absolutely fine too! I'm also more than happy to address any questions or concerns that you might have.

Thanks very much for reading this – and I hope to speak to some of you soon!

Best wishes,

[REDACTED]

APPENDIX C: Information Sheet



Plain Language Statement

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what taking part in the research will involve. Please read the following information carefully and discuss it with others if you wish. If you have any questions or would like more details, please ask! Thank you for taking the time to read this.

Project title: Understandings and experiences of asexuality and disability

Researcher: [REDACTED] postgraduate student, sociology, University of Glasgow

Email: 0705067c@student.gla.ac.uk

Supervisor: Dr Matt Dawson (email: Matt.Dawson@glasgow.ac.uk; telephone: 0141 330 5169)

What is this study about?

My name is [REDACTED] and I am doing a Master's degree in Sociology and Research Methods at the University of Glasgow. For my dissertation, I am conducting research which looks at the understandings and experiences of people who identify as asexual and have a disability. It is my aim to try and understand asexuality and disability in **social** terms, and as a **social experience**, rather than medically. For example, I would be interested in exploring how you came to identify as asexual, if you feel your disability has had any impact on your asexuality, how (or if) people react to you being an asexual disabled person, if you feel your gender has any impact on your experience of asexuality and disability, your involvement in asexual and/or disabled communities and your feelings about asexuality and disability activism.

I am doing this study because there is a lack of research which directly explores the experience of those who identify as asexual and are disabled, and I think this is an important and worthwhile topic to address.

Who is invited to take part?

I am interested in talking to individuals who are **over the age of 18**, who **identify as asexual** and **consider themselves to have a disability**.

Do I have to take part?

No - it is entirely up to you to decide whether or not to take part in the study. If you decide to take part, you are also free to withdraw again at any stage without having to give a reason why. If you withdraw from the study, you also have the choice to withdraw any data that you have previously given.

What will happen to me if I take part?

If you decide to take part, you will be invited to participate in an **online** interview with myself. This can be in the form of an **email** interview, where I will send you a few questions to start with and ask that you reply with as much information as you can. I will read your responses, and will then ask some more questions based on what you have said, and so on. Or, we can do an interview via **Skype**, either as text/instant messaging only, telephone/voice only or as a video call. With your permission, I would like to save and record these Skype interviews.

If you choose to take part in a Skype interview, we can agree on a day and time that will be suitable for both of us. If you choose to take part in an email interview, you can respond in your own time and at your own convenience - however it is my aim to complete the interviews by **7th July 2013**.

Regardless of how you choose to take part, you do not have to answer any questions that you feel uncomfortable with.

Once we have completed the interview, I will make a transcript of what we have both said or collate what we have written, which I will then analyse as part of my research.

What will happen to the results of the research?

The information you have given me will be used in my dissertation, which forms part of my Master's degree in Sociology and Research Methods. My dissertation will be submitted on the 30th August 2013. If you like, I can provide you with a written summary of the research soon after this date. I may also use the results from this study in my future PhD research, and potentially in publications arising from my PhD research – for example, in an academic journal article or in a conference paper.

Will my taking part in this study be kept confidential?

The transcripts/collated text I make of our interview will be anonymized, which means I will remove any personal information that could identify you or other people that you might mention. Once I have made a transcript, I will delete the original interview recording/emails using software that meets recognised standards of secure electronic data disposal. However, you should be aware that copies of emails will still remain on the servers of internet service providers.

Both the email and the computer I work on are password protected and only I have access to them. Any documents or information relating to the interviews will also be stored in a password protected folder. All information will be held in line with the UK Data Protection Act (you can read more about this here: <https://www.gov.uk/data-protection/the-data-protection-act>). With your permission, I would like to retain a copy of the anonymized transcript/collated text of the interview for a maximum period of ten years after submission of my Master's dissertation for future research purposes.

When I come to write up my dissertation and any other pieces of work arising from the research, you and any information that you give me will remain anonymized.

All information will be treated confidentially. However, it is important that you know that research data is not 'legally privileged' – this means that the police/courts can request the research data if such a situation ever arises.

Who has reviewed the study?

The College of Social Science Ethics Committee at the University of Glasgow has reviewed and approved this study. If you have any concerns about the way the research is being conducted, you can contact John McKernan, the College of Social Science Ethics Officer. His email address is: John.McKernan@glasgow.ac.uk

What next?

If after reading this you would like to take part, please send me an email at: 0705067c@student.gla.ac.uk and I will get back to you. I'm also happy to talk about any concerns or questions you may have!

