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‘PRENATAL SCREAMING’ DECISION-MAKING FOLLOWING A PRENATAL DIAGNOSIS OF DOWN SYNDROME

Abstract

Within the framework of the OTKA K111917 research entitled ‘From Equal Opportunities to Taygetus?’, we examined, through narrative interviews, how mothers took a decision after learning of the positive Down Syndrome diagnosis of their foetus, and who and what events influenced their decision to go on with their pregnancy or not. In our article, after a focused analysis of the narrative interviews we conducted with 10 women about their life, our aim was to draw attention to the complexity and stratification of the social context and to pose questions. Our goal was to reveal the cultural background of the decision-making and the pieces of information which seem simple and unequivocal at first sight, in order to gain a clearer picture of the social and medical attitude and knowledge that surrounds mothers pregnant with a Down Syndrome foetus.

Key-words: feminism, disability studies, foetus diagnosis, power, risk, decision-making

1. INTRODUCTION

As part of the OTKA research, we conducted narrative interviews with six women who opted for abortion after their foetus had been diagnosed with Down Syndrome and with ten other women who decided to give birth to a child considered disabled. In this study we analyse only the interviews conducted with the women who decided to go on with their pregnancy. The concepts of prenatal screening, motherhood, the female body and normality are analysed within a feminist interpretation and within the framework of disability studies, since we are interested to find out what factors and/or people could influence women’s decisions to continue with their pregnancy.

In the social discourse related to Down Syndrome different groups participate with sometimes overlapping or contradictory narrative content. Our current knowledge about Down Syndrome derives, on the one hand, from the knowledge and experience of people who live with the syndrome, their families, relatives and friends and on the other hand, from the scientific knowledge of professionals in different fields, health care workers, special education teachers, social workers etc. They use different discursive categories and deal with different contents of the lives of the people concerned. Besides, they also know about the economic, political, legal and historical dimensions of the life of the people with Down Syndrome, which is also part of the discourse. Apart from this, disability studies offer a new framework to structure and critically interpret the knowledge and therefore our study has a multi-disciplinary character as well (Yong 2007, p. 5).

The research tries to answer questions on the basis of critical feminist theory of disability studies and by conducting and analysing the interviews with women whose life circumstances were described above. When interpreting them we make use of the

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theories of anthropology, sociology, history and law, as well as the results of genetic diagnosis. The research and analytical method considers the life-story narrative as a discursive event and focuses on the continuous changes of the narrative subject, whilst at the same time dissecting the issues of reproduction, the evaluation and devaluation of female and disabled bodies, the parameters of normality and disability and the complexity of social constructions.

We focus in this study, amongst the various factors influencing the decision, on the reaction of the health care system, the relevance of the information provided at the moment of establishing the diagnosis, as well as the health of the foetus.

After formulating the research questions we briefly introduce the methodology and the sociological features of the interviewees involved in the study. In the following chapter we try to present the process of prenatal diagnostics and the different layers of its social interpretation by analysing the power dynamics of the agencies participating in the process. We draw attention to the doctors' ambition to exercise power and control in the Foucault sense during the scanning procedures and to the technicalisation of the pregnancy. We point out the changes in the mother's role and the possible impacts of the medicalisation of pregnancy or motherhood.

After describing the attitudes towards Down Syndrome in Hungary and the corresponding changes in the statistical data, we present the experiences gained from the ten narrative interviews in relation with the prenatal diagnostics and we compare it to the international experiences within the context of feminist disability studies literature. We also mention the Susan Wendell concepts of the 'healthy disabled people' and 'unhealthy disabled people' and their appearance. In our paper we talk about the experiences and decisions unfolding from the narratives. And finally we summarise our results and point out the layers of analyses of the present study which will be published in the future in separate articles.

2. RESEARCH QUESTIONS

Important questions of feminism are echoed in our research questions: how the subject is constituted in the Foucault sense, how power, knowledge and resistance create subject compositions? What is the balance between inscription, subordination and agency? We pose the question of what it means to a mother to expect a child regarded as disabled. What are the social/cultural factors determining our concepts and practices related to motherhood, a normal foetus, a high-risk pregnancy or social commitment? We ask the question of what is considered risky, normal, disabled or responsible behaviour.

As to agency and active subjectivity, we should mention that we do not consider agency as a normative concept, but much rather a dynamic force line in a given context. We depart from post-structuralist theories which profess that the individual is both the object and the subject of power, so agency exists only if there is a continuous movement between choice, inscription, active subjectivity and subordination, or only when it is possible to change the rigid power structure or re-interpret the normative experiences and attitudes.

