

THE LIVED EXPERIENCES OF VISUALLY IMPAIRED MOTHERS AND THEIR PERCEPTION OF SOCIAL ATTITUDES TOWARDS THEM



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SUMMARY

Background and aims: There is a cultural stereotype that considers women living with disabilities unfit for reproduction. The aim of this study is to investigate the experiences of visually impaired women regarding motherhood and their perception of the dominant social group's attitude.

Methods: In the current study we conducted semi-structured interviews with five visually impaired mothers, which we analyzed with interpretative phenomenological analysis (IPA) due to the sensitivity of the topic.

Results: In our analysis of the interviews, we identified the attitude of the broader environment's as the master theme. Several new themes appeared within the other themes we examined. Within the master theme of gender role expectations and stereotypes, the themes of maternal identity and the experience of motherhood, the coordination of roles and the contribution of the husband/father surfaced. Additionally, within the master theme of microenvironment, the themes of small communities and family's attitude emerged, while within the master theme of health and social care, the themes of prenatal care and giving birth, health visitors and paediatric and social care appeared.

Discussion: The typical experience of visually impaired mothers is primarily that they are treated as a person with disability by members of the dominant social group. Emphasizing their competence plays a major role in their lives as, based on their experiences, members of the social majority question its existence, while their families' attitude towards them is characteristically paternalistic. It is not only the family members but also health care employees who express doubts regarding their suitability as parents. And similarly to family members, occasionally, they go so far as to suggest the possibility of abortion.

Keywords: visually impaired persons, motherhood, attitudes of dominant social group, interpretative phenomenological analysis (IPA)

THEORETICAL BACKGROUND

Motivation

We have been investigating the attitude of the dominant social group towards visually impaired persons since 2012 (see Lendvai and Nguyen, 2017). In that study we conducted a quasi-experiment on the effects of inclusive playgrounds, then gradually our focus narrowed down to the perspective of mothers with visual impairments (Lendvai and Nguyen, 2016). The investigation of the frequently stigmatized position of visually impaired mothers requires an interdisciplinary approach. Our current study incorporates social psychology, special needs education, disability studies and gender studies with regard to both our approach to the topic and the methods we employ in examining it. Gender stereotypes and role expectations as well as the stereotypical and commonly prejudiced attitudes of the social majority greatly affect the daily lives of visually impaired mothers.

The attitude of the social majority

The “acceptance of disability as being different” has not yet been achieved in Hungary (Kálmán and Könzei, 2002: 178), as members of the dominant social group view those living with disabilities as people to be pitied (Harper, 1999), and thus they are also often stigmatized (Green, 2007). The word *stigma* basically refers to a discrediting trait, and so it has a negative connotation (Goffmann, 1963). The stigma connected to people living with disabilities, according to McLaughlin et al. (2014: 304), is “...associated with disability in terms of perceived negative attributes or consequences of

the disability”. Kurzban and Leary (2001) think that stigmas have evolutionary backgrounds (e.g. a disease or sickness, with all the aversion felt towards sick people). Those living with disabilities may internalize the negative effects and feedback pertaining to a stigmatized existence (Taleporos and McCabe, 2002), which may have a negative effect on their self-esteem as well as on their identity. Perceived competence and warmth can be determining factors for the self-esteem of a disabled person (Kervyn et al., 2015; Cuddy et al., 2007). Kervyn et al. illustrated the attitude of the dominant social group using a stereotype content model. The two dimensions used were competence and warmth, as group stereotypes, in which persons living with disabilities were considered to be warmhearted but less competent by the social majority, basically proving the existence of a paternalistic stereotype. Another group similarly thought to be well-meaning but incompetent is that of “housewives”, those women working at home and occupied with household chores.

Gender stereotypes and role expectations

The general perception of female roles dictates that women are responsible for nurturing children and housekeeping, and Hungarian society adheres to this traditional view (Pongráczné and S. Molnár, 2011). The findings of Pongráczné and S. Molnár (2000), show that apart from the important role of being a mother, the role of earning an income has also gained emphasis, yet the strengthening of the “working mother” role has not resulted in a more critical attitude towards the role of “housewife”. Based on the conservative view of gender roles and of

the male-female allocation of roles, men are still regarded as being the breadwinners, while women are still seen in terms of taking care of the family.

