The Lived Body – Both the Vehicle and the Message: A Longitudinal Case Study

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From early childhood, Hanna, born with Spinal Muscular Atrophy II, has adhered to a standing posture for all her independent locomotion.

Aim: To investigate why Hanna in childhood chose to stand and the meaning that standing holds for Hanna as an adult.

Method: Single case study of a single person, Hanna, based on her contemporary statements as an adult about her lived experience from childhood, introduced in a phenomenological context and analysed using hermeneutics.

Result: Standing gives Hanna access to bodily comfort in an active posture, influences how the world presents itself to her, how she presents herself to the world, and improves interacting with others.

Conclusion: Although just a single case study, the findings may stimulate further research on the possible benefits of standing combined with independent locomotion from early childhood and the meaning it can hold for people with SMA II.

Keywords: Spinal Muscular Atrophy; Standing posture; Locomotion; Life-World Phenomenology; Social Model

Introduction
What meaning does the ability to stand have for people who are unable to do so or to walk independently? What meaning does the use of standing devices have for them? This has not been studied to any extent. There is some research, though, and the results show that standing alters a person’s sense of self, signals his or her availability to the world, strengthens social interplay, and changes motivation and expectation over time (Nordström, Näslund, and Ekenberg 2013). From a medical point of view, it is well establish that people who are unable to stand and/or walk because of different impairments benefit from the standing posture. Clinical experience suggests that wheelchair users often experience painful, problematic, and costly secondary complications due to long-term sitting and that standing is an effective way to manage many of the negative effects of constant sitting (Dunn et al. 1998; Eng et al. 2001). If used in an activity, the standing position holds a meaning for the person using it (Nordström, Nyberg, Ekenberg and Näslund 2014). To my knowledge, no one have yet tried to understand the meaning that standing, independent locomotion has for a person with SMA II from toddlerhood to adulthood. This study focusses this topic and argues that standing gives a person access to an active comfortable body posture, enhanced accessibility to the world, and has positive influences on interactions with others.

Purpose and Research Question
From childhood to adulthood, Hanna, born with Spinal Muscular Atrophy II (SMA II), has consistently chosen the standing posture for all her independent locomotion. This study elaborates on why she chose standing as a child and what meaning standing holds for the adult Hanna of today. As viewed from a life-world perspective, the questions is: Why was the standing posture such an appealing experience to Hanna that she consistently chose it as a child? What meaning does ‘standing’ hold for the adult Hanna today?

The Person in the Study
Hanna was diagnosed with SMA II at the age of 13 months. SMA is a hereditary neuromuscular disease, the most prominent symptom of which is the lack of motor capacity and muscular strength in the body’s voluntary muscles. https://www.mda.org/disease/spinal-muscular-atrophy. This made it impossible for Hanna to accomplish the usual motor development. She was introduced to the standing posture soon after she received her diagnosis. It was a physiotherapeutic activity among others and one she liked very much. A motorized walking aid that combined the
standing posture with independent locomotion was developed as an option for her locomotion when she was 2 years old. In addition, Hanna had access to an array of different assistive technology devices to help her move about in childhood: manual wheelchairs, powered wheelchairs, trolleys and different seating options with wheels. At the age of 6 years 9 months, Hanna decided to only use the standing posture for all her independent locomotion (Flodin 2008). Today, Hanna is 34 and in a university PhD programme. She still uses a motorized walking aid for all her independent locomotion and new ones were built as she grew. Standing has become her posture of choice. The long-time follow up on Hanna has been possible because the author of this article is Hanna’s mother as well as a registered nurse and a researcher. This can, of course, be a source of bias, which will be discussed in the section on ethical considerations.

Theoretical Framework

The Medical Model of Disability

Managing SMA on a daily bases includes a diverse medical subspecialty approach. Since 2007, there has been a consensus on the management of the secondary symptoms of SMA (Wang et al. 2007).

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) argues that the standing posture (achieved in their example by a wheelchair standing device) will give a person with a physical disability considerable bodily benefits in addition to the social and psychological ones that include enhanced psychological wellbeing, independence and productivity (Arva et al. 2009). From a medical point of view, it is quite common to recommend standing as a means of managing secondary symptoms in general for people with different physical impairments, among them SMA II. This implies that standing is a way to reduce impairment effects as defined by Thomas (1999).

