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Parental and professional agency in terminations for fetal anomalies: analysis of Finnish women's accounts

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This study explores the construction of parental and professional agency in the written accounts by women who have undergone selective abortion ($N = 8$). The analysis of the data was based on qualitative, linguistic discourse analysis. The accounts indicate that the mothers themselves exhibited both strong and weak agency during the process of prenatal diagnosis. The role of the professionals was usually discussed in these accounts concerning only the phases of pregnancy when something out of ordinary had been detected. After the termination, the mothers expressed that they were forced to exhibit strong agency and find ways to cope with their distress unaided due to a lack of professional support. The findings provide new viewpoints for discussing the realization of parental autonomy in prenatal counseling as well as knowledge about the various emotional reactions which prenatal diagnosis and selective abortions evoke.

Keywords: mother; agency; prenatal diagnosis; selective abortion; account

Introduction

Prenatal screenings and selective abortion are emotionally and ethically highly charged issues. Prenatal screening tests indicate if the pregnancy is at increased risk for a congenital anomaly and diagnostic tests indicate whether the fetus is affected with a genetic anomaly (Autti-Rämö et al. 2005, 35–40). The salient justifying principle of these medical practices in Finland, as well as in most Western countries, is the enhancement of parental autonomy. The official policy states that participating in screening should be both possible and voluntary. In other words, parents have the inalienable right to know or not to know about their prospective child's possible impairments. An essential rationale behind screening procedures is that it allows couples to make an informed choice about proceeding with a pregnancy after they have been informed about their risks. Genuine informed choice also requires that the provided information is objective, correct and sufficient (Autti-Rämö et al. 2005, 62). Respect for autonomous and informed choice is a corollary of various Finnish health care laws (Act on the status and rights of patients 785/1992; Medical research act 488/1999) and also explicitly stated in the recent statute on screening (Government decree on screenings 1339/2006).

An important reason for the current emphasis on parental autonomy and non-directiveness in health care is eugenics which thrived in the Nordic countries in the first half of twentieth century. Eugenics aimed at preventing the procreation of

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people considered as undesirable (e.g. individuals with disabilities) by encouraging or forcing sterilizations and abortions. Eugenic sterilizations and abortions were enacted in the law in Finland from 1935 to 1970 (Broberg and Roll-Hansen 1996; Mattila 1999). The eugenic past is a tremendous trauma to the medical community and during the past few decades, the official policy has aimed at fulfilling ethically justified values and practices.

However, prenatal screening practices have been criticised by a number of disability activists as well as scholars in the fields of bioethics, disability studies and medical sociology. According to these critical voices prenatal screening has become a routine that women often take part in with little or no thought. And it seems to be assumed that if a fetal abnormality is found, terminating pregnancy should automatically take place; around 90% of women choose termination after they have been informed that their fetus has Down's syndrome (e.g., Louhiala 2004, 139–40). It has been also argued that prenatal diagnostic counseling concentrates almost exclusively on medical facts and thereby gives a distorted image of what it is like to live with a disability or to parent a child with a disability (see, for example, Jallinoja 2001; Jennings 2000; Mansfield, Hopfer, and Marteau 1999; Press 2000; Shakespeare 1998; Vehmas 2001). In addition, various empirical studies, as well as anecdotal evidence, suggest that the realisation of autonomy and informed choice in prenatal counselling is often questionable. This is due to time constraints in counselling, communication problems between parents and the professionals, as well as uncertainties about the diagnosis and its effects on the child's future well-being (Bryar 1997; Garel et al. 2002; Hall, Abramsky, and Marteau 2003; Williams, Alderson, and Farsides 2002). In other words, various critics have argued that the current prenatal diagnostic routines have, in fact, something in common with eugenics that aimed to prevent disability at all costs.

In this article, we explore the materialisation of parental autonomy in terms of parental and professional agency. By agency, we refer here to a socially and discursively constructed phenomenon and concept, rather than to an internal psychological characteristic of people (Emirbayer and Mische 1998; Fuchs 2001). In other words, being an agent refers simply to the ways our informants display their own agency as well as the agency of health care professionals in their discourse (see Kurri and Wahlström 2007). Agency often involves views about the limiting and enhancing things that affect one's decision-making. Also, people can be seen to execute their agency on different levels. *Strong agency* is characterized by voluntary and certain choices that are the result of conscious aims and target-oriented actions. *Weak or low agency*, on the other hand, leans on vague goals with the result that subject's actions are directed by 'necessities,' obligations and compulsion, and that the subject's decision-making is guided strongly by other agents (see Mykkänen 2010). In addition to strong and weak agency, we recognised in our data so-called *expected agency* which refers to the kind of action and agency that is in line with the narrators view about a natural way, the way 'anyone' would have acted in a given situation.