Observing the activities involved in taking care of the family, we can see that this is not only limited to the actual care and nurturing of family members, but it also involves performing household chores and maintaining contact with the family's social acquaintances, keeping the social network alive. The Hungarian women taking part in Gregor and Kováts' (2018) study believed caring to be the woman's task, and considered the monetary costs of bringing up a child as well as experiencing feelings of abandonment to be major problems, among other considerations. These women reported that they felt the expectations of society to be a burden, being the ones mainly expected to provide aid as well as struggling with coordinating these roles.

The Polish stereotype regarding the roles within the family is somewhat similar to the Hungarian one in freeing men from doing most household chores, as for men to perform them is considered to be merely a way of helping the women. However, in the case of women with disabilities, this type of oppression can be overcome, as some of the household chores are done by the man, which promotes the desired equality (based on Wołowicz-Ruszkowska, 2016).

Women with disabilities in the role of mother

By denying them the role of motherhood, members of the dominant social group also negate the suitability of women with disabilities for the traditional female role and question their parental competences (since

caring is traditionally viewed as the central role), as they solely view women with disabilities as persons requiring help or aid (Garland-Thomson, 2002; Hernádi, 2014). Traditional gender stereotypes consider motherhood to be indispensable (Hernádi, 2014) and the most sensitive part of womanhood; and view mothers, based on the gender expectations of the dominant social group, as "recreators of the nation" (Hernádi and Könczei, 2013: 21). This cultural stereotype regards mothers as the main contributors in nurturing their children, and gives them exclusive rights and obligations in this task. We consider it important to emphasize that the concept of ideal motherhood is defined by the majority and that the perspective and experiences of women with disabilities (or women belonging to any other social group without power) are completely excluded.

The cultural stereotype requires mothers to be mentally and physically fit (Wendell, 2011). Reproduction, i.e. bringing healthy babies into the world, is the main focus, which is considered to be a privilege according to the gender stereotype of dominant social group, yet this is denied to women with disabilities (Fine and Asch, 1988). According to the cultural stereotype, women with disabilities do not possess the major attributes of womanhood, their bodies are asexual, unsuitable for reproduction, and too dependent compared to a normative physique (Garland-Thomson, 2002). They can be caregivers as well as being cared for, giving aid and receiving it at the same time (Wołowicz-Ruszkowska, 2016; Wendell, 2011). The denial of the caretaking, aiding role is well-illustrated by the fact that children seen walking with their disabled mother often get asked the question "Where are your parents?" (O'Toole and Doe, 2002: 90).

Coping with the stigmatization of women with disabilities

Women with disabilities are robbed of the chance to face and cope with female gender stereotypes and role expectations because they are denied their womanhood (Lloyd, 2001: 716), but these women are also often denied the right to bear children or even to sexuality itself (O’Toole, 2002). Women with disabilities consider their right to reproduction to be more than the right to simply make decisions regarding childbearing. For them, other factors are also important, such as the society’s acknowledgment of them being active persons, capable of sexuality, suitable for motherhood regardless of whether their child is also living with a disability or not (see Kallianes and Rubinfeld, 1997 for references to the feminist perspective, cited by Vaidya, 2015). Hence, they have to develop their own coping mechanisms for visibility and advocacy, which can serve as an adequate response to the dominant social group’s stigmatization and rejection of diversity (Hernádi and Könczei, 2013). Such strategies, however, are very limited in number. Women with disabilities have to make an extra effort to prove their parental competence, to meet the public’s requirements and to free themselves from stigmatization (Wołowicz-Ruszkowska, 2016).

Motherhood with disability as social identity

The internalization of the mentioned stigmas can affect a person’s social identity. Mothers with disabilities may belong to several non-dominant social groups simultaneously (e.g. women, women living with a disability, mothers) and these multiple social group

memberships may affect their perceptions and experiences (based on Palombi, 2012). Multiple social group membership may also result in multiple stigmatization at the same time. Tajfel (1978) presented the idea that every human being strives for positive self-esteem, so the evaluation of any group of which they are a member influences how they see themselves. Forber-Pratt et al. (2017: 16) thought that the identity associated with disability affects a person’s behaviour and the interaction between their body and the environment. They claim that it is necessary to discuss and at the same time coordinate disability and its social meaning, since persons with disabilities can shape their identities in accordance with their disabilities (possibly based on aspects in which they differ from members of their immediate environment). Identifying with a group is important because it can facilitate self-esteem in the face of social discrimination (Branscombe et al., 1999).

