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Loneliness in life stories by people with disabilities

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ABSTRACT

This study investigates loneliness in life stories by people with disabilities. By approaching loneliness from a relational perspective, this study attempts to illustrate how loneliness and disability are intertwined in the life course. The research question was as follows: How do people with disabilities understand loneliness in their life stories? Life story data 'Life of Disabled Persons in Finland 2013–2014' was analysed with a narrative life course approach. Loneliness was narrated in accordance with normative life course expectations. People with disabilities narrated loneliness as unbelonging in childhood, disjointed youth and disaffiliation to normative institutions in adulthood. This study suggests that relation between loneliness and disability concern the conditions of inclusion that is the conditions of living and telling.

Points of Interest

- Loneliness involves both unwanted emotions and social isolation.
- In many societies, both loneliness and disability bear a stigma. This so-called double stigma affects the lives of people with disabilities.
- This study explores loneliness and disability in life stories by people with disabilities in Finland from a life course perspective. Although scholars have widely studied loneliness in Finland, they have not studied loneliness in people with disabilities in any great depth.
- Loneliness in life stories by people with disabilities was narrated in relation to a sense of bodily difference and occurred as a disconnection from a socially 'standard' life course. Loneliness was located within three main phases: childhood, youth and adulthood. Negative attitudes towards disability feed social isolation and emotional loneliness.

- Further research on disability and loneliness throughout the life course as well as more discussion about the conditions of inclusion and the emotional patterns of social relations are needed.

Introduction

This study investigates loneliness in life stories by people with disabilities in Finland. By approaching loneliness from a relational perspective (Burkitt 2014; Weiss 1973; van Baarsen et al. 2001), this study attempts to illustrate how loneliness and disability are intertwined in the life course. The relationship between disability and loneliness is situational (i.e. rooted in some specific situation or situations during the life course) but the situational experience of loneliness can have complex long-term effects. This study employs a life course approach to loneliness in life stories by people with disabilities and analyses self-narratives by people who participated in the collecting of such stories in Finland between 2013 and 2014. Throughout their stories, the participants deliberated on their disabilities and their relation to disability. This study encompasses self-narratives by approximately middle-aged (and a bit older) male and female narrators with different kinds of physical disabilities who discussed loneliness explicitly in their life stories. This study attempts to investigate how loneliness is interpreted against the background of different life events and conditions of inclusion. The research question is as follows: How do people with disabilities understand loneliness in their life stories?

Loneliness, disability and a life course approach

Loneliness is commonly perceived as undesirable emotions as well as rupture in social connections (Bound Alberti 2018; Weiss 1973; Wenger and Burholt 2004, 116). Loneliness studies tend to distinguish social isolation and emotional loneliness (e.g. Weiss 1973; van Baarsen et al. 2001; Tiilikainen 2019, 14–16). Emotional loneliness refers to lack of 'a close emotional attachment', whereas social isolation concerns 'the absence of socially integrative relationships' (Weiss 1973, 33). Additionally, loneliness is not a single emotion but more of an 'emotion cluster' (Bound Alberti 2018).

According to Fay Bound Alberti (2018), loneliness studies need 'more engagement with the languages', and they need to pay more attention to the experiences of the lived body in social relations and emotional responses. Loneliness is considered an important issue of contemporary life, but the complex relationships between emotional responses, social configurations and loneliness as 'a bodily and embodied experience' has remained somewhat understudied (Bound Alberti 2018; also Burkitt 2014; Bound Alberti 2019).

Nevertheless, emotions can be considered responses to the given conditions of living as well as relations with others (Bound Alberti 2018; Burkitt 2014; Lupton 1998, 165; Goodley, Liddiard, and Runswick-Cole 2018). Ian Burkitt (2014, 168) argues that 'feeling and emotion are about patterns of relationship, or, more specifically, social relationships which are intersected by personal biographies that are interwoven through them' (see also Wetherell 2012; Goodley, Liddiard, and Runswick-Cole 2018).

According to Lars Christian Sønderby (2013, 22–23), 'if loneliness is a set of reactions, causes and feelings that together in various ways combine into a specific feeling', it needs to be investigated 'as such'. Moreover, understanding the complexity of loneliness demands research on 'cultural items linked to loneliness' (Sønderby 2013, 23). Regarding disability, ableism is noticed as one of the most dominant 'cultural items' that affects disability narratives in the Western societies (Campbell 2009); indeed, it is relevant regarding disability and loneliness because talking about emotions relates to the prevailing ideas about the body in society (Lupton 1998, 33). Ableism refers to a system of relationships that produces ways of thinking the body (Campbell 2009; Mik-Meyer 2016, 1342). The crux of ableist logic is the body. According to ableist thinking, disability is considered an unwanted difference (Campbell 2009, 3–30, 197), which has caused alienating and othering conditions for people with disabilities.

