

Disturbing bodies – reimagining comforting narratives of embodiment through feminist disability studies

Carolin Ahlvik-Harju

Theological Ethics and Philosophy of Religion, Faculty of Arts, Psychology and Theology, Åbo Akademi University, Åbo, Finland

ABSTRACT

The world responds to us because of our embodied selves, and we respond to the world through our embodiedness. Some bodies are admired, some are rejected. Some are perceived as normal, some as abnormal. Hence, bodily differences are not neutral facts. In society there are normative standards of embodiment that people ought to live up to, and anyone who does not is stared at, ignored, feared, or in various ways marginalized through oppressive practices. These practices are legitimated by dominant systems of representation and by cultural narratives that shape the material world, inform human relations, and shape our sense of who we are. This article discusses and challenges the dominant cultural narrative – the normalcy narrative – that makes the able-bodied, rational, male subject the normative standard in society. From a feminist disability perspective, narratives of embodiment are rethought, reimagined, and re-conceptualized.

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Introduction: body narratives

It was a warm summer day. I and a group of friends decided to enjoy this wonderful day at a café by the sea. Since a few of us weren't able to walk nor talk we paired up in two's at the arrival; a walker with a non-walker, a talker with a non-talker, and so forth. I paired up with one beautiful young woman who could neither walk nor talk. She grumbled impatiently in her wheel chair, probably in pain after the drive. I placed her blanket on the terrace floor and I took out a pillow ready to put down her head on. While half the group waited outside the rest of us went off to buy drinks and ice cream. Meanwhile the grumbling sound of my friend had almost turned into screaming. Tears were pouring down her cheeks and her twisted body moved aggressively back and forth in the wheel chair. I knew her well enough to know this was her way of telling me that she needed me to act faster. She needed me to ease her pain by moving her out of the wheel chair. So I did. I embraced her in my arms. I sang quietly in her ear. I stroke her hair. I could sense that she knew this was my way of telling her that I feel her pain. I understand. I am sorry. Eventually she relaxed and smiled at me. In this way she let me know that she was ok. We were good. And we had our ice cream. One spoon for her. One for me. One for her. One for me. While we sat there, two grown up women on the terrace floor, people had a bit of a difficulty passing us by. I didn't notice at first, but after a while I became aware of all the people walking towards us – staring. I watched them turn away muttering something about us being there. One woman took her daughter by the hand and said: 'Let's go inside, this is no place for us'. Another woman said to her friends, while observing us with a disgusted look on her face, that they should've come another day. A man passed us by to sit down, but changed his mind and said to his friend laughing: 'I didn't know that the owner had started a circus!'

*Let's leave! Our presence was clearly unsettling. The body of my friend, twisted and in pain was evidently provoking. Why are disabled bodies so disturbing?*¹

The twisted body of my friend evoked stares, anxiety, and humiliation in the people encountering her. The reactions bothered me profoundly, so later I discussed what had happened with a few people. Many of them reacted much like me: horrified, surprised, and with sadness, but some expressed great sympathy for the people who came across me and my friends at the café. They suggested it to be quite natural to stare when someone looks that different, indecisive of in a good, bad, or simply an astonished way; it is also quite expected to get a little scared when a grown-up woman throws her body back and forth in a wheel chair, especially while screaming at the same time; it is also quite common to cover such a fear in bad jokes or hostility. Garland-Thomson (2006) frames this point well as she writes:

The unexpected alien is always both an affirmation of our own humanity and a challenge to our complacent understandings. [...] Staring witnesses an interruption of our comforting narratives – variously called truth, knowledge, certainty, or meaning. What embodies the contingent, the unpredictable, the strange, the disordered prompts our stares as we seek to find order in apparent disarray. (174)

The comforting narratives of the people at the café – their truth, knowledge, and certainty – were simply interrupted, and their reactions were perhaps just attempts to regain order. James B. Nelson writes in his pioneering book *Body Theology* that the world responds to us because of our embodied selves, and that we respond to the world through our embodiedness (1992, 42). The initial story demonstrates how the world tends to respond to a body disturbingly different from contemporary body ideals. But can we settle with the explanation that people reacted in a 'natural' or 'normal' way, not asking why it is 'normal'? Can we settle on the truth, knowledge, and certainty that produce, in Garland-Thomson's words, comforting narratives, even when they are everything but comforting to some; even when they are oppressive and marginalizing towards anyone who does not verify the founding truth of that narrative? Can we settle knowing that there are various comforting narratives in society and without question accept that some of them are more dominant than others?

