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Forbidden Option or Planned Decision? Physically Disabled Women's Narratives on The Choice of Motherhood

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Forbidden Option or Planned Decision? Physically Disabled Women's Narratives on the Choice of Motherhood

This narrative study explores personal narratives by disabled women on their choice to become a mother. Eleven Finnish physically disabled mothers were interviewed. The interview data were analyzed using Greimas' actant model. The women produced three types of narratives about their journeys to motherhood: compensation, forbidden option and planned choice. In these narratives, the disabled women struggled with the disabling, over-simplifying and suppressive cultural master narratives of 'good' motherhood. Through the narratives, the women distanced themselves from these dominant cultural narratives and constructed strong agency for themselves as mothers.

Keywords: choice, motherhood, disability, narrative research

Introduction

Motherhood is often considered a self-evident goal or a natural choice in every woman's life (Rich 1991, 26). Historically, however, disabled women have not been afforded this choice and have often been excluded by gender studies and by mainstream society (Morris 1992; Thomas 1999). Disability and motherhood are words that seem to sit uneasily together in our society (Malacrida 2009), and many studies have highlighted the prejudices disabled women have faced in their journeys to become mothers (Campion 1995; Prilleltensky 2004; Thomas 1997).

When studies on disabled women are examined (e.g. Prilleltensky 2004; Thomas 1999), the reasons for these prejudices become apparent. Disabled women are not expected to aspire to such norms as femininity and womanhood; instead they tend to be perceived as asexual or genderless persons. Reinikainen (2008) found that sociocultural discourses of womanhood (e.g. caring discourse) produced gender-based disabling obstacles, such as the denial of reproductive rights, for disabled women. A number of other studies (Grue and Lærum 2002; Lawler, Begley, and Lalor 2015; Malacrida 2009; Nosek et al. 2001) confirm the fact that disabled women are seen as disabled

first and as mothers second. Thus, living with impairment is thought to compromise a woman's capacity to fulfill her options to nurture.

Thomas (1997) identified two discourses that explain the ambivalence around the mothering by physically disabled women. The first discourse is *risk.* This discourse focuses on impairments that are defined medically as posing a risk to the welfare of the woman or to that of her baby. Thomas talks about the internalization of social ideals that cause disabled women to think that having a disabled child is not right because of various risk factors. The second discourse is *good-enough* mothering which means that the traditional views of good motherhood virtually exclude disabled women from the chance to be a 'good' mother, a standard which is normally related only to white, heterosexual, married and middle-class women (see also Arendell 2000; May 2008).

The earlier studies on the experiences of motherhood by disabled women with different kinds of impairment have mainly focused on their practical mothering of their children (Aune 2013; Grue and Lærum 2002; Lawler, Begley, and Lalor 2015; Malacrida 2009; Prilleltensky 2004) or on their experiences with social services and health care professionals (Starke 2011; Thomas 1997; Walsh-Gallagher et al. 2013). Only a few studies (Johnson et al. 2001; Prunty et al. 2008) have investigated the choice or decision by disabled women to become a mother. This paper addresses this gap in the research by examining the choices made by disabled women to become mothers through narrative interviews with Finnish physically disabled women. The focus of the analysis is both personal and social. It looks at the subjective narratives of motherhood and at how social interaction with the surrounding community contributes to the mothers' experiences.

The Choice of Motherhood

The desire to have children has traditionally been explained by the existence of the maternal instinct: motherhood is considered as a normal part of every woman's female identity. Since the feminist movement of the 1970s, diversity in women's ways of living has come to be recognized.

The emphasis on women's bodily integrity and reproductive self-determination has further shaped people's understanding of motherhood as a woman's own choice (Miller 2005).

Choosing motherhood is a multilayered process rather than a clear-cut or plainly rational choice. On the one hand, motherhood is considered one part of a reasonable female life, but on the other hand, becoming a mother requires careful life planning and timing (Sevon 2005). Even though motherhood is nowadays regarded as a women's personal choice, the decision to become a mother is not as autonomous as it is generally thought to be (Meyers 2001). In the Nordic countries, in particular, parenthood is based on gender equality and on both parents' strong involvement and shared responsibility, where fathers are expected to participate in child-rearing and family life (Perälä-Littunen 2007) and have an influence on women's decision-making concerning potential pregnancy (Eerola 2015).

Women's choice of motherhood is also regulated by professional and cultural narratives, through which women evaluate their own individual decisions (Miller 2005; Sevon 2005). These normative narratives, including norms for the optimal timing of motherhood and recommendations for prenatal screenings, are defined by medical and health professionals. The dominance of cultural narratives has long-term implications for how mothers construct their personal accounts of becoming a mother. They may encounter difficulties in constructing personal narratives when their experiences do not fit with the cultural ideal of good mothering (Miller 2000, 2005). As a result, motherhood can be an ambivalent choice and being a mother a conflicting experience (Sevon 2005).