Loneliness is a relational phenomenon that entails both social and emotional connections in given conditions. Emotional, corporeal and social conditions are entwined in the experience of loneliness. According to Ian Burkitt (2014, 149), 'emotion is about embodied meaning-making that shows pattern and order through iteration and habitual dispositions to emotional situations'. Affective configurations are experienced individually (e.g. emotional loneliness) and socially (e.g. social isolation) (Goodley, Liddiard, and Runswick-Cole 2018; Burkitt 2014, 131; Wetherell 2012, 159). Hence, emotional loneliness is not an individualised experience that is separate from social patterns of relationships. Thus, social isolation is not disconnected from emotional configurations in given social conditions.

This has been acknowledged in recent loneliness studies, in which loneliness is perceived in relation to conditions that feed exclusion and isolation (e.g. Bound Alberti 2018, 2019; Shiovitz-Ezra, Shemesh, and McDonnell-Naughton 2018; Tiilikainen 2019, 192). The conditions for societal inclusion are not equally accessible for all and this is one of the sources of loneliness and social isolation (e.g. Tiilikainen 2019, 192; also Weiss 1973, 21). Disability has been noted to have 'a significant indirect effect on loneliness through the mediating variable social resources' (Burholt, Windle, and Morgan 2017, 1020). Social structures can disempower people and lead to exclusion and feed a sense of loneliness (ibid.).

Recently, more and more studies have explored disability and loneliness (e.g. Macdonald et al. 2018; Olsen 2018; Andersson et al. 2015), and researchers have examined loneliness somewhat widely in Finland (e.g. Saari 2016; Tiilikainen 2019; Rönkä 2017). Nevertheless, the experiences of loneliness among people with disabilities, as well as disability and loneliness in general in Finland have been understudied (Teittinen 2015). Previous studies have opened 'a barrier-based approach' to social isolation and emotional loneliness, which attempts to diminish pathologisation of the relationship between disability and loneliness (Andersson et al. 2015; Macdonald et al. 2018). Some of the loneliness scholars (e.g. the investigators of the conditions of inclusion in ageing studies) use a similar approach (e.g. Shiovitz-Ezra, Shemesh, and McDonnell-Naughton 2018).

A life course approach to loneliness means studying loneliness as for time: a time perspective is crucial for understanding loneliness and its effects (de Jong-Gierveld 1998, 74). A life course approach has been recently employed in studies on loneliness among elder people (e.g. Tiilikainen 2019) and youth (e.g. Rönkä 2017). A life course perspective attempts to critically investigate normative life course expectations and the consequences of normative expectations (Irwin 2001; Tiilikainen 2019); Sarah Irwin (2001) conceptualises such expectations as 'social claiming'. People who do not meet culturally dominant life course expectations can experience a sense of alienation (Fleischer 2012). Disabling practices and isolating conditions cause a rupture with the so-called standard or socially claimed life course (Irwin 2001; Fleischer 2012). This study attempts to study loneliness in life stories by people with disabilities by employing a life course approach.

Method

The background of this study is as follows. I am involved in the Narratives of Bodily Difference research project, in which I am investigating disability, agency and the body. Due to this, I was asked to write an article on disability and loneliness in Finland for the *Aspa Foundation* journal some years ago (Tarvainen et al. 2018). During the writing process, I noticed that studies on loneliness and disability in Finland were somewhat scant. Nevertheless, I found narratives of loneliness in the data that I was using in my ongoing research project.

The data used for this study are taken from a life story collection entitled 'Life of Disabled Persons in Finland (2013–2014)'. The collecting of the data was organised by Archive Materials in Traditional and Contemporary Culture of the Finnish Literature Society (SKS) and Kynnys (the Threshold Association). Kynnys is a disability organisation in Finland. The life story collection is housed in the above-mentioned archives in Helsinki, which collect contemporary

culture and oral history through organising different projects; some of them are organised together with a partner. These data are available to be used in research, but permission must be received from the archives.

The collection consists of 1,797 pages by 37 writers. The multifaceted collection includes different text types. Some of them follow the ordinary script of a life story (from early childhood to present), whereas others are shorter and focus typically on the present moment. Furthermore, besides prose, some narrators express themselves in verse form. The texts also vary regarding content and length.