The analysis of agency in this study is based on the accounts written by mothers who have terminated a pregnancy on the grounds of fetal abnormality. The accounts were analyzed by using the analytic conventions of discourse analysis. Agency discourse provides useful tools to analyze the realisation of parental autonomy in prenatal counselling as well as viewpoints for considerations about the possible uniformities and discrepancies between the mothers' representations and the general

principles of health care. It seems clear that empirical evidence sensitive to parents' experiences and to the dynamics of prenatal counselling is required in order to get a full picture of current practices, and ultimately, to be able to develop them to cater more appropriately for parents' interests and rights. The specific research questions in this study were the following: (1) How is the agency of parents and health care professionals constructed in the accounts of mothers concerning the terminated pregnancy?; (2) What kinds of hopes and expectations are directed at the action of mothers themselves as well the action of professionals in these accounts?

Method

The study was based on the written data which consisted of the accounts of eight mothers who had terminated a pregnancy on the grounds of fetal anomalies. The mothers were contacted through a Finnish Internet discussion group called *Enkelinkosketus* (Angel's Touch). The aim of this discussion group is to provide a private online forum for parents to share their experiences, exchange information and receive peer support from others who have undergone selective abortion. The mothers were informed about the study and encouraged to describe their experiences in their own words and write a personal story about the things of significance from their subjective perspective. In addition, the request to participate in the study consisted of some loose suggestions for the content of the accounts (e.g. thoughts and feelings related to undertaking prenatal testing, encounters with the health care staff).

The actual stories alternated according to the writing style and initiatives of each mother. The stories were, however, quite coherent descriptions about mothers' personal experiences. This may be due to the nature of written texts as data; writing gave mothers a possibility to choose carefully what to share and how to construct a story about the past events. Spoken accounts would evidently have been more fluctuating and inconsistent. Since the intention of the study was to examine how mothers use language to construct agency in the process of termination rather than their own characteristics, personalities or attitudes towards disability, the information about the mothers' wider life histories, biographical details or socio-economic status was not collected (see Antaki et al. 2002; Burck 2005). Despite the random sampling, all the mothers, however, reported that they had terminated pregnancy due to severe injuries of the fetus that would have likely resulted in a premature death. The fact that all the mothers who finally agreed to participate in the study reported that their child suffered a mortal impairment, probably tells in its part that selective abortion in these kinds of cases is found morally more acceptable than in the case of mild impairment. Consequently, telling about such experience, albeit anonymously, is easier.

The analysis of the data was based on qualitative, linguistic discourse analysis. The main idea of discourse analytical approaches is to examine how people construct, give meanings and assess various phenomena through their language use, and at the same time construct, maintain or reconstruct reality (Potter and Wetherell 1987; Wetherell 2001). Thus, our analytical interest was to examine how mothers ascribed meanings to those experiences, events and situations they narrated, reflected on their own agency in them and how they aimed to make these experiences intelligible to us in their accounts.

The data was analyzed on a cross-case basis by identifying both the semantic contents of the accounts (e.g. explicit writing about one's agency or responsibility) and the grammatical features of the accounts (e.g. the ways in which the mothers more implicitly referred to their own or to professionals' agency). The most interesting grammatical features in relation to the construction of agency were the following person references (see Fairclough 1992; Hakulinen et al. 2004; Halliday 1985; Halonen 2008) which formed the basis for coding of the data:

- Active and passive voice. An active voice refers to a clause whose subject expresses the agent of the main verb who does the action marked by the verb (e.g. *We didn't want any tests, E*). In contrast, passive voice is used when the performer of the action is not individualized, known or revealed (e.g. *You were left to cope with everything on your own, H*).
- Zero-person utterance refers to the sentences which do not have any personal pronoun, subject or the agent (e.g. *The decision has to be lived with for life, D*).
- Nominalization means phrases where a verb has been converted into a noun (e.g. I've found it more difficult to cope since several of my friends have achieved conception).
- Personification refers to the way to give human traits, feelings, or characteristics to non-living objects, things or ideas so that they are represented as persons (e.g. *Guilt plays on your mind, B*).
- Deontic modality utterances express either one's permission, obligation or requirement to do something. They can either communicate one's agency by signaling one's possibility to act as one wants (e.g. *We got to choose*) or convey the restriction of one's full agency (e.g. *Everything you'd dreamt of had to be buried*).

