

‘Am I a *real* disabled person or someone with a dodgy arm?’: a discussion of psycho-emotional disablism and its contribution to identity constructions

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Abstract

One of the most important contributions to self-identity arises from social interaction with others – how we see ourselves is affected by how others perceive and react to us. Therefore the ways in which people with impairments see themselves as disabled or not (whatever that may mean), is affected by interactions with other people, both disabled and non-disabled. The psycho-emotional dimensions of disability - a form of social oppression which operates along emotional pathways – are most evident within interpersonal interactions and so make an important contribution to the self-identity of disabled people.

Drawing on an analysis of the experiential accounts of people with physical impairments talking about their disability experiences, this paper will explore the different ways in which the experience of psycho-emotional disablism affects self-identity as ‘disabled’ or not. Interview data was collected using the free-association narrative interview method in which fractures that occur within the narrative - inconsistencies, contradictions, irrationality – are taken to be as illuminating as linear narratives.

I will discuss the experience of internalised oppression and prejudiced attitudes – examples of psycho-emotional disablism - and show the impact this had on a participant’s self-identity, as well as their emotional well-being. Particular problems arise when self-identity conflicts with how others perceive that person and I will illustrate the ontological stress that this causes together with the strategies people devised to deal with it.

Whilst disablism within relationships between disabled and non-disabled people has been well-documented, I will highlight the significance of disablism caused by the attitudes and behaviours of disabled people towards each other. This will be illustrated through a discussion of perceived hierarchies of impairment and the undermining effect that these can have on how one self-defines as disabled or not.

This discussion of the interactions between self-identity and the psycho-emotional dimensions of disability will also reveal the complex nature of this form of social oppression and the manner in which it is intertwined with elements of structural disability, impairment effects and psycho-emotional dimensions of impairment, as well as other facets of social identity such as gender and age.

It will become clear that a consideration of the psycho-emotional dimensions of disability need to be included in any discussions about the ‘disabled identity’ if a more complete understanding of the disability experience is to be achieved.

To this end I will draw on the work of the post-structuralist feminist Braidotti to show how her concept of a ‘nomadic’ subject (1994) provides a useful metaphor for examining the myriad ways in which people with impairments see themselves as ‘disabled’ or not, and how this is highly context dependent.

Introduction

I am going to briefly describe what psycho-emotional disablism is before moving on to explore two related examples of this particular dimension of disablism – internalised oppression and the hierarchy of impairment.

Whilst acknowledging that it is more common to consider this from the viewpoint of non-disabled people towards people with impairments, I am considering the effects of the hierarchy of impairment when it becomes enacted between two disabled people.

I will then discuss the dilemma which is represented by the term ‘disabled identities’ and propose a theoretical foray into feminist poststructuralism, introducing Rosi Braidotti’s concept of the nomadic subject.

Extended social relational definition of disablism

Within UK disability studies, disability is seen as a form of social oppression experienced by people with impairments because of systems, structures and behaviours which privilege the non-disabled, or ‘normal’ people in society.

In her forthcoming book *Sociologies of Disability, Impairment, and Chronic Illness: Ideas in Disability Studies and Medical Sociology* Carol Thomas amends her earlier social relational understanding of disability in *Female Forms* (Thomas, 1999) to instead refer to the term *disablism*.

This is because of the ongoing difficulty in trying to remould the definition of disability to be that of social oppression rather than limitations in activity (impairment effects). Thus:

“disablism is 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*” (Thomas, forthcoming:115, my emphasis)

What’s in a name?

An advantage to using the term disablism as opposed to disability means that discussions about the different forms of social oppression experienced by people with impairments will remain in the realm of the social relational, like the sister terms of racism, sexism and ageism which people are more familiar with.

Disablism operates along different pathways. The structural dimensions of disablism refer to barriers which affect what people can *do*; for example environmental restrictions which prevent people with impairments physically accessing buildings and social spaces.

On the other hand psycho-emotional dimensions of disablism refer to barriers which affect who people can *be*; for example dealing with the thoughtless comments and stares of strangers which can leave people with impairments feeling psychologically and emotionally undermined. Whilst disability studies has been excellent at theorising the structural dimensions of disablism, the psycho-emotional dimensions remain relatively understudied (Reeve, 2004a; Thomas, 1999).

It is important to note that the experience of psycho-emotional disablism is not an inevitable consequence of being impaired (a medical model view) or a ‘private trouble’ which distracts from the real battles against a disabling society (Thomas, forthcoming). It was precisely in order to clarify this confusion that Thomas reformulated the original UPIAS definition of disability into a more explicit social relational formulation.