The collection consists of responses to a call for submissions, in which the main question was as follows: 'What is life like for people with disabilities in Finland?' (SKS 2013). Narrators could make their own choices and tell what they wanted to tell about their lives concerning their relationship to disability. The typical participant of the whole project was a middle-aged woman with physical disabilities (see SKS 2014). In this particular study, the typical participant is also a middle-aged woman with physical disabilities, some of them were somewhat older, and all of them experienced different kinds of physical disabilities. The whole data set also entails narratives by parents of children with disabilities and a couple of accounts by people who just discuss 'what life is like for people with disabilities in Finland' in general. This study includes only self-narratives.

Loneliness was not mentioned in the cover letter of the call for submissions. Additionally, the use of such expressions as 'loneliness' or 'lonely' is neither easy nor common because expressing loneliness bears negative social connotations and may even be even stigmatised (de Jong-Gierveld 1998, 74; Rokach 2012). Nevertheless, loneliness was written explicitly in some of the life stories. From a narrative perspective, writing a life story can enable narrators to reflect on difficult emotional and social experiences. Furthermore, participants had time to re-think and possibly revise what they wanted to share.

The methodological basis of this study is the model of narrative circulation (MNC) (Hänninen 1999, 2004). The MNC is employed in narrative analysis as follows. According to the MNC, people tell their inner story to themselves and may tell different stories to other people. People construct their stories in a dialogue with the cultural stock of stories, which connects individual stories to wider sociocultural narratives and offers resources to interpret life events (Hänninen 1999, 2004). One of the key concepts of the MNC is conditions. The concept of conditions refers to the conditions of living and telling (Hänninen 1999, 22), which are not equal to all, people have different access to narrative circulation.

The analysis was carried out as follows: the author searched for expressions of loneliness from the data set mainly regarding direct, explicit

expressions of loneliness, such as 'loneliness' or 'I am lonesome'. Eleven narrators, nine of whom were women, discussed loneliness in their life stories. Furthermore, as such expressions were found in the life story, the whole life story was read and analysed carefully regarding loneliness. Only those narratives in which loneliness was explicitly referenced to were analysed. Therefore, the number of narrators who have experiences of loneliness in the life story data would be even more if indirect expressions of loneliness and social isolation are included the analysis. I translated the texts from Finnish to English for this work.

The extracts of the loneliness narratives were analysed through the life course approach. In the narrative analysis, connections between the individual's life story and the cultural stock of stories were investigated (e.g. Polkinghorne 1995). I read the data several times, collected the accounts in which loneliness was discussed and noticed the emplotment of accounts followed a socially claimed life course. Therefore, I organised the accounts according to their relation to the life course and noticed that loneliness was narrated as misrecognition as well as a rupture in the relationship with a socially claimed life course. The experiences of loneliness were specified in this study as follows: unbelonging in childhood, disjointed youth and disaffiliation in adulthood. The key findings are presented below.

Findings

Loneliness in life stories by people with disabilities was situated in three different phases in the life course: childhood, youth and adulthood. Three different phases followed the normative life course expectations where loneliness was experienced as unfulfilling certain normative expectations. The experience of loneliness in the different phases of the life course results in different meanings. In the childhood narratives, loneliness was connected with concealed or untold feelings and the experience of a troublesome body. These experiences could have affected the later life course. Loneliness in youth was situated in the experiences of bodily difference among peers. In these narratives, loneliness was described mainly as otherness due to social isolation. Loneliness experiences in adulthood were mainly related to a disaffiliation from formal institutions, such as family or work, and loneliness was also related to social exclusion.

Unbelonging in childhood

In some cases, loneliness has long historical roots, since experiences of loneliness in childhood had effects later in life. The narratives of loneliness in childhood were emotionally charged, as they discussed concealed feelings.

In the following account, a male narrator discusses his childhood experiences as follows:

> I was lonesome and different. … I did not have many friends. … I was not involved in farm work. … I was not able to do physically demanding work. … [Later] I had quite a [different] life story and had some capabilities too, but I never found my place. I have never been an able-bodied person … (533)

Loneliness is entwined with the narrator's sense of difference. His emotional loneliness and social isolation are located to his experience of bodily difference. The narrator thinks that because he was 'not able to do physically demanding work', such as farm work, in which other family members apparently participated. As a result, he experienced loneliness due to his bodily difference. Given his sociomaterial conditions, his experience of disability is intertwined with loneliness. The effects of the experience extended from childhood to the later life course, as in when he says, 'I never found my place'. The narrator argues he was 'not an able-bodied person' and that was