All this happens in a complex discursive space where the agency of self-representation can exist only if the majority society 'listens' to the stories of women and is capable of interpreting these as a desire to break out from the power structures. In order to achieve this, it is necessary to widen the discursive space and one of the possible methods is to apply narrative interview-techniques through which we can listen to the voice of those affected.

In our research we were interested in finding out who and what events influenced women in their decision-making, whether the health care system provided them with sufficient, relevant and neutral information about Down Syndrome, the life of people living with the disability and what the available services are in our country? Our goal was to explore, understand and demonstrate the macro-level cultural and social mechanisms and the cultural context which could play a role in the decision-making of the expecting mothers. Our primary research question was in which cultural discourse, what information, attitudes, expectations and ideas influenced their decision of either continuing with or terminating their pregnancy, i.e. how the interviewees' stories relate or converse with the social discourse.

We would like to emphasize that neither as researchers nor as private individuals do we have the right to judge the narratives presented by the women, so we do not label their story, nor do we give advice, make proposals or pass judgements. We are merely gathering social reflections which point to the complexity of the questions and their cultural determination.

3. RESEARCH METHOD AND RESEARCH SUBJECTS

In our research we have used the so called narrative interview technique. Narrative analysis is a collective concept, which contains many methods of cognition. This is the least directive methodology of all the known interview techniques. Whilst the presence, gender, age and behaviour of the interviewer has an impact on the situation, it influences the thread of thoughts or use of language of the interviewee less than in the case of pre-formulated questionnaires (Creswell 2007; Curie 1998). During the interview, after getting informed consent, we explained to the interviewees the main subject of the study and asked them to tell us their life-story. Thus the interviewees told their story in their own words and in the order and style that they considered important. In the second stage of the narrative interviews, after having listened to their life-story, we asked them to elaborate on some aspects of the elements and events they did not detail. With the consent of the interviewees we recorded the interview which later was transcribed (Hernádi-Kunt 2015).

Although within the framework of this study the interviewees became a group, the starting point of the research was that the interviewees were a complex and loose group of different women with different identities. We got hold of the interviewees by placing adverts in social media and also with the help of key people dealing with the subject. Participation in the study was always voluntary and anonymous. Our study did not gather the narratives of women living in extreme poverty or in multiple deprivation, but we consider it very important to carry out a similar research about this segment of the population, where the complex impact of intersectionality is even more marked. The interviewed women were not a homogenous group based on where they lived or their level of schooling, age, or marital status. Those invited for interview were open and interested women with good advocacy skills who were happy to make a statement, and for many of them it was not the first time that they had spoken about their life-story.

For each of our interviewees the Down Syndrome was established during pregnancy, except in one case where another type of health disorder was diagnosed, yet the baby was born with Down Syndrome. There was one woman among the interviewees who, after having learnt about the Down Syndrome diagnosis, decided to continue with her pregnancy, but in the end the baby did not have Down Syndrome as far as she knows. We regarded these narratives as nevertheless relevant for our

research, since we were investigating the circumstances of decision-making and in the case of this woman (whose child was not born with Down Syndrome) and who took her decision believing that the child would have Down Syndrome. We also included the other case, where the mother was informed about another type of disorder yet she decided to continue with the pregnancy even if her child would have to live with Down Syndrome. We also conducted an interview with a woman who took such a decision twice, since during two pregnancies she got a positive Down Syndrome diagnosis, yet she decided to go on in both cases, although in the end it turned out that only one of the children was born with Down Syndrome.

4. POWER STRUCTURES IN PRENATAL SCREENING

Throughout the whole research, and also in the current paper, we felt the need to understand the experiences of these women. Our research widens and surpasses the stereotypical definitions, construction and complexity of womanhood, motherhood, normality or disability. This construction and complexity can be most strongly perceived in the personal experiences narrated by the mothers. This article, therefore, gives 16 literal quotations from the narrative interviews.

Our research aims to show the similarities and differences of the self-representations unfolding from the narratives provided by the interviewees. The analysis of the interviews brought to the surface several similar features, but also some biographical strategies that differ substantially from one another. The similarities derive from the embodied experiences and the cultural narratives of motherhood, disability, femininity and normality. The differences are due to the individual lives and the variety of interpretations. The diversity of narratives outlined the complexity of the issue, whilst the *personal* and *cultural* aspects outlined the meeting points as well as the patterns of the power field.

The narratives of the interviewees acquire a political role if we interpret them as a method to review the cultural and social norms. Although the space of discourse in which the narrators place themselves is relatively narrow, their narration confuses and breaks down the established concepts of power.

According to Foucault power is a mechanism of disciplinary power. And this disciplinary power is achieved by surveillance. This means that the power becomes efficient by the tool of surveillance. There is no need for external control, because of visibility an internal urge makes us docile disciplined and normal citizens. And those who fail to comply the rules are stigmatised as irresponsible and dangerous to the society (Foucault 1990; 1982).