Elsewhere I have talked about psycho-emotional disablism which manifests within relationships between disabled people and professionals/strangers (Reeve, 2003; Reeve,

2004b). In this paper I will be focusing on internalised oppression which is a form of psycho-emotional disablism operating within the relationship a disabled person has with themselves (as opposed to other people), and the hierarchy of impairment which has connections to internalised oppression.

Internalised oppression

Internalised oppression is common to any minority group in society. Young (1990) provides an excellent analysis of this phenomena and illustrates the manner in which people in minority groups can end up internalising “the cultural knowledge that dominant groups fear and loathe them, and to that extent end up assuming the position of the dominant subjectivity towards themselves and other members of the groups with which they identify.” (Young, 1990:148).

So internalised oppression happens when a disabled person believes the negative myths and stereotypes about disability which abound in society – but as Young points out, this internalisation not only affects how they feel about *themselves*, but also how they feel and act towards other disabled people. And this dual aspect is important.

Internalised oppression within disability studies is not new – it was documented back in Hunt’s seminal 1966 text called “A Critical Condition” (Hunt, 1966) and Micheline Mason wrote in 1992:

“We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives.” (Mason, 1992:27)

Rather than arising from relationships with other people internalised oppression arises from the largely unconscious relationship someone has with themselves, fuelled by the continuing negative images and stereotypes about disabled people which abound in society.

So I would regard this phenomenon as psycho-emotional disablism apparent within a relationship with the self, rather than within relationships with strangers or professionals as I have discussed elsewhere.

I am talking about this subject today because I feel that its long-term, insidious effects are often underestimated. It can have significant effects on the self-esteem and confidence of people with impairments and because of the way in which it operates at an unconscious level, it is particularly difficult to challenge and change.

I am also going to talk about the hierarchy of impairment, internalised oppression based on value judgements of impairment, acted out between disabled people – Young’s second point - which is another area, the effects of which I think are also underestimated.

Methodology

In order to illustrate these two areas I am drawing on a new subset of data from my as yet unfinished PhD (!!).

I used the free-association narrative interview method devised by Holloway and Jefferson (2000) to generate narratives – it is a 2-stage interview method which I believe is particularly suited to the study of psycho-emotional disablism. If anyone wants to know more about this method I am quite happy for them to come and talk to me during the rest of the conference.

I now need to introduce you to Lucy who takes central stage in this paper. Lucy became disabled following a car accident 15 years ago when she was in her mid 20s. Her impairment means that she has restricted use of her left side and walks with a noticeable limp.

I will present several extracts from Lucy’s story which provide an example of internalised oppression and her response to it, as well as her account of a hierarchy of impairment which

she felt was in operation at work. I will then discuss how this affected how Lucy identified as disabled.

The red wedding dress

Lucy talked about how she felt about her wedding dress when she remarried for the second time – now that she was disabled.

Lucy: Because I didn't want to walk down the aisle again, all in my perfect white dress, whatever I chose to wear, realising that I wasn't perfect anymore. Because on your wedding day - I had been married before and it was such a special day and you feel all - and I didn't feel I could do it this time - walk down the aisle and look special, because of my new-found disability.

Donna: So it wasn't because you were marrying for the second time –

Lucy: No. And I didn't feel perfect anymore, as you do when you're going down the aisle. That was quite an important thing I thought. [cut] I wanted a red dress. I went round everywhere, [friend] went with me – [city name], [city name] - everywhere, couldn't find a red dress.

Donna: Why red?

Lucy: Because I wanted to be shocking. If everyone was going to look, bloody look at my red dress.

Lucy walks with a pronounced limp – and she was very familiar with the experience of being stared at by other people because she didn't walk 'normally'. She talked a lot about this particular form of psycho-emotional disablism in our interviews and the distress it caused her.

She is very aware therefore that 'walking up the aisle' will be different now that she has this new impairment. But she has also internalised the prejudice that disabled women are *flawed* women - hence her statement about not feeling perfect anymore now that she was disabled. So for her, the strong image in our UK society about brides in long white dresses walking up the aisle was something she didn't feel able to match up to. So this illustrates a gendered dimension of psycho-emotional disablism.

Her reaction - she chooses a red dress to shock people, to give them something else to stare at instead of her limp.

She has challenged the conventional image of the blushing bride by choosing a colour which is more usually associated with a brothel than a church – her way of dealing with feeling imperfect.

The red wedding dress as a form of resistance.

However, she is also using the colour as a way of concealing her impairment, so this is an example of how impairment effects can interact with psycho-emotional disablism (in this case internalised oppression) and have an effect on the manner in which someone challenges their internalised oppression.

