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The Work of Disabled Identities in Intimate Relationships

Abstract

This article details a thematic analysis of disabled men and women's accounts of past and present intimate relationships. Drawing upon the sexual stories of 25 disabled people, informants' intimate relationships are explored as a site of emotional work (Hochschild 1983), as well as a site of other forms of (gendered) work. This article critically questions the work carried out by informants and considers the ways in which it was shaped by their lived experiences of gender, sexuality, impairment and disability. It concludes that the requirement to carry out forms of work within intimate and sexual life constituted a form of psycho-emotional disablism (Thomas 1999).

Keywords: disability; gender; sexuality; intimate; emotional work

Points of Interest

- This article considers disabled people's experiences of "love" relationships.
- The research found that both disabled men and women carried out "work" within these relationships.
- Usually, this work was shaped by the ways in which they felt about, or experienced, their gender, sexuality, impairment and disability.
- I question what this work means for disabled people, and argue that it is a form of disablism.

Introduction

The oppressions experienced by disabled people in their sexual and intimate lives have long been overshadowed by wider fights for their rightful place within civil and public life (Shakespeare, Gillespie-Sells, and Davies 1996). The consequences of this, Shakespeare (1999, 54) argues, have been the marginalisation of disabled people's sexual politics and the

omission of the ‘personal and individual dimensions of oppression’. Feminist authors within disability studies have challenged these important omissions, and have at the same time located gender and other social categories within analyses of disability (Thomas 1999; Baron 1997). Much of this critical scholarship has been through writing openly about their own embodiment, intersectional identities, and lived experiences of impairment (see Wendell 1996; Thomas 1999; Morris 1989), causing what Sherry (2004, 776) called a crucial ‘deconstruction of the public/private divide’.

While social model orthodoxy holds the psychological ‘as epiphenomenal, diversionary, and potentially misappropriated in the buttressing of pathologising accounts of disablement’ (Watermeyer, 2009, iii), feminist authors, markedly Thomas (1999), and later, Reeve (2002), have argued for the inclusion of the psychological and emotional dimensions of disability and impairment within disability studies (see also Goodley 2011). For example, in her social relational model of disability, Thomas (1999, 60; emphasis added) redefines disability as ‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments *and* the socially engendered undermining of their psycho-emotional well-being.’ Thus, ‘disability’ is reimagined to have political, material, economic, structural, emotional, intimate, and personal dimensions. Redefining disability along these lines contextualises that ‘the oppression disabled people can experience operates on the ‘inside’ as well as on the ‘outside’’ (Thomas 2004, 40); or as Reeve (2004, 84, original emphasis) articulates, ‘operates at both the public and personal levels, affecting what people can *do*, as well as what they can *be*’.

Psycho-emotional disablism is defined by Thomas (1999, 60) as ‘the socially engendered undermining of emotional well-being’. Reeve (2004, 86) proposes that this form of social oppression occurs through ‘the experience of being excluded from physical

environments' (which, she argues, instigates a feeling of not belonging); through routine objectification and voyeurism perpetrated by (but not exclusive to) non-disabled others; and through internalised oppression, which she defines as, when 'individuals in a marginalised group in society internalise the prejudices held by the dominant group' (Reeve 2004, 91). Thus, psycho-emotional disablism is a relational form of disablism embodied through experiences of 'hostility or pitying stares, dismissive rejection, infantilisation, patronising attitudes, altruism, help and care on the part of non-disabled people' (Goodley 2010, 96) which 'frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden' (Thomas 2006, 182).

Building upon existing knowledge of psycho-emotional disablism, particularly its potential impact within the personal, intimate and sexual spaces of disabled people's lives, I present findings from a relevant empirical study which explored disabled men and women's lived experiences of sexuality and intimate relationships. To clarify, my use of the term 'intimate relationship' refers to a (non-commercial) shared intimacy with another person, which my informants identified as significant and a source of sexual, physical and/or emotional intimacy. The doctoral research, which took place in England, UK, between 2008 and 2011, examined disabled people's management and negotiation of their sexual and intimate lives, selves, and bodies in the context of ableist cultures where they are, as Brown (1994, 125) states, assigned the paradoxical social categories of 'asexual, oversexed, innocents, or perverts'. This article draws upon the sexual stories of 25 disabled people, detailing a thematic analysis of their accounts of intimate relationships which reveal the – often routine – carrying out of considerable emotional work (Hochschild 1983), as well as other forms of (gendered) work, such as sex work (Cacchioni 2007). By making visible their work of 'telling, hiding, keeping up, waiting, teaching, networking and negotiating' (Church et al 2007, 10), I explore the ways in which informants' work was shaped by their lived

experiences of gender, sexuality, impairment and disability. Crucially, I critically question such work, suggesting that, while it was often strategically and consciously employed to manage competing intimate oppressions, for the most part, the requirement of informants' to carry out forms of work within their sexual and intimate lives constituted a form of psycho-emotional disablism (Thomas 1999).