Micro-environment

The family is a determining factor concerning quality of life and social circumstances, which is why it is extremely important to examine the social networks of people with disabilities (Nagy, 2011). In Hungary the “safety net” for women is typically the immediate environment: the family and the micro-environment (Gregor and Kováts, 2018: 42), which is also the case for women with disabilities. Family relations, potential supporters, social embeddedness and emotional support are supporting pillars for everyone (Nagy, 2011), and being part of a supportive network can lead to a greater degree of independence with respect to motherhood for mothers with disabilities

(if they open up to their community) (Wołowicz-Ruszkowska, 2016).

Parents rarely prepare their disabled daughters for leading a self-sufficient life or see them as being complete as an independent adult until they get married, so they often retain the status of dependent child in the family (O'Toole and Doe, 2002). The question of control is of paramount importance to women with disabilities. It is often their family members who put pressure on them to transfer control of their lives. The proxy control (practised by a benefactor to bring about needed changes in the environment of the requester in case of lack of power, skills of the latter) could be a positive control orientation (Yamaguchi, 2001). However, if family members of the women with disabilities unsolicitedly “help”, this is undesirable to anyone pursuing autonomy, as it impedes self-efficacy.

Opposition to childbearing

Limaye (2015) thought that mothers with disabilities have to comply with the dominant social group's concept of ideal motherhood as well as oppression from different family members. Limaye found that during pregnancy women were afraid of their child being born with a disability (which was reinforced by the family members' and doctors' attitudes). The fear of passing on a disability is reinforced by the firm social belief that women with disabilities cannot handle the responsibility of being a mother (Saxton, 2000; Frederick, 2014). Therefore, it can be said that mothers with disabilities feel threatened by the reaction of others and the pressure it puts on them regarding childbearing and the possible passing on of their disability. The attitude of those working in

healthcare, which is determined by a deficit oriented medical model (Hernádi, 2014), only serves to reinforce and feed this fear.

Healthcare employees and the social welfare system

Information about giving birth and childcare is not easy for women with disabilities to access, and likewise it is difficult to meet personal needs and the chances of receiving answers to individual questions are very limited (Hernádi, 2014; Wołowicz-Ruszkowska, 2016). Typically, there is no assurance of equal access and universal planning in healthcare institutions, and employees disregard the patients' views of their own state and their experiences, treating them as children, thus creating an aversion in women with disabilities to being completely open with their doctors (Becker et al., 1997).

The attempts of healthcare employees and family members to exercise control over women with disabilities pose a great obstacle to the development of their identities as mothers (Wołowicz-Ruszkowska, 2016). The importance of institutions supporting persons with disabilities is undeniable, providing appropriate services and support for mothers with disabilities, especially in rural areas (Vaidya, 2015). The unsatisfactory welfare system and support services force mothers with disabilities to look for other solutions and sources of support as well as to develop different coping strategies against the prejudice that denies them their femininity and suitability for parenthood (Wołowicz-Ruszkowska, 2016).

The Hungarian healthcare system and social sphere is not yet ready to support women with disabilities. as necessary special services and supportive functions are

missing. Cooperation within the social and healthcare spheres is vital, between doctors, health visitors and social workers, not only with regard to the division of labour, but also possibly for informing and supporting the client (Gyóri, 2009).

PREVIOUS STUDIES IN THIS TOPIC

The current study was mainly influenced by those of Hernádi (2014) and Wołowicz-Ruszkowska (2016), in which the authors published their findings on mothers with disabilities. Wołowicz-Ruszkowska (2016) conducted a qualitative study with twenty-five women living with physical or sensory disabilities, and it focused on a feminist approach to motherhood. The aim of the author was to provide a feminist reflection on motherhood from the perspective of women with disabilities. They regarded disability not only as an individual experience, but also as a social construct. One of the key findings was that being a mother with disabilities requires a great degree of commitment and determination, since in their case the social sanctions regarding the lack of motherly obligations are more severe than those against mothers without disabilities. Another important finding in this study was that interviewees experienced difficulty finding a doctor and midwife, because they were viewed as a high-risk group. The interviewees reported that not only did they meet physical barriers, but also psychological ones, such as members of staff infantilizing their patients (e.g. talking about them in the third person).