The grammar-based coding together with the systematic way of dealing with the data diminished the possibility for biased interpretations and rendered the analysis more controllable and non-judgemental (Wetherell 2001). The reader can also partly assess the credibility of the interpretations by comparing our way of interpreting agentive and agentless writing to the authentic data examples appended to the Results section. Despite the small data size, we have tried to find the core of the phenomenon through the concept of agency, which can be applied to different settings. In addition, the transferability of the research results may be justified by the presumption of the discourse analysis approaches, according to which mothers' way of exercising agency cannot only be reduced to the individual minds but to the general culturally and socially shared meanings (Hammersley 2003; Silverman 2005).

Results

In this section, we describe how the mothers who had undergone selective abortion construct their own agency during the whole process of prenatal diagnosis and the following termination in their written accounts. Since agency seems to take different forms during various phases of the process, the findings are presented in the following chronological order: prenatal screening, the termination of the pregnancy, and the time after termination. The abbreviations consisting of the letters A–H combined with page numbers, separate the accounts from each other and indicate the

place of each extract in the data. Two dashes within a sentence – indicate that we have omitted irrelevant text from the original data.

Prenatal screening

Mothers' descriptions of their participation in prenatal diagnostic practices can be divided into two kinds of accounts with a different emphasis. The first category consists of stories where the mothers emphasize their own subjectivity in the decision-making process whereas in the second category of their stories the mothers represent themselves as passivized objects of the institutional practices of maternal clinics.

In my view, prenatal screening causes too much unnecessary anxiety and leads to too many needless abortions – So I refused the blood screen and so far I've also refused all other tests that have been offered (G3).

Then the second time round I thought that, seeing as I didn't do any the first time, this time I'll do every single test there is, and then decide what I'll do if something shows up (H4, 7).

For me, screening started with the 20 week scan (E1).

In the first two extracts, mothers clearly take personal responsibility for taking or not taking part in prenatal tests. They tell about their thoughts and motives in terms of strong agency by using the active voice, in the first person singular 'I.' At the same time, the style of writing is strictly personal; the mothers clearly do not wish to express any general normative comments about the prudence or morality of screenings but, rather, they point to their own subjective viewpoint that applies only to themselves. Thus, the mothers indicate that they are aware of other viewpoints, and that by providing rationales for their own choice, they implicitly defend their personal view against them.

In the last extract, the focus is on the screenings while the mother's own role in the process is bypassed. In this case, the mother only reports objectively what has happened in the past (*screening started*) without specifying her own reasons for partaking in the available tests. The way of writing in this extract implies the certainty and neutrality of prenatal tests. Consequently, explaining further the reasons for participating in these reliable and objective tests appears unnecessary.

Professionals play only a minor part in mothers' accounts in the phase of prenatal screening. Professionals are presented as mechanical performers of the measures, rather than as significant agents whose actions would convey meanings and norms in the process. The construction of the professional agency is embedded in short factual statements such as *the midwife did the scan* (E7) or *the amniocentesis test was next* (B6). In the latter clause, the focus is on the examination method, and the professionals' action is hidden by referring to technology as the primary agent. This creates an image of the measures being objective, neutral and reliable to the extent that mentioning their performers seems inessential.

The role of the professionals becomes significant only when they take a stance regarding fetal or maternal well-being.

The 12 week scan [nuchal scan] laid my fears pretty much to rest, – according to the experienced midwife everything was fine. (G10)

The mother's description demonstrates her strong confidence in the *experienced* midwife's expertise, which to the mother, obviously was the foundation of her

authority. The midwife is presented as someone whose knowledge is relevant and definite to the extent that it is to be quoted. The midwife's authority is strengthened in the mother's description by her emotional relief that originated from the midwife's professional observations and conclusions.