The Social Model of Disability

The social model of disability makes a distinction between impairment and disability: impairment is the way the body functions (or does not function) for a certain person; disability consists of the obstacles that arise when this person meets society and is excluded from social activities (Barnes and Mercer 2003, 2008). Instead of trying to change or cure the person with impairments, it is society that ought to change to meet the needs of every individual. Thus, the disability community has often criticized the mainstream emphasis on ‘cure’ for impairment, and has opposed the maximizing of functioning’ (Shakespeare 2002, 12). New definitions to describe the complexity of disability and impairment have been elaborated. Among them is ‘impairment effects’, which are the impacts people’s impairments have on their everyday life (Thomas 1999). Thomas states that people’s lived experience is directly related to definitions of disability and that the root of disability is an unequal social relationship. This results in “the social imposition of restrictions of activity on impaired people” by non-impaired people, either through “barriers to doing” or “barriers to being” according to Thomas, as cited and discussed by Connors and Stalker (2007, 21). ‘...the latter refers to hurtful, hostile or inappropriate behaviour which has a negative effect on an individual’s sense of self, affecting what they feel they can be or become’ (ibid., 21). This is of great importance to anyone growing up with an impairment, as a child will go ‘through important stages of identity formation which may lay the foundation of self-confidence and self-worth’ for the future (ibid., 31).

Previous Research in Rehabilitation Medicine

The influential theories on motor development in children have changed over time. The old neuromaturational model from the 1930s and 1940s strived to attain ‘normal movement patterns’ and was widely advocated in the mid-1900s (McGraw 1945; Shirley 1931; Gesell and Amatruda 1947). A new philosophy in paediatric rehabilitation medicine evolved stating that normal movement patterns and strategies may not always be the best or most efficient for a child with an impairment (according to the definitions from the social model). Children with physical impairments should thus be assisted to discover their most functional movement patterns (Burton and Davies 1992). Butler (1991) states that it is essential for children with physical disabilities to have access to an array of different aids for independent locomotion to discover the most optimal way of ambulation, which is supported by the research of Burton and Davies (1992).

The assumption that people with impairments aspire to normalcy has also been debated in the disability studies context and described as an oppressive experience (Johnstone 1998). The disability movement has demanded the right of disabled people to be proud of whom they are and not be forced to conform to standards of normalcy defined and determined by those without impairments. This is supported by Viarth and Darra who claim: ‘[...] the possibility that restoration to a normal state may be neither possible nor desirable by the individual with the disability’ (2002, 493).

Bleeker and Mulderij (1992) have highlighted that if we experience pain or other forms of bodily discomfort, our bodies will be the focus of our attention. Thus, we risk missing the experience of the body passed over in silence, i.e. a body that doesn’t hurt or in other ways troubles you; a concept of Sartre’s drawn on by Bleeker and Mulderij (1992).

Life-world Phenomenology

This article draws on life-world phenomenological theory in which the experiencing subject is central. As human beings, we are all body subjects (Merleau-Ponty 1999). This means we are all intentionally and dynamically involved in the world through our body (Mulderij 2000). ‘The body is the vehicle of being in the world,’ Merleau-Ponty states.
A child has a special bodily existence: ‘[…] prior to reflecting on his or her body, and prior to knowing about the body, the child lives the body […] the child does not explicitly focus his or her consciousness on the body but acts through the body’ (Moss 1989, 66). There is also a mutual dependence between the embodied subject and the world. The way we perceive the world is connected to the way we as embodied subjects exist in it. Merleau-Ponty, states: ‘I’m conscious of the world through the medium of my body’ (1999, 82). This is what can be understood as ‘a relational body image’ (Mulderij 2000, 42).

