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Abstract

This paper investigates the 'space' and 'place' of disabled bodyspace in healthcare. The manner in which the body is mapped depends on perspective and location. Disabled women have had little input in 'mapping' the medical technological landscape in which they find themselves. With the advent of Disability Studies and Disability Geography, social and cultural elements of disability and impairment have begun to emerge. The voices of disabled women are reshaping the terrain of the body reflecting the reality of bodily difference from a positive viewpoint.

Key Words body technology, disability, healthcare, women

Remapping the Medical Terrain on Our Terms

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Introduction

This paper investigates the "space" and "place" of disabled bodyspace in relation to medical technology. The manner in which the body is mapped depends on perspective and location. Women with disabilities have had little input in "mapping" the landscape in which we find ourselves at present. With the advent of Disability Studies and Disability Geography, social and cultural elements of disability, impairment and technology have begun to emerge.[1] The voices of women with disabilities are reshaping the terrain of the body and technology, reflecting the reality of bodily difference from a positive viewpoint.[2]

Bodies out of place

Western society has yet to develop a "comfort level" with so-called "messy" or "leaky" bodies and accordingly, there is an assumed right of public "correction".[3] It is as if the presence of impairment or disability is threatening and destabilizes the "natural" boundaries of normalcy.[4] This need to "correct" may have its origins in the widely held belief that able-bodiedness is a condition highly coveted by people with disabilities.[5]

Disability or impairment is not seen as a natural variation in human biology but rather as biology "gone wrong".[6] The level of access or accommodation provided often remains tentative and rudimentary. The doctrine of separate not equal appears to remain intact.[7] There appears to be an aversion to providing a "space" for people with disabilities.[6] Indeed, "reasonable accommodation" is often code for "minimum" as to nature and cost and it is implemented in such a way that established patterns are minimally disrupted.[7,6] The nature of the built environment and accommodations

within it go a long way in illustrating the value placed on social participation of individuals within the community.[7] Devalued population groups are often referred to on the basis of race (e.g. blacks), gender (e.g. women), age (e.g. the elderly), and ability (e.g. the disabled).[8] In this manner difference is transformed through reductionism to sameness and the complexities of daily life are ignored.[9,6] Groups are effectively silenced through generalization.[10] The boundaries between the community, the individual and the body are fluid although they are often presented as fixed and unchanging.[11] Certain bodies have yet to "belong".[12] People with disabilities would seem to get caught up in a cycle of limited social expectation on the part of the able-bodied mainstream, perhaps fuelled by a combination of factors ranging from lack of exposure to people with disabilities in regular social situations to projected discomfort levels arising from the assumed helplessness regularly associated with varying levels of physicality. As a result, people with disabilities may spend significant amounts of time and energy negotiating their way through public spaces.

In Western society individual worthiness, indeed "humanness", is often defined on the most primitive level by the body.[13] The presence of people with disabilities challenges the entrenched social ideals of what is the acceptable adult body. In many ways people with disabilities are viewed as not fully human by society at large, although this form of dysfunctional reductionism is rarely perceived or acknowledged within the collective social consciousness. Disability is not readily subsumed as part of identity in the same manner as gender, ethnicity, and sexuality have been.[6] A "normal body" (whatever it may be) is equated with a "normal" life although the parameters of the concept are not clearly defined 6. Social understanding of disability and impairment seems to be one-dimensional.[9] Many times the level of engagement would seem to be evaluated in unsophisticated ways, namely in terms of the individual's apparent dysfunction.

"Civilizing" influences

A limited understanding of disability hence gets all too readily coupled with the common misunderstanding that a perceived physical difference somehow informs a lack of maturity or emotional development. It would seem that disability is often equated with a lack of development or immorality.[4] There would appear to have been a colonizing approach adopted toward those individuals with disabilities in Western society. In the possible belief that the appropriation of certain levels of able-bodiedness can turn people with disabilities into

something approaching the norm, normalizing or corrective are measures are often presented as a "civilizing" influence ostensibly for the betterment of the individuals toward whom it is directed. Here "civilizing" stands for being able to fit in with the expected time-space routines of respectable Western society. In many ways medical authority is perceived as the "civilizing" agent.[14] Indeed, those individuals perceived as acquiring greater degrees of "able-bodiedness" are more readily "accepted" by the majority, at least in certain contexts.[10,6]