Termination of pregnancy on the grounds of prenatal diagnosis

When the mothers look back at the times of receiving their fetus' diagnosis and the decision to terminate the pregnancy, some of the mothers leave their own agency fully unspecified and use only technical, formal and externalized language in their descriptions (e.g. *termination, wk 14, (D1)* or *a problem was identified during the anomaly scan: x dd.mm.yyyy (C1)*). More typically, however, the mothers describe the decision-making after being informed about their fetus' disability in strong emotional terms such as *one of the worst things of my life (F7)*, and even as being an experience so painful that *the thought of killing yourself as well crosses your mind (B1)*. Their position in the decision-making process was fluctuating between the exercise of agency and the denial of having an actual possibility of choice.

My husband and I discussed it together and we came to the conclusion that if the situation really turned out to be as bad as it seemed, the only option would be termination– we decided to apply for an abortion. (E2, 6)

I started crying pretty hysterically– I've been grateful for the fact that the case was so definite – there was no hope. I really can't say what I'd have done, though, if the whole thing hadn't been quite so certain. (G4)

The extracts show a tension between mothers' way to attribute a decision to terminate pregnancy to their own control and to explain it in terms of serious, unchangeable medical conditions. On the one hand, mothers describe the decision-making process in terms of conscious reflection and strong agency (*My husband and I discussed, we came to the conclusion*) but then again, the choice of words in their descriptions imply that the decision was not really within their control (*the only option would be, the case was so definite – there was no hope*). Thus, although they communicate the intentionality of the decision, they also present themselves to be partially unaccountable and, due to medical reasons, forced to settle for termination.

In contrast to the phase of prenatal screening, actions of the professionals are at the center of attention regarding the descriptions of both being informed about the fetus' impairments as well as when choosing whether to terminate the pregnancy. Regarding this phase of the termination process, the mothers do not emphasize the received knowledge or performed measures as such but, above all, they evaluate the way the information was given to them and the way the measures were performed.

I was treated really well and everything, but as far as getting any information, you were on your own– After the initial diagnosis was made, the only source of information was the Internet and the Angel's Touch chat forum. No other support or information was given from anywhere, and the feeling of not knowing while waiting for the final results was horrible– You had to search the Internet and the Angel's Touch forum yourself to get any decent information– They just gave me a piece of paper [= a brochure], but that's not the same as actually talking it through with someone in person, at the family clinic or wherever. (F3 – 4, 8)

In this extract, the mother speaks positively about her treatment in general, but also expresses dissatisfaction regarding the doctor's laconic communication (the quality

of delivering information). Extreme expressions such as *the only source of information was, no information was given from anywhere, the feeling of not knowing was horrible* and the so-called zero-person construction of the utterances reinforce an image of the mother's situation as extremely inconvenient. In addition, the zero-person utterances construct the lack of information as a typical and general experience that could happen to anyone who has to go through a similar experience.

Although the source of the knowledge remains unidentified in the mother's account, the knowledge can be understood to derive from professionals as opposed to information the mother had acquired herself as a layperson. The description also contains one reference to a concrete act of a professional (*They just gave me a piece of paper*) which is clearly depicted as inappropriate. The mother, however, does not specify the professional who acted indifferently towards her. All in all, the mother's message seems to be that she was forced to be active, to practice agency in an overwhelming situation where she would have rather preferred to count on the help of the professionals, on their own initiative. Thus, the extract expresses the mother's feeling of helplessness as well as invites professionals to take the position as authorities of appropriate knowledge.

He [the doctor conducting the examination] was very kind – The midwife who did the scan before the doctor arrived was really tactless when she found something was wrong – When he [the senior physician] left he said he was sorry for the unpleasant news. – [During the abortion] I was given pain relief whenever I needed it, and nobody seemed to mind even when I felt ill and was sick on the floor. – The delivery was quick. I was allowed to deliver in a hospital bed, not on one of those horrible potties. The midwife supported and encouraged me, just like any other birth. – We were allowed to look at him in peace. He was only taken away when we were ready. – Everything went well, the placenta delivered intact and there wasn't much bleeding, so we were allowed home the same evening. So a big thanks to the X department staff, really. (E3–4, 8 – 10, 13–14)

In this extract, the mother's focus is on the interactional skills of the professionals (the quality of giving emotional support). The description contains various positive, affective expressions which refer to the professionals' way of acting. These descriptions depict the situation as a positive experience (under the circumstances) to the extent that the professionals deserve acknowledgement for their thoughtfulness. The text is written in an active and open form, where both the mother's own experiences and the action of the professionals become transparent to the reader. The most important features in the actions of the professionals seem to be their undivided concentration on the parents' needs regarding, for example, pain management and their need for professional's presence as well as for the parents' own private time at the time of bereavement.