I now want to move on to the hierarchy of impairment.

The hierarchy of impairment

One of the things Lucy talked about a lot was how she saw herself as disabled, and the different ways in which she represented herself to others. Related to this was a hierarchy of impairment which she felt was in operation at work. She works at a disability organisation aligned with the aims of the disabled people's movement.

I've summarised this from a long conversation.

First of all she described how at the top were the employees who used wheelchairs, people with visual impairments and Deaf people i.e. those who sign.

She also considered that people who had “one of the biggies, like cancer, arthritis, multiple sclerosis, spina bifida, whatever” were also above her.

It was only people with hearing impairments who were deaf rather than Deaf that she considered to be below her in the ranking as a ‘real’ disabled person.

This hierarchy was significant to Lucy as she felt it explained why her access needs were often not met (she was lower down the list and therefore somehow less deserving) and how others in the organisation – who had these impairments – viewed her.

Lucy’s hierarchy was very close to the culturally normative hierarchy of impairment found in society – not really a surprise that she had internalised this form, particularly as she had acquired her impairment as an adult.

Obviously the way in which a hierarchy of impairment is acted out on others is affected by what is known/unknown, visible/invisible to that person.

One significant effect of her internalised hierarchy was that Lucy felt she had to fight to get her access needs recognised in the face of the more visible/recognisable access needs of wheelchair users or those with visual/hearing impairments – to prove that she was not ‘faking’ it.

Another consequence of this hierarchy was that she felt her identity as a ‘real’ disabled person was open to challenge by other people in the organisation. She recounted an example at a disability show where a fellow employee questioned Lucy’s limited ability to walk and consequently her right to be claiming the mobility component of Disabled Living Allowance.

This is one significant difference between hierarchies of impairment and hierarchies found in other minority groups. Benefits such as incapacity benefit and disabled living allowance are based on degree of impairment and the difficulties faced by many people in claiming their rightful entitlements can lead to this form of infighting/challenge. The link between hierarchies of impairment, identity and benefit entitlement would benefit from further research.

I would argue that the experience of being subject to a hierarchy of impairment is a form of psycho emotional disablism. Lucy continually felt undermined as a disabled person, that her identity was always open to challenge, leading to ontological insecurity and stress.

In my research I came across other examples of the acting out of hierarchies of impairment within disability organisations and it is an issue that needs to be addressed urgently as it is undermining and damaging. As Deal in his recent paper on the hierarchy of impairment commented:

“Thus, we, as disabled people, may need to acknowledge our own prejudices before we can truly argue we demand a wholly inclusive society” (Deal, 2003: 907)

The hierarchy of impairment has very important connections to the ways in which people may see themselves as disabled, both from their own internalised hierarchy and where they place themselves, but also by where others place them within these often unspoken orderings.

At the very end of my second interview with Lucy she asked me a question which still affects me physically in the stomach each time I read it:

“Do - do I [long pause] Do you feel that I am a disabled person or do you feel that I am sort of trying to jump on the band-bandwagon just because I've got a limp - limpy thingamabob?” (Lucy)

Lucy works for a political organisation where she should feel able to be seen as a disabled person. But because of the way she feels others see her as 'faking' it, she doubts her right to claim this identity.

I thought this was really sad. The fact that the question came when it did, at the very end – shows its significance to her.

I now want to end this paper by considering the issue of 'disabled identities' in particular in relation to internalised oppression and the hierarchy of impairment and to consider a possible way forward theoretically for this complex area.

'Disabled identities'

I have shown how there is a connection between internalised oppression, hierarchy of impairment and identity.

These two related forms of psycho-emotional disablism affect the ways in which people with impairments identify or not, and how, as disabled. This builds on other material I have written about elsewhere linking psycho-emotional disablism and identity.

Context is always important when considering identity and Lucy's story showed good examples of this. At home her husband refused to recognise that she was disabled, at her darts club she was someone with a 'dodgy' arm, at work she was a disabled person (most of the time). But Lucy was also a woman, a mother, wife, worker, daughter etc – identity is composed of many intersecting axes.

And finally, as shown by the example of the red wedding dress, the interaction of impairment with identity can lead to some creative and surprising outcomes.

Now, much of this is not new. There is a lot of literature about disability and identity, we know that for example the UK disabled people's movement is not truly representative of all people with impairments. In Nick Watson's (2002) paper he used data to show the degrees to which people rejected impairment as an aspect of themselves, saw themselves as 'normal' – they rejected 'disabled identities'.