> … a hard thing to my parents, we neither talked much nor expressed feelings. You just had to go on in some way. In my early years, I experienced very hard things. … I had to be brave and nice at the hospital. I did not dare to cry or express my need for care or love. I would like to say things aloud but I did not dare. … I had to hide all of my feelings and needs inside. (533)

In this account, the narrator discusses the emotional distance he experienced in his childhood. Social isolation and emotional disconnectedness fed a sense of unbelonging. The narrator depicts in a subtle way how he learnt to hide his emotions and stay voiceless. In this narrative, emotional loneliness and social isolation are connected: he felt emotional loneliness and distancing in his family and among his peers and thought that his disability was the reason for these feelings of unbelonging. Additionally, he hid his emotions and concealed his 'need for care or love'. Many of the narrators share similar experience of bodily difference in relation to loneliness in childhood. Just like the above-mentioned narrator, other narrators discussed their experience of loneliness in relation to their sense of bodily difference, the emotional responses of family members and in some cases, peers. In the following account, a female narrator discusses disability and loneliness by recalling some situations in her childhood and emotional load it took later in life:

> I was ashamed because I was different. Now, I think that my mother was more ashamed due to my incompleteness. My life has been shadowed by shame all of the time. If I was without prosthesis and someone just blew in for a visit, I might hide myself under the table. If the prosthesis was on, and I did not hurry to go away, I would stand even in the middle of the room and avoided moving. I did all of that because I did not want the to notice that I limped on one leg. Yet, I was afraid of questions about me. (1)

In this account, the narrator's emotions are interlinked with her parent's emotional responses; the narrator reflects her emotional responses and negative self-perception in relation to her family members' emotional responses to her bodily appearance. Here, loneliness is connected with distant childhood family relationships, and bodily difference is or assumed to be the reason for such distancing. The narrator reflects how her childhood experience had emotional consequences later life: 'my life has been shadowed by shame all the time'.

Many of the narrators describe a period spent in the hospital, a rehabilitation institution or a special boarding school in which pupils spend time without their parents. The following narrators, both middle-aged women with physical disabilities, recall their emotional and social experiences living in these places. One remembers how she had few visitors but does talk about the one time her teacher came to her: 'It was a real highlight [to me]. Shame was rooted in my mind: [I thought that] I was different as nobody came to see me when I was in the hospital' (48). Another narrator shares a similar experience:

> I have no recollection of my time in the hospital. Maybe it is self-protection or something that led to those memories being swept away. Visits from parents or other relatives were not allowed. They thought it as a way to avoid the distress of separation. … Luckily, times are different now, and children are not left alone in the hospital. (641)

Besides family relations and the context of hospital, the school was narrated as a site of loneliness. The following account concerns loneliness in relation to disability.

> The weaker pupils, those who could not defend themselves, become bullied. Disability was one of the reasons. It caused anxiety for me: I neither trust people nor make acquaintances easily. I want to be alone. I enjoy when I am able to live without mockery. I do not want to meet my former classmates; I was so distressed at that time. I blamed myself: I thought it was my fault that I was not able to stop being bullied. (625)

According to the narrator, she was bullied and socially isolated, which affected her later life course. She wants 'to be alone' and has trouble trusting people and making acquaintances. The narrator seems to have ambivalent feelings about loneliness; she wants 'to be alone' but she wants this because of her experience of profound loneliness in childhood. Yet the narrator, like many other bullied people, blamed herself. According to the narrator, 'Sometimes the bully was understood better, even the teachers seemed to understand the bully better [than the bullied person]. I was bullied, and I no longer felt motivated to study. I felt anguish because of the bullying, it scared me … ' (621).

Many other narrators had similar experiences. One of the narrators, a late-middle-aged man, shares a similar experience on loneliness in school and narrates that his disability brought on his bullying: 'I was bullied in the school due to disability' (644). The experience of being disconnected from peers was intertwined with the experience of bodily difference and different forms of exclusion in several accounts. In the following account, a middle-aged woman shares a similar experience: '[Other pupils] did not recognise me. They excluded me. … They called me names, nasty names. … Bullying left scars on me. … Nevertheless, I made a friend. This friendship has continued since those days … ' (498). The account reveals how loneliness can entail both social isolation and unwanted attention. Many other narrators use the metaphor of 'scars' to describe the consequences of childhood loneliness: 'These experiences [in the school] left scars on me. I think that I am not good enough and nobody can love me. I still have this feeling. I still can hardly receive positive feedback. Thus, I guess that I will live with the fear of exclusion all of my life' (58). Many of them also share experienced profound loneliness, which still affects them today: 'My classmates laughed at me. I felt inferior … It still affects me. Little by little, I try to rid myself from the load of the past' (524). These stories show how a profound experience of social isolation can follow participants throughout their life course; loneliness is not constant and can exist, for instance, as fear and lack of self-esteem.