The Choice of Motherhood by Disabled women

Owing to both the external and internal oppression that disabled women encounter, the choice to become a mother is more complex for them than it is for nondisabled women. Clarke and McKay (2014) claim that disabled people are more likely than other people to face disadvantages in family formation and, moreover, they are more likely to remain single over time. Disabled women with differing impairments have also reported restrictions on their reproductive freedom (see Kallianes

and Rubenfeld 1997), and stories of being recommended to have abortions and hysterectomies can be found in many studies on their experiences (Nosek et al. 2001; Olsen and Clarke 2003).

According to Prilleltensky (2004, 133), the disempowering experiences of disabled women regarding their reproductive choices often stem from their childhood home and lead to them shutting the possibility of having children out of their lives. In order to choose motherhood, young disabled women have to reject the traditional subservient role of disabled people, dare to dream of having children and, along with this, to see themselves primarily as women instead of as disabled women. This requires that they have sufficient agentic power (Barron 1997). Motherhood may then be one means through which disabled women can capture a gender or re-capture a lost gender (Grue and Lærum 2002) and construct identities of themselves as women and as valuable persons (Barron 1997; Grue and Lærum 2002).

Disabled women with different kinds of impairments have also been reported to encounter disabling attitudes among health care professionals regarding their family planning. Their decision-making ability has been questioned, especially in cases of intellectually disabled women (e.g Mayes, Llewellyn, and McConnell 2006). They have received too little or inappropriate information concerning their pregnancy and disability, or they have not received any support in the motherhood decision-making process (Blackford, Richardson, and Grieve 2000; Prunty et al. 2008). These kinds of experiences have been found to be a cause of the complicated feelings, such as anxiousness, experienced by disabled women and to intensify these mothers' fears during pregnancy (Johnson et al. 2001; Prunty et al. 2008; Walsh-Gallagher et al. 2013). However, the experience of being heard has been found to ease their decision-making (Mayes, Llewellyn, and McConnell 2006).

The Present Study

This study is situated at the junction of two theoretical perspectives: the fields of Disability Studies and narrative research. In Disability Studies, disabled women are primarily seen as an oppressed social group whose rights should be better taken into consideration. From this perspective,

impairment means any medically defined difference. In this connection, disability should be differentiated from impairment, which refers to any exclusion from mainstream activities, such as motherhood, imposed by a society which is unable to take into account the diversity that exists between individuals (Oliver 1990). Narrative research explores how people actively make sense of their experiences through narrative (Miller 2000) and at the same time, retell and reconstruct their identities (Riessman 2008). Narratives can be particularly useful in the study of life changes and how people attribute meaning to difficult and sensitive experiences in their lives.

The purpose of this study is to analyze the physically disabled women's narratives in Finland about their choice to become a mother. The study aims at shedding light on the many-sided processes of becoming a mother in the context of disability and related oppression, and examining the narrated psychoemotional experiences of negative environmental attitudes that may influence the decision by disabled women to have children (Reeve 2006; Thomas 1999). Our research questions are the following: (1) What types of narrative can be identified from the descriptions given by physically disabled women on their choice to become mothers and (2) How do physically disabled women position themselves and other people in the different types of narrative?

Method

Participants and Data Collection

The study is based on interview data collected among Finnish disabled women. Homogeneous sampling (see Patton 2015, 267−268) was used to recruit participants from a specific group of disabled people, namely, physically disabled mothers. The call for potential interviews was published in the national journal of the Finnish Association of People with Mobility Disabilities, which gave ethical approval for the study. Originally, twenty-four women with a wide range of physical impairments voluntarily contacted us. Owing to data saturation (Patton 2015, 271), only sixteen women were interviewed. The participants were informed of the purpose and process of the

study before they gave their informed consent. They were assured that the information they gave would be treated confidentially and used only for this study.

The majority of the interviewed women (n = 11) were already disabled before they had children while the remainder (n = 5) had become disabled after childbirth. This article focuses on the findings concerning the eleven women who had been disabled before becoming a mother. These women ranged in age from 31 to 57 and each had from one to four children (see Table 1). The children's ages varied from 2 to 30 years. Eight of the mothers were living in a heterosexual relationship, two were divorced and one was single. Four of the mothers were working full-time, three were taking care of their children at home and four were retired. Three mothers had a Master's degree and eight had vocational training. Five mothers had mild physical impairments (which had only a minor influence on everyday life) and six mothers had moderate physical impairments (which significantly weakened their mobility). Diagnoses and any other factors that could potentially reveal the identity of the research participants have been kept anonymous. The term 'disabled mother' is used therefore to refer to all of the participants (see Table 1).