APPENDIX D: Consent form



Consent Form

Title of Project: Understandings and experiences of asexuality and disability

Name of Researcher: [REDACTED]

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I also understand that any identifying details I give will be anonymized in all transcripts and submissions and publications arising from this research.
3. I consent to take part in a: (PLEASE DELETE AS APPLICABLE)
 - a) Email interview
 - b) Instant-messaging interview (via Skype)
 - c) Voice-only interview (via Skype)
 - d) Video interview (via Skype)
4. If you have chosen a **voice** or **video** interview, do you give your consent for it to be recorded? (PLEASE DELETE AS APPLICABLE)

I give my consent for the interview to be recorded

I do not give my consent for the interview to be recorded

[only answer if you have chosen option c or d in part 3, above]

5. I hereby consent to take part in the research

[PLEASE TYPE YOUR NAME]

[DATE]

APPENDIX E: Interview guide

1. To start, would you mind telling me a bit about yourself?
 - Whereabouts are you from
 - Your age
 - What you do for a living
 - How you would describe your gender
 - How would you describe your ethnicity
2. What is your asexual orientation? (e.g. do you identify as asexual/grey-A/demisexual etc.)
3. What is your romantic orientation? (e.g. aromantic, heteroromantic, homoromantic etc.)
4. How long have you identified as such? Can you say a bit about coming to this identity – e.g. where do you first hear the terms, did you seek out information about it? What did it feel like when you first started identifying as such?
5. Have you always felt like this? Do you feel like it was something you were born with?
6. Are you ‘out’ to anyone? Why/why not?
7. Are you happy about being [identity]? If you could change it, do you think you would?
8. Could you say a bit about the nature of your disability? (How) does it affect your everyday life? (ask about diagnosis/onset if applicable)
9. In terms of identity, do you consider yourself to be a disabled person? Is this an important facet of your identity? What about [asexual orientation]? Is that an important aspect of how you understand yourself? Are there other aspects of your identity that you consider to be just as, or more, important?
10. Do you see any connections or links between your disability and your [asexual orientation]? Has anyone ever suggested a connection? [probe response]
11. [experiences with health professionals if relevant]
12. Do you feel that your experiences have been any different from non-disabled asexual people? [probe response]

13. Do you think your gender has had any impact on your experiences as a disabled [asexual identity]? (for example, in assumptions people make about your sexuality etc.).
14. Are there any other factors you feel impacts on your experience as a disabled [asexual identity]? (e.g. class, ethnicity, age, nationality)
15. How 'open' do you think the asexual community is to people with disabilities or health problems? [probe response – why might this be, etc.]
16. Some people have written about how disabled people might be excluded from the asexual community – they suggest that in an effort to make asexuality more 'accepted' in the mainstream, asexuality activists/community members tend to talk about how 'healthy' and 'normal' asexual individuals are. Have you ever experienced this, or do you have any feelings about this?
17. Do you think there are any tensions between being accepting of disability on the one hand, and wanting to present asexuality to broader society as 'healthy' 'normal' etc.?
18. Do you have any thoughts on the strategies asexual activists use to promote visibility and acceptance of asexuality? Or how asexuality is represented to wider society?
19. Are you involved with any disability organisations or groups?
20. [if relevant] How aware do you think these groups are of asexuality?
21. There is often an assumption or expectation that disabled people are asexual, or non-sexual, and a lot of disability rights campaigners are involved in challenging this. Do you have any thoughts on this, as a disabled person who actively identifies as [xx]? Experiences of marginalisation?

APPENDIX F: Participant demographic information

<u>Pseudonym</u>	<u>Age</u>	<u>Location</u>	<u>Gender</u>	<u>'Race'</u>	<u>Occupation</u>	<u>Asexual/romantic orientation</u>	<u>Disability/impairment</u>	<u>Interview format</u>
Bobby	18	USA	Male	White	Recently left education, seeking work	Asexual, heteroromantic	Partial sightedness	Skype
Camille	28	France	Female	French with Spanish/Italian roots	On State disability benefit	Asexual/demisexual, demiromantic, straight	Dyspraxia, coeliac disease, pancreatitis	IM
Dawn	31	UK	Female	White British	Writer	Asexual, heteroromantic but bordering on aromantic	M.E., mental health problems	Email
Erin	29	USA	Cisgender non-femme female	Caucasian	Waitress	Grey-A, panromantic	Ehlers-Danlos Syndrome (disease of the connective tissues)	Email
Helen	28	Australia	Female	White Scottish Australian	Graduate student	Asexual, aromantic	Blindness (Albinism), mental health problems	IM
Jo	28	USA	Cisgender, moderately femme woman	White	Director of a program for international students	Demisexual, panromantic	Osteochondromatosis (bone disease)	Skype
Kate	19	UK	Female	White British	Student	Asexual, bi-romantic	Asperger's, mental health problems	Email
Lauren	23	USA	Female	White	On State disability benefit	Asexual, aromantic	Mental health problems	Email
Natalie	20	USA	Cisgender female	Eurasian	Works in admin	Grey-A, heteroromantic	Mental health problems, IBS, Cyclical Vomiting Syndrome	Email
Ryan	24	Australia	Male	Caucasian, Scottish/Irish descent	Works in admin	Grey-A, aromantic	Bilateral hearing loss	Email
Steff	22	USA	Female	Caucasian of Newfie/Scottish descent	Student	Asexual, bi-romantic	Asperger's	Email