Another theory this article draws on in is Sartre’s (1934/2004) analysis of human existence where the interactive sphere is important: ‘Let us therefore state that we have discovered a world we may call intersubjectivity and it is within this world the human being decides what she and the others are’ (p. 38, author’s translation). The most threatening to a human being is the when another person gazes at you, and with this gaze, will make that person an object (Sartre 1943/1983). The Dutch psychiatrist van den Berg (1950) has, in the past, criticized the purely negative connotation that Sartre usually assigns to the gaze of other people: ‘p. 44 of the Mulderij, 2000 paper. Van den Berg states there is also a loving gaze that will make a person’s actions and the body that carries them out accepted (in Mulderij 2000).

**Method**

*Life-world phenomenology and hermeneutics in a single case study*

This is a longitudinal case study based on a single case, dawning from multimodal sources (Yin 1994). It has a phenomenological approach and explores the everyday life-world (Schutz and Luckman 1973) of Hanna, the single case in this study. It uses hermeneutics to interpret the material. Heidegger articulates the case for a hermeneutic phenomenology where lived time and engagement with the world are our access to the phenomenon, which is the base of our experiences. Our access to these things is always through interpretation, though, which is mainly a hermeneutic act (Smith, Flowers and Larkin 2009). A rationale for a single case study is that it represents an extreme or unique case and/or ‘when an investigator has the opportunity to observe and analyse a phenomenon previously inaccessible to scientific investigation’ (Yin 1994, 39–40). Hanna’s case meets both these criteria as her choice to use a standing aid for all her independent locomotion is highly unusual. The length of the process studied (over 30 years) is also highly unusual even for a longitudinal study. This was only possible because of the close relationship between the author and the person representing the single case. Only a person who is close can take part in the life-world of another person on a daily basis for so many years. In a scientific context, this close relationship needs to be discussed, which is done in the ethical considerations section.

*Hermeneutics and fore-conception*

A person has always his or her fore-conceptions, which are prior experiences, assumptions and so forth, and this threatens to blur or be an obstacle to interpretation (Smith, Flowers, and Larkin 2012). In hermeneutics, fore-constructions are to be declared (Ödman 2007). As stated above I have a close personal relationship with the person who is the single case in this study: Hanna is my daughter. When Hanna was a child, I had two perspectives: that of a parent and that of a registered nurse. With a blend of a mother’s caring eye and a nurse’s medical eye, I tried to understand what made Hanna’s life the most fulfilling. My medical education greatly influences the way I reflected on the effects of SMA on Hanna’s body and physiognomy and on ways to avoid the secondary symptoms of SMA. I also tried to facilitate her ability to participate on as equal terms as possible in different activities despite her lack of muscular strength This is supported by Molander who states: ‘ […] a practice, which occurs over a span of time, may be reflective without any particular activity called “reflection” being carried out.’ This is ‘a form of knowledge in action’ (Molander 2008, 4) and is equivalent to what the author did. After receiving a Licentiate Degree in Rehabilitation Engineering and a Master’s Degree in Pedagogy, I also gained an academic perspective, which I use in analysing the events in Hanna’s life-world.

*Idiographics*

This article draws on methods that highlight the unique elements of the individual phenomenon, i.e. idiographics, to study how a phenomenon has been understood ‘from the perspective of particular people, in a particular context’ (Smith, Flowers, and Larkin 2009, 29). One can argue that a single case study simply can only show us how something is in this particular setting. One can argue that a single case study only show us how something is in this particular setting. Thomas (1999, 78) writes in favour of experience as an important way of understanding and sees ‘life history accounts … as evidence that “the micro” is constitutive of “the macro”’. This study further argues that a single case study also indicates the direction where more research is needed.
Material – contemporary statements from Hanna

This article takes its departure in life-world phenomenology where the lived experience is crucial and considered a source of knowledge (Schutz and Luckmann 1973). It is based on contemporary statements from the Hanna of today, the single case person in this study, and the lived experience from Hanna’s childhood. Hanna’s contemporary statements about her experiences of her walking aid have been the topic of open-ended phenomenological conversations (Foran and Olson 2008; van Manen 1990). I took notes during these conversations and transcribed them thoroughly directly afterwards. Hanna then read them and translated them from Swedish to English, choosing the words carefully to capture her experiences as honestly and clear as possible. These statements are used in full with no further editing under the label ‘Adult Hanna’.