Table 1 The participants

Pseudoname	**Age**	**Children's ages**	**Marital status**
Jenna	31	8, 5	married
Kerttu	37	2	single
Kaarina	47	24, 22, 15	married
Teija	31	3	married
Taina	57	30	divorced
Anja	43	15	cohabiting
Helena	41	8, 6, 3	married
Sinikka	46	6, 3	married
Marjatta	55	27, 23	married
Merja	34	12, 7	divorced
Saara	41	15, 11, 8	married

The thematic and narrative interviews were carried out (Riessman 2008) by the first author, who is a mother although not disabled. She had also been a midwife for nine years and had subsequently specialized in disability studies. First, the interviewees were asked a broad opening question, such as "Tell me about your life and when you felt like having children." The focus then shifted to free narration by the participants around such themes as their childhood experiences, the process of becoming a mother, everyday motherhood, their relationship with their partner and future plans. The interviewer tried to be as discreet in the interview situation as possible and to allow the women to tell their stories in their own way. On average, the interviews lasted for 90 minutes and were audiotaped. They were conducted at the homes of the participants. The participants were offered the possibility to receive a written transcript of their own interview and could withdraw from the study at any time.

Analysis

Our focus in this study was on those passages in the interview data that concerned the choice to become a mother (e.g., dreaming of motherhood, becoming pregnant). The first author transformed these authentic passages from each interview into individual, thematically coherent stories presented in the first person singular. The stories were analyzed using Greimas' actant model. The purpose of this model is to investigate the different actors and the relations between them in the narratives told (Schleifer 1987). According to Schleifer (1987), six different actants can be found in all narratives: the subject (the central actor of the narrative), the object (the target of the action of the subject), the sender (one who motivates the subject to obtain the object), the receiver (the destination of the narrative or process), the helper (one who supports the subject in achieving the object) and the villain (one who prevents realization of the subject's aims). Applying the model was motivated by our observation that the interviewed women talked extensively about the role and significance of other people in making their choice to become a mother. The actant model enabled a

systematic analysis of how the women positioned these people and themselves in becoming a mother, and clarified the differences between the narrative types.

After the first author had created individual actant models from each participant's narrative, all the authors contributed to the data analysis by reading the data independently and identifying congruencies and similarities between the individual models. This kind of researcher triangulation enabled us to compare our interpretations and share diverse views of the same phenomenon (see Patton 2015). On the basis of this comparison, we formed three narrative types: these we labeled compensation, forbidden option and planned choice. The object of each narrative type was always the choice to become a mother and the disabled women as narrators were the subjects, although they positioned themselves differently in the three narrative types. All the other actants (senders, helpers, villains, receivers) were specific to each narrative type (see Table 2). To illustrate the three narrative types, we constructed a composite of all the individual narratives that represented the same narrative type. Each composite narrative is comprised of authentic utterances from several interviews. The purpose of the composites is to highlight and merge the central features of each narrative type rather than to present individual stories (see Eerola 2015). This enabled us to both emphasize the similarity of the experiences shared by the mothers in each narrative type and ensure the mothers' anonymity by concealing unique, identifiable and often sensitive details of their lives.

The narrative approach is open to the same issues of credibility as any other qualitative research with regard to the data collection and interpretation of the participants' experiences (Miller 2000). We applied Greimas' actantial analysis systematically to each woman's individual narrative so as not to ignore any detail in our data and to recognize the individual variety of each woman's narrative. Nevertheless, we also aimed at identifying regularities and storylines shared by the different narratives. Although our data set was relatively small, the discovery of three distinct narrative types strengthens the transferability of our findings.

As we analyzed the women's narratives, we remained aware of our responsibility as nondisabled researchers to do ethically sensitive research that empowers rather than exploits disabled women. The aim at empowering women was supported by the presumption of the Disability Studies, according to which the experience of disability cannot only be reduced to the individual minds but also to the culturally shared meanings. Therefore, giving voice to the disabled women assists them and other women to better understand their own choices of motherhood or non-motherhood and recognize how their personal experiences are shaped by dominant cultural expectations. This can be empowering in itself and strengthen women's maternal and female agency.

The Findings

The stories disabled women tell about their choice of motherhood were divided into the three narrative types described above: compensation, forbidden option and planned choice. A summary of the actants in each narrative type is given in Table 2. In the following sections, we present each of the three narrative types, first, by presenting an authentic composite narrative and then by contemplating the various actants in the type.