If one decides not to settle, and one starts pondering about the 'why-question', some interesting aspects emerge. For example; a study on stereotyping showed that the general public perceive not only people with disabilities but also housewives, blind people, the so-called retarded, and elderly people to be similarly incompetent in society. As well as in the initial story, this indicates that the dominant comforting narrative is one about the young, able-bodied, rational, male, and that in a society where *he* is the representational norm, other bodies are portrayed and perceived as deficient and expendable. In such a society women and people with disabilities, in particular, are portrayed as helpless, dependent, weak, vulnerable, and incapable, which reveals that in a sexist society, female embodiment is a disabling condition (Garland-Thomson 2011; Wendell 1996).

Feminist disability theorists have insightfully pointed out that there is an evident connection between the politics of appearance and the medicalization of subjugated bodies. It is suggested that appearance and health norms often have similar disciplinary goals and that the female body has been medicalized in modernity. Feminist disability theorists claim that women and people with disabilities have been viewed as medically abnormal, which also means that sickness is gendered feminine (Garland-Thomson 2011).

In such a society, bodies marked and selected by dominant representational systems are targeted for elimination by a variety of oppressive practices. For example women, people with disabilities, people with unorthodox appearances, gays and lesbians, and people of colour have variously in the medical context been objects of infanticide, selective abortion, eugenic programmes, assisted suicide, and normalizing surgical procedures. Not only have these bodies been victims for medical control, but they have also been subjugated by hate crimes and neglect. These practices are legitimated by dominant systems of representation, by cultural stories that shape the material world, inform human relations, and shape our sense of who we are (Bishop 2011; Garland-Thomson 2011; Wendell 1996).

The short observations above show that disability and the disabled body are part of a greater historically constructed discourse and ideology of thinking about the body. While often conceived as a physical or mental flaw, disability is a social and cultural process closely linked to everyone being a body and to structures of power. Garland-Thomson explains disability as 'a culturally fabricated narrative of the body, similar to what we understand as the fictions of race and gender'. Thus, the concept of disability regulates bodies – those perceived as normal and those perceived as abnormal. The reactions of the people in the initial story are a testimony of their comforting narrative being one informed by the cultural story about normalcy. Within feminist disability studies, this comforting narrative of embodiment is argued to be the dominant one in western societies and is sometimes referred to as the normalcy narrative (Creamer 2009; Garland-Thomson 2011; Hirschmann 2013).²

The aim of this article is to challenge the normalcy narrative and the more or less taken-for-granted body talk that makes the able-bodied, rational, male subject the normative standard in society. While my standpoint is indeed critical, the task is not to claim *another* set normative standard of embodiment, but to enable a reimagination of comforting narratives of embodiment. The theoretical basis for the critical discussion and analysis is found primarily among feminist disability scholars who on the one hand address a wide range of feminist issues, and on the other hand make the body, bodily variety, and normalization central to analyses of all forms of oppression.³

Body standards

The body is highly idealized and objectified in Western societies and the social pressure to shape, regulate, and normalize one's body in order to fit a normative standard is strong. The normative body standard is defined by deeply rooted conceptions of normalcy – the normalcy narrative – and governed by a normalcy structure in culture and society. The corporeal manifestation of culture's collective normative characteristics is by Garland-Thomson (2011) called the *normate*. The normalcy narrative not only shapes our sense of who we are, but also restricts the life of people with deviating bodies, and limits the imaginations of those who think of themselves as keeping up with the normate, that is, embodying the ideal (Garland-Thomson 2005, 2011; Wendell 1996).

Already as children people begin to internalize the normalcy narrative. People learn from childhood onward how to seem normal and meet the standards of normality. This is a process of inheriting a system of judgements that enables us to make sense of ourselves as agents. The standards of normality are thus important to our self-understanding, and the automatic internalization of the standards is not likely to be questioned until our ability to meet them is threatened in some way (Garland-Thomson 2001; Owen 2003; Wendell 1996).

To better grasp exactly how the normalcy narrative influences the shaping of ourselves, one can explore cultural discourses of health and/or appearance. As the body is an important show-ground for social control, most of us struggle with meeting the standards of normality in our attempts to control, mould, and maintain our bodies. The notion of control entails the presupposition that we can have the bodies we want by means of human actions, which is true for the 'healthy' as well as the 'beautiful' body. Thus, the normal has inflected beauty. The sense of being in control fools us into the belief that it is possible to escape the abnormal body – the negative body. However, no one fortunate to live long enough can escape ageing, and people with disabilities can often not even attempt to control their bodies. Hence, not being able to keep up with the normate can have devastating consequences (Barron 1997; Garland-Thomson 2011; Shildrick 2009; Wendell 1996).