The current study, the first major Hungarian study conducted in this topic, provides great support with its theoretical background. Hernádi (2014) used narrative

interviews conducted with thirteen women living with visible physical disabilities. The study focused on the women's experiences regarding living with a disability. It examined how these women felt about disability, femininity, sexuality and motherhood and what experiences they had regarding these areas, while it also tried to determine what factors lead someone to reconstruct themselves. The results indicate that these women are marginalized in several ways, while showing that the interviewees felt the pinnacle of their femininity to be their romantic relationships and motherhood. Society's prejudiced way of thinking and the surprisingly hostile attitudes found in healthcare, as well as the family's fear of difficulties and the interviewee's confidence in her suitability for motherhood were all factors that appeared in the analysis.

PRESENTATION OF THE CURRENT STUDY

Methods

Due to the sensitivity of the topic, we found interpretative phenomenological analysis (IPA) to be the most suitable for our analysis. The process (sampling, data collection, interview analysis) was conducted according to the IPA method. When using the IPA (cf. Rácz et al., 2016; Kassai et al., 2017) during the interpretation of the results, it is imperative to focus on the individual's experiences, on the details of their account and on their interpretation. The aim of the current study is to explore the experiences of visually impaired women regarding motherhood.

In accordance with IPA, our research question is open, explorative and aimed

Table 1. Participants

Name	Age	Type of Visually Impairment	Highest educational attainment	Marital status	Visual status of husband	Number of children
Gabriella	46	acquired: profound low vision	college	married	sighted	2 (adults)
Anita	38	acquired: blind	college	married	sighted	1 (primary school)
Rita	33	congenital: profound low vision	university	married	visually impaired	3 (from small child to primary school)
Sára	37	acquired: profound low vision	college	married	visually impaired	1 (small child)
Júlia	34	congenital: profound low vision	university	married	visually impaired	1 (small child)

at delving into the topic of phenomenology (Smith et al., 2009): How do visually impaired women experience motherhood? How do they interpret the dominant social group's view of their motherhood? The results of our analysis, due to the small sample and the chosen method, do not permit any generalization of our findings, but this is not the aim of IPA.

Participants

Based on IPA methodology, a purposive sample was recruited because idiographic inquiry requires a small and homogeneous sample (based on Oxley, 2016). The interviewees can be considered homogenous from the aspects of visual impairment and motherhood. In our analysis we treated the visually impaired women as a homogeneous group even though the wider group of women with disabilities is heterogeneous,

having multi-faceted identities (Shakespeare and Watson, 2001). However, we suppose that the state of stigmatization and the prescribed mother-role are such "group-forming elements" (Hernádi and Könczei, 2013: 18) that make it possible for them to be analyzed as a group. When describing their perceptions regarding motherhood and the social majority's attitude, we found no major differences based on the type of visual impairment, so the idea of treating them as a group was in no way contradictory.

In our sample all the interviewees were visually impaired persons, all of them mothers and all married (in three cases the husband was also visually impaired). The interviewees characteristically had a higher level of education, all of them had attained a college or university degree and the average age was 37.4 years. Their names were changed to preserve their anonymity.

Since the interviewees were members of a socially active small group, and thus could be identified based on the collected data even after changing their names, when presenting our results, we chose not to disclose details of the provided answers (e.g. exact occupation, type of child's disability).

Data collection

In recruitment we asked for the participation of women who do not live with cumulative disabilities, are older than 18, have a congenital or acquired visual disability (near-normal vision, low vision, total blindness) and who would gladly take part in a study in which they would be asked about their thoughts regarding femininity and the attitude of the social majority. The recruiting letter was sent to various organizations dealing with visually impaired persons. The letter contained a prospectus with relevant information as well as a statement of consent, which stated that taking part in the semi-structured interview was purely voluntary and could be ended at any time, and that any answer could be denied; it would last approximately 90 minutes, anonymity was guaranteed, no monetary compensation would be given and that if need be the involvement of a psychologist could be requested (in the event that we touched upon a sensitive subject during the interview).