The body: re-mapping the terrain

The body is never a single physical thing so much as a series of attitudes toward it.[15] Society subjectively defines certain characteristics as valuable, while others are to be avoided or eliminated.[16] Gesler and Kearns[17] explain how this subjective process is used to validate differential treatment:

> The strategy is often used in constructing cultural difference is to naturalize it or make it appear as though it is only natural, the way of the world, an understood truth, not subject to question. Naturalization serves also to legitimise a system of difference.[17]

Western society arbitrarily imposes fixed bodily expectations on its membership.[18] Acceptable shape, size, colour, height, sexuality and physicality are all culturally mediated.[19,16]

> Concepts of race, gender and class shape the lives of those who are not black, poor or female, so disability regulates the bodies of those who are "normal". The concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability. Normalcy and disability are part of the same system.[20]

Agents of normalization

Medical science mirrors the cultural norm and "profoundly shapes our assumptions about what a normal body is …".[21] Medical science is often presented as the benign purveyor of information concerning impairment and disability.[4] Medical professionals are not immune to the widely held perceptions concerning disability and impairment.[22] Globalizing, outdated images of disability and incapacity may colour expectations.[23,24] Functional limitation and difference continue to dominate the discourse in medical school training.[25] The focus remains correction or normalization.[13] Often disability is framed as an apparent failure of medical science where "cure" is not an option.[25] A lack of knowledge concerning disability and "quality of life" issues may influence healthcare decisions and not reflect the reality of daily life with disability.[25,24] Disability is often not as debilitating as it is presented and many individuals

lead full lives.[24] However, a possible lack of information or awareness of disabilities and related support services can create greater difficulties for the women seeking information concerning their changed circumstances.[23] In many ways physicians are "gatekeepers" to the broader social mainstream 9. Medical professionals provide needed authorization for required non-medical provisions and accommodations, yet often fail to recognize their crucial role in liberation and independence for people with disabilities.[23,25]

Disability may be equated with the non-standard deviant population.[26,20] Genetic research will not eradicate impairment or disability, nor will it abolish affliction.[27] In reality, only a minuscule portion of disability or impairment results from genetic difference.[24] The disability rights movement has largely ignored the concept of impairment perhaps because of assumed links to the medical or pathology model of disability.[28,29] Avoiding the intimate aspects of disability or impairment has meant that much of the disability/abnormality dichotomy remains intact and unchallenged.[30,31]

According to Thomson[32], public and private environments are designed for the non-disabled privileged body. Fear of difference is arguably the underlying rationale, although it is rarely articulated as such.[33,16] In many ways disability has been a pivotal factor in defining cultural norms of the body.[34] As a society we have yet to develop a comfort level associated with impairment, pain, or fatigue that ventures much beyond avoidance.[29] Women with disabilities for example are viewed as somewhat removed from the "normal",[32] and here the disability/abnormality/pathology continuum is firmly entrenched.[16] Science objectifies and dominates much of the discussion about disability,[16] while assumptions about the static nature of disability and impairment permeate the discourse.[35]

Society has medicalized disability in much the same way that it has childbirth.[36] The elements of contested control, choice and integrity over, for and of the body present in much of mainstream feminist writing are found here, the difference is only a matter of degree. Technology presents opportunities for disabled and non-disabled women alike, and this possibility has been touched on in Haraway's[37] writings about feminism and cyborg technology. However, disabled writers approach such theorizing with reservation, maintaining that it presents an oversimplification of technology and the body, ignoring the real-life complexities that impairment presents.[34,38] The high cost associated with technology is an insurmountable barrier to disabled men and women, most of whom live in poverty. Reliance on technology, while in some cases facilitating action, may create a reluctance in society to remove other barriers, thereby leading to further social isolation.[39]

Standard tests for non-standard bodies

Diagnostic tests are a standard element of the health care regime.For example, women are routinely sent for breast examinations. However, when impairment and disability are present the experience may not be "routine". It is as if disability is disruptive to established practice:

> I also found it very difficult to stand to get the test done, to get a mammogram. …, you've almost got to like arch your back to get your breast between the: plates, and I think the woman (the technician) was just completely not used to, somebody that wasn't flexible and wasn't the same shape as all the rest of her patients. I had to take the rest of the day off and lie down because my back was so sore. (Electra, Glasgow)