Learning to Labour: Emotional Work and Disability Performance

Church et al (2007, 1) state that 'complex invisible work is performed by disabled people in every day/night life'. In their research on disabled employees' experiences of corporate settings, Church et al (2007, 1) uncovered multiple kinds of work that employees routinely utilised within the workplace in order to 'stay corporately viable'. Types of work included hiding impairment and its effects; being extra productive to counter employers' negative assumptions; and carrying out informal teaching around disability issues for co-workers and managers (Church et al 2007). Similarly, Wong (2000, 303) has documented the multiple forms of (emotion and other) work employed by disabled women in reproductive and sexual health care; she states, 'work has become an umbrella code that encompasses both the barriers women face and the agency they exercise in dealing with them'. Likewise, Goodley (2010, 92) has identified the *performances* disabled people are expected to give, he states: 'disabled people learn to respond to the expectations of non-disabled culture – the demanding public – in ways that range from acting the passive disabled bystander, the grateful recipient of others' support, the non-problematic receiver of others' disabling attitudes'.

However, while the psycho-emotional dimensions (Reeve 2002; Thomas 1999) and 'work' and 'performances' of the disability identity have been explored within disability studies (Church et al 2007; Goodley 2010), the concepts of 'emotional work' and 'emotional labour' have seldom been applied to disabled people's experiences (Wilton 2008). The little empirical work that has taken place has related to work settings and public spaces and

systems (see Church et al 2007; Wilton 2008; Bolton and Boyd 2003; Wong 2000). To clarify, ‘emotional work’ and ‘emotional labour’ are terms coined by Arlie Hochschild (1983, 7) to represent the ‘labour [which] one is required to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind to others’. Emotional labour is mostly required within employment settings and refers to the ‘management of feeling to create a publicly observable facial and bodily display that is sold for a wage and therefore has an exchange value’ (Hochschild 1983, 7; original emphasis). In contrast, ‘emotional work’ or ‘management’ are forms of work that are required in private settings, such as the family or home and which have ‘*use value*’ (Hochschild 1983, 7; original emphasis). ‘Emotional work’, then, is a better-fitting conceptual framework for explorations of disabled people’s lived experiences of their intimate relationships. My definition the term follows that of Exley and Letherby (2001, 115, emphasis added) and refers to the ‘effort and skill required to deal with one’s own feelings and those of others within the *private* sphere’.

Emotional work takes many forms and serves a variety of functions; for example, work can be on or for the self (Hochschild 1983); on or for others (Exley and Letherby 2001); have both positive and negative consequences (Wilton 2008); and be both a collective and individual labour (see Korczynski 2003). Predominantly, women, ‘as traditionally more accomplished managers of feeling’ (Hochschild 1983, 11), have been found to carry out the majority of emotional work in the private sphere (Strazdins 2000) – largely because they take prime responsibility for the emotional well-being of other family members (Devault 1999). Identifying this work serves important functions. Early works by Blumer (1969, 148), argue that identifying the ‘invisible’ work carried out as part of our daily lives can act as a ‘sensitising concept’, in that it can thrust previously neglected activities (e.g. childcare, caring for relatives) on to the public agenda. Furthermore, Devault (1999, 62) suggests that identifying the customary emotional work which takes place within family life is invaluable

towards providing ‘fuller, more accurate accounts of how family members work at sustaining themselves as individuals and collectivities’, an understanding which, she argues, provides ‘an essential foundation for equitable policy aimed at enhancing the well-being of all citizens’.

Before outlining the research methodology, I must stress that by utilising the concept of emotional work (Hochschild 1983), I am not individualising, pathologising or psychologising disabled informants’ emotional experiences. The psycho-emotional, psychological and now psychoanalytic (see Goodley 2011) aspects of disability remain contentious within disability studies for fear that they encompass a return to early ‘individual, medical, bio-psychological, traditional, charity and moral models of disability’ (Goodley 2011, 716) which ‘locate social problems in the head and bodies – the psyches – of disabled people’ (Goodley 2011, 716). On the contrary, through deconstructing informants’ work I highlight the very social, cultural, political and material processes through which their work is produced.

Methodology

Approaches to mainstream disability research have historically been criticised by disabled people, disability organisations, and disability rights movements (Oliver 1997). With this in mind, certain principles formed the aetiology of the methodology. The first was that the research process be developed and designed in consultation with disabled people through a Research Advisory Group (RAG). The second was that the research process be an accessible and inclusive space through the adoption of a multi-method and multi-format approach to collecting disabled people’s sexual stories in a format which suited their individual requirements and preferences (e.g. in person, or via Skype, instant messaging, email or telephone, journal writing). The third was that opportunities for empowerment via participation and story-telling could be offered. While the notion of ‘empowerment’ and