One example of the normalcy narrative at play is the medical practice of prenatal screening and selective abortion. Prenatal screening is a widely accepted medical practice in the Nordic (Western) countries, and selective abortion is the most common way of handling positive results, that is when abnormality is found. Being part of contemporary biomedicine prenatal diagnosis is a major source of

expressed notions about what it means to be human and to have a human body. A healthy body is expressed to be a normal body – a sick body is expressed to be abnormal. The assumptions about normality thus make people with chromosomal deviations particularly vulnerable in society and an easy target for social control (Ahlvik-Harju 2014; Ash 1999; Scully 2005).

Another example of the devastating consequences and the social control that the normalcy narrative can give rise to is brought forth through a qualitative study done by Barron (1997) in which the societal constraints with regard to womanhood for physically disabled young women are investigated. The study makes clear that normates *devalue* not only deviating bodies, but also the very *people* in those bodies. Disturbingly enough, the study also shows that these women devalue themselves because of their bodies. They all found the question of beauty completely irrelevant to them because they had never thought of their physical appearance in such terms. Their bodies had namely throughout their whole lives been devalued and marked with one single purpose: to be repaired and normalized (Barron 1997). Susan Wendell has elsewhere observed:

In a society that idealizes the body, people who cannot come close enough to the ideals, and those whose bodies are out of control, become devaluated people because of their devalued bodies. [...] Moreover, they are constant reminders to the temporarily 'normal' of the rejected body – of what the 'normal' are trying to avoid, forget, and ignore. (1996, 91)

Hence, current perceptions of embodiment devalue some people making having a disability or an unorthodox appearance a clear disadvantage in society, which leads to an immense fear of not living up to the standards. Not only do we fear the societal disadvantages, but also pain, illness, limitation, suffering, and dying. This fear might explain why the presence of disabled bodies causes such anxiety in non-disabled people who encounter them. This fear might explain why so many chose to abort fetuses diagnosed with some kind of disability. Disabled bodies – people with disabilities – are reminders of our own vulnerability, and they confront us with the possibility of our own pain (Garland-Thomson 2001; Shildrick & Price 1999).

The natural way of coping with the anxiety and the fear, then, seems to be to ignore those, in Wendell's words, rejected bodies. In the article 'Queer/Fear: Disability, Sexuality, and the Other' (2013), Nancy Hirschmann observes, with reference to Tobin Seibers, that it is only in the sphere of disabled existence that people actually risk waking up one morning having become the persons whom they feared the day before. This makes people with disabilities the ultimate *others*. By othering people with disabilities, the inevitability of one's own corporeal vulnerability can presumably be ignored (Hirschmann 2013; Shildrick & Price 1999; Wendell 1996).

In line with those who were sympathetic towards the hostile reactions in the initial story, one could suggest that othering people with disabilities merely is an expression of anxiety on a personal level (see e.g. Shildrick 2009), but I believe it is crucial to recognize the normalcy structures in society and the power mechanisms that make this expression possible, legitimate, and 'normal'. Internalizing the normalcy narrative is not only about learning how to meet the bodily standards ourselves, but also about how to react to bodies outside those standards. Hirschmann (2013) elaborates on the idea that the anxiety experienced in the presence of disabled bodies in its essence is not about fear of the other –the non-self – but of oneself. In this view it becomes impossible to draw a sharp line between the subjective experience and the cultural narrative.

Garland-Thomson (2007) describes normalcy as a story that structures our shapes. Our bodies and the stories we tell about them are shaped to fit the standard bodily forms and functions. In contrast, she suggests, disability is a story structured by shape, and the story about disabled bodies is often a story about weakness, suffering, and unhappiness. For the purpose of challenging the normalcy narrative, alternative perspectives such as feminist and queer theory have emerged and influenced scholars to pay attention to differences of the body by focusing on real bodies instead. Real bodies are not just corporeal but filled with meaning, which means that how we perceive and experience our bodies is similarly important (Hirschmann 2013; Wendell 1996).