The data was recorded in the spring of 2016 and its costs were covered by a research fund given by the ELTE PPK Doctoral School of Psychology. As part of the research, twenty-one interviews were conducted, from which five were selected to be analyzed using the IPA method. The five chosen interviewees were mothers, and the perspective, experience, depth and detail

of their accounts were suitable for analysis by the IPA method. The interview was conducted by a female interviewer. During the interview we were interested in hearing about the interviewees' personal experiences and their interpretations. So the questions were open-ended, aimed at thoroughly examining those experiences deemed important by the interviewees. In every case, voice recordings were later transcribed and the transcripts (on which we marked the more important verbal elements) were analyzed.

Data analysis

Analysis of the interviews was conducted with the IPA method. After reading the transcripts several times, we performed a free content analysis and took notes in the right-hand margin of the transcripts. The aim was to create descriptive and explicative notes on the interviewee's answers in order to gain a general understanding of the interviewee herself (based on RÁCZ et al., 2016). In the next phase of the analysis, we identified the emergent themes appearing in our notes and sorted them into master themes. The emergent and master themes identified during the analysis are enlisted in *Table 2*.

RESULTS

During the analysis we identified the following emerging themes: "Maternal identity, experiences of motherhood" (B1), "Coordination of roles" (B2), "Contribution of the husband/father" (B3), which we grouped together within the theme of "Gender role expectations and stereotypes" (B) master theme. The themes of "Micro-communities" (C1) and "Family's attitude" (C2)

Table 2. Master and emergent themes

Master theme	Emergent theme
A. Attitude of broader environment	
B. Gender role expectations and stereotypes	B1. Maternal identity, experiences of motherhood
	B2. Coordination of roles
	B3. Contribution of the husband/father
C. Microenvironment	C1. Micro-communities
	C2. Family's attitude
D. Healthcare and social welfare system	D1. Prenatal care and childbirth
	D2. Health visitor and paediatrician
	D3. Social welfare system

emergent themes were grouped together within the theme of “Micro-environment” (C) master theme, while the themes of “Prenatal care and childbirth” (D1), “Health visitor and Paediatrician” (D2) and “Social welfare system” (D3) were grouped together within the Healthcare and social welfare system” (D) master theme. The “Attitude of broader environment” (A) master theme affected all the other master and emergent themes, but also appeared as a completely different theme in the interviews as the dominant social group's attitude towards visually impaired mothers.

**The attitude of the broader environment
– “Society is having a hard time
imagining how this can be accomplished”**

“A prejudice exists, and they don't see visually impaired women as competent or able to do anything or something like that, but I don't think that it's only visually impaired women but other disabled people as well as those with a visual impairment who are thought to be inadequate for a social role for example.” [Rita]

The attitude of the dominant social group towards visually impaired mothers is extremely paternalistic, as proven by our findings. The stereotypes regarding persons with disabilities are determinative, and the interviewees shared their experiences about non-disabled people not seeing them as people, especially in the case of disabled women, but only seeing their disability.

When asked about tasks connected to child raising, the interviewees responded that “society is having a hard time imagining how this can be accomplished” [Júlia], and that people believe women with visual disabilities to be unable to fulfill the role of mothers: “they wouldn't even think visually impaired women capable of it” [Rita].

The interviewees thought that members of the dominant social group asked them questions that they would possibly never ask a sighted mother. Such questions would be “What happens if you fall? What will happen to the baby?” when using a sling or, “Wow, such a cutie! Are you a little boy or girl?” when asking the child, but “Wow, such a cutie! Is he also blind?” when asking the mother [Sára].

Total strangers often inquire whether visually impaired mothers can pass on their

disability to their children. Sometimes members of the dominant social group cannot even imagine a visually impaired woman being a mother: “Wow, such a cute child! Is it yours?” [Júlia]. The interviewee thought that the reason for being asked such questions was not simply belonging to any group but due to her visual disability. But nonetheless, she found these questions “funny”. Later she said that for her this interpretation is partly due to her positive thinking and openness.

It is also typical for pedestrians to praise the mother as if she were also a child, proving the existence of a paternalistic attitude: “Wow, you are both so clever!” [Júlia], which she also interpreted in a positive way, or “Apple of her eye. Surely you also remember when you led your mom by the hand to the kindergarten” [Anita].

The interviewees thought it was a stereotype of the social majority and a general misconception in the dominant social group that their children are competent and fully capable of making grown-up decisions when they are together: “You are leading mommy so well!” [Júlia].

The visually impaired mothers feel as if they are tilting at windmills when it comes to their struggle against the social majority, because a visually impaired woman does not choose to have a child to “have a personal helper” [Anita], which the social majority tends to assume.