So how can one consider this slippery concept in theoretical terms?

Making connections: the 'nomadic subject'

As some of you know, I have been drawn to poststructuralism, because of the manner in which it allows for people to *negotiate* identity, rather than be saddled with one fixed identity.

Given my interest in psycho-emotional disablism and the ways in which it contributes to identity, for me, any theories of identity have to contain both social and psychological aspects. For example if internalised oppression results in a person believing they are asexual/unattractive because of the myth/absence of sexual discourses involving disabled people, then this asexual disabled identity has to include a psychic aspect, albeit unconscious.

However at the same time these negative cultural representations of disability also need to be considered – the social aspect of disability which foists predetermined identities on to people with impairments.

The examples I discussed here of Lucy using her red wedding dress to 'conceal her limp' and doubting her 'right' to be seen as a 'real' disabled person because of her positioning in a hierarchy of impairment both show how impairment can figure in disability identity constructions.

Elizabeth Grosz points out that:

"Human subjects never simply have a body; rather, the body is always necessarily the object and subject of attitudes and judgments. It is psychically invested, never a matter of indifference." (Grosz, 1994: 81)

Thus, in addition to psycho-emotional disablism, I also need to include impairment, and psycho-emotional dimensions of impairment – in any discussion about disability identities.

Trying to bring together the social, psychic and embodied aspects of identity has recently – in the last month - led me to look at the work of Rosi Braidotti – a post-structuralist feminist who builds on the ideas of Foucault, Butler, Deleuze and Irigaray. She works at the intersection of feminism and poststructuralism and advocates thinking across disciplines – thinking outside the box.

For those who are interested – she is one of the more accessible poststructuralist writers!

Braidotti locates subjectivity in the body and see it as “a point of overlapping between the physical, the symbolic and the social” (Braidotti, 1994: 4).

In her book of the same name, Braidotti introduces the nomadic subject as an alternative account of individual gendered identity and issues related to political subjectivity. Whilst her work is mainly applied to gender and sexual difference I think it could be used to explore the many different ways in which people with impairments identify as disabled or not.

The nomadic subject is a difficult concept to explain in 60 seconds but here are some of the characteristics which I see as being valuable to a discussion of ‘disabled identities’. The nomadic subject is (Braidotti, 1994:22-3, 35, 169):

- An identity made up of transitions, successive shifts, co-ordinated changes
- Focuses on ‘becoming’ rather than ‘being’
- Enacts political resistance to hegemonic and exclusionary views of subjectivity
- Is multiple, embodied and therefore cultural
- Is inherently transgressive, creative, fluid identities
- Includes both conscious political choices and unconscious desires

If I return again to Lucy. Her red wedding dress could have been seen as a transgressive act, but it produced a creative, new outcome.

Her identity as disabled/impaired/whatever continually changes depending on context as well as having a temporal element. When she first became disabled she saw herself as hopeless, undesirable and a burden – now she is powerful, sexual and productive. But tomorrow might be different – a few intrusive comments by strangers about her disabled hand or leg whilst out shopping can shatter that.

So ‘becoming’ is a more useful term in connection with her identity than the more static term ‘being’.

Allowance is also made for an unconscious aspect of identity which is important if internalised oppression is going to be considered as a contributing factor to how someone with an impairment identifies as disabled – whether as an invalid or a Disabled Person?

Sadly, like much literature in the sociology of the body, although Braidotti believes in the importance of the materiality of the body, she fails to take any account of impaired bodies.

Nonetheless I think that her ideas can be applied to impaired bodies, and her work contains many fertile kicking-off points for disability studies to rectify this omission.

Conclusions

Internalised oppression and the experience of the hierarchy of impairment are forms of psycho-emotional disablism which impact on the emotional well-being of people with impairments.

There is a dire need to challenge hierarchies of impairment held by both disabled and non-disabled people – particularly within organisations of disabled people at a time when the disabled people's movement in the UK is at a very low ebb.

How/when people identify as disabled is affected by impairment and the psycho-emotional dimensions of both disablism and impairment.

Braidotti's 'nomadic subject' offers a valuable theoretical approach for considering 'disability identities', in particular the multitude and sheer creativity of ways that people with impairments negotiate their disability identities.

The feminist nomadic subject described by Braidotti is a political project. As such she stresses a need for action at the level of identity, of subjectivity and of differences between women and sees politics as being about bonding, coalitions and non-exclusionary interconnections.

These are areas which should be of particular interest to disability studies and the disabled people's movement because they generate a much more inclusive view of who is seen as, and who might see themselves as a 'disabled person'.

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