The sense of unfairness and other relational aspects of loneliness can be seen in the following poem from a female narrator:

> You still live with the sense of difference that you got as a child/your unmet needs cry from your body./As you are filling up a shopping trolley now, you are trying to catch something that you did not get in the past/still much remains empty: love, affection, recognition – you can't buy them./You have still hungry eyes and distress catch you out: your words slam you and you shiver. Then comes grief and exhaustion … and once you will be drowned in your own tears, those you will never cry. (94–95)

The poem expresses an unfulfilled need to be recognised and have a meaningful feeling of belonging, which includes a spectrum of emotions such as fear, love, longing or desire and anxiety that are entwined the experience of loneliness.

Disjointed youth

The time of youth and the early adult years were for the participants a cross-roads regarding loneliness and disability. They narrated youth as the time of transformation, particularly for social relations, the body and capabilities. A transformative body and the need to fulfil some expected bodily standards were discussed in many of the life stories. For some of the narrators, youth

was an era in which they disconnected themselves from earlier experiences of loneliness. One narrator experienced loneliness in her childhood and tied the experience with her disability. For her, getting a driving license created a sense of capability and diminished her sense of difference and loneliness, which she had experienced as a child: 'My dream of a car was realised … Having a car was so meaningful to me. It was wonderful that nobody noticed my legs in the traffic. I was a brave driver' (3). Driving a car was an opportunity for her to join a socially claimed youth.

Many of the narrators shared an experience of disjointed youth. One of the female narrators writes 'as a young person, I did not dare to discuss my [visual impairment] but now I am laughing at my fate' (105). The narrator reflects how her disability no longer bothers her. Another narrator expresses herself in verse form and describes herself as 'an elderly person' due to her disability: ' … eighteen-year-old girl/already an elderly person, an elderly person who has just the past./I was thinking over and over my past days' (280). Her disability seemed to freeze her time horizon, as she describes herself as 'an elderly person who has just the past'. She continues 'I realised that my mother was upset that I was a person with disabilities. [I realised that] even though she did not put her feelings into the words' (281). She thinks that her mother 'realised the meaning of peer support' (281), although 'she was ashamed without a need to be ashamed' (299). The narrator continues that regarding shame, she does it 'the same way' (299). She was ashamed even though she knew that there was no need to be ashamed.

Youth was a time of social isolation and loneliness due to disability for some of the narrators. One of the female narrators describes how her impairment became a disability during her youth.

> When I was a child, I was never called a person with disabilities. … Pupils in [the special school] and [a hospital] were alike, and nobody was called disabled. Disability came up in youth, as my friends … began to go to the dance hall. Nobody called me to come along. They expected that I would not go. I accepted the situation for a quite long time, but once when one of my favourite artists had a gig, I decided that I can go alone; nobody had to call me. (56)

The narrator describes how she became conscious about disability in her youth. She was not asked to join the people going to the dance hall, even though those people were her childhood friends:

> As [I entered] the dance hall, I was shocked: it was the first time when I realised what it is to be a person with disabilities. Many people were there around and all of them knew me. However, all of those people averted their eyes from me. (56)

She faced scornful questions, such as 'Why are you here?' (56). She 'decided to stay', although she 'instinctively knew' she was 'unwanted' there (56). She continues 'It was hard to think what this meant. … It was so hard to see that people who knew me were ashamed because of me. I thought it

meant that I had to live alone. At that moment, I decided to let it be. I would live my life even though I was alone' (56). However, she also says the following:

> This terrifying experience hurt me. It is still smouldering in my mind. I was not able to explain to myself why I was scorned. Then I realised that I was different… I accepted that I was different, and my thoughts were different, too. … I decided that this would hurt me no longer. I have kept that promise. (56)

The dance hall was described as an arena where young people get together. For the narrators, however, the dance hall was mainly an arena of bodily difference, social isolation and emotional loneliness:

> I was in the dance hall and a chap who used a wheelchair asked me to dance with him. I wondered how to dance with a person who uses a wheelchair, but then I realised how it went. He danced with his wheelchair – very well, indeed. I tried to follow him. We danced, but it irked me that some of the able-bodied people told us: 'Get out of the way!' (104)

According to the narrator, 'able-bodied people' told them to 'get out of the way' indicating that these dancers were in their way. Yet another narrator also suggests that visible bodily differences caused social isolation and emotional loneliness in their youth:

> My friend … taught me to dance. I was excited and decided that I wanted to have a family. I looked for a boyfriend. Sometimes I had fun at the dance hall; sometimes nobody asked me to dance. I remember how [a close person of mine] passed me and did not recognise me. I was angry, bitter and jealous of her because she was popular and I was not and I thought that all this happened due to my [impaired] leg. (2–3)

Her friend just bypassed her, without recognising or even greeting her. The narrator explained this to herself in terms of internalised oppression and bodily difference: 'all this happened' because of her physical disability. Hence, physical disability became experienced as bodily difference: the sense of bodily difference became explained as the source of social isolation and loneliness.