'[...] the attitude of the health care workers. That was very bad. They tried to label us as irresponsible parents, because we were not ready to undergo the intervention. Whereas I think that we took this decision consciously. And everywhere we just got this, the worst. Whether we knew what it meant to have a disabled child and how horrible it would be.'

The technology of power described by Foucault infiltrates our everyday life: power is gradually extended over our bodies. The body is the object and target of power and the place of resistance at the same time. The supervision and control of the body is exercised in the institutions of the dominant ideology and prescribe what happens in everyday life to our body. We do not notice it and it influences every area of our life.

But when Foucault writes about docile bodies, he considers the body as if there was only one type, as if there were no differences between the embodied experiences of men and women. He does not reveal the disciplinary practices and activities which impact only the female bodies, forcing and shaping them in a way that they meet the social requirements.

In our analysis, apart from the linguistic discursive space, we focus on the embeddedness of memories, because although memories change and transform over time, they are always embedded and rooted in the body.

Our starting point is that by now the body has become the metaphor of danger and worries, 'it has become a property the ownership of which is a responsibility' (Csabai-Erős 2000, p. 142). The responsibility of the individual has become more and more pronounced in the acceptance of discipline, control and the avoidance of risky behaviours.

By discipline we mean the micro-mechanisms of power techniques of 'surveillance' (e.g. ultrasound exams) or *objectification* (e.g. doctors considering the foetus an object), *normalisation* (e.g. genetic screening) and *control* (Foucault 1990; 1982). In this situation the female and expectant female and foetus bodies become subordinated. We are interested to learn how reproductive practices under the auspices of bio-medicine influence the thinking and the behaviour of the individual.

Discipline means mostly the discipline of the female and pregnant female bodies. By discipline we mean the power dynamics that avoid risks, objectify and control pregnancy and which surround our ideas related to normality, femininity, ability, disability or a normal society.

'[...] there are some minor anomalies, which can be anything, because there is a kidney pelvis dilatation. That is possible because he is a boy. And they said that we should keep on checking him [...] and so they did the ultrasound here and there, left side right side, I don't know.'

Observation and monitoring are partly due to the fast development of bio-medicine and technology. Medical science is capable of mapping the human genome, so it is possible to determine precisely the degree of our normality even before birth. In Hungary foetal tests are available and in some cases also compulsory. (Takács 2015)

Practices to discipline the female body and the concepts around normality can be interpreted only within a given cultural and social context. We want to analyse and understand this context. It is obvious to us that, e.g., the medical-biological decisions related to disability (what type of disability is tolerated in the foetus, what are those types where much effort is invested in order to eliminate it, in what cases is it considered important to intervene etc.?) are taken in accordance with cultural values.

'It is in the interest of society to have productive and healthy citizens, and therefore testing and termination of potentially impaired or unhealthy babies are required' (Shakespeare 2014, p. 130). Scientific knowledge has an exclusive and normative character, so there is a huge pressure on expectant women after the diagnosis. The responsibility to decide is theirs. But how independent is their decision-making under the pressure of the society?

'[...] when they realised it, then many people blamed me, saying that everything is because of me [...] anyway, always, before and during the pregnancy and also after birth, if a problem arose, I alone was responsible for that.'

'And there are those compulsory tests, where you are supposed to go. Now, for example, I would probably not go.'

Health tests and services, as well as discourses qualifying a behaviour as risky, are the way in which discipline is exerted by society. These represent everything that society considers fit, normal, risk-avoiding and healthy during the pregnancy with regard to eating, exercising and behaviour.

This aim and worry is represented by the ever growing menu of prenatal tests offered. This is what Ettore writes about the issue: 'The workings of reproductive genetics expose the long-standing feminist unease that the medicalisation of reproduction, pregnancy and childbirth has more often than not been against the interest of pregnant women, making them objects of medical care rather than subjects with agency and rational decision-making powers' (Ettore 2002, p. 20). The appearance of genetic screening continues to raise new and important questions related to disability, normality, autonomy and valuable life. Tremain, making use of Foucault's bio-power concept, establishes that screening techniques have an excluding and normalising function. He states that the power 'ensures that impairments are generated in utero' (Tremain 2006, p. 36).

Feminism and feminist disability studies tackle questions of the maternal body too and how that shapes identity. From Foucault's perspective motherhood, as a social institution of key importance, strengthens subordination, but it also offers the possibility of self-definition, empowerment and agency. Motherhood is an accentuated part of the stereotypical construction of femininity.