‘emancipation’ through research production and participation is both strongly contested and contestable (see Oliver 1992), personal and political empowerment were conceptualised as achievable through storytelling itself. As Langellier (2001, 700) argues, ‘personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities, and ‘get a life’ by telling and writing their stories’. Echoing the initiatives found in feminist and anti-racist methodologies which ‘place the minoritized at the centre of analysis’ (Dei and Johal 2005, 2), the impetus was to facilitate a platform from which disabled people could tell their own sexual stories (see Davies 2000; Shakespeare, Gillespie-Sells, and Davies 1996; Leibowitz 2005). This approach also counters much existing research into disabled people’s sexual lives which has, paradoxically, mainly been on those who govern the sexual lives of disabled people (Shakespeare, Gillespie-Sells, and Davies 1996; Gillespie-Sells, Hill and Robbins 1998). The fourth guiding principle was a commitment to ensuring that research findings are relevant and accessible to disabled people both within and outside of the academy; this is currently happening through the execution of a dissemination plan¹ co-produced by myself and the Research Advisory Group.

Research Advisory Group

The Research Advisory Group (hereby RAG), (affectionately called “The Rag” by its members), ran from the initial stages of research design and ceased after the creation of a dissemination plan. Group members favoured a supportive and collaborative role whereby they could impart expert knowledge, help set the research agenda, and ‘influence the direction of the research’ (Kitchen 2000, 38) without taking on the responsibility or accountability of being a research partner. Group members also requested I be responsible for the more technical aspects of the research and declined involvement in a joint analysis of data – outlined as a central practice in true partnership research (Whitaker & Archer 1994). Overall, the RAG assisted with research design and planning; provided crucial social

networks and ideas for accessing informants; directed the production of accessible research methods and materials; advised on matters of sampling; offered preliminary data analysis (via group discussions on collected data); and co-produced a dissemination plan. Importantly, the group's laughter, support, guidance, and enthusiasm fostered a relaxed space through which I learned to speak to fellow disabled people about sex and intimacy. In particular, some RAG members warmly shared their own stories as a prerequisite to designing how the stories of others could be collected and used.

Informants

In total, 25 disabled people, and one non-disabled partner (who participated in a joint interview at the disabled informant's request), took part (n=26). Informants were sampled through purposive and snowball sampling methods, and recruited via feature articles and advertisements in popular disability press and via postings in 'online forums' and 'chat spaces' within disability-related websites. In terms of impairment types, informants predominantly had physical impairments (n=23) with only one person having only a sensory impairment (n=1), and another having both a physical and sensory impairment (n=1). Of all disabled informants (n=25), eight had acquired impairment (n=8), with the remainder having either (i) congenital impairment with symptoms experienced since birth (n=11) or (ii) congenital impairment with later onsets/diagnoses (n=6). A diverse sample containing (16) men and (10) women, aged between 20 and 64, and from a range of socio-economic groups was gained. All except one were in heterosexual relationships; and only one disabled informant was currently in a relationship with another disabled person.

In terms of intimate relationship histories, 21 informants reported that they had been in an intimate relationship with a partner before, with just 12 of 26 (46%) being in a relationship with a partner at the time of taking part in the research. This latter figure echoes statistics reported in '*Exploring disability, family formation and break-up: Reviewing the*

evidence' (Clarke and McKay, 2008), which reveals that 'among those living alone and with a limiting health condition some 4.7 per cent each year find a partner, compared with 7.6 per cent for those who are not disabled' (Clarke and McKay 2008, 4). Further, the report proposes that of working age disabled people there are 'a higher proportion remaining single; a lower proportion being in their first marriage or being married at all: a slightly lower proportion cohabiting; a higher proportion of disabled people being divorced or separated from marriage' (Clarke and McKay 2008, 3). Thus, informants' relationship histories were largely reflective of these trends.

Narrative Data Collection, Analysis, and Ethics

The emphasis of data collection was upon eliciting informants' sexual and intimate relationship stories which could later be subjected to a thematic analysis. All face-to-face and Skype interviews were transcribed verbatim and transcripts produced through instant messaging, email or written were 'cut and pasted' into Microsoft Word documents but otherwise kept in the format in which they were produced and as intended by the authors. While multiple standard ethical guidelines were adhered to throughout the research process², the ethics of narrative – of asking (disabled) people to tell intimate and sensitive stories, and of hearing, interpreting, and retelling people's stories – formed another layer of ethical (and political) consideration. This was particularly pertinent given the extent to which disabled people's lives and bodies are routinely objectified, harmed and denied privacy through oppressive social and cultural practices (Sandahl 2003).

Research Findings and Discussion

The Strategic Work of Staying

In keeping with Western conceptualisations of coupledness, all informants who had been in an intimate relationship before (n=21) reported it as having considerable *benefits*. For example,

the intimate relationship was narrated as a 'safe space' from a range of oppressions, discrimination, and prejudices experienced in the 'outside world', and as a powerful means to challenge ableist discourses of disabled people as sexless and as not being 'prospective' partners (Gillespie-Sells, Hill and Robbins 1998). It was further described as a space where gender and sexual selves could be confirmed and (re)built. For example, Rhona³, a 21 year old recently-single woman with a congenital impairment, said, "being in a relationship is a constant reassurance in my worth as a person and a woman." Therefore, the intimate relationship could serve as a space to embody (gendered) desirability, contradicting dominant cultural representations of disability and the impaired body as both degendered (Shakespeare 1999) and monstrous (Shildrick 2002).