The time after the termination

The lack of professional support is the most striking feature in mothers' descriptions about the life after the termination. Although they give examples of the unofficial help such as peer support, their accounts mainly centre around the insufficiency of appropriate support.

THERE'S NO REAL CARE AT ALL, ITS JUST GET THE FETUS OUT AND SEND THE MOTHER OFF. Nobody's interested in the mother's psychological well-being. (D5–6)

It's up to you to get yourself some sort of counselling– There's no support group or anything, and the hospital doesn't even put you in touch with a psychotherapist who you could talk to– Luckily I got help from the hospital pastor. (A 12)
You're left pretty much out in the cold after the abortion. More help should have been offered. (B8)

The extracts are strikingly unfavourable regarding professionals' actions and omissions after the termination of pregnancy. The use of negations (e.g., *there's no real care at all*, *nobody's interested*, *there's no support group*) discloses mothers' unfulfilled expectations for the expected professional support. Unrealized expectations are also accompanied by a normative view that more extensive and appropriate support for the mothers should have been available. This appears especially clearly in the last extract where the mother indicates by means of directive and binding modal expression that *more help should have been offered*. Otherwise, mothers' descriptions of the life after the termination are full of emotionally charged expressions that reflect their mixed feelings about prenatal diagnosis and the resulting selective abortion.

After the abortion came tears, sorrow, and emptiness. Life was turned completely upside down, like the rug had been pulled from under your feet, everything you'd dreamt of had to be buried, and you had to start planning life all over again.– I no longer live in an 'it'll never happen to us' glass bubble; I've learned to value health more, I've learned that the world is incredibly unfair. The experience has left me bitter, angry and envious of others. (H5–6)

Life somehow went on in a strange way, although the months afterwards were pretty bleak– Still, it's easier to deal with the idea and to say that the baby died, as opposed to being aborted effectively by your own choice. You can get through an abortion, but you never forget it, and it changes who you are – how you see yourself. I suppose you try to harden yourself.– It's been over a year since the abortion, and I still sometimes have tears, and the feeling that something's missing from our family. Guilt plays on your mind. (B1–2, 4)

In the first extract, the mother first describes her feelings by means of a list of affective noun-like nominalizations. The focus is on individual emotions and experiences which are separated from the subject, the writer herself. This way of writing together with the use of the passive form distances the mother from the description and produces an image of powerful emotions that are not under her control and, hence, she has no means to control their manifestation either. In the second extract, the same kind of coping is described by means of the phrase *life somehow went on in a strange way*. In this phrase, the dominion of the negative emotions is emphasised by an image that the mother cannot lean on her own resources to manage, but more like wonders the gradual easement of her life. In addition, the mother of the second extract uses her own agency in the termination of pregnancy as a negative factor which makes her coping more difficult; her child had died due to her own choice. She makes a comparison between an uncontrollable and unforeseen death of one's child on the one hand, and the selective abortion on the other, where the former would not trigger the kinds of feelings of guilt which she had to live with.

The descriptions are not, however, completely filled with agony. They also contain positive aspects in otherwise negative accounts. The common feature of the accounts is the construction of prenatal diagnosis and the termination of pregnancy as a kind of turning-point in one's life, after which something has either inevitably

changed (*it changes who you are – how you see yourself*, B) or which triggered the mothers to intentionally change their lives (*you had to start planning life all over again*, H). Thus, the change may mean addressing an ethically sensitive experience in a resilient manner, and in terms of strong agency, to form a coherent sense of oneself as a good enough person (*I've also had to change my way of thinking*, (G6); *I've realised I'm not such a soft touch after all. I'm pretty strong-willed, once something's decided that's that*, (D2)), or adopting a more passive and embittered victim status in relation to the undesirable circumstances to which one has been exposed to (*I've learned that the world is incredibly unfair. The experience has left me bitter, angry and envious of others* (H5–6)).