Material – photos and written experiential anecdotes

As Hanna does not remember the events drawn upon in her childhood, there was a need to use other material to capture the events, thoughts and feelings that constituted her childhood process. Pictures from Hanna’s childhood life-world were used to try to capture the essence of the historical process in combination with the author’s recollections. In phenomenological words, it is my experience of Hanna’s life-world at the time.

The photos and recollections from Hanna’s life-world are the basis of the written ‘experiential anecdotes’ that tell us something about her life-world (van Manen 1990, 68) using ‘descriptive text and language to craft the lived experience’ (Foran and Olson 2008, 26). An anecdotal narrative highlights the lived experience, the ‘phenomenological now’ (Moran 2001, 43). ‘The paradoxical about anecdotal narrative is that it tells something particular while really addressing the general or the universal’ (van Manen 1990, 210). ‘Experiential narratives offer a route to understanding the socio-structural’ (Thomas 1999, 78). Still, every description of the life-world, as in an anecdote, must inevitably mean a reduction of it (Bengtsson 1999) and one can never get to know another person’s life-world like that person knows it (ibid. 1999). As Hanna cannot remember her toddler and childhood life-world, what is presented here is my experience of it. As such, it still has value as a route to Hanna’s toddler and childhood life-world. Hanna herself can only share her contemporary experiences. Adult Hanna: ‘I don’t know why this came to be. I only remember that when I, as a child, tried motorized wheelchairs, I didn’t like it.’

Procedure of analysis

The material was analysed using hermeneutic phenomenological reflection inspired by van Manen (1990). In this process the material has been interpreted in a search for themes, what in phenomenology is referred to as the ‘structures of experience’ (van Manen 1990, 79). Van Manen goes on to state: ‘So when we analyse a phenomenon, we are trying to determine what the themes are, the experiential structures that make up that experience’ (ibid., 79). The themes that emerged have been further elaborated by connecting them to contemporary knowledge in the field.

Ethical Considerations

The Regional Ethical Review Board in Sweden approved this study in November 2008 (Dnr 558/2008). Written informed consent was also obtained from all participants in the study. As a PhD student herself today, Hanna approves of the fact that the article is based on her life. She also approves of all information and details in the article. The longitudinal aspect of this study was possible because the researcher is also a family member of the person in this study: They are mother and daughter. This close relationship can be a possible source of biases and ethical issues. But without some kind of close relationship, it hardly would have been possible to gain access to so many aspects of another person’s life from toddlerhood to adulthood.

Still it can be argued that this approach is a delicate balance because of this close relationship. I may be biased and unable to draw sustainable conclusions because of this relationship, at risk of seeing what I want to see. An example of this would be a denial of my daughter’s impairment and/or a hope for her improvement, or that I wanted her to be more like other children, more ‘normal’. To some extent, I influenced what happened as a parent and a nurse. This was because I was trying to determine what would make Hanna as happy and as free from secondary symptoms as possible and in so doing, changed the environment accordingly. In this interactive process I tried to be very responsive to Hanna’s expressions and what she wanted. When it came to standing, she just hesitated a little the two very first times. After that, Hanna was more than happy to use the device. As I am well aware of all the possible biases, there are no far-reaching conclusions drawn in this article regarding the results. The article instead describes Hanna’s case closely and indicates directions for further research.

Result and Analysis: In Hanna’s Life-World

Anecdote: The choice

The garage is fully lit as the last work is to take place tonight. The frame is ready, painted in the chosen colour. The old standing device is adaptable. Now it is only the fixation points for Hanna’s sitting device that remain. Urban, Hanna’s father turns to her and holds up the seat in front of her. The seat is the same as in her old prototype. We are just going to adapt it to the new frame to make it possible for her to sit and move independently even with the new walking aid, as a complement to standing. ‘I think I will make the fixation points here,’ her father says, pointing at the base of the seat, showing it to Hanna. Hanna walks around her father in her old walking aid as she starts measuring the fixation points of the seat. ‘Daddy’ Hanna suddenly says, ‘never mind this; I just want to stand up and walk, all the time.’
At the age of almost 7 years, Hanna decided to use only the standing posture for all her independent locomotion (Flodin 2008). We will never know exactly why she chose standing but we know that she did and has adhered to this posture since.