However, a common theme centred on informants residing in intimate relationships for reasons beyond (romantic) feelings for a partner, and exacerbated by a disabled identity within an ableist heteronormative sexual culture. For example, Robert, a 26 year old wheelchair user with congenital impairment, said that "having" or "being with" an intimate partner was an important symbol to *others*:

Robert: "I've discussed with my [disabled] best friend, how we need a girlfriend to show "Look a real girl likes me, I have sex with her and we are in love - I must be ok, world""

Robert's strategy openly acclaims a sexual identity and thus, he feels, "puts right" the dominant ableist assumptions of asexuality and sexual inadequacy cast upon impaired male bodies (Shakespeare, Gillespie-Sells, and Davies 1996). This indicates that, as De Vault (1999) suggests, merely surviving oppression is a form of work in itself.

However, for others, residing in intimate relationships, even where informants had expressed they were often unfulfilled and/or unhappy, was a means through which to avoid

oppressive dimensions of dominant sexual cultures; for example, ‘being single’ once again (and thus losing many of the benefits listed above); being rejected on the ‘dating scene’ (because of disability and impairment); and negotiating the (often risky) disclosure of disability and impairment to prospective partners. Notably, this strategy required the employment of considerable emotional work (Hochschild 1983):

Shaun: “Because of my disability I thought ‘oh well, I need to stick with this because I might not find anybody else’ ...”

Tom: “Because I am disabled, it gives you the worry about getting a girlfriend, you hold onto it for dear life, until it’s like flogging a dead horse and that’s no good for anybody.”

The accounts of Shaun, a married man who acquired spinal injury at the age of 11, and Tom, a single man with congenital physical impairment, show how their choices to stay in (former) unfulfilling intimate relationships were shaped by the potential difficulties of finding a partner as physically impaired men within a gendered sexual culture which privileges hegemonic masculinities – from which disabled men are largely excluded (Shakespeare 1999). Further, I suggest that phrases like ‘sticking with it’, and ‘flogging a dead horse’ emphasise their *emotional* efforts. For example, Shaun said that in previous intimate relationships with (nondisabled) women he had painfully and silently worked past partners’ infidelities because he desperately “wanted to be in a relationship and wanted to have a partner”. Therefore, Shaun had to employ an acute form of what Hochschild (1983, 33) calls (emotional) ‘mental work’, whereby he not only had to perform the appropriate ‘display work’ of a contented partner (Hochschild 1983, 10), but carry out significant ‘mental work’ on his emotional self to really *feel* like – or *become* – a contented partner (Hochschild 1983, 6).

Another common chapter in many informants' stories (n=23) related to the way that they felt that a relationship, love, and sex were 'out of reach' as a disabled person – a form of sexual oppression internalised through ableist constructions of disabled people as lacking sexual agency and opportunity (Siebers 2008). For those with congenital impairments, such thoughts were reported as having been internalised from a young age and had often been confirmed by (usually, well-meaning) family members; for example, telling them 'not to get their hopes up'. This was narrated to have substantial impact upon sexual self-confidence and esteem (and thus constituted significant sexual oppression) and supports the notion that psycho-emotional disablism can be at its most acute when carried out by known agents (Reeve 2002). Graham, a 52 year old single male who acquired physical impairment at age 20, told of how he'd had intimate relationships with women to whom he was not attracted and didn't like because saw them as the 'only opportunity' to have a relationship; but also because these relationships provided an (albeit, temporary) solution to his isolation and loneliness:

Graham: "I didn't like her... my attitude was entirely 'I've got no choice... she likes me for some reason and it's her or nothing'... Never liked her; never fancied her. I didn't like her touching me... It's horrible but there's no other option. You either just spend your life entirely alone or try and be with someone who's willing to be with you."

Graham spoke at length of the multiple emotional performances that such relationships required. For example, he talked about performing emotional displays of sincerity, honesty, and authenticity when 'pretending' to like these intimate partners. The abhorrence Graham reveals in the above account shows that these situations required routine surface acting (Hochschild 1983). Rather than *becoming* an intimate partner, through what Hochschild (1983, 33) defines as 'deep acting' or 'mental work', the emphasis for Graham was upon

imitating the 'correct' emotional behaviours synonymous with love, intimacy and affection. To add context, Graham reported experiencing significant marginalisation and isolation, which many disabled people experience: he lived alone, said he had no real friends or family, and rarely went out. Using Thomas' (1999) social relational model of disability, Graham's marginalisation and feelings of loneliness sit at the nexus of structural, psycho-emotional and material dimensions of disability: he dropped out of university upon acquiring impairment because, he said, his institution couldn't cater adequately for a disabled student; a lack of qualifications combined with having to negotiate a disabled identity within an ableist labour market and capitalist economy led to both long-term underemployment and unemployment, which has in turn impacted upon his social mobility and his access to material resources (see Oliver 1990). Graham described these structural oppressions, then, as having significant impact upon his self-esteem and confidence (especially with women), denoting to him the feeling that he didn't belong in, or didn't have the attributes to attain, a meaningful intimate relationship (see Reeve 2004).