The sanctity of motherhood, the abledness of the nation and the new technologies are organically interlinked with control, supervision and normalisation. One of its pronounced manifestations is the medicalisation of pregnancy. The presence of medical gaze and the controlling attention permeate the days of pregnancy. To be sure of the perception of your own body has become a risky behaviour, which takes less account of medical results (Sawicki 1999; Parens–Asch 2000; Tremain 2005; 2006). It has become natural that women are referred for more and more tests and screening, whilst mothers' intuition and experience are becoming increasingly marginalized. Erzsébet Takács makes reference to the belief in the omnipotence of technology: 'the pseudo-objectivity of the 'foetal image' introduces a 'normless and valueless' reference - often the only possible one - that appears in place of reality and truth, as opposed to the experiences and intuitions of women who thus become false witnesses.

The authenticity of technology creates a 'reality' and a 'truth' which can contradict the internal experiences of the subjects... childbirth has become more a technique and less something where mother or foetus are important' (Takács 2015, p. 401). As a consequence of medicalisation women trust their own competence less and less. 'Pregnancy frequently is full of worries and fears, and women's faith in their own competence of giving birth and the wisdom of their own body are utterly weakened or even totally lost among the professionals and machines, not to speak of the natural experience of pregnancy and birth' (Varga–Andrek–Herczog 2011, p. 244).

The narrative of the interviewees reveals that, in hindsight, they feel that the successive tests made it impossible for them to enjoy their pregnancy. The medicalisation of pregnancy is considered a negative practice by them.

'Because I was expecting a baby and I was also gravid. This word 'gravid' was something grave indeed, because you need to run here, to run there, that

you are pretty old, so have this checked! And this was horrible, a disaster. I wouldn't do it like this again. I wouldn't go to half of the tests, or even less, but instead I would just watch the telly or the moon or the stars or the sun or whatever. And I would be happy about the little baby who lived in my belly. I would not allow anybody to call me gravid again, because I was just expecting a little baby.'

The medicalised system and the quick sequence of tests prevent women from a well-considered and relatively free decision, since they can always focus only on the next examination.

'There was something like this, I think, that during the second genetic examination the blood test result was on the limit. It is weird that I do not really remember now what it was exactly'.

There is a fierce discussion taking place among researchers, activists, parents and the affected concerning prenatal screenings and how to approach selective abortion. The voice of those who support technical developments and welcome diagnostic procedures becoming more and more precise can also be heard. They consider it a good thing that there are procedures that provide information about the foetus. There is an advert on the internet where mothers are fighting to get the most sophisticated tests available free for every pregnant woman. Others, on the other hand, consider these tests dangerous. They think that these tests convey prejudices against people living with a given syndrome and the message is that it is not worth living with a disorder that can be screened. They are afraid that if tests become wide-spread, the possibility of individual choice will very soon become 'social necessities' (Wendell 1996, p. 156).

The participation of expectant women in genetic screening and their chance to decide on the basis of informed consent has not been fully investigated so far. The article published by Bekker et al. in 2004 tackles exactly this question. They underline that in the UK the primary goal is to provide women with the right to take a decision about whether they want to participate in prenatal screening of Down Syndrome or not. In order to achieve this, it is important that the gynaecologist and health care workers cooperate together with the pregnant woman and provide her with the most precise and full information and that they remain absolutely neutral about the women's decision. Making reference to other pieces of research carried out earlier, the authors establish that it is the women's knowledge of Down Syndrome and their attitude towards abortion which predominantly determine their decision. Hungarian studies are in total agreement with the opinion voiced by the pregnant women participating in the British research, namely that they did not receive sufficient information during their pregnancy about what alternatives existed to the diagnostic procedures. They felt that they were expected to say yes to the compulsory diagnostic tests and later they said that they could not assess the advantages and disadvantages of taking or rejecting the tests (Bekker–Hewison–Thornton 2004).

In the UK a variety of intervention methods have been developed to support pregnant women and health professionals in the decision-making process. The so-called decision-analysis is one such tool. It is based on the perspective model of decision-making and uses the subjective expected utility (SEU) theory. The SEU claims that individuals make decisions 'by balancing evaluations of the likelihood of outcomes occurring with their own preferences' (Bekker–Hewison–Thornton 2004, p. 266). The method aims to make the individual's values and viewpoints explicit with regard to the

expected result of the decision, and to support him/her in finding the balance between their own values and the possible risks. Decision-analysis is the technique used in the UK in the process of prenatal diagnostics, but hardly any research has been done to find out its efficiency. The Bekker–Hewison–Thornton study in 2004, nonetheless, targeted explicitly the role of decision-analysis methodology in the case of pregnant women who needed to take a decision concerning a prenatal Down Syndrome diagnosis they had received. The authors also draw the attention to the possible risks of the decision-analysis method with regard prenatal diagnosis. They expressed their worries that if pregnant women are encouraged to use the method systematically in order to evaluate their decision that can constrain the decision-making process. It can increase the anxiety of pregnant women and can lead to them regretting their decision. The above mentioned research showed in fact that women using decision-analysis did not feel that the consultation was more directive nor did it give them more concern, instead the perceived risk was more realistic to them and the decisional conflict was milder (Bekker–Hewison–Thornton 2004, pp. 265–266).