Many of them thought that during pregnancy they were already being treated differently from sighted pregnant women. Other people found it astonishing and irresponsible for visually impaired women to “date in order to have children” [Júlia]. Many of the interviewees felt that during their pregnancies a lot fewer people gave up their seats for them than when they were not preg-

nant (Júlia’s experience was shared by many of her visually impaired female friends). They interpreted this to mean, “it’s so absurd for a blind woman to be pregnant that it just boggled their minds, or they thought that if she was capable of being pregnant than she would also be capable of standing” [Júlia].

Gender role expectations and stereotypes – “Super moms”

According to the interviewees, women are expected by the social majority to be mothers, yet the members of the dominant social group think differently about women with disabilities.

Motherly identity and experiencing motherhood – “In a typical female role”

“A very cool time to experience your femininity is when you really become a mother, so it’s really important” [Júlia].

Except for one case, motherhood was an important aspect of the interviewees’ lives. When introducing themselves as being a mother was typically in the top three qualities they mentioned about themselves. They emphasized that being at home “in a typical female role” [Rita] was a determining factor in how they viewed themselves. Mothers with small children thought their most important task at the moment was taking care of the children. They typically viewed motherhood, pregnancy and breastfeeding as integral parts of womanhood. In one case, the mother did not want to have children but still went through with it under pressure from her husband, although she did not feel motherhood to be an integral part of her identity.

The interviewees had children after overcoming their doubts, which were the effects of the mostly offish but sometimes hostile attitudes of the broader and micro-environment. Prior to and during pregnancy they gathered information about their possibilities and the process and techniques of baby care. Júlia said that “learning to take care of a small baby is no big deal. [...] I find that in my circle of friends the case is different or it’s generally the opposite for sighted parents, who are scared, thinking “Oh my God, oh my God, what’s going to happen to that little baby?” [...] I was never scared of that but I knew that the crucial period would be after he started walking but before he could talk, because he could possibly harm himself and others, in the playground for example, so when a person has a visual impairment, then these difficulties appear a little bit later on.”

Anita spoke of similar experiences. They felt that they had no fears that were different from those of sighted mothers, but they were less afraid of the new-born phase, since having the prior knowledge required to provide proper care they had nothing to fear. They had mixed feelings about the phase when the child was able to move around on its own but was still unable to speak. Further concerns emerged on the topics of using playgrounds and transport, for example not walking into someone while carrying their child in a sling [Sára], or whether to go to the playground with a chaperon [Rita]. Typically fears and sacrifices connected to having and raising children were not linked to visual impairment but instead to motherhood, and to the coordination of roles (for example Júlia took a year off from the university after she gave birth, Rita, apart from having to change her group of friends, also made sacrifices when she cut her hair, which she really loved, due to her baby).

Coordination of roles – “It’s hard to coordinate so many roles”

“Right now I feel that it’s hard to coordinate so many roles. [...] To be a mother, a housewife, a wife, working as a ... [she named her job]” [Júlia]. “To be a super mom and a super working woman at the same time” [Rita].

In the current context these cultural female roles were used to refer to the difficulty of coordination, to the impossibility of meeting social expectations. The interviewees, while sharing their points of view, spoke about female role expectations, emphasizing the role of motherhood and how it could be coordinated with other roles, and they were not talking about the identity of mothers with a disability. The interviewees typically thought that they had to achieve in several fields of life: they had to be “super moms”, who prepare every meal from the freshest ingredients [Júlia] and working women, besides running the household and being a “superwoman” [Anita] who has to meet a number of requirements regarding her looks. This type of pressure as well as the constant struggle to meet expectations was seen as a serious burden and a source of stress, even though they typically want to succeed in these roles. For Sára it was also important how to be “a woman next to the child”, how to experience her desired femininity while also doing well in the role of mother, how to achieve the look she wants to wear (“I go into the sandbox in a skirt. So what? I have a washing machine”).

Apart from taking care of the child, the interviewees typically perform the household chores allocated to them based on cultural gender stereotypes. Even the

description of an average day shows that apart from taking care of the family in the morning (e.g. waking the family, preparing breakfast, coffee and so on), chatting with the child and helping out with homework, the household chores are also mostly left to the interviewee. At this point we have to differentiate between those participants with sighted husbands and those whose husbands are also visually impaired, because the division of labour and the role of the father/husband differ in quality.