Discussion

The women's accounts in our study were diverse and versatile. Some of the mothers described their own agency in very strong terms and emphasized their reflective attitude towards prenatal screening and selective abortion, whereas the others represented the prenatal tests as a self-evident and routine part of the medical journey related to pregnancy. In the latter case, the women were not always able to distinguish clearly prenatal screening from ordinary pregnancy follow-up. This contradicts the official guidelines that dictate that women partaking in prenatal tests should be aware of the distinctive nature of these tests (Ministry of Social Affairs and Health 2007). One possible solution for this dilemma would be to remove prenatal screening from the routines of maternal clinics. After all, the main function of maternal clinics is to secure the well-being of the mother and the fetus. In this scenario, those who wish to know in more detail about their future child's possible impairments could ask for detailed prenatal tests. This kind of arrangement would probably correspond better to the ideal of freedom of choice than the present system where prenatal screening is a routine in which virtually all women take part.

Another problem regarding women's autonomous decision-making is the polarity of roles that the professionals are expected to fulfill. Namely, on the one hand they are expected to act as neutral experts who deliver objective information to parents. On the other hand, they are expected to act empathetically and to support parents emotionally. What united all the women in our study was that they expressed expectations regarding professionals and their actions after something out of ordinary in the fetus had been detected. These expectations, however, do not match easily with the requirement of non-directiveness because it seems to require a certain emotional distance between professionals and clients (Anderson 1999). Especially after the mothers had made the decision to terminate pregnancy, they hoped to count on the healthcare professionals, and expected them to exhibit strong agency and to act determinedly. Yet, according to the mothers' accounts, and contrary to their expectations, the professionals did not offer emotional support nor did they seem to have a clear aftercare agenda. The professionals' perceived weak agency seemed to force the mothers to exhibit strong agency, and find ways to cope with their distress unaided. The mothers described the offered support after the termination as insufficient which in its part prolonged their psychological recovery (see Korenromp et al. 2005, 2007). It appears that in prenatal counseling professionals face a situation where certain principles and virtues of good healthcare, like fidelity to trust, compassion and beneficence (Beauchamp and Childress 2001; Pellegrino and Thomasma 1993) are difficult to reconcile with the requirements of non-directiveness

and autonomous decision-making. In general, prenatal counseling seems to differ from ordinary healthcare where professionals have the permission, and sometimes even an obligation, to *advise* their patients (Santalahti et al. 1998; Williams et al. 2002).

The mothers in our study described the decision-making regarding selective abortion as a matter of a choice between two bad or, as some of them wrote, two wrong options. Either choice would somehow conflict with their personal values. Clearly, one crucial concern for them was to preserve their moral self-worth and cope with the attitudes of other people. This became clear to us already when we first contacted the mothers. They were worried that the research would be used for criticizing prenatal screening, selective abortion, and by the same token, their personal choices. The fact that all the mothers who volunteered to participate in our study reported to have had the kind of situation where they were virtually forced to terminate the pregnancy due to the severity of fetus' impairment, reflects in its part the mixed feelings related to selective abortion. It seems safe to conclude that it is easier for women to tell about their personal experiences regarding selective abortion when they end up terminating pregnancy due to a potentially mortal impairment rather than due to a mild impairment. The mothers in our study described their decision-making as artificial; they really did not have any other choice than to terminate the pregnancy in order to avoid unnecessary suffering. At the end of the day, however, determining what kinds of impairments are severe to the extent that they result in unnecessary suffering, is controversial (e.g. Wertz and Gregg 2000).

Prenatal diagnosis and selective abortion are significant and sensitive issues in the field of disability research. These practices are understandably seen to have an expressive character that is hurtful and demeaning of disabled people. Selective abortion is thus interpreted to send the following message to people with impairments: 'Your birth was a mistake. Your family and the world would be better off without you alive' (Saxton 2000: 160). While we are sympathetic to this view, we have intentionally aimed at refraining from making any normative judgments about the ethics of prenatal screening and selective abortion on the grounds of the accounts of our study – and not merely for methodological reasons. In order to understand the complexity of the phenomenon, we feel that it is crucial in disability research field to give voice to those people who have opted for selective termination. If the various means with the aim to prevent the birth of disabled children are seen to reflect disablism (Thomas 2007) in our societies, then the more we should strive to acquire a thorough understanding of the values and social mechanisms that support this particular form of discrimination. In order to have fruitful social dialogue with the purpose of abolishing sources of discrimination, one would benefit from an understanding about the mindsets of those who, often unintentionally, may contribute to maintaining discriminative attitudes and practices.