“Women's Work”

The carrying out of emotional work could also be couched within particular forms of gendered work, most notably, 'sex work' (Cacchioni 2007, 299). In her exploration of heterosexual women's perceptions of their sexual problems, Cacchioni (2007, 301) found that women carried out 'sex work', which she defines as 'the unacknowledged effort and the continuing monitoring which women are expected to devote to managing theirs and their partners' sexual desires and activities'. Of my informants, while it was not uncommon for both men and women to openly question their role as a sexual partner, particularly their ability to sexually 'fulfil' partners (in ways fitting with heteronormative sexual practices), three women (of 10 in total) in the sample took it further and were explicit about the ways in

which they consciously (sex) ‘worked’ to ‘compensate’ non-disabled male partners in order to ‘make up’ for having an impaired body.

For example, Jenny, aged 64, who acquired spinal injury at the age of 11, talked about how she would “get involved in every aspect of sex you could think of, any way that was pleasurable to him [her ex-husband]”. She said, “I would put myself out to give him that pleasure even if I wasn’t getting any that particular time”. Jenny carried out this sex work in order to not be perceived as ‘sexually inadequate’ by her husband in comparison to his non-disabled ex-wife. The sacrificing of her own sexual pleasure shows the ‘entwined nature of embodied and emotional performance work’ (Wilton 2008, 367). Similarly, Lucille, 36, who became tetraplegic at age 23 (when she was already married), told how following her injury she’d offered her non-disabled husband multiple chances to be unfaithful: “I felt so bad about not wanting sex that I kept telling him to have an affair”. Lucille and Jenny’s actions cannot be separated from their identities as disabled women; their sex work is indicative of the low sexual self-esteem which is widespread among disabled women generally (Gillespie-Sells, Hill and Robbins 1998), and more likely to occur in women with severe impairment who ‘tend to be furthest away from cultural constructions of ideal feminine beauty’ (Hassouneh-Phillips and McNeff 2005, 228).

However, while Jenny and Lucille talked very matter-of-factly about their sex work, acknowledging that their labour was *conscious* towards embodying desirability for their non-disabled male partners, most women in the sample spoke about hiding bodily difference during sexual encounters – but seldom questioned such practices. Hiding was described by women to take place through a complex (yet remarkably routine) organisation of duvets, bed sheets, clothing, and lighting in a bid to both perform and embody the highly gendered role of the seductress. I suggest that this hiding can be seen as a *private* form of ‘aesthetic labour’, which Wolkowitz (2006, 86) defines as ‘employers’ attempts to make the body more visible

in customer service work through a focus on the body's aesthetic qualities'. Carrying out some form of aesthetic labour, whether private or public, is, undoubtedly, a likely reality for *all* women due to the ways in which heterosexist and patriarchal constructions of femininity instil, as Bartky (1990, 40) suggests, an 'infatuation with an inferiorised body' against which women will always feel inadequate. However, for the disabled women in my research this was undoubtedly compounded by (impaired) bodily difference being wholly intolerable within the rubric of the normative body. Actively hiding the body in this way affirms that disabled people fear that their departure from bodily normalcy can be a basis for rejection (even from intimate partners), and thus the need to 'pass', (and all of the work which goes with this), remains.

The Emotional Work of the Care Receiver

Emotional work through surface acting (Hochschild 1983) took place most explicitly when informants' received care from partners within intimate relationships. Of ten informants who said they regularly received care and assistance from a partner, all said that this arrangement could be a site of tension which required emotional management (see Morris 1989). Many narrated care from partners as something they had to 'put up with', in that partners did not carry out tasks correctly or in preferred ways. Even though this could be a central source of frustration – and often anger – it was a situation where the disabled partner had to show incredible tolerance, grace, and be grateful through surface acting (Hochschild 1983), often when they fervently felt the opposite. Thus, in order to manage the 'feeling rules' present within the caring relationship (Hochschild 1979, 552), rules which 'govern how people try or try not to feel in ways appropriate to the situation', disabled informants had to show emotions which were 'appropriate' for those receiving care (see Morris 1989). Importantly, this extensive emotional work was crucial towards simultaneously maintaining functioning care relationships alongside intimate partnerships.