Table 2 The summary of actants in three narrative types

The actant	**Motherhood as a Compensation**	**Motherhood as a Forbidden Option**	**Motherhood as a Planned Choice**
The subject	A woman searching for a purpose in life	A women as a victim of circumstances	A woman as an autonomic agent
The object	A choice of motherhood	A choice of motherhood	A choice of motherhood
The sender	Feeling of incompleteness	Coincidence, chance	Strong will
The helper	Good relationship with the partner	Understanding professionals	Good relationship with the partner
The villain	Disabling environmental attitudes	Disabling environmental attitudes, negative sense of self	Disabling environmental attitudes, health restrictions
The receiver	Becoming a mother Empowerment	Becoming a mother Integrity	Becoming a mother Coping in everyday life

Motherhood as Compensation

I don’t remember all that much about my illness as I was really so young. I was in hospital for six months and then when I finally got home, it must've been really weird for my folks like there's this child who can’t move anymore.

My mother saw me as just another burden in her life, so I spent a lot of time with relatives and acquaintances. Maybe as a consequence of this, I’ve always felt this longing and homesickness.

Somehow I then fell in love and everything else was forgotten. What love brought along with it was that I started to blossom as a woman. I was accepted for who I was, and all along that’s what has bound our relationship together. At the same time, as far as this disability goes, I started to become more whole.

With the careers counsellor I started wondering if I could go off and study. I got sort of excited about that, but because I was becoming less and less mobile all the time, so, that I couldn’t handle long trips anymore, then I started thinking, what am I going to do with my life. I want to do things that actually mean something to me. I want children. The idea of having a child gave me some faith in the future. I believed that I could take care of a child and if I couldn’t, well then, my husband would.

I went for my first check-up, and the doctor said he would send me to hospital for some tests because I was such a special patient. I went to the hospital, and the doctor said, ah, I suppose you’re here for an abortion. I said no way. Then he read the referral paper again and it clearly stated that the child was wanted, but nevertheless the pregnancy would be terminated. With the doctor at the clinic there hadn’t been any talk about terminating the pregnancy. It came as a huge shock to me.

As for my family, my mother was shocked at first. Since then, she’s been a great help and supported me all the time. But my sisters and brothers haven’t. For example, when I was expecting my second child, my sister gave me a lecture about how dare I have a child that will only be a burden on others.

But then if you were to ask me what’s been the most meaningful event in my life or the purpose of my life, it’s that I’ve had a child. I’ve subconsciously longed for a child, see myself as born to be a mother. My children have been a great thing for me. Having children tops everything, tops getting a degree and studying. I believe it’s been the main factor in making me whole as a person.

In the compensation narrative told by Kaarina, Marjatta and Taina, the choice of motherhood is characterized as a turning point towards a better life. The subject is a vulnerable woman who is

searching for a purpose in life. The sender for the need to change one's life is either unhappy childhood experiences, which cause a longing for home (lines 1–6), or restricted possibilities for realizing one's professional ambitions (lines 11–13). Awareness of one's deficiencies supplies the motivation to do something important in life. The expression of intent in lines 13−14, "I want to do things that actually mean something to me", describes the subject's strong agency in choosing motherhood. The same commitment to motherhood as a personal compensation project is strengthened by the use of the personal pronoun *I*, not *we*, when describing the decision to have children.

The narrator's partner plays important roles in this narrative type as the helper. Meeting the partner is described as a positive turning point in the subject's life as a woman: she became a person who was accepted as she was and seen as something other than disabled (lines 7–10). In addition, the child-to-be is not narrated as the subject's sole responsibility because she reports trust in her partner's willingness to share responsibility for taking care of the child (lines 15−16).

Environmental attitudes, as the villains in the narrative, represent typical negative assumptions about the motherhood of disabled women. The subject's motherhood is questioned in two ways: her ability to make a decision about her pregnancy is overridden by health care personnel (lines 17−22) and her ability to take care of her children is distrusted by her siblings (lines 24–26). For example, the comments by the subject's sister about the pregnancy are the complete opposite of the subject's own thoughts. The sister is said to position the subject as an advantage-taker, whereas the subject positions herself as an able person. The experience of being labeled as a risk mother by other people does not, however, undermine the subject's choice of motherhood as her main object.

Finally, the whole narrative shows that becoming a mother is valued as a positive alternative in the subject's life course – an alternative through which she re-positions herself as an empowered person. In fact, the subject's self-empowerment as the receiver gives meaning to the whole process of becoming a mother. The role of motherhood as an integral part of the subject's womanhood is

particularly foregrounded at the end of the narrative (lines 27−31), when the subject describes her children as “the main factor” which has played a great role in “making me whole as a person”. These words represent a strong, long-lasting commitment to motherhood as a wish that has come true.