Disaffiliation in adulthood

Loneliness in adulthood was narrated as disaffiliation with ordinary, socially claimed normative adulthood institutions such as a stable relationship and participation in working life. Affiliation to socially claimed adulthood institutions was precarious; it was neither stable nor permanent and it was dominated by uncertainty. The lack of a relationship was narrated in relation to disability and emotions. One of the narrators who had a profound loneliness experience earlier in her life course, describes how receiving positive emotions can be difficult due to previous emotional difficulties, which had been

constructed along with negative emotional responses and social isolation during the life course:

> My relationships have ended often due to my incapability to receive the other person's emotions, [especially] love. I have much love to give, but receiving love is the hardest thing. … It demands [that you recognise the] wholeness, recognise the ragged self-esteem and all of you that you think as poor. It is hard to understand how someone could love you despite all of these issues. (86)

Emotional responses and social relations are entwined in this subtle account; the narrator specifies how receiving another person's emotions, especially love, demands self-recognition, which is constructed in relation to others and their emotional responses.

The following account crystallises disaffiliation from socially claimed normative institutions in adulthood. One of the narrators shares her following experience:

> It is so hard for people with disabilities to be included in working life. It has weakened my self-esteem. Having a permanent job is just a dream, a faraway dream. … I live alone … I have no spouse to whom I could share the household or my joys and sorrows. … I can't think what my life would have been like if I had been born as an able-bodied person. (506)

The narrator discusses social exclusion in relation to her emotional responses and her self-esteem. Additionally, she links loneliness to able-bodiedness, as she wonders what her 'life would have been like' if she had been born as an able-bodied person'.

One of the female narrators says that 'it is a common idea that a person with disabilities has to have a relationship with another person with disabilities – or live alone' (65). The account discloses a socially claimed (ableist) norm of relationships, in which disability is considered a hindrance to having a close relationship and a family. Thus, people with disabilities are assumed to have no relationship or have a relationship with another person with disabilities. In most of the life stories, loneliness in adulthood was tied with disability as bodily difference. However, one of the female narrators describes her loneliness experience as not exactly tied with disability. She describes a life event, a loss of a family member, when 'loneliness came suddenly' and asks, 'What should I think?' (300) Here, loneliness is linked with a life event (a loss of a family member) without a specific connection to disability. Though the narrator has 'wondered what aloneness … could be' (300), she experienced aloneness as loneliness and disaffiliation from her previous social relationships, as she suddenly faced it. Aloneness as a peaceful moment was wanted, but aloneness was loneliness in practice.

Acquiring a disability may diminish the sense of capability temporarily or for a longer time. One of the narrators describes how acquiring a disability broke her social relations. Her 'friendships broke down' (323). She writes 'my co-

workers have always been my friends' (323). Acquiring a disability disaffiliated her from her former social relations and disrupted meaningful connections (323).

Sometimes loneliness and aloneness have blurred lines. According to one of the narrators, 'No one of my friends tried to meet me. But it was good because my loneliness was also my own choice' (279). Hence, she wanted to be alone but, she was still lonely. 'My thoughts spun around the past. The future was like a wall in front of me. My days were made up of nothing but a daily walk' (279–280). Her daily routines did not include much, and her time horizon was focused on the past; her future was 'like a wall' in front of her: 'I dwelled on the loss. It took time' (280). She thinks that her loss was her disability or the loss of her former corporeal self. She thought that she was inept because of her blindness. 'My ineptness increased because of my blindness. Therefore, the capability to read [Braille] was not a minor thing to me. It was my first capability as a blind person' (280). Reading was her way to start re-connecting with other people.

As people with disabilities are underrepresented in working life, the disaffiliation of people with disabilities from working life relates to the experiences of social isolation and socio-emotional detachment. A work place is also a place of social relations. According to one of the female narrators who had experienced loneliness earlier in her life course, 'my co-worker … was very supportive to me in working life. She was friendly and stood up for me. Meeting a nice person has always given strength to go on' (3). Work life offered an opportunity to have the company of the other people and to be included in a socially claimed institution (i.e. paid work). The affiliation offers social relations, the sense of belonging and participating and the ability to have reciprocal emotional connections with other people.