Disability and corporeal difference

Hirschmann (2013) proposes that feminist and queer theory can help us see *how* fear (of unorthodox bodies) works, and that disability theory can help us see *why* it exists. A wonderful realization of such an undertaking is *Unruly Bodies* (2007) by Susannah B. Mintz in which she analyses the life stories of eight women with disabilities. Her aim is to generate a more critical understanding of how the categories of gender and disability interact in the formation of a woman's identity, and thus challenge common conceptions of disability as deviance, helplessness, and dependency. Mintz writes:

These stories of embodiment go beyond simply critiquing the able, male body of patriarchy to confront feminism's presumption of certain types of female corporeality, thereby rewriting the myths of self-control that problematically exclude some women from feminism's theoretical and political agendas. Feminism has historically failed to engage critically with disability – with the physical or sexual limitations, the dependence on others, and even the discomfort experienced by many women who live with disability and/or chronic illness. (2007, 4–5)

Life stories about bodies different from society's body standards can serve well as counter-narratives to the normalcy narrative, and challenge the political agenda of feminism that claims women to be strong, independent, and controlled. Life stories about corporeal difference have the power to point at the intricate connections between subjective experience and the cultural narrative and exemplify how narratives about the 'normal body' damages and hurts people embodying something else. Feminist disability theorists, and other critics, have argued these stories to be fundamental to a project of rethinking relations between bodies and selves, subjects and societies. These stories can truly support the important undertaking of feminist disability studies in confronting the limits of how we understand human diversity, the materiality of the body, and the social formations that interpret bodily differences (Garland-Thomson 2011; Mintz 2007; Wendell 1996).

Elizabeth Grosz (2003) suggests that difference generally can be understood in two ways: firstly, as a difference between two pre-existing entities, like the difference between a strawberry and a banana; secondly, as a constitutive difference, a difference that pre-exists the entities it produces. For example, according to Grosz, there has never been a space in culture for women *as* women. Women have only been represented as a lack, as the opposite, as the complement of the one subject – the male. This means that there has never really been a space in culture for two sexes – only one sex and its counterpart. Not to say that women have no identity in culture and society. Women do indeed have a strong identity in, especially, motherhood or as wives, but female identity is usually constructed in relation to other identities.⁴

Feminist theory has often described difference in terms of othering and in line with Grosz's example of women, I argue that disability too can be understood in light of constitutive difference, which in the case of women with disabilities becomes especially clear. Not only have women with disabilities been othered to men, but also to non-disabled women. This can be understood as a dual oppression, but since women with disabilities are not seen as women in society at all, it can also be understood to be a completely different kind of oppression (see e.g. Schriempf 2001). Although I understand the reasoning behind the second option well, I believe the feminist account of difference and othering can be helpful for the aims of this article.

As Wendell (1996) describes the feminist concept of othering, it entails two processes: (1) grouping people together as the *objects* of our experience instead of regarding them as *subjects* of experience with whom we might identify and (2) seeing them as symbols for something we fear. The symbolic meanings of a person can thus make someone the other, and characteristics of a person such as race, gender, or sexual identity may further alter the symbolic meanings. For example, cultural assumptions about disability that entails weakness, dependency, and helplessness clash with cultural assumptions of masculinity, but overlap cultural assumptions of femininity so that a disabled man is perceived as a 'wounded male', while a disabled woman is redundantly fulfilling cultural expectations of her. This further shows how disability and illness are gendered feminine (Garland-Thomson 2011; Wendell 1996).

Otherness is thus maintained by culture but can also be said to limit the culture, or otherwise put: the normalcy narrative as the dominant narrative hinders counter-narratives to be equally important in culture. People with disabilities are rarely included in descriptions and images of ordinary life, and the daily struggles, thoughts, and feelings of people with disabilities are oftentimes excluded from any shared cultural understanding of human experience. Even though the interest in real-life stories (e.g. the growing literature in celebrity biographies) is greater than before, these are usually about people within the dominant paradigms of identity. This tends to obscure the needs, shapes, and sensations of deviant bodies – or make them completely invisible in culture. As people with disabilities are the hidden others in society, the gap between disabled and able-bodied people continues to exist (Mintz 2007; Wendell 1996).