The body passed over in silence and the active agent in the world

Adult Hanna states:

When I’m standing in my walking aid I feel capable and mobile. The standing posture is the only posture I find comfortable and active enough to really do things in the physical world. The other position I find comfortable is to lie down. Lying down allows me to be really active online via my smartphone and somewhat active in the physical world, but not as active in the physical world as I can be when I’m standing in my walking aid. Sitting down is not a viable option for me. My back gets very tired and pain-ridden when I sit and I soon find it hard to breathe because I don’t have the strength needed to keep my back straight. I quit sitting when I was a tween (except for when using the toilet) because at that time I didn’t find sitting ’useworthy’ (Eftring 1999) anymore.

One of the symptoms of SMA in Hanna has been bodily fatigue. The two best positions to fight this off are standing and lying down. It has always been hard for Hanna to sit for any length of time due to lack of strength. ’Even the most comfortable position is uncomfortable if one cannot move at all’ (Bleeker and Mulderij 1992, 7). Bodily discomfort will prevent normal orientation towards the world; the body will be the main focus of attention (ibid.). This was probably part of why a technical aid that could provide her with a body that went unnoticed by her; ’the body passed over in silence’ (Bleeker and Mulderij 1992 sid), highly attractive as ’the body is the vehicle of being in the world’ (Merleau-Ponty 1999, 82).

Anecdote: The active agent in the world

Hanna is in the garden. I see her using her walking aid to go down to our swing where the troll made of plaster now has his bed. She approaches the garden swing from behind, all the way up to the back support and puts her hand on it. She easily gains access to the desired object and starts rocking it. She has to work hard because making it swing is a heavy activity in Hanna’s world. She increases her power by pushing and pulling the walking aid’s joystick back and forth, thus making the device go back and forth. This manoeuvre adds the strength of the walking aid to her and she is able to accomplish what she aimed at. (see Figure 1, the authentic picture of the anecdote).

The walking aid provided Hanna with the ability to be active and change positions in the lived room (Bengtsson 1998) independently, without losing access to a comfortable bodily position. By using the walking aid as an extra source of power and reach, as seen in Figure 1, she was able to increase her strength and do things she, would not be able to do otherwise. The combination of independent locomotion and standing was essential in this aspect. It enabled Hanna to stand while doing something else, supporting the findings of Nordström, Nyberg, Ekenberg and Näslund (2013) that standing holds a meaning if used in an activity. This was probably the reason why Hanna chose the standing position for several hours a day throughout her childhood and into adulthood. The same is true today, although the activities have changed.
The world presenting itself to Hanna

Adult Hanna states:

To me, standing upright is the best way to get an overview of the physical environment. In my experience lying down is not a posture made for exploring. This in no way means that I think one MUST stand just for the sake of it, or that I stand because I aspire to ‘normalcy’. It only means that since my tweens, it has been hard for me to be truly active in the physical world in any other way than by standing.

Technology has made it possible to add the standing posture to Hanna’s repertoire. Thus she has been able to perceive the world as it presents itself through the ‘medium’ of the [erect] body (Merleau-Ponty (1999,) as seen in Figure 2. This does not imply that it is better or even necessary to perceive the world from a standing posture. Such a standpoint would reinforce normalizing tendencies regarding the body in society and Hanna does not aspire to normalcy. Rather she aspires to the option to be active in the physical world while maintaining physical comfort. Shakespeare and Watson (2002) states that people are disabled by social barriers and their bodies. Hanna’s walking aid could to some extent, and still can, help her overcome both barriers by enabling her to be an active agent in society and to add physical competence to her body.

Hanna presenting herself to the world

Adult Hanna states:

I don’t consider my motorized walking aid to be a part of me, but to be a prerequisite for me to be me in many situations, and as such it is very important to me. Thus, I guard my motorized walking aid quite ferociously from meddling hands, haha! In keeping with that, I strongly dislike when something needs to be repaired or replaced on my walking aid; not because I have to be without it for an hour or two – although that can be difficult – but because the smallest change can mean that I no longer can find my comfortable baseline in which my body passes over in silence. No other assistive technology has this great an impact on me.