Motherhood as a Forbidden Option

As a kid I don’t remember dreaming about having children. It felt like it was completely out of my reach. This is because we, disabled children, were born out in the country where we were seen as useless, as a burden. I’ve always felt this horrible guilt about existing at all.

I haven't been able to build human relationships, in other words, I never had much confidence. I knew that I would never get to have a proper family. I thought that, oh, if only it were possible to leave school and start a family. I didn’t even dare to say that out loud then.

Then I went through a kind of bigger phase when I tested my limits in my relations with men. I forgot to take the pill just once and that’s when I got pregnant. Then I had an abortion, because in those days services for the disabled weren’t as good as they are now. At that time when I was young and expecting, they [my family] threatened me by saying that if you keep the child, then you won't be allowed back home.

One beautiful evening it so happened that an old boyfriend who at one point I’d had some kind of thing with, came along and made a pass at me. He didn’t have any interest in dating me, in his opinion because of this physical difference. He wouldn't use protection either. So that’s how it went, that from this one and only occasion this little lady popped into the world. I think that if Elina hadn’t gotten her start from that, then there would probably be no Elina today either and I wouldn't have become a mother.

It was only after I’d been to two ultrasounds that I told my family. My closest sister was really worried that I didn’t understand the realities of life. I didn’t have the ability to manage, and the child wouldn't do well as a result. Our mother was so confused, because she’d assumed that I hadn’t burdened myself with a man, let alone started making babies.

When my belly started to show, it was somehow terrible. I went through a horrible struggle seeing myself though other people’s eyes and when they made comments about how can I have a child.

At the maternity clinic, a friendly woman working there said I could go and talk to the psychologist. I went to talk about my fear of being a mother, that I was scared, that I didn't have any feelings towards the child. I never had a role model when I was little.

> In that sense, it's been a test from the beginning, everything has had to be proved from scratch. It's only now that I've come to realize that I've done pretty okay as a mother. I'm still amazed at how well things are going with Elina and what a smart and wonderful kid she is.

In the forbidden option narrative provided by Kerttu, Anja and Sinikka, the choice of motherhood is constructed as an option that has been forbidden ever since the subject's childhood. Motherhood is something so impossible to realize that even a wish about it in the subject's mind needs to be suppressed (see lines 5-6). These negative self-thoughts are explained by childhood experiences of rejection which have caused the subject doubt her right to be and live. The subject positions herself as a victim of circumstances who aimlessly drifts from one place or relationship to another seeking to find her own niche in the world.

What is striking in this narrative is the subject's weak agency concerning her choice of motherhood. Becoming pregnant is constructed as a more or less a lucky event or a coincidence rather than as a conscious decision (as the sender). Her ambivalence over motherhood is increased by absence of a partner and negative environmental attitudes. These negative attitudes and lack of support are interpreted as having led to the termination of the subject's first pregnancy (lines 8-11). In the second pregnancy, which was also not planned, the subject, however, decides to keep the baby. Without this coincidence, then "probably not today either" would she have become a mother (line 16-17).

The narrative type contains many villains. In addition to ending up as a lone mother out of necessity, the subject's experiences tell about problematic woman-to-woman relationships, such as her mother's expectations of a childless daughter and her sister's doubts regarding her ability to cope with the tasks of mothering. Disabling environmental attitudes also contribute to the way in which the subject first responds to her impending motherhood. She feels embarrassed, and doubts her ability to be a good mother (lines 22−27). During this phase, professionals play an important role as helpers by giving the subject a possibility to process her difficult emotions.

The receiver, becoming a mother, implies personal growth and integrity in the narrative. Motherhood gives the subject an opportunity to change her life course in two ways. First, when she decides to continue the pregnancy, the role of victim (passive subject) changes into the role of a responsible mother (active subject). Second, the narrative compromises the barriers constructed by the culturally dominant narratives of motherhood, which exclude disabled women. In the end, the subject no longer relates to the narrative of being unfit for motherhood, but expresses belief in her abilities to be a good enough mother for her child. The change of attitude also comes as a surprise to her (lines 28-30).