References

- Act on the status and rights of patients N:o 785/1992.* <http://www.finlex.fi/fi/laki/kaannokset/1992/en19920785.pdf>
- Antaki, C., M. Billig, D. Edwards, and J. Potter. 2002. Discourse analysis means doing analysis: A critique of six analytical shortcomings. *Discourse Analysis Online 1*.
- Autti-Rämö, I., H. Koskinen, M. Mäkelä, A. Ritvanen, and P. Taipale. 2005. *Raskauden ajan ultraäänitutkimukset ja seerumiseulonnat rakenne- ja kromosomipoikkeavuuksien*

- tunnistamisessa* [Maternal ultrasound and serum screening in the detection of structural and chromosomal abnormalities]. FinOHTAn raportti 27. Helsinki: STAKES.
- Anderson, G. 1999. Nondirectiveness in prenatal genetics: Patients read between the lines. *Nursing Ethics* 6, no. 2: 126–36.
- Beauchamp, T.L., and J.F. Childress. 2001. *Principles of biomedical ethics*, 5th ed. New York: Oxford University Press.
- Broberg, G., and N. Roll-Hansen, eds.. 1996. *Eugenics and the welfare state: Sterilization policy in Denmark, Sweden, Norway and Finland*. East Lansing, MI: Michigan State University Press.
- Bryar, S.H. 1997. One day you're pregnant and one day you're not: Pregnancy interruption for fetal anomalies. *Journal of Obstetric, Gynecologic and Neonatal Nursing* 26, no. 5: 599–66.
- Burck, C. 2005. Comparing qualitative research methodologies for systemic research: The use of grounded theory, discourse analysis and narrative analysis. *Journal of Family Therapy* 27, no. 5: 237–62.
- Emirbayer, M., and A. Mische. 1998. What is agency? *The American Journal of Sociology* 103, no. 4: 962–1023.
- Fairclough, N. 1992. *Discourse and social change*. Cambridge: Polity Press.
- Fuchs, S. 2001. Beyond agency. *Sociological Theory* 19, no. 1: 24–40.
- Garel, M., S. Gosme-Seguret, M. Kaminski, and M. Cuttini. 2002. Ethical decision-making in prenatal diagnosis and termination of pregnancy: A qualitative survey among physicians and midwives. *Prenatal Diagnosis* 22, no. 9: 811–7.
- Government decree on screenings 1339/2006. <http://www.finlex.fi/fi/laki/kaannokset/2006/en20061339.pdf>
- Hakulinen, A., M. Vilkuna, R. Korhonen, V. Koivisto, T.-R. Heinonen, and I. Alho. 2004. *Iso suomen kielioppi* [The Finnish Grammar]. Helsinki: Finnish Literature Society.
- Halliday, M.A.K. 1985. *An introduction to functional grammar*. London: Arnold.
- Hall, S., L. Abramsky, and T. Marteau. 2003. Health professionals' report of information given to parents following the prenatal diagnosis of sex chromosome anomalies and outcomes of pregnancies: a pilot study. *Prenatal Diagnosis* 23, no. 7: 535–8.
- Halonen, M. 2008. Person reference as a device for constructing experiences as typical in group therapy. In *Conversation analysis and psychotherapy*, ed. A. Peräkylä, C. Antaki, S. Vehviläinen and I. Leudar, 139–51. Cambridge: Cambridge University Press.
- Hammersley, M. 2003. Conversation analysis and discourse analysis: Methods or paradigms? *Discourse and Society* 14, no. 6: 751–81.
- Jallinoja, P. 2001. Genetic screening in maternity care: Preventive aims and voluntary choices. *Sociology of Health and Illness* 23, no. 3: 286–307.
- Jennings, B. 2000. Technology and the genetic imaginary: Prenatal testing and the construction of disability. In *Prenatal testing and disability rights*, eds. Erik Parens and Adrienne Asch, 124–44. Washington, DC: Georgetown University Press.
- Korenromp, M.J., G.C.M.L. Page-Christiaens, J. van den Bout, E.J.H. Mulder, J.A.M. Hunfeld, C.M. Bilardo, J.P.M. Offermans, and G.H.A. Visser. 2005. Long-term psychological consequences of pregnancy termination for fetal abnormality: A cross-sectional study. *Prenatal Diagnosis* 25: 253–60.
- Korenromp, M. J., G.C.M.L. Page-Christiaens, J. van den Bout, E.J.H. Mulder, C.M.A.A. Potters, J.J.H.M Erwich, C.J.M. van Binsbergen, J.T.J. Brons, J.R. Beekhuis, A.W.J. Omtzigt, and G.H.A. Visser. 2007. A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenatal Diagnosis* 27: 709–16.
- Kurri, K., and J. Wahlström. 2007. Reformulations of agentless talk in psychotherapy. *Text and Talk* 27, no. 3: 315–38.
- Louhiala, P. 2004. *Preventing intellectual disability: Ethical and clinical issues*. Cambridge: Cambridge University Press.
- Mansfield, C., S. Hopfer, and T.M. Marteau. 1999. Termination rates after prenatal diagnosis of Down Syndrome, Spina bifida, Anencephaly, and Turner and Klinefelter syndromes: A systematic literature review. *Prenatal Diagnosis* 19, no. 9: 808–12.
- Mattila, M. 1999. *Kansamme parhaaksi: Rotuhygieneia Suomessa vuoden 1935 sterilointilakiin asti* [For our nation's best: Racial hygiene in Finland until the 1935 sterilization act]. Helsinki: Suomen Historiallinen Seura.