For another narrator, working was a source of social connection: 'Over time, I blended so much into the crowd [work community] that my co-workers did not pay special attention to my disabilities. I was one of [the group], and I was capable of doing my job' (67). Working provides an opportunity to belong. Nevertheless, disability is depicted as a source of unwanted attention, as she 'blended into the crowd' and her 'co-workers did not pay special attention' to her disability. Disability was constructed as an unwanted difference in working life. The narrator thinks that she has been integrated into the work community in a way that her fellow workers did not pay attention to her body. Hence, her affiliation was 'integration', in which she attempted to avoid her co-workers' unwanted attention to her body.

According to several narrators, exclusion from working life meant social exclusion and loneliness. Respectively, inclusion in working life connected participants to formal institutions and offered them an opportunity for social inclusion. Work life inclusion, however, was also presented as a kind of

assimilation, a 'blending into the crowd'; hence, social isolation and loneliness in adulthood can be complex in their socioemotional configurations.

Discussion

Taking a life course approach, this study documented loneliness in life stories by people with disabilities. The findings were connected with the normative orientation of a life course and 'emotional tones and evaluations of others' (Burkitt 2014, 113; also Sønderby 2013, 22). Ableist and othering emotional tones and evaluations of others generated a sense of difference that fed the experience of loneliness. From a life course perspective, the experiences of loneliness among people with disabilities were situated mainly in three different phases of the life course: childhood, youth and adulthood. Loneliness was depicted as a disconnection from a socially claimed life course. It was mainly situational: the key experience of loneliness was situated at some point of the life course. In many cases, loneliness in childhood was narrated as a profound emotional experience, which followed participants throughout their life. This finding corresponds with previous research: deep experiences of loneliness in childhood that are associated with a sense of difference and unbelonging can affect the later life course (Rönkä 2017; Weiss 1973, 20; Margalit 2010).

A profound experience of loneliness occurs as different negative social relations and experiences become intertwined together (for more on negative social relations, see Warner and Adams 2016). Some of the narrators experienced that they did not fit in with their childhood family. Ami Rokach (2004, 24) calls this a 'distanced' family relationship. According to the narrators, the reason for this distanced relationship was disability as bodily difference, whereby their family members were not able to cope with the disability. This experience of being like a fish out of water was connected with a sense of bodily difference (see also Soulis & Andreou 2007).

Furthermore, Ami Rokach argues that undisclosed loneliness 'leaves emotional scars' (Rokach 2004, 34). Many of the narrators used this metaphor, scars, to depict how a profound experience can affect the life course. 'From the earliest years … the words, intonations and evaluations of others inform our own self-feeling', writes Ian Burkitt (2014, 113). These 'emotional tones and evaluations of others' regarding loneliness in life stories were negative and othering. These negative feelings can feed a sense of difference at both the individual and social level (Lupton 1998, 22), since loneliness can lead to a sense of worthlessness (Tiilikainen 2019, 21).

The time of youth was narrated as the time of transformation regarding loneliness. For some of the narrators, youth was time when they were able to disengage themselves from the normative and othering conditions of childhood, whereas some of the narrators became aware of difference and

loneliness in their youth. Lack of recognition among their peers in youth was narrated as a source of social isolation. According to Robert S. Weiss (1973, 146–147), social isolation is a painful experience, and because 'self-definition is achieved, paradoxically, by group membership', isolation generates othering condition and harms identity construction.

Social isolation relates to alienation, which originates from ableism (Campbell 2009). Ableism feeds alienation, negative attitudes towards disability and, thus, promotes conditions of social isolation and emotional loneliness among people with disabilities. Loneliness as 'a set of reactions, causes and feelings' (Sønderby 2013, 22) is relational. From a relational perspective, loneliness and disability can be considered 'patterns of relationship, or, more specifically, social relationships which are intersected by personal biographies that are interwoven through them' (Burkitt 2014, 168).

Loneliness in adulthood was narrated mainly as a disaffiliation from normative institutions, such as family and work (on exclusion in working life, see Östlund and Johansson 2018). According to experiences of loneliness among people with disabilities, exclusion from working life meant social isolation and emotional unrelatedness. A working life connected to formal institutions, however, offered an opportunity for social inclusion. Disability as a contextually situated functional barrier is closely aligned the idea that the loss of capabilities is experienced as a (potential) source of loneliness. According to Elisa Tiilikainen (2016, 145; 2019, 121) exclusion from working life is a rupturing event in the life course that increases vulnerability regarding loneliness.