Motherhood as a Planned Choice

1 I never thought that I'd never have children or that I wouldn't want or I wouldn't be able to have
2 them because of my disability. I took it for granted, even though nobody really does that about
3 having children. My parents were against it, but I made my own rules. I would otherwise have
4 stayed with my parents for the rest of my life, not gotten married, not moved out. I just decided
5 by myself that I'm leaving. I said I'll live my own life, you live yours. Then I went on a course
6 so that I could learn to cook and be a mother.
7 But before I got pregnant with my first, I saw a doctor to find out if my disability is
8 hereditary. It rather worried me. I would probably still have wanted a child but it would have
9 been a lot more difficult if I'd had a disabled child. I guess I would have wanted a child even
10 then, but I certainly would have spent longer thinking about it.
11 Then after we got engaged we started planning our first child. We'd talked about having
12 children and both of us wanted them. So we decided to have a child, and succeeded on the first
13 try.
14 At the maternity clinic, my husband was always with me. I imagine they thought those
15 two'll probably make it, because they've done it together. Now when I look back on it all, being
16 pregnant was hard. I never got the feeling that now my life is at stake, although with Lotta that
17 may have been the case. The doctor also more or less said that with this second pregnancy I was
18 playing with my life.
19 When I was expecting Lotta I said that I can't handle it anymore. Then I told the clinic that
20 I didn't want any more children. So when Lotta was born, I got my tubes tied. If I were healthy,
21 I would have a whole slew of kids, if only I didn't have these physical limitations. So there was
22 an element of longing.

In the planned choice narrative told by Jenna, Teija, Helena, Merja and Saara, the choice of motherhood is described as a self-evident option (lines 1–2). Although the subject's parents are positioned in the role of villains who resist their daughter's marriage (lines 3–4), the narrative emphasizes the subject's strong autonomic agency and her use of power over parental authority. The subject talks about fighting for her rights to do things on her own so that nothing could have shaken her strong will to become a mother, which is the sender in the narrative. A similar strong construction of agency also appears in the expressions through which the subject

describes her becoming pregnant as a conscious and well-considered decision (see lines 11–13).

The description of planning the pregnancy reveals the shared commitment to parenthood and decision-making between the subject and her partner. The subject has a good couple relationship, and her partner is one of the helpers on whom she can rely. The shared responsibility is also a protection against potential disabling attitudes, since the partner's presence in the maternity clinic convinces the professionals that "those two'll probably make it, when together they've done it" (lines 14–15).

The major villain and concern in this narrative is the subject's health. The hereditary risk of having a child with an impairment introduces a conflict in the subject regarding her wishes and actions. The desire for motherhood represents her emotional consideration while not to have a child represents rational alternative. However, the strong desire to become a mother transcends the fear of the child's having an impairment and the consequent uncertainty over one's ability to cope with a disabled child in everyday life (see lines 9–10).

Coping in everyday life is the receiver in the narrative. Similarly, it is one of the questions that the subject has to consider before pregnancy on account of the constraints imposed by her health. Although the subject has a strong belief in her right to be a mother, her planned choice of motherhood is not free from uncertainty and ambivalence. The subject in this narrative, however, has strong agency over her reproductive decisions, when her ability to cope with daily life is tested beyond its limits (lines 19–21). Ultimately, the risk of a further pregnancy to the lives of both the subject and the child leads to the decision to be sterilized after the second child. This decision is described as one of the most difficult in the subject's life.

Conclusions

The purpose of this article was to explore the choice made by physically disabled women to become mothers. The interviewed women produced three types of narrative about their journey to

motherhood. In the compensation narratives, motherhood changed the women's somewhat unsatisfactory life course for the better and gave them a purpose in life. In the forbidden option narratives, the disabled women encountered motherhood through coincidence and chance, but it gradually became part of their personal integrity. In the planned choice narratives, the women did not question their reproductive right in itself, although their personal health restrictions labeled them mothers at risk.

The findings of this study are consonant with Mason's (2004) earlier findings about identity construction as a relational experience. The way in which the women of the present study constructed their maternal agency in relation to others and to culturally dominant narratives was particularly noticeable in the compensation and forbidden option narratives. In these narratives, the disabled women talked about problematic woman-to-woman relationships, abusive childhood experiences and psychoemotional disablism (see also Reeve 2006). These often caused them to feel worthless and excluded the possibility of motherhood from their lives, although the women in the compensation narratives also managed to retain a hold on their childhood wish to become mothers. At its worst, in the forbidden option narratives, negative environmental attitudes, not only expressed by strangers or professionals, but also by very close persons and family members, complicated the women's identity construction as a good mother-to-be and left them isolated with their decision to become a mother.

Consistent with past research (see Aune 2013; Lawler, Begley and Lalor 2015; Prunty et al. 2008; Thomas 1997), in the disabled women's narratives, external pressures seemed to form the most significant obstacles to the choice to become a mother. Despite this, other people could also play a role in de- and re-constructing the negative narratives produced by these women. For example, understanding professionals might strengthen a woman's narrated identity as a good-enough mother whose decision to opt for motherhood is right. In addition, an equal and harmonious couple relationship was narrated as changing a woman's sense of self as a woman in a more

positive direction. The importance of partners was emphasized in both the compensation and planned choice narratives, whereas the forbidden option narrative was characterized by the absence of partner support. This does not mean, however, that women without a stable partnership would not be able to construct a planned choice narrative. Nevertheless, in the Finnish context, where shared parenthood is more typical than in other western countries (see Eerola 2015; Sevon 2005), making the decision to have children alone as a disabled woman requires strong reflection and agency to combat potential cultural stigmatization.