> I had a lump in my breast that needed to be … investigated but I was aware that a mammography would not be practical and so it turned out. So when I did go up to the hospital to have to go through the process I didn't, I couldn't do that bit but I could do the scan. And … that was ok. It was fine, I didn't have to move out my wheelchair. (Rainbow, Edinburgh)

Rainbow also spoke of the need to bring her own equipment for certain procedures at times:

> [E]very place which … requires you to be sitting other than in your wheelchair. For me a hoist that is absolutely necessary. I can take a hoist that I have, and it fits in my car. However, if my GP needed to examine me it would probably be done on my bed at home. (Rainbow, Edinburgh)

Jennifer relates her experience during the quarterly visit to the eye clinic:

> [W]ithin the hospital eye service … in the eye clinics, doctors are very bad at not introducing themselves, nurses don't introduce themselves. … [W]hen I'm getting my eyes examined I have … to wear a contact lens and I have to take it out. So I have no useful vision, once I take my lens out, I'm completely blind.. … They have no visual impairment awareness whatsoever. … and it's something that's extremely frustrating, 'cause it's quite humiliating for me when they say, … have a seat over here and … they're sort of thinking why are you not moving forward, but if you can't see what's in a room, it's really difficult to know where a chair is. (Jennifer, Stirling)

It would appear that the arrival of "non-standard" bodies on the scene is unexpected and "out of place". Therefore, in many cases women with disabilities must adapt and manoeuvre in an environment that is largely unprepared for them.

The "knowledge" question: who "knows"

Many women with disabilities have a detailed knowledge and an understanding of their impairments drawn from daily life experience. Yet, medical personnel often do not utilize this resource.[23] Most of the women I spoke with talked of instances where this knowledge was questioned or dismissed when seeking medical treatment:

> [I]t's an absolute lottery, as to which doctor you are going to see. And that person … could have no knowledge of you whatsoever. … a condition within my eyes has changed, and that has needed quite specific treatment. But, I think that, it took longer to get under control, because I was being seen by different people. They were starting from scratch each time… I insist on seeing the senior consultant [specialist] and … the last time I was there I refused to see the doctor who had taken my notes off the top of the pile, ….what the doctor had said to me was, … 'you can't see the consultant because if everybody wanted to do that, it would hold up the whole clinic, and if you want to do that, you are going to have to wait a long time'. And I said to her, well that's fine, I'll just wait. (Jennifer, Stirling)

Meranda and Jess spoke of the difficulty communicating with their consultants [specialist]:

> I mean this is a man with a communication problem. ... He really couldn't get his head round this, and I became aware of that from the point when I was referred to him … And I would have understood that if he had actually explained it to me, but he did not explain it to me. So he wasn't using, quite aside from the disability, he wasn't using my knowledge of myself. The patient's knowledge of herself, to help in this situation. (Meranda, Glasgow)

> I used to go to the pain clinic … The first couple of times I went there I felt … At the time you were telling him something he was contradicting you saying well that can't happen. He is telling you that there's nothing wrong with you apart from your weight. Your weight gets blamed for everything … I had a back brace which didn't fit properly and I was told to go home and just get used to it. .. and it was a case of well you [cannot] be that bad if you refuse certain things. … these symptoms just do not sound like the condition you have. And then I asked 'How many people he had seen in my condition'. 'One'. He had read everything in a book. … I haven't been back for a good few years. (Jess, Falkirk)

Sally and Hazel talked about the difficulty they have at times, trying to impart the specifics of their impairment to health care professionals in order to avoid serious health complications:

> If I get a chest infection it does cause a pile of difficulty because my rib cage is quite constricted … I don't know that the GPs always understand that, … they … say 'well we don't like to prescribe antibiotics' ...

> They treat you like they'd treat anybody and … it's difficult to … try and explain to them 'well actually … it's a bit more difficult for me'. (Sally, Edinburgh)

> Quite a lot of times if you're given a new drug you have to ask, … what the effects are and I have to say I double check for instance if a new drug has steroids in them because I am not allowed to have them in them in one of my drugs for epileptic. Because it happened once, I don't believe that everyone will remember. (Hazel, Stirling)

Rainbow's experience with her specialist demonstrates what can be achieved through respect, communication and understanding:

> It's kind of strange because with most doctors nowadays I can tell them exactly what I need and … we talk about it from that point … I met my longstanding consultant … and knew that he was dead straight with me but with a wry sense of humour, which I appreciated. … and he's just so direct and I know that he's in control … but in control without putting me on the sidelines and he very clearly said to them 'Rainbow knows her lungs better than any of us she knows what she needs'. And that is just so supportive. (Rainbow, Edinburgh)

The "place" of technology in health care

Discussions concerning technology clearly meant different things to different people and explored a wide range of topics. Fred, a physician with a disability, speaks of technology as providing an assistive role to people with disabilities:

> I think technology clearly can be important either in assisting the disabled person to … not be so disabled … by allowing them to do things they wouldn't otherwise do and I suppose also by … technology it just doesn't apply to disabled, I think it applies more generally, ... technology can often be useful in providing information to patients and people with disabilities in a way that is … perhaps easier for them to assimilate, and that they've more time to assimilate. And … things like having good web sites that people can go to actually is very helpful ..., because we know that whether someone is disabled or not, the amount of information that gets across at any consultation. (Fred, Physician, Glasgow)

The internet is a key health information access tool for many of the women that I interviewed:

> We use the Internet for health information … because they have it in here and it's easily accessible for us if we need it. …On my own condition. … Because it's quite a rare condition that … even my GP had problems trying to get information on it. (Jess, Falkirk)

> I think for the first time I've been able to type the name of my impairment in on the Internet and it came up with information whereas in libraries … anywhere else that I've, medical dictionaries even, looking up

the name of my impairment … doesn't…happen. So ... the Internet's definitely got … better access to information. (Sally, Edinburgh)

Well its normally … quite good because he [Doctor] has got a computer so sometimes they can punch it up on the computer and give you wee leaflets and things like that. (Kylie, Stirling)

Asch[24] documents how the nature disability can be distorted and is often presented as complete dependency. Similarly, Molly speaks of the negative manner in which disability is often presented in terms of genetic screening:

I think that it's… that the way it's, … sold to people is very negative … I think it's very ... disability is a life less worth living attitude that's taken. And I don't think people are given the full range of facts, I don't think people are supported to consider well if a person has this particular condition, ok there might be these kinds of limitations in their life, but there are lots of people who are living very valuable and fulfilled lives who do have this particular condition. (Molly , Health Service Administrator, Glasgow)

The technology for large or non-print formats is readily available but mainstream society has yet to recognize it as a regular part of the information network. Jennifer talks about the lack of access to health information available in these alternative format materials:

[T]here's really no information available in accessible formats [accessible to people with vision impairments]. So usually … in terms of … some information … I'm sent out a letter, then I can read that sort of stuff using a closed circuit television. (Jennifer, Stirling)

Rainbow tells of the lack of simple physical access technology in a health care setting:

The provision of more hoists, particularly, at health care centres could be very useful. (Rainbow, Edinburgh)

Internet technology has made accessing health care and impairment information much easier for some women with disabilities. However, it would appear that there is as yet some way to go in making the links between technology and disability as being a "natural" part of the health care environment.

[I] think it's very important that the disabled and disabled groups continue to push at the health care professions. And continue to push at medicine. I mean medicine … is changing but it needs a stimulus. and medicine in some ways is a very conservative profession and will not change unless there is some stimulus. Or will not change from what it thinks is important unless there is some external stimulus. It will change in detail, it will change in scientific approach … but in terms of the broader perspective whilst there will be individuals who may change, the profession as a whole won't change unless there is continuing stimulus from the outside. (Fred, Physician, Glasgow)

Conclusion

Health service professionals and the disability rights movement can together play an important role in moving away from "perfect body syndrome". This will require significant attitudinal shifts at a fundamental level re-examining tenets and moving well beyond tinkering with the existing system.[25] Every "body" is a natural part of humanity.[13] Deeply held truths about what comprises the "woman's body" require critical and creative analysis outside of the narrow objectifying boundaries of science.[13] We need to reject simplistic approaches that embrace physical and cognitive essentialism in favour of diversity.[13,27] There are real consequences to the choices we make and these choices should be motivated by respect and understanding rather than ignorance.[27] In many ways, it represents the natural progression in how the disability movement has created a new group of perspectives beyond the overreaching normative which has gone before. Knowledge, science and technology are not exempt from critical analysis and here the authority of medical science cries out for critical mediation.[25,27] Above all, the disability/pathology dualism must be abandoned in favour of a model that values and respects bodily difference rather than fearing it.[32,27]

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