Both Hungarian and foreign studies corroborate that the decision-making process can be greatly enhanced if the health care service provides conscious, systematic and relevant information and if it ensures conscientious consultation possibilities.

5. PRELIMINARY RESEARCH RESULTS

In this paper we are presenting some preliminary research results. We summarise the focused consequences of the 10 interviews we conducted with women who after a positive Down Syndrome diagnoses decided to continue with their pregnancy and keep the foetus. In the analysis we focus on the reactions of the health institutions and the information that was shared, as well as the health status of the foetus, because these are the factors that potentially influence the decision.

The number of births in Hungary has not reached 100,000 in recent years, (Kapitány–Spéder 2015) and the number of those born with Down Syndrome annually is between 150 and 170. The data of the National Registry of Congenital Anomalies (VRONY 2015) show that this number has not changed in the last 15 years. Since 1985 a prenatal test has been available to screen for Down Syndrome. According to the VRONY database the frequency of Down Syndrome, including the cases diagnosed during pregnancy, is 1.64% (MoH 2012). According to the latest data 151 fetuses were diagnosed with Down Syndrome in 2013, all 151 were aborted. In the case of the 24 live-born children Down Syndrome was not diagnosed during pregnancy (VRONY 2015).

Hungary is essentially characterized by a strongly medicalised discourse concerning disability. Disability is something pathological with deviant difficulties, it is an individual non-compliance and a medical problem. The top priority is *prevention*. When this is not possible, then *cure* and, as a last resort, *elimination*. Complementing Titchkosky's and Michalko's interpretation, this discourse defines not only disability, but also disabled people, as objects (Titchkosky–Michalko 2009, p. 4). From the medical model perspective, the concept of disability is a bad 'thing', and it is a term attached to a disabled person who functions as the object of the interventions and professional policies. Those who exercise power in this model are the decision-makers at different levels. The leading actors are the professionals: doctors, health workers, researchers, politicians and the managers of institutions. At one level, apparently the function is to correct disability and to serve people living with disabilities by minimizing the negative impacts of disability in everyday life. At another level, it is to maintain

the basic structure dominated by professionals and, simultaneously, the allocation system of finances and to attach and delegate everyday power to the professionals.

Katalin Heksch also made a declaration concerning the general aversion towards Down Syndrome: *'The truth is that these concerns are not entirely unfounded in our country. Today in Hungary, compared to western countries, parents much less willing to accept a baby with Down Syndrome, and in our country a diagnosis at the foetal stage is almost synonymous with abortion and children born with a malformation are often left in the hospital. (In comparison, for example, 70 percent of British mothers accept the birth and upbringing of a child known to be ill)'* (Heksch 2016).

The stories told by the interviewees echo the prejudices and negative attitudes of society.

'It is very hard to cope with the, how shall I put it, with the negative attitude towards unhealthy children. Starting from the visiting nurse, well, everybody else too.'

'[...] what I felt was, yes, that they are a millstone around the neck of society. This is what you can feel. You feel it with strangers.'

One of our interviewees, as a reaction to the negative judgments, is considering leaving the country:

'It seemed difficult then when I took my Down Syndrome child to the playground, what will he get there? Because I was convinced that they would not look at me when I walk through the street with him, everybody will, how shall I say, will look at us with aversion. At me and at him too. I can stand it. It would not be a good feeling, but not because of my child, but because of their attitude. It would be a bad feeling if they looked at him with aversion, if I felt that the others didn't feel like looking at him. But the worst of all would be, if he sensed that too. If, for example, I took the child to the playground and the other parent dragged his child away from him so that they would not play together. How could he stand that and how could I stand how he feels. One of the solutions, my husband said, is that if he is born with Down Syndrome then let's leave the country immediately. To a country where we know that the attitude towards not only the disabled, but also towards, say, the Roma or other people with different skin colour is better.'

5.1. Institutional and professional attitudes

Though from the Professional Protocol for Prenatal Screening and Diagnostic Procedures of Down Syndrome of the Ministry of Human Capacities in 2016 it appears that during the genetic consultation professionals are obliged to provide information so that the pregnant women can make informed decisions and that the advantages/disadvantages have to be clearly explained (MoHC, 2016). However, listening to the life-stories of the interviewees, questions arose with regard to the quantity and relevance of the information and the neutrality of health care services.