- Medical research act No: 488/1999*. <http://www.finlex.fi/fi/laki/kaannokset/1999/en19990488.pdf>
- Ministry of Social Affairs and Health. 2007. *Seulontaohjelmat: Opas kunnille kansanterveys-työhön kuuluvien seulontojen järjestämisestä* [Screening programmes: A handbook for municipal authorities]. Sosiaali- ja terveysministeriön julkaisuja 2007:5. Helsinki.
- Mykkänen, J. 2010. *Isäksi tulon tarinat, tunteet ja toimijuus* [Becoming a father – types of account, emotions and agency]. Jyväskylä Studies in Education, Psychology and Social Research 382. Jyväskylä: University of Jyväskylä.
- Pellegrino, E.D., and D.C. Thomasma. 1993. *The virtues in medical practice*. New York: Oxford University Press.
- Press, N. 2000. Assessing the expressive character of prenatal testing: The choices made or the choices made available? In *Prenatal testing and disability rights*, eds. Erik Parens and Adrienne Asch, 214–33. Washington, DC: Georgetown University Press.
- Potter, J., and M. Wetherell. 1987. *Discourse and social psychology: Beyond attitudes and behaviour*. London: Sage.
- Santalahti, P., E. Hemminki, A.-M. Latikka, and M. Rynänen. 1998. Women's decision-making in prenatal screening. *Social Science and Medicine* 46, no. 8: 1067–76.
- Saxton, M. 2000. Why members of the disability community oppose prenatal diagnosis and selective abortion. In *Prenatal testing and disability rights*, eds. Erik Parens and Adrienne Asch, 147–64. Washington, DC: Georgetown University Press.
- Shakespeare, T. 1998. Choices and rights: Eugenics, genetics and disability equality. *Disability and Society* 13, no. 5: 665–81.
- Silverman, D. 2005. *Doing qualitative research: A practical handbook*. London: Sage.
- Thomas, C. 2007. *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. Basingstoke: Palgrave Macmillan.
- Vehmas, S. 2001. Just ignore it? Parents and genetic information. *Theoretical Medicine and Bioethics* 22, no. 5: 473–84.
- Wertz, D.C., and R. Gregg. 2000. Genetics services in a social, ethical and policy context: A collaboration between consumers and providers. *Journal of Medical Ethics* 26, no. 4: 261–5.
- Wetherell, M. 2001. Debates in discourse research. In *Discourse theory and practice: A reader*, eds. M. Wetherell, S. Taylor and S.J. Yates, 380–99. London: Sage.
- Williams, C., P. Alderson, and B. Farsides. 2002. Is nondirectiveness possible within the context of antenatal screening and testing. *Social Science and Medicine* 54, no. 3: 339–47.