For example, Helen, who is 21 and has a congenital and progressive impairment, emphasised the extensive emotional work required in having to ‘teach’ her new partner how to care, which involved “smiling through” what she called “bad care” while he learned her preferred way of doing particular caring tasks. She warned that this meant always appearing “tolerant” and “grateful”, for fear that, “he could just tell me to get stuffed!” Often these difficult dynamics increased when the disabled partner had an increasing level of need, for example, on becoming ill or through impairment progression. Gemma, a 42 year old lesbian who has immunity impairment, told how a cancer diagnosis meant she had to be cared for full-time by her then-partner. Gemma spoke of the ways in which she had to manage her partner’s anxiety around her cancer, even when she was the one who had it. Notably, this emotional work had to be carried out at a time of significant personal emotional anxiety, emphasising the ways that emotional work is often on or for others (Exley and Letherby 2001). Some informants (n=4) said that receiving care from a partner affected the way in which they dealt with conflict within their intimate relationship. Thus, caring was often conceptualised as something a non-disabled partner could offer, rather than a requirement. As such, it was also something that could be denied. For example, Robert, 26 and Terry, 20, both who have a congenital physical impairment, said that they avoided conflict or arguments with a partner, as a strategy to ensure continued care:

Robert: “If an argument arose, could I really defend my point even if I’m right, but then ask for help knowing they’re annoyed with me?”

Terry: “With a girlfriend, I know that I can’t be easily irritated by things they do, because I’ve got to rely on them to help. In the past I haven’t had an argument with a girlfriend unless it’s been at a time where I don’t need them for any help.”

Robert and Terry’s actions to purposefully avoid conflict are evidence that receiving care from an intimate partner can mean having to consciously mediate and manage these complex

relationships through very careful strategies. Such strategies undeniably required various forms of emotional work, management, and performance – notably, tolerance; ‘submission’; graciousness; the assessment of when and when not to assert oneself; and the general management of a very problematic set of power relations, in order to continue to receive the required care or assistance from intimate partners.

Drawing Some Conclusions

The stories (re)told throughout this article have uncovered the work and labours of disabled men and women within multiple locations of their intimate relationships. Throughout their stories, informants cast *themselves* as active subjects, revealing their diverse roles as teacher, sex worker, negotiator, manager, mediator, performer, and educator. Paradoxically, much of the skilled emotional work disabled informants carried out is highly valued within Western labour markets (Hochschild 1983), from which they are largely excluded. Irrespective, recognising and labelling the work of disabled people within their sexual and intimate lives is important. Firstly, doing so provides fuller, more accurate and inclusive descriptions of the complex ways that disability, impairment, gender and sexuality interact within sexual and intimate life – as well as of the potential psycho-emotional dimensions of such interactions. Secondly, by identifying informants as skilful managers of their intimate and sexual lives – regardless of the outcome or efficacy of their work – their labour challenges dominant ableist constructions of the disabled sexual identity and subjectivity as passive and lacking agency (Siebers 2008).

However, clearly evident within informants’ stories and in the analysis of their feelings was the extent to which they devalued their (sexual) selves, revealing the ways in which low sexual self-esteem and self-worth, feelings of inadequacy (in relation to heteronormative discourse), and low body confidence can be common parts of the disabled (sexual) psyche in ableist heteronormative sexual cultures. Despite exercising a form of

sexual agency as active ‘emotional workers’, then, the requirement of informants’ to carry out forms of work within their sexual and intimate lives, I argue, constituted a form of psycho-emotional disablism (Thomas 1999). For example, rather than overt transgressive resistance, much of the (invisible) work uncovered in this research was carried out largely through *necessity* – in order to survive; to be loved; to be human; to be included; to be ‘normal’; to be sexual; and to be valued. Thus, it is crucial not to underestimate the sizeable extent to which work was rooted in and thus indicative of the oppressive and inherent inequalities of ableist culture.

Further, analysis has shown that informants’ work was both located and produced at the intersections of disability, gendered and sexual identities, emphasising the value of appreciating relational and psycho-emotional dimensions of disability (Reeve 2002, 2004; Thomas 1999) when exploring the sexual lives of disabled people. The fact that much of informants’ work was routinely employed for the benefit of *others* supports Goodley’s (2010, 92) notion of disability performances which fit with ‘expectations of non-disabled culture’. Significantly, where emotional and other work did take place on or for the self it extended only to emotional and/or bodily management; typically, either through a conscious and rigid policing (or hiding) of emotional responses or bodily difference – forms of work which seldom bought informants *pleasure* or personal fulfilment. For example, ‘surface and ‘deep’ acting within intimate relationships; engaging in forms of sex work; and providing ‘appropriate’ performances of gratitude and gratefulness when receiving care, were markedly detrimental to a positive sense of (sexual) self in most cases and constituted a distinct form of psycho-emotional disablism which operated at a level which required informants’ complicity.