Promisingly, there are some efforts made in telling stories about people with disabilities. The difficult challenge, though, seems to be how to tell these stories well. It seems as if the only stories that manage to the public sphere are either hero-stories – stories about people who have overcome their obstacles and achieved success – or stories that make people a curiosity. Hero-stories are naturally inspiring for people who *want* to, and are *able* to, overcome their disabilities, but they also send a message that disability is something that *should* be overcome. The danger is that the only good thing about a person with a disability is portrayed to be the conquering of the disability itself. The problem with these kinds of messages is, as for example, Robert McRuer points out, that they function as truth effects. One becomes either a miracle story or the one who has given up in a ‘death-like move of resignation’ (Eiesland 1994; McRuer 2003, 151). These are the kind of truths that inform the normalcy narratives.

An important aspect that queer and feminist disability scholars have brought forth regarding the portrayal of people with visually obvious disabilities in the media is the multiple cultural meanings of embodiment that they constantly need to balance. On the one hand they are *invisible* as active members in society, and on the other hand they are *hyper-visible*, categorized as a passive consumer and victim in much of the popular imagination (Kuppers 2001). Because disability is portrayed as a curiosity in media, it sends a message that disability legitimizes objectification, humiliation, and disrespect towards people with disabilities. Similarly to the women in Barron’s (1997) empirical study, this not only reflects how people with disabilities are perceived by others, but also how they oftentimes end up perceiving themselves. They are disabled first, and people second. The fact that stories about ordinary life, real challenges, or how to live well with a disability are rarely seen in the media bears witness of how the culture secures the dominance of able-bodied identities (McRuer 2003; Swinton 2000). Garland-Thomson connects this further to the ‘spectacle’ of being a woman in the social world:

Women are the proper object of the male gaze, while disabled people are the proper object of the stare. Beauty contests, girlie shows, freak shows, telethons, and medical theater all testify to an appropriating to-be-looked-atness that supposedly inheres in the female and or the disabled body. Leering at women and gawking at disabled people are historical practices that constitute female and disabled personhood in the social world. (2001, 9)

I argue for the need of different stories – counter-narratives – that can serve to challenge the cultural narratives blurring our imaginations of disabled (and female) personhood. However, many people with disabilities experience inevitable daily struggles for which a deconstruction of social or attitudinal barriers cannot be the only solution. Viewing disability as difference is thus not just to say that biological variation is a neutral fact, but to acknowledge that it might actually be difficult to have an impairment of some kind. And this is a fundamental point when simultaneously discussing gender issues and disability issues. There is, in principle, nothing undesirable about being a woman and a change in the cultural imagination can make the disadvantages of female personhood go away, whereas some disadvantages for a person with disabilities cannot (Gatens 1999; Scully 2005).

Feminist disability theory presses us to ask what kind of knowledge is produced through bodies radically different from the standard, bodies that materialize the extremes of human variation

(Garland-Thomson 2011). Acknowledging stories about lived, experienced, different embodiments is a first step away from the notion of one standard body and towards an understanding of the link between difference and sameness. A question is then how to relate to the struggles that some of the experiences involve without moral evaluation. One could claim that there is a necessary ethical judgement in the acknowledgement of the struggles of people with disabilities in order to change discriminatory social practices (see e.g. Vehmas & Watson 2014), but I would like to make a clear distinction between valuing some aspects of life as less desirable and valuing a (disabled) person or an entire life as less desirable. Acknowledging the presence of less desirable aspects in, my own and others', life might actually be a key to an acceptance of them and learning to cope with them. By challenging what Kafer (2003) calls compulsory able-bodiedness and embracing the connection between sameness and difference, a widened moral imagination can also emerge. In Shildrick's words:

It is precisely here in the midst of a public discourse ostensibly based on reason that it becomes necessary to add in – at the level of both the individual psyche and the cultural imaginary – that a deep anxiety pertaining to difference. And it is an anxiety less about an absolute separation of the categories of the normal and the abnormal, than about the unbearable ambivalence of not being able to definitely settle on difference. People identified as disabled provoke anxiety, not because of their difference as such, but because *they are too much like everyone else*; worse yet, anyone could become one of 'them'. (2009, 55, my emphasis)

In line with many feminist disability scholars, I believe binary categorizations such as able-bodied/disabled are just as illuminating for understanding the meanings of embodiment as man/woman is for understanding the meanings of gender. However, as Shildrick points out in the quote above, the anxiety pertaining to difference is probably less about the binary categories than it is about the ambivalence of not being able to settle on difference. I believe that counter-narratives that challenge as well gender stereotypes as body standards is the only way towards relieving the anxiety. Garland-Thomson (2011) proposes that we study disability in a feminist context to focus the critical gaze at the dual scholarly task of exposing and reimagining disability, not only for people with disabilities, but also for everyone. Studying disability is one way of attaining greater understanding of society and human experience, of gender and sexuality, individualism and quality, autonomy, and wholeness. Inspired by Wendell (1996, 84), I would like to summarize what it would mean to understand and value disability as difference. It would mean being willing to learn about the unfamiliar – in others and in me. It would mean respecting the unfamiliar – in others and in me.