Only one single narrative mentioned that the doctor outlined both the risks and the advantages during the consultation.

'So he explained the difficulties too of the Down Syndrome. And he also said that it shouldn't be like that by any means and I don't know what else. He

represented a very honest medical attitude and it did help for sure [...] there they did a perfect job and they were ethical too.'

In light of the Protocol of the Ministry, the calls for screening of the prenatal centres, as well as listening to the life-stories of the interviewees, questions arose with regard to the quantity and relevance of the information and the neutrality of the health care services.

The interviews showed that on the basis of the diagnosis the probability of Down Syndrome is the primary, in most cases the only piece of information that is shared with the pregnant woman. However, there are many examples where the results are not reliable and even a high percentage of probability does not mean a certain diagnosis.

'The chance that the child has Down Syndrome is 1 in 40.'

'And then they said that the probability that the baby has Down Syndrome is 99.9%.'

'And indeed the nuchal fold was thicker and he held his neck as if he had a little scarf.'

'In the end, according to the integrated test the risk was 1 in 430, which is considered a medium risk and in theory they proposed to repeat the amniocentesis.'

Doctors explain to expectant women what further tests are available, as a kind of information.

'[...] and he took out a brochure about the additional tests which would have to be paid for.'

'[...] that I should go on to the chorionic villi, or I do not know what kind of tests.'

'[...] the doctor did not like something at all, so he said that he recommended the amniocentesis anyway. And I should decide what I want to do, but to him this child is suspicious.'

On the basis of the narratives we can see that after having been informed about the risks, the next step for the pregnant women is to gather more information about the received diagnosis.

'And at that time I have spared tasks for myself. I was walking with eyes wide open thinking what could be good for what.'

They rarely get the required information from the health care system. Only in few interviews did we hear about them receiving a brochure about Down Syndrome in the hospital.

'In that little brochure they gave us in the hospital there were specific pieces of information and also web-sites.'

From the vast majority of the interviews it turned out that during the health tests, after being informed about the diagnosis, the women did not get information about the parents' groups, or about the everyday life of those affected nor was there a way to get in touch with the families.

'We had to find out everything ourselves. This is not good.'

'It is rather shocking what kind of a chaos there is. That there is no manual about what you have to do with a Down Syndrome child when he is one month

old or two months old or what can be expected. In short, what is that you have to do?’

The majority of the interviewees had to search in order to get hold of the information concerning the support services provided by the Down Foundation or the Down Nurse. Health services did not provide them with such help.

‘It was my husband’s idea, which was very, very good, that we should immediately get in touch with the Down Foundation and talk with somebody there.’

‘[...] my husband was the one who was checking the internet day and night and read everything he could. And then he conveyed the essence to me.’

‘We got in touch right at the very beginning... It was us who looked up the information and searched and read a lot and looked around.’

The interviews reveal that it is possible and easy to gather a lot of information quickly on the internet, but at the same time it is difficult to find your way around the huge amount of data. It was mentioned as a positive fact in the narratives that in some cases there was a professional available who gathered and forwarded the relevant information to the pregnant mothers.

‘He sent an email which included links to a great deal of articles, saying that these were worth reading. So, he filtered the internet a little bit for us, because everything is there of course.’

Almost every interview mentions that, apart from finding information concerning the medical diagnosis, it was important to find reports from peers.

‘[...] while I was mostly reading the parents’ reports, my husband read medical case studies.’

‘And there are the personal reports, many people write blogs and post videos.’

Before the internet it was difficult to access to these.

‘And the internet did not exist at that time. I wasn’t able to meet people sharing the same fate.’

Professional literature raises the amount and content of the information as a basic question, and so is the dilemma of whether or not, in the decisive moments of our lives, we take decisions exclusively on the basis of the information that we have and led by rational criteria (Gál–Szántó 2003).

Only one of the interviewees reported that she was asked in the first place about the continuation or termination of her pregnancy. We could find only one piece among the analysed interviews where the chosen gynaecologist did not give advice or make a judgement concerning the pregnancy, not even in the form of a question: *‘I am here to help and not to express an opinion’*, the interviewee quoted the words of her doctor. From the other narratives it turned out that each woman came across a physician who gave specific advice or made a proposal concerning the continuation or termination of the pregnancy. The various positions of the different doctors are reflected in several interviews.

'[...] what happened during the course of the following weeks was nothing else but whichever doctor I met, except one, everybody thought that I was not normal. They were trying to make me see that I was an idiot. And I felt in their questions that they were trying to find out whether I myself was an imbecile or not.'