APPENDIX G: Ethical approval

CSS/REVTEMP/V1/FEB11



Ethics Committee for Non Clinical Research Involving Human Subjects

NOTIFICATION OF ETHICS APPLICATION OUTCOME – UG and PGT Applications

Application Type: New
(select as appropriate)

Application Number: 195

Applicant's Name: [REDACTED]
asexuality and disability

Project Title: Understandings and experiences of

Date Application Reviewed:

APPLICATION OUTCOME

(A) **Fully Approved**
(select from drop down as appropriate)

Start Date of Approval: 27/3/13

End Date of Approval: 30/6/2013

If the applicant has been given approval subject to amendments this means they can proceed with their data collection with effect from the date of approval, however they should note the following applies to their application:

- | | |
|--|-------------------------------------|
| Approved Subject to Amendments without the need to submit amendments to the Supervisor | <input type="checkbox"/> |
| Approved Subject to Amendments made to the satisfaction of the applicant's Supervisor | <input checked="" type="checkbox"/> |
| Approved Subject to Amendments made to the satisfaction of the School Ethics Forum (SEF) | <input type="checkbox"/> |

The College Ethics Committee expects the applicant to act responsibly in addressing the recommended amendments.

(B) **Application is Not Approved at this Time**

Select Option
(select from drop down as appropriate)

Please note the comments in the section below and provide further information where requested.

If you have been asked to resubmit your application in full then please send this to your local School Ethics Forum admin support staff.

Some resubmissions only need to be submitted to an applicant's supervisor. This will apply to essential items that an applicant must address prior to ethical approval being granted, however as the associated research ethics risks are considered to be low, consequently the applicant's response need only be reviewed and cleared by the applicant's supervisor before the research can properly begin. If any application is processed under this outcome the Supervisor will need to inform the School ethics admin support staff that the application has been re-submitted (and include the final outcome).

The following section is only for completion for applications that required amendments to go to SEF

(C) **Select Option**
(select as appropriate)

This section only applies to applicants whose original application was approved but required amendments.

APPLICATION COMMENTS

Major Recommendations:

Section 2.4A - anonymity is not restricted to who people are or what they look like. Revise this section to include a more comprehensive specification of information which may make participants and third parties identifiable. This is particularly important given the possibility of PhD research and conferences/ publications.

Section 4 - consult with your supervisor and revise this section to including procedures/ recommendations for both researcher and interviewees which recognise the possibility of emotional impacts relating to the topics discussed.

PLS - it is not adequate to state that 'I may use the results from this study in my future PhD research' without further explanation. Make a specific statement that anonymised data may be presented at conferences or used in publications arising from the research.

PLS - will my taking part in this study be kept confidential? Clarify here that all consented communications (email/ messages) will be retained and used for research purposes.

PLS - destruction of research data. We would suggest that there is a tension here with University research guidelines which suggest that research data should be retained for 10 years. Consult with your supervisor and if you wish to retain data for a period of NOT EXCEEDING 10 years, stipulate in the PLS arrangements for archiving ANONYMISED transcripts.

Consent form - as necessary based on discussions with your supervisor regarding the above point: add a separate line to the consent form with Yes/No boxes, stating 'I agree to anonymised transcripts of my interview data being securely archived in [SPECIFY] until [DATE].

Consent form - add a separate line specifying that all identifying details such as names and places will be anonymised and replaced by pseudonyms in transcripts/ conference presentations/ publications based on the research

Minor Recommendations:

The research design is considerate of the nature of the topic and the recruiting methods are appropriate to addressing an important gap in knowledge. Working through forums is a reasonable step given the ever-present problem of identify when using with online methods; consider addressing the possibility that you may be speaking with someone who mis-represents themselves as a limitation of the methods employed unless there is scope for snowballing using personal contacts - although that itself would bring another set of difficulties

Please retain this notification for future reference. If you have any queries please do not hesitate to contact your School Ethics forum admin support staff.

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