In certain spaces, typically gendered performances which affirmed dominant constructions of masculinity and femininity were offered; notably seen within the different strategies men and women employed to sexualise themselves, either in their own eyes, or in

the eyes of others. Thus, disabled male informants' employment of forms of emotional work within intimate spaces challenges the idea of the male identity as privileged within emotional working (Hochschild 1983) and sheds light on the ways in which alternative (non-hegemonic) masculinities interact with emotional work and labours. Moreover, women's employment of normatively gendered labours such as sex work (Cacchioni 2007) and 'private' aesthetic labour (Wolkowitz 2006) reveals how emotional work is rooted in their social and political positioning as disabled people and – as with the motivations of non-disabled heterosexual women – by normative notions of womanhood, femininity and (hetero)sexuality. This emphasises the similarities between the experiences of disabled and non-disabled women, who occupy analogous subordinate positions within heteronormativity and heterosexuality. It also illustrates – as other disabled feminists already have (Thomas 1999; Wendell 1996; Morris 1989) – the need for mainstream hegemonic feminism to be more inclusive of all types of women and thus broaden its contextualisation of the female experience which, while diverse, is unified by women's suppression under patriarchy and male (sexual) power.

In sum, the analysis detailed in this article supports feminist contributions to disability studies – particularly those which have called for inclusion of the gendered and psycho-emotional dimensions of disability (Thomas 1999; Reeve 2004). Crudely, a 'pure' social model analysis would simply not have bared the intimate, personal and gendered oppressions central to informants' lived experiences. As Thomas (1999, 74) points out, rather than psychologising disabled people's emotions, applying a (feminist) disability studies or social relational lens to disabled people's emotional lives removes these from being "open season" to psychologists and others who would not hesitate to apply the individualistic/personal tragedy model to these issues'. In this vein, then, revealing linkages between structural and psycho-emotional forms of disablism can actually serve to de-pathologise disabled people's

experiences in ways advocated by social model politics, at the same time as theorising and reframing disability in ways which best attends – most importantly – to the emotional well-being of disabled people.

Notes

1. The dissemination plan, co-produced with the RAG, is currently being implemented as part of the Ethel Louise Armstrong Foundation Postdoctoral Fellowship, within the School of Disability Studies, Ryerson University, Toronto, Canada.
2. Ethical approvals were granted by The University of Warwick Humanities and Social Sciences Research Ethics Committee (HSSREC). The British Sociological Association's (BSA) Statement of Ethical Practice and the Economic and Social Science Research Council's (ESRC) Research Ethics Framework were also used.
3. All informant names used within this article are pseudonyms.

References

- Barnes, C. and Mercer, G. 1997a. *Doing Disability Research*. Leeds: The Disability Press
- Barnes, C. and Mercer, G. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press
- Barnes, C., Oliver, M. and Barton, L. 2002. *Disability Studies Today*. Cambridge: Polity Press
- Baron, K. 1997. The Bumpy Road to Womanhood. *Disability and Society* 12, no. 2: 223–240
- Bartky, S.L. 1990. *Femininity and Domination: Studies in the Phenomenology of Oppression*. New York: Routledge
- Barton, L. 2005. Emancipatory Research and Disabled People: Some Observations and Questions. *Educational Review* 57, no. 3: 317–327
- Blumer, H. 1969. *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice Hall
- Bolton, S. and Boyd, C. 2003. Trolley Dolly or Skilled Emotion Manager? Moving on From Hochschild's Managed Heart. *Work, Employment, and Society* 17, no. 2: 289–308

- Brockmeier, J. And Carbaugh, D. 2001. *Narrative and Identity: Studies in Autobiography, Self, and Culture*. Amsterdam: John Benjamins
- Brown, H. 1994. An Ordinary Sexual Life?: A Review of the Normalisation Principle as it Applies to the Sexual Options of People with Learning Disabilities. *Disability and Society* 9, no. 2: 123–144
- Cacchioni, T. 2007. Heterosexuality and ‘the Labour of Love’: A Contribution to Recent Debates on Female Sexual Dysfunction. *Sexualities* 10, no. 3: 299–320
- Church, K., Frazee, C., Panitch, M., Luciani, T., and Bowman, V. 2007. *Doing Disability at the Bank: Discovering the Work of Learning/Teaching done by Disabled Bank Employees Public Report*. Toronto: Ryerson RBC Foundation Institute for Disability Studies Research and Education
- Clarke, H. and McKay, S. 2008. *Exploring Disability, Family Formation and Break-Up: Reviewing the Evidence*. Norwich: Department for Work and Pensions
- Davies, D. 2000. Sharing Our Stories, Empowering Our Lives: Don’t Dis Me! *Sexuality and Disability* 18, no. 3: 179–186
- Dei, G. J. S. and Johal, G. S. 1995. *Critical Issues in Anti-Racist Research Methodologies*. New York: Lang
- DeVault, M. L. 1999. Comfort and Struggle: Emotion Work in Family Life. *The ANNALS of the American Academy of political and Social Science* 561, no. 1: 52–63
- Exley, C. and Letherby, G. 2001. Managing a Disrupted Life course: Issues of Identity and Emotion Work. *Health* 5, no. 1: 112-132
- Gillespie-Sells, K., Hill, M., and Robbins, B. 1998. *She Dances to Different Drums*. London: King’s Fund
- Goodley, D. 2010. *Disability Studies: An Interdisciplinary Introduction*. London: Sage
- Goodley, D. 2011. Social Psychoanalytic Disability Studies. *Disability & Society* 26, no. 6: 715–728
- Hassouneh-Phillips, D. and McNeff, E. 2004. “I Thought I was Less Worthy”: Low Sexual and Body Esteem and Increased Vulnerability to Intimate Partner Abuse in Women with Physical Disabilities. *Sexuality and Disability* 23, no. 4: 227–240
- Hochschild, A.R. 1979. Emotion Work, Feeling Rules, and Social Structure. *The American Journal of Sociology* 85, no. 3: 551–575
- Hochschild, A.R. 1983. *The Managed Heart: Commercialization of Human Feeling*. Berkeley, CA: University of California Press
- Kitchen, R. 2000. The Researched Opinions on Research: Disabled People and Disability