Common to all the narrative types was that, at the time of interviews, the women ultimately distanced themselves from the dominant negative cultural narratives of disability and constructed strong agency for themselves as mothers. Especially in the compensation and forbidden option narratives, when opting for motherhood, the women changed their negative sense of self and reconstructed themselves as more empowered. This is an interesting finding when compared to the perspective taken by the women's movement, which rejected the idea that a woman's identity is defined solely through motherhood. Instead, the movement emphasized that all women must have the right to make decisions regarding their bodies and lives, including whether or not to have children (Kallianes and Rubenfeld 1997). Therefore, although the women studied here had chosen to become mothers and found the motherhood empowering, or even compensatory, it is nevertheless important that all women should feel that they are complete and valuable human beings irrespective of whether they are mothers or not.

In the planned choice narrative, the women were externally labeled mothers-at-risk, but this did not confuse their carefully considered choices of motherhood or their positioning of themselves as legitimate decision-makers. Generally, in all three narrative types, the women struggled with the dominant disabling and suppressive cultural narratives of 'good' motherhood (see Miller 2000, 2005; Sevon 2005), and ended up describing their choice of motherhood as a strongly personal choice and commitment. This finding is supported by Miller (2000, 2005), who found that the

conflict between women's personal experiences and public narratives may initially induce confusion but eventually lead women to construct personal counter-narratives.

The present findings have a number of implications for professional practices. The negative experiences with health professionals reported by the disabled women are generally in accord with the results of previous studies (see Malacrida 2009; Starke 2011; Walsh-Gallagher et al. 2013). As noted before, the medicalization of pregnancy emphasizes the expert knowledge in family planning of health professionals. Simultaneously, it also allows professionals to provide psychological support and space for expectant mothers to process their potential negative emotions and any obstacles to enjoying their future motherhood (see Miller 2000, 2005). This kind of counseling recognizes and strengthens the self-determination of disabled women in making choices regarding motherhood.

References

Arendell, T. 2000. "Conceiving and Investigating Motherhood: The Decade's Scholarship." *Journal of Marriage and Family 62* (4): 1192−207. doi: 10.1111/j.1741-3737.2000.01192.x

Aune, G. 2013. "Everyday Challenges for Mothers with Spinal Cord Injury: A Qualitative Study." *Scandinavian Journal of Disability Research* 15 (2): 185−198. doi:10.1080/15017419.2012.692708

Barron, K. 1997. "The Bumpy Road to Womanhood." *Disability & Society* 12 (2): 223−239. doi: 10.1080/09687599727344

Blackford, K., H. Richardson and S. Grieve. 2000. "Prenatal Education for Mothers with Disabilities." *Journal of Advanced Nursing* 32 (4): 898−904. Doi: 10.1046/j.1365-2648.2000.t01-1-01554.x

Campion, M. 1995. *Who Is Fit to Be a Parent?* London: Routledge.

Clarke, H. and S. McKay. 2014. "Disability, Partnership and Parenting." *Disability and Society* 29 (4): 543−555. doi: 10.1080/09687599.2013.831745

Eerola, P. 2015. Responsible Fatherhood: A Narrative Approach. PhD diss.. Jyväskylä: University of Jyväskylä.

Grue, L., and K.T. Lærum. 2002. “Doing Motherhood: Some Experiences of Mothers with Physical Disabilities.” *Disability & Society* 17 (6): 671−83. DOI: 10.1080/0968759022000010443

Johnson, K., R. Traustadottir, L. Harrison, L. Hillier and H.B. Sigurjonsdottir. 2001. The Possibility of Choice: Women with Intellectual Disabilities Talk about Having Children. In *Disability and the Life Course. Global Perspectives.* Edited by M. Priestley, 206−217. Cambridge: University Press.