'I tried to contact the people I knew about – the obstetrician, maternity nurse etc. – who I knew would relate to me normally, even if I am ready consciously to accept a disabled child.'

The majority of the interviewees said that after having taken the final decision, although previously they experienced many questions and questioning, the health staff accepted the decision and were supportive afterwards up to the moment of birth.

'After each ultrasound examination they said that there was still a possibility to take a decision. We knew that! There is nothing to decide about, we said. Then after a while they stopped asking.'

There was also an interviewee who reported having positive experiences with regard to the reactions of the health care workers after the birth.

'[...] as far as I can remember, it was damn sweet of them, they even answered the questions which can arise under such circumstances and then...that was a pretty positive experience. In the hospital too and the staff there as well. They were pretty decent, really. So, I got only good words there. From everybody, even my midwife, when she learnt about it, she came to see me right away and that felt nice.'

The question arises again and again as to how much the obsessive desire for perfection of our society allows women to take an autonomous decision concerning reproduction. In addition to the rational choice theories, we found that the socio-cultural embeddedness of serious individual decisions, the negative social perception of disability in general, the wide-spread approach that disability is a personal problem and an abnormal condition, reduce the whole question to one of personal fate, on the other hand, it is shown as an economic burden (Barberic 2013; Goodley 2014). In this sense, can we expect neutral information from healthcare workers in a society where disability is always perceived as negative or valueless and symbolises a digression from normality and where there is a consensus with regard to what is a happy form of life worth living? (Shakespeare 2014; Saxton 2006; Hubbard 2006; Parens–Asch 2000)

'And he told me that Hungary is not set up for idiot people, he literally said that, to walk arm-in-arm on the streets with idiot people.'

'and then he raised the issue of how much burden we will place on society and on the health care service, if he turns ill.'

'And then his reaction was more or less that: was it conceived right away? Then have it removed immediately. You will have a Down idiot child.'

'[...] it was dreadful how they treated me, how they treated my baby and how they treated the other pregnant mothers. I met several mothers-to-be there and when the subject of Down Syndrome was raised they told me how they were treated. And we did not meet those who were persuaded to have

an abortion. My gynae told me when I had the 12 week scan, this is the 6%, then I said to him that I was unable to do it, that I wouldn't like to have an abortion, because I feel that I don't have the right, that a child with Down Syndrome can become a grown-up and live a happy life. Then he said ok, but this won't be like you think that he will be so cute, but a bit stupid. In this style. But this was not the worst during the pregnancy. Then we talked about it, I don't know, for half an hour perhaps about how a Down Syndrome child looks like. And he said that his IQ level would be max seventy. He won't be able to live an independent life, I will always have to be dealing with him and I won't have energy for anything else. And that I won't have energy for other children either.'

Influencing appears many times implicitly, in the form of a question.

'He immediately asked whether we want to keep the baby then? This is how he asked it. And I started to become upset already, how dare he ask this? How is it that he doesn't feel the responsibility of his questions?'

The conversation with the professionals and their negative attitude towards Down Syndrome is often evoked as something traumatic in the narratives.

'The doctor started to persuade me that I should have an abortion. This happened when [...] probably before the 18 week test [...] I asked the doctor to stop it. To stop this. But he repeated it three times. He practically begged me to have the abortion, because I should believe him that this won't do any good to the other child. In week 20 he asked me again whether I was sure, it wasn't too late yet to undergo it. With a baby who could be clearly seen already by the ultrasound. Whom I felt in my belly. And that I am supposed to know that we are fighting for the baby's life, so that I would not lose him. So I am not planning to take him away from me. This was one of the worst experiences. Otherwise, the doctor looked like, I don't know if I may say such a thing, but really, he looked like the Nazi leaders are depicted in films or books.'

In this case the interviewee connects the aggressive, inhuman treatment and trauma with the historical memory of genocide, torture, exclusion and humiliation hidden in the collective consciousness, this is how she strengthens remembrance itself. The hospital appears as the violent scene in the story, a memorial site by now. In order to understand this, we can use Pierre Nora's concept called *lieu de mémoire*. According to Nora, remembrance is rooted in the specific, be it a place, a gesture, a picture or an object. The creation of a memory place is the symptom of the lack of memory. Since there is no longer a real medium (*milieu de mémoire*) our memory creates places (*lieux*). These places are where memories pop up, come to the surface, where pain is still able to raise the problem of the embodiment (Nora 1999, p. 14).

5.2. Disability and illness

Susan Wendell makes a distinction between 'healthy' and 'unhealthy' disabled people. In relation to her chronic disease, she writes about her experience that the acceptance of disability is higher in the case of 'healthy' disabled people. Disability is often a stable, predictable and given physical condition, it does not necessarily

mean weakness and, at the same time, it ensures a highly rated health status as well. A predictable body is comforting, does not cause fright and is easier to adapt to. Disease is unpredictable and often associated with pain and suffering. It's hard to plan with it, you need to adapt to it. Wendell regards herself as an unhealthy disabled person, and the biggest challenge for her is the incomprehensibility of her disease (Wendell 1996, 2001).