Hence, acknowledging counter-narratives about disability as difference can help us resist oppression, but the counter-narratives can further at best have an additional important purpose, namely as corrective narratives. By this I mean that through first-person narratives about bodies in distress, we can better understand the histories of embodiment as open-ended. That is, bodies are always in a process of becoming. The stories we tell about them are therefore never finished, but in constant change (see e.g. Mintz 2007). In the remaining part of the article, I will exemplify some experiences of embodiment that I believe define the body as an open-ended story. They are experiences of vulnerability, suffering, and pain.

Vulnerable subjects

In recent years, political, philosophical, theological, and critical theories have begun to embrace vulnerability as a core aspect of human being and human embodiment. Human beings are increasingly perceived not to be autonomous in their concrete, individual, and societal lives, but instead dependant on others. Some scholars even claim that the very essence of human embodiment is vulnerability, that embodiment in itself is a reminder of the limits inherent in the human condition (see e.g. Sigurdson 2009).

However, in the normalcy narrative concepts such as vulnerability, suffering, and pain are alien. In fact, these are specific aspects of embodiment and human being that the normalcy narrative teaches

us to ignore or even – in ‘best’ case scenario – eliminate. These aspects are the ultimate symbols of a life not worth living, a life that lacks in quality. As with the body, vulnerability has traditionally been linked to feminine attributes, which is particularly true when vulnerability is linked to bodily degeneration in connection to ageing, disability, or otherwise a condition of dependency on others for basic needs (Hall 2011; Vaittinen 2015; Wendell 1996).

The bodies of people with disabilities regularly cause pain and suffering and therefore they expose corporeal vulnerability in society. To able-bodied people, the body tends to be absent to consciousness except when pain and suffering strike. A body in pain takes up one’s complete attention and the primary wish is usually for it to go away. Consequently getting rid of pain becomes the focus of all intentions and actions. In a medical context, getting rid of pain is a question of quality of life and what kind of life that is worth living, but from a feminist disability perspective it is rather a question of *what makes possible* a life that can be lived (Hall 2011; Wendell 1996). How can a life of suffering and pain be made liveable?

Wendell (1996), suffering from chronic pain herself, is posing that one of the greatest aspects of pain in fact is the suffering in constantly trying to make it go away. She describes that the suffering of the pain itself often is relieved when giving into it. A greater acceptance of her bodily pain has taught her how to live with it and that life can be good even with the pain. She says that experiences of the body can teach consciousness a certain freedom from the sufferings and limitations of the body. One step towards accepting the pain as part of life can be to deprive it of meaning. To a healthy person pain means that something has to be done about it, while for a person in chronic pain it means nothing. To deprive pain of meaning does not necessarily mean ignoring bodily messages, but a reinterpretation of bodily sensations (Wendell 1996, 1999).

What I find to be the most important point of Wendell’s view is that by depriving pain of meaning, it can also be moved away from the common assumption that pain is equal to unhappiness. If the body is not the totality of one’s experience, the painful messages of the body can be overlooked. This can clearly be perceived as ignorance of the body, but I believe that accepting pain actually is to identify oneself with the body and that this can enable a reimagination of a good life encompassing pain (Wendell 1996, 1999).

In the article ‘The Power of the Vulnerable Body’ (2015), Tiina Vaittinen argues for the importance of reintroducing the vulnerable subject to challenge rationalist thinking. She describes the vulnerable body as a living organism that is internally and persistently vulnerable to life itself. But not only is the body vulnerable to life itself, but it is also excessive to its own boundaries in what Shildrick (2009) calls intercorporeal vulnerability. She explains that to touch another person is to compromise on one’s own control as the touch is affecting both parties. Hence, the touch opens up the risk of vulnerability. The touch transcends both the material and the mental as it can involve physical contact, or simply refer to ‘being in touch’. In this way intercorporeal vulnerability turns out to be a fundamental essence of, what Shildrick describes as, being in the world or becoming in the world. The emphasis on becoming is important since becoming is a process that shifts and changes as the body itself in irregular transformations that unsettle the subjectivity and identity of a person.