Kallianes, V., and P. Rubenfeld. 1997. “Disabled Women and Reproductive Rights.” *Disability & Society* 12 (2): 203−21. doi: 10.1080/09687599727335

Lawler, D., C. Begley and J. Lalor. 2015. “(Re)constructing Myself: The Process of Transition to Motherhood for Women with a Disability.” *Journal of Advanced Nursing* 71 (7): 1672−1688. doi:10.1111/jan.12635

Malacrida, C. 2009. “Performing Motherhood in a Disablist World: Dilemmas of Motherhood, Femininity and Disability.” *International Journal of Qualitative Studies in Education.* 22 (1): 99−117. doi: 10.1080/09518390802581927

Mason, J. 2004. “Personal Narratives, Relational Selves: Residential Histories in the Living and Telling.” *The Sociological Review* 52 (2):162−179. doi: 10111/j.1467-954X.2004.00463

May, V. 2008. “On Being a ‘Good’ Mother: The Moral Presentation of Self in Written Life Stories.” *Sociology* 42 (3): 470−486. doi:10.1177/0038038508088836

Mayes, R., G. Llewellyn and D. McConnell. 2006. “Misconception: The Experience of Pregnancy for Women with Intellectual Disabilities.” *Scandinavian Journal of Disability Research* 8 (2−3): 120−131.doi: 10.1080/15017410600774178

Meyers, D. T. 2001. “The Rush to Motherhood: Pronatalist Discourse and Women's Autonomy.” *Signs* 26 (3): 735−773. http://www.jstor.org.ezproxy.jyu.fi/stable/3175538

Miller, T. 2000. “Losing the Plot: Narrative Construction and Childbirth Research.” *Qualitative Health Research* 10 (3): 309−23. doi: 10.1177/104973200129118462

Miller, T. 2005. *Making Sense of Motherhood: A Narrative Approach.* Cambridge: The University Press.

Morris, J. 1992. “Personal and Political: A Feminist Perspective on Researching Physical Disability.” *Disability, Handicap and Society* 7 (2): 157−166. doi**:**10.1080/02674649266780181

Nosek, M.A., C. Howland, D.H. Rinalta, M.E. Young and G.F. Chanpong. 2001. “National Study of Women with Physical Disabilities: Final Report.” *Sexuality and Disability* 19 (1): 5−39. doi: 10.1023/A:1010716820677

Oliver, M. 1990. *The Politics of Disablement.* London: MacMillan.

Olsen, R. and H. Clarke. 2003. *Parenting and Disability: Disabled Parent's Experiences of Raising Children.* Bristol: The Policy Press.

Patton, M. Q. 2015. *Qualitative Research and Evaluation Methods.* Fourth edition. Thousand Oaks: Sage.

Perälä-Littunen, S. 2007. "Gender Equality or Primacy of the Mother? Ambivalent Descriptions of Good Parents." *Journal of Marriage and Family* 69 (2): 341−351. DOI: 10.1111/j.1741-3737.2007.00369.x

Prilleltensky, O. 2004. *Motherhood and Disability: Children and Choices.* New York: Palgrave Macmillan.

Prunty, M., L. Sharpe, P., Butow and G. Fulcher. 2008. "The Motherhood Choice: Themes Arising in the Decision-making Process for Women with Multiple Sclerosis." *Multiple Sclerosis* 14 (5): 701−704. http://dx.doi.org.ezproxy.jyu.fi/10.1177/1352458507086103

Reeve, D. 2006. Towards a Psychology of Disability: The Emotional Effects of Living in a Disabling Society. In *Disability & Psychology. Critical Introductions & Reflections.* Edited by D. Goodley and R. Lawthom, 94−107. New York: Palgrave MacMillan.

Reinikainen, M-R. 2008. "Disablistic Practices of Womanhood." *Nordic Journal of Feminist and Gender Research* 16 (1): 19–32. doi:10.1080/08038740701772790

Rich, A. 1991. *Of Women Born: Motherhood as Experience and Institution*. New York: Norton & Company.

Riessman, C.K. 2008. *Narrative Methods for the Human Sciences.* Thousand Oaks: Sage.

Schleifer, R. 1987. *A.J. Greimas and the Nature of Meaning: Linguistics, Semiotics and Discourse Theory.* Lincoln: University of Nebraska Press.

Sevon, E. 2005. "Timing Motherhood: Experiencing and Narrating the Choice to Become a Mother." *Feminism & Psychology* 15 (4): 461−482. doi: 10.1177/0959-353505057619

Starke, M. 2011. "Descriptions of Children's Needs and Parenthood among Mothers with Intellectual Disability." *Scandinavian Journal of Disability Research* 13 (4): 283−298. doi: 10.1080/15017419.2010.507374

Thomas, C. 1997. "The Baby and the Bath Water. Disabled Women and Motherhood in Social Context." *Sociology of Health & Illness* 19 (5): 622−43. doi: 10.1111/j.1467-9566.1997.tb00423.x

Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability.* Buckingham: Open University Press.

Walsh- Gallagher, D., R. McConkey, M. Sinclair, and R. Clarke. 2013. “Normalising Birth for Women with a Disability: The Challenges Facing Practitioners.” *Midwifery* 29 (4): 204−299. doi:10.1016/j.midw.2011.10.007