Some studies claim that a technical aid will be an extension of the persons’ body once he or she is used to it (see, e.g., Bleeker and Mulderij 1992). Merleau-Ponty states that once the blind man gets used to his stick, the stick becomes an extension of his body (1999). Later studies have debated this, making a distinction between the tool as an extension of the body and the tool as incorporated in the body-model after long-time use (De Preester and Tsakiris 2009). If Hanna saw the walking aid as an extension of her body or as incorporated into it during her childhood is, in retrospect, hard to determine (Author 2008). Today she does not see the standing aid as being incorporated into her body-model or even

Figure 2: The world presenting itself to Hanna.
as an extension of it, but rather as a prerequisite for what she needs to be herself in many situations: her base line for being, like in the hectic transfer at LAX California seen in Figure 3.

Adult Hanna states:

Every person has their individual baselines from which they experience their body. I gauge myself against my baselines. In my opinion there's no reason to compare yourself to an ‘ideal’ baseline as long as you feel healthy. That is why I, for example, consider it to be completely meaningless to undergo a spirometry test. I have no use knowing that I have only this or that percent of average vital lung capacity. As long as I feel good, it’s all good. For me to feel good regarding my breathing during an average day, I don’t need any aid as long as I avoid sitting for more than a few minutes. For me to feel good with respect to my breathing during an average night, I need my none invasive night-ventilator; BiPAP. It’s as simple as that. When I’m out and about, my baseline when it comes to my bodily position is the standing posture, although I require my walking aid to accomplish that.

**Interacting with others**

Adult Hanna states:

The fact that I choose to stand when I meet people face to face who don’t know me, indicates that I consider the alternative to be worse. In my experience, I usually get a more contrived and/or patronizing reception when I meet people for the first time lying down; hence I go to great measures to stage meetings standing. If lying
down didn’t connoted inferiority, vulnerability and inactivity in our society, I believe things would be different and I might choose otherwise. That’s not the case, though. How you present yourself to others mediates something (socially constructed) that causes reactions. Different presentations generate different reactions. I think people sometimes argue against this because they don’t want it to be like this – they like to think they treat all people well and equally no matter what, but in reality that is just not the case. That needs to be changed. I know that refraining from meeting people for the first time lying down when I can might be considered a part of the problem. I acknowledge that this action is problematic. I still believe, however, that we can and do contribute to change nonetheless.

We live in the world through the body and interact with other human beings in a world of inter-subjectivity where the human being decides what she and the others are (Sartre 2004). Like most children, Hanna enjoyed participating in different activities and she constantly chose the standing aid to do so, see Figure 4.

Sartre (1943/1983) states that the gaze of the others is the most threatening to a human being as it determines who I am and makes me be what I am allowed to be, and Thomas talks about ‘barriers to being’ and ‘barriers to doing’ (1999, 45 ff.). For several reasons, the standing posture felt better to Hanna in this respect and still does. There is also a gaze that helps, that will make my actions and the body that carries them out accepted (Mulderij 2000). That Hanna as a child consistently chose to use the walking aid and today at 34 articulates that presenting herself in the walking aid improves social interactions, could indicate that she experienced, and still does, fewer barriers (from others) regarding what to be and what to do (Thomas 1999). In the standing posture, the child Hanna felt comfortable and capable to take part in any activity even physical ones such as skating or skipping ropes, shown in Figure 5.

One interpretation is that it gave her more self-esteem in addition to the ability to be active, which supports the Nordström, Näslund and Ekenberg findings (2013). Her decision could also be seen as an argument that reinforces old ways of thinking about normalcy, claiming that the ability to stand made Hanna and others experienced her as being more ‘normal’. This, in turn, enabled deeper and more positive interactions with others, because others interacted differently with her when she presented herself standing. Hanna still experiences interactions with others as more fulfilling when she is in a standing posture, although she now thinks the social model approach to disability is important and she has no wishes to be labelled ‘normal’.