- Research'. *Disability and Society* 15, no. 1: 25–47
- Korczynski, M. 2003. Communities of Coping: Collective Emotional Labour in Service Work. *Organization* 10, no. 1: 55–79
- Langellier, K. 2001. 'You're Marked': Breast Cancer, Tattoo and the Narrative Performance of Identity. In *Narrative and Identity: Studies in Autobiography, Self, and Culture*, eds. J. Brockmeier and D. Carbaugh, 145–184. Amsterdam: John Benjamins
- Leibowitz, R.Q. 2005. Sexual Rehabilitation Services after Spinal Cord Injury: What Do Women Want? *Sexuality and Disability* 23, no. 2: 81–107
- Morris, J. 1989. *Able Lives: Women's Experience of Paralysis*. London: The Women's Press
- Oliver, M. 1990. *The Politics of Disablement*. Basingstoke: Macmillian
- Oliver, M. 1992. Changing the Social Relations of Research Production. *Disability and Society* 7, no. 2: 115–120
- Oliver, M. 1997. Emancipatory Research: Realistic goal or impossible dream? In *Doing Disability Research*, eds. C. Barnes And G. Mercer, G, pgs 15–31. Leeds, The Disability Press
- Reeve, D. 2002. Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity constructions. *Disability and Society* 17, no. 5: 493–508
- Reeve, D. 2004. Psycho-emotional Dimensions of Disability and the Social Model. In *Implementing the Social Model of Disability: Theory and Research*, ed. C. Barnes and G. Mercer, 83–100. Leeds: The Disability Press
- Sandahl, C. 2003. Queering the Crip or Crippling the Queer? Intersections of Queer and Crip identities in Solo Autobiographical Performance. *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1: 25–56
- Shakespeare, T. 1999. The Sexual Politics of Disabled Masculinity. *Sex and Disability* 17, no. 1: 53–64
- Shakespeare, T., Gillespie-Sells, K., and Davies, D. 1996. *Untold Desires: The Sexual Politics of Disability*. London and New York: Cassell
- Sherry, M. 2004. Overlaps and Contradictions Between Queer Theory and Disability Studies. *Disability & Society* 19, no. 7: 769–783
- Shildrick, M. 2002. *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage
- Siebers, T. 2008. *Disability Theory*. Michigan, MI: University of Michigan Press
- Strazdin, L. 2000. Integrating Emotions: Multiple Role Measurement of Emotional Work.

Australian Journal of Psychology 52, no. 1: 41–50

Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.

Thomas, C. 2002. Disability Theory: Key Ideas, Issues and Thinkers. In *Disability Studies Today*, eds. C. Barnes, M. Oliver, and L. Barton, 38–58. Cambridge: Polity Press

Thomas, C. 2004. Developing the Social Relational in the Social Model of Disability: A Theoretical Agenda. In *Implementing the Social Model of Disability: Theory and Research*, ed. C. Barnes and G. Mercer, 32–47. Leeds: The Disability Press

Thomas, C. 2006. Disability and Gender: Reflections on Theory and Research. *Scandinavian Journal of Disability Research* 8, no. 2–3: 177–185

Watermeyer, B. P. 2009. Conceptualising Psycho-Emotional Aspects of Disablist Discrimination And Impairment: Towards a Psychoanalytically Informed Disability Studies. PhD diss., Stellenbosch University

Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge and Kegan Paul

Whitaker, D.S. and Archer, L. 1994. Partnership Research and Its Contributions to Learning and To Team-Building. *Social Work Education* 13, no. 3: 39–60

Wilton, R.D. 2008 Workers with Disabilities and the Challenges of Emotional Labour. *Disability and Society* 23, no. 4: 361–373

Wolkowitz, C. 2006. *Bodies at Work*. London: Sage

Wong, A. 2000. The Work of Disabled Women Seeking Reproductive Health Care. *Sexuality and Disability* 18, no. 4: 301–306