Regarding their lack of intimacy and of meaningful relationships in adulthood, the narrators went back to their earlier experiences of loneliness, which caused them to underestimate themselves and to withdraw from emotional closeness or to reject it completely. According to van Baarsen et al. (2001, 120), lacking a partner is one of the key sources of emotional isolation in adulthood (also Weiss 1973, 93). Furthermore, the participants' accounts revealed the alienation and stigmatisation of people who are considered 'not share the symbols of the society and are not fully involved in social interaction' (Fleischer 2012, 184, 191) due to prevailing ableist claims. Furthermore, social isolation can mean lacking adequate social support (Wenger and Burholt 2004; de Jong-Gierveld 1998). The narrators referred to cultural assumptions regarding the life course and disability, in which people with disabilities are often cast in an abnormal role.

Ableist narratives present disability is as an unwanted difference (Campbell 2009, 3–30, 197). Hence, they internalise oppression within the biographies of people with disabilities (Campbell 2009, 16–29). Bodily difference was narrated as the source of social isolation and emotional loneliness. According to Ian Burkitt (2014, 133), 'in the bodily act of speaking we fundamentally reconstruct what we feel through language, not simply name a prior feeling'. This suggests

that social and emotional experiences are relational and corporeal. Ian Burkitt (2014, 134) continues by suggesting that 'the way others see us is not separate from, but fundamental to, our own sense of self as it develops, so that my-feeling is never divorced from feelings to others'.

In the life stories of people with disabilities, emotional loneliness and social isolation were intertwined in relation to the lived body. Correspondingly, Fay Bound Alberti (2018, 251) argues that loneliness is an 'embodied, lived experience' and highlights the intersections between 'the material culture of the body', social configurations and emotional responses (Bound Alberti 2018). The social pattering 'of bodily practice within social relations' was narrativised as otherness, emotional unrelatedness, social isolation and loneliness (Burkitt 2014, 171). According to Burkitt (2014, 155), emotions are 'created from within the pattern of relationship'. The feelings of unbelonging in childhood, as well as the feelings associated with a disjointed youth and a disaffiliation in adulthood, were narrated against normative and often ableist assumptions.

This study focused only a small number of life stories, in which the time frame varied. Yet the analysis employed a relational approach and paid special attention to social relations, emotions and the lived body. Additionally, according to the project's call for submissions (SKS 2013), the narrators were encouraged to write their stories by themselves, with an assistant and use different mediums (e.g. audio recording) if they wanted. Nevertheless, most of the narrators seemed to write their stories themselves. Such a data collecting method is one limitation of the work; some stories may remain untold because of their unavailability. However, this data collecting method seemed to offer an opportunity for the participants to reflect and rethink on their experiences.

Conclusion

Loneliness may be a potentially shared experience for everyone, but as Fay Bound Alberti (2018, 242) argues, 'it is not enough to view loneliness as an inevitable and negative human experience when, like all emotional states, it can be historically situated'. Loneliness as socioemotional response concerns the lived body. In this data, all but one loneliness accounts were connected with disability as unwanted (bodily) difference. Social isolation and emotional loneliness were narrated in relation to a sense of bodily difference, which interwove emotional and social loneliness into the biographies.

It is important to highlight that the experiences of loneliness are deeply tied with the contextual life of an individual: different life trajectories cause different responses to (potential) loneliness throughout the life course (Tiilikainen 2019, 169–192). While most of the experiences of loneliness in this life story data were connected with the experience of bodily difference,

all of the experiences of loneliness among people with disabilities were not necessarily connected with bodily difference. Moreover, loneliness is a structural matter: people have different opportunities to affiliate, belong and participate (Tiilikainen 2019, 192; Goodley, Liddiard, and Runswick-Cole 2018). Inaccessible material environments can hamper and even alienate, which can, thus, feed social isolation and emotional loneliness (Tiilikainen 2019, 134–153).

However, 'sharing a physical space is not the same as sharing an emotional space' (Bound Alberti 2018, 243). Therefore, this study suggests that further empirical studies on affective, emotional and social conditions of inclusion are needed. Studying loneliness and disability in a life course informs both loneliness and disability studies. There are many policy implications for loneliness and disability that need to be advanced, including diminishing the double stigma between loneliness and disability in practice and working for more inclusive material and discursive conditions. Arguably, this would inform wider public discussion and general awareness on and attitudes towards loneliness, disability and conditions of inclusion.

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