Figure 4: Hanna interacting with others.
Discussion

The standing posture is recommended as a physiotherapy tool for persons with SMA II because it is beneficial for body functions, and childhood Hanna was no exception. It is widely advocated by RESNA (Arva et al. 2009) in their general guidelines as a health-promoting strategy for wheelchair users because ‘despite the obvious advantages that wheelchairs provide there are also serious consequences associated with their chronic use’ (Shields and Dudley-Jarovsky 2005, 142).

Once Hanna got the taste of standing with her aid, she often tried to achieve the standing posture and was happy when she got help from others to do so (Author 2008). ‘Standing seems to be something highly appealing to the child [...]’ (Mulderij 2000, 41). One interpretation is that it made her able to overcome ‘the stubbornness of the body and the resistance of the world’ (Mulderij 2000, 40). Standing also provided Hanna with a body that did not hurt, ache and make itself noticed, that is, a body passed over in silence (Bleeker and Muldreij 1992). Merleau-Ponty states: ‘I’m conscious of the world through the medium of my body’ (1999, 82). This is important as the body is both the medium of being in the world and the medium of experiencing the world.

From a disability studies and social model perspectives, however (see, e.g., Barnes and Mercer 2008; Shakespeare 2002), the standing posture may be problematic as it can be interpreted as aiming for normalcy: that some bodies and postures are superior to others, something Hanna is highly aware of. Hanna also recognizes that people do treat her better when standing (apart from the pure bodily aspects) and this is something the adult Hanna experiences as a dilemma. She blames herself for conforming to this and refrains from meeting people for the first time if she has to lie down. Hanna as a toddler and child did not think of this and probably used the posture most agreeable for her from many aspects. A child has a special bodily existence, ‘prior to reflecting on his or her body, and prior to knowing about the body, the child lives the body; the child does not explicitly focus his or her consciousness on the body but acts through the body’ (Moss 1989, 66). The adult Hanna thinks about it, though, and considers it to be an ethical dilemma as the disability community often has criticized the mainstream emphasis on ‘cure’ for impairments and has opposed the maximizing of functioning (Shakespeare 2002).

From a medical point of view, it was natural to put Hanna in a standing posture as part of her (re)habilitation plan in an effort to manage the secondary symptoms of SMA II. One can speak of Hanna’s walking aid as an interactive functional design, the main purpose of which was to avoid or diminish the effects of the impairment (Thomas 1999). It was designed to meet Hanna’s needs for comfort and useworthiness (Eftring 1999), not to strive for normalcy. Still, to Hanna, standing quickly transformed into something more and the assistive technology was developed accordingly. It can be argued that the world perceived by Hanna – what she felt the world had to offer – changed with the enhanced bodily competencies she acquired with her walking aid. Furthermore, the use of a standing device augments availability to the outside world (Nordström, Näslund, and Ekenberg, 2012). It made it easier for others to relate to Hanna and in so doing, also affected the way the world (i.e. the people around her) perceived Hanna. This was a matter of great significance as well. In her standing aid, Hanna gained new competencies defined by the “Gaze of the Others” (Sartre, 1943/1983) telling Hanna, and themselves, who she was, and in so doing, tearing down “barriers to being” (Thomas 1999).

Figure 5: Hanna participating in skating activities.
Conclusion and Future Work
This study has identified four possible reasons why Hanna as a child chose the walking aid: 1) It gave her access to bodily comfort in an active posture; 2) It influenced how the world presents itself to her; 3) It influenced how she presents herself to the world; 4) It improved the meeting when interacting with others. The same is true for Hanna as an adult. Still, to adult Hanna, standing is somewhat more complicated as she realizes her dilemma between viewing the erect body as a marker of normalcy, and still claiming the right to use standing as her posture of choice.

As this is a single case study, no conclusions are drawn. It might be fruitful to include standing independent locomotion in the array of options offered to children who are unable to learn to walk because of physical impairments; not as a means to achieve normalcy but to give each child the option to try the standing posture for independent locomotion. Perhaps others, like Hanna, will appreciate and benefit from it and use it as extensively as Hanna has. Further research is needed to evaluate this. Hanna’s experiences can serve as an inspiration.

Competing Interests
The author has no competing interests to declare.

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