To exemplify what this could mean, I draw on Nancy Eiesland’s analysis of the life stories about Diane DeVries and Nancy Mairs, two women with disabilities, in *The Disabled God* (1994). The story of DeVries highlights in a practical way what can be understood with intercorporeality when she describes how DeVries through her intimate relationship with her sister included herself in images of running and dancing, even though she has no legs herself. She uses her sister’s body as a resource for constructing her own body image (Eiesland 1994). Through learning, observing, and touching someone else’s body we can gain greater understanding of theirs and our own body.

The story about Mairs is a story about a woman who has not overcome the bodily pain that her disability causes her, but one who has come to terms with her body and accepted it to be a body with limitations. The story of this woman, angry and furious over a body betraying her, is very powerful. Through a roller-coaster of depression and breakdowns, the boundaries of her body became routine. More importantly, she felt like she was becoming a body for the first time in her life. The insight of the

limits of her body was humbling and the awareness of her movements and bodily actions was only amplified through the pain (Eiesland 1994; see also Couser 1997; Mintz 2007). Eiesland writes:

These horrible things need not diminish us; they can make us more fully aware of the full range of things human. Performing an authentic alchemy using disability and honesty, Mairs has fashioned a difficult life, in contrast to our constant search for ease and painlessness. Her difficult life need not be denied or descried. It need only be lived. 'Because a difficult life is more complicated than an easy one, it offers opportunities for developing a greater range of response to experience: a true generosity of spirit.' It also opens a space for honesty about death as part of an ordinary life. (1994, 46)

The problem of suffering and pain need, and should, not be ignored. It is a real – (inter)corporeal – issue, especially in many of the lives of people with disabilities. It is rational that the aim of medicine is to eliminate suffering caused by bodily pain. Nevertheless, the connection between pain and suffering is not obvious. Garland-Thomson (2012) stresses that pain became a medical anomaly around the same time as suffering shifted from being a central part of the human condition to an exception worthy of elimination. This move has led to the strong belief that curing pain through medical treatment is a necessity and a possibility, and that suffering too can be cured through medicine.

In this article I have used prenatal diagnosis followed by selective abortion as an example of the normalcy narrative at play. As prevention of suffering is one of the main arguments for implementing prenatal diagnosis, the concept of suffering is an important topic for discussion in bioethics. Garland-Thomson (2012) argues that our failure to imagine another person's life determines the actions we take when wanting to alleviate suffering. Our inability to tolerate or witness in others what we fear will happen in our own lives sometimes leads to what she refers to as mercy killing. The presumption that life with a disability is equal to a life with complete suffering and unhappiness leads us to legitimize eliminating the very people with disabilities.

The reflections above show what a reimagination of suffering and pain could entail. The disqualification of concepts such as vulnerability, suffering, and pain in the normalcy narrative legitimizes oppressive practices such as mercy killing. Corrective narratives withholding stories about how to live a good life encompassing pain, and stories that bear witness of the gift in corporeal vulnerability could lead to people focusing on mercy *living* instead. As embodied beings we constantly live in uncertainty of tomorrow, and disability can offer what Garland-Thomson (2012) calls an experience-based counter-narrative to the modern subjects' understanding of the present moment as an opportunity to shape the future.

Concluding reflections

Feminist disability studies make visible how identities, especially those of women and people with disabilities, are shaped by particular embodiments and perceptions of those embodiments. So can we settle on the truths, knowledge, and certainties that produce the dominant comforting narrative that in this particular context is referred to as the normalcy narrative, even when it is shown to be oppressive and marginalizing towards anyone who does not appear to fit the story? Can we settle knowing that there are various comforting narratives in society that the dominant comforting narrative leads us to 'other' by not acknowledging their existence?

Physically and cognitively I am a privileged person. Academically and socially I am a privileged person. While privileged on so many levels myself, I am deeply committed to the scholarly task of questioning, critically discussing, and challenging such discourses and practices that marginalize and oppress people with disabilities. But whereas I remain privileged, people (especially women) with disabilities remain marginalized in society. The dynamics of oppression are increasingly complex, and therefore experience-based counter-narratives become more and more acute in critical theory (see e.g. Carlson 2001). By opening with the personal story about people's reactions to the disturbing body of my friend, I wanted to set a narrative trajectory for this article – and also position myself. Yes, I am indeed socially, academically, physically, and cognitively privileged, but I am also

privileged to have befriended people with disabilities so that my own comforting narrative could be reimagined. Hence, I am also deeply committed to theorizing from the perspective of experience-based counter-narratives, that is, from the perspective of people with disabilities.