When our interviewee was informed that she was expecting a healthy Down Syndrome child, she said that this piece of information induced her to continue with her pregnancy.

'It did play a role (in the decision-making) that we could see that he was a relatively healthy child... Because if we had seen that he was just a little kitten who didn't know what was happening, probably we would have given it a thought.'

Mothers who learnt about the health problems of their child only after birth told us that the different diseases they developed apart from Down Syndrome significantly influenced the child's quality of life.

'His diabetes is a big drag [...] I don't know what I could say concerning his independence. But only because of his diabetes. Otherwise he could easily live and independent life. But because of this, it is difficult to leave him alone. Because his life is in continuous threat.'

'Well, his illness (epilepsy) is shit, a big shit.'

Movements working for the rights of disabled people are rightly fighting to separate the different layers of illness and disability. Linking the two concepts together contributes to the medicalisation of the condition, where disability is considered a personal misfortune. This medical approach sends out a false message that people living with disabilities are *suffering* from physical and/or mental impairment or deviation. The healthcare system, therefore, is the primary framework where these people should be treated and cured. Disabled people consciously differentiate themselves from those who are ill. Wendell, nevertheless, underlines that legislators, employers or disability studies experts should not lose sight of the fact that there are disabled people who are ill. 'Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it' (Wendell 2001, p. 18).

Our interviewees whose children recovered from their illnesses reported an improvement in the quality of life.

'And how wonderful it is that his heart is working well... Down Syndrome was not a primary issue then, but that he was ill and had to recover.'

'It gave me strength, as the tests were following one another, that he is a child in quite good shape. That he has no serious heart problems, he has a bit of an atrial septal defect though, but no need to take medicine so far and they said that this could even disappear on its own or, even if it had to be operated, there is still a lot of time till then. Well, this is still an open issue, but it doesn't set him back in his development. As far as we can see it now, there are no major health problems for the time being. This is good, and apparently he is quite a gifted young lad.'

Although it would have been of utmost importance for them, the majority of our interviewees were not aware of the health condition of their child in the foetal stage apart from the diagnosis of Down Syndrome.

'Everybody said to me that I would have a physically healthy child with Down Syndrome... Despite of all this he was born... ten weeks early, in fact with the septal defect... The absurdity of the whole thing is what would have been really important for us to know, we did not get any, not satisfactory, but any kind of answer, so what we expected was a healthy child to be born. That he will be mentally disabled to a degree that could still be accepted. Who is normal and who is not, this is a pretty relative thing.'

The words of these women support the fact that possible illnesses complicate the decision-making further.

6. SUMMARY

In our article we presented the partial analysis of ten narrative interviews we conducted with women who decided to go on with their pregnancy even after having received a positive Down Syndrome diagnosis. We did it in the framework of feminist disability studies, separating the layers of the power mechanisms of the prenatal diagnostic procedure. We did not try to analyse the interviews in a holistic manner.

In the narratives we focused on the period between the diagnosis and the birth of the child, where the interviewees told their stories about their experiences of the health care system and where disability and illness were linked.

From the experiences related to the health care system, we focused on the content, amount and neutrality of the information, as well as its social and cultural embeddedness. With the help of these we shed light on the interlinking and complex issues of pregnancy, motherhood, normality, disability, risk-taking, biomedicine and the body. Based on Susan Wendell's thoughts regarding illness and disability, we were able to understand another complex aspect of decision-making. During our research we got an insight into the medical presence infiltrating the everyday life of pregnant women and the complex and multi-layered interpretation of normality within society. We pointed at the hidden tensions created by the need to take action and to the difficulties deriving from imbalances in accessible information.

In future we would like to concentrate on wider analyses of all the 16 interviews. We cannot analyse the different interpretation of prenatal diagnostic tests without taking into account the way pregnant women see the world and humanity or what their beliefs are. This is confirmed by the fact that women who received a positive Down Syndrome diagnosis during their pregnancy spoke about their religious belief, faith or relationship with God in their narrative. Therefore, in our next article, we will focus our attention on the relationship between abortion and the Christian faith and the interpretations of life, death and human existence. Discussing the subject, it will be necessary to tackle how feminist philosophies and disability studies deal, sometimes in a contradictory way, with the question of abortion. During our future work, apart from gathering experiences and interpreting the socio/cultural correlations, we will try to find the hidden *questions* as well. This is justified by the intricacy of our subject.

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