In this article I have critically discussed and challenged the normalcy narrative and the more or less taken-for-granted body talk that makes the able-bodied, rational, male subject the normative standard in society; shapes the sense of who we are; and regulates how to interact with others. The aim has not been to articulate another set normative standard or ideological standpoint, but to elucidate and critically discuss the connections between the dominant cultural narrative and subjective experiences. I have thus tried to offer a counter-narrative, or counter-logic, to the common conceptions of normalcy and beauty that seem to offer people comfort, but also demanding people to repair, mould, and control their bodies, which leads to legitimizing oppressive practices and elimination of deviant bodies.

In order to understand why and how disciplinary practices are so commonly legitimized and accepted, I have discussed the anxiety that disabled bodies tend to cause so many of us. To overcome this anxiety, I believe attention to the concept of difference is one important step or possibility. Acknowledgement of the constitutive difference and the practice of othering can help create a conceptual framework that reveals what is at stake in dominant representational systems. I argue that it is only in such a framework that the symbolic meanings of bodies can be challenged. I stress that stories about ordinary life are needed to overcome the dual experience of invisibility/hyper-visibility that people with disabilities currently balance. From a feminist disability perspective, experience-based counter-narratives about the body are a demand in critical theory, moral reasoning, and bioethics.

One example of the possible consequences of the normalcy narrative that I repeatedly have returned to in the article is prenatal diagnosis followed by selective abortion. Being part of routine maternity care in the Nordic countries, prenatal diagnosis is a major source of expressed notions about what it means to be human and to have a human body. These notions affect most pregnant women (and their partners) in important decisions regarding the pregnancy, and due to the strong focus on finding fetuses with genetic and chromosomal deviations, people with disabilities are clearly affected by the practice and the values expressed – in one way or another. As reproductive technologies are often discussed in the light of reproductive autonomy – the right to make decisions about one's reproduction – I believe it is important to note that the will to control our own bodies also might affect our moral judgements with regard to prospective children.

Another key issue and topic for discussion in this article is the apparent equalization between pain and unhappiness that people with disabilities seem to embody in society. Through a narrative trajectory, I have argued for a different view on pain and suffering that can serve to challenge the presumption that these are aspects of human embodiment that people at all cost ought to avoid. Stories about how to live a good life that encompasses pain, and stories that bear witness of the gift in (inter)corporeal vulnerability could lead to people switching the focus from avoiding pain to the question posed by feminist disability scholars: how to make a life of suffering and pain liveable. The answer to such a question is not simple, obvious, or singular, because not only do we *have* bodies, but we *are* bodies. To be a body is to be unstable. To be a body is to be in constant change. To change is to become. In order to start the journey of becoming, one has to invite vulnerability along. One way of inviting vulnerability along is to get in touch, physically or mentally, with bodies in distress; bodies that seemingly are more vulnerable to life; bodies that have been forced to accept painful sensations; bodies that the normalcy narrative has taught us to ignore.

Experience-based counter-narratives of embodiment expand our comforting truths and reveal that there are no given certainties. I believe that re-conceptualizing the meanings of embodiment ultimately is what can lead us to reimagining our comforting narratives of embodiment and hence create a more compassionate and just society.

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Notes

1. The story is a personal story of mine.
2. The genealogy of body ideals and the emergence of the standard/ideal body are well described by, for example, Lennard J. Davis who is focusing on the linguistic birth of normalcy in the article "Constructing Normalcy" (2010) and by Margrit Shildrick in *Dangerous Discourses of Disability, Subjectivity and Sexuality* (2009).
3. For one of the most comprehensive overviews over feminist disability theory, see: *Feminist Disability Studies* (2011) edited by Kim Q. Hall, especially the introduction chapter "Reimagining Disability and Gender through Feminist Disability Studies" by Kim Q. Hall, and chap.1 "Integrating Disability, Transforming Feminist Theory" by Rosemarie Garland-Thomson.
4. In the article "Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation" (2001), Licia Carlson analyses the dynamics of oppression and power relations in five groups of women who were instrumental in the emergence of the category of 'feble-mindedness' in the USA. The article serves as a good background to increasing complex dynamics of oppression. Especially interesting is Carlson's description of how the boundaries of womanhood and motherhood are indicative of the belief that women with cognitive disabilities are the ultimate others.

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