*Contribution of the husband/father –
“We divide it between each other”*

“Many of the women with disabilities take on the roles of men, [...] the woman is blind, the man can see, and [this difference exists] to such an extent that roles are reversed, the man taking care of the child, or both of them assuming an almost female role, meaning that the man takes up the following female role: he cooks, washes, cleans and has another child to take care of, namely his wife” [Rita].

Rita thought that it was the woman’s role to keep the household in order and to take care of the child, so she thought about the gender roles along the lines of the typical gender role expectations and stereotypes. In this case, the man does not acquire the status of a “child”, while in the event of a woman failing to meet this role expectation, then the dominant group will regard her as a “child” in need of care – thought Rita. Rita tries to meet these expectations and expects the same from her husband, since she thinks it is the father’s responsibility to teach the child “how to compliment women”. In the event of the father/husband also having a visual

impairment a sighted acquaintance would take the children to nursery or school [Rita]. The equal division of tasks was not seen by everyone as “a switching of the roles” [Rita].

Anita, who has a sighted husband, said, “I am trying to shape our lives in such a way that we have a division of tasks.” Equal division of tasks is important to her, and they are trying to make it so that her husband does his part of the household chores as well as taking care of their child, just as she does (e.g. taking turns washing the dishes, the father taking the child to school and back). However, she later confessed to being “prone to doing everything within the family and instead of others as well”, and even though she is striving for equality (“We divide the chores between each other, my husband and I, so sometimes I do the dishes in the evening and sometimes he does [...], although usually I’m the one who does the cooking [...], I have yet to get him to do any cooking”) the fact that the household chores are still not equally divided between the genders can still be seen, but this was exactly the point on which she most clearly expressed her need for equality.

Micro-environment – “She always worries about everything, constantly telling me how to do things”

The interviewees said that it was not only the wider society that doubts their adequacy as mothers, but often the attitude of their micro-environment is negative. A high degree of ambivalence seems to be the characteristic attitude, and while friends and close acquaintances do not, at least openly, voice their doubts, the parents and close relations of the interviewees often speak about their fears and doubts.

Micro-communities – “They were extremely cooperative”

“I can tell you that our experiences are positive with our immediate environment” [Júlia]. The interviewees found their children’s institutions flexible (e.g. nursery). They are ready to compromise and are open to smaller suggestions, which contributes greatly to mothers with disabilities feeling like full members of the micro-community, just like sighted people. They take note of their needs on shaping interior space, where to put their children’s chair or storage space, and notify them about any changes: “in the nursery they were very cooperative, [when] I asked them to put my child’s storage space at the end of the lockers, because it would be easier for me that way” [Júlia].

Apart from this, the reactions of friends were also positive upon hearing about the pregnancy. Rita neglected and changed her group of friends, which she did not account to being visually impaired but to becoming a mother and its effects (e.g. switching the circle of friends from university mates to “sling-wearers”, because with them she could discuss her grievances about “getting badmouthed”, then after having given birth to a visually impaired child she established connections with members of the mentor parental network, which since then has also disbanded). Micro-communities are also important with regard to the division of labour, since in Rita’s case an acquaintance takes the children to school, and once a friend of the husband accompanied her abroad when taking the child to an eye operation.

Family’s attitude – “Overanxious”

“She [the interviewee’s mother] always worries about everything, constantly telling me how to do things” [Sára]. Like Sára, Anita also said that her mother was “overanxious”. “She always said, ‘If neither of you can see, then something could happen, you will need help, so how will you work things out, raise your children or make a living?’ [...] Then, after I gave birth, these [fears] were proven wrong. I think that’s also the case for those slight doubts that remain, my mother keeps telling me that I notice things about my child immediately, before anyone else can take a look”.

The family’s attitude was often typically ambivalent: fears about childbearing and anxiety during pregnancy usually diminished after the parents proved their competence in their roles as parents. The interviewees’ parents’ overprotectiveness often arose as a common subject during the interviews, and the women were only believed to be competent mothers after they have proved themselves. However, this was different in the case of Sára, because she and her mother had not been speaking for a long time, since her mother did not respect her decisions and her role of caring mother: “because I want to raise my child in such way that at least his environment does not have a negative influence on him, this overprotection, this is a negative effect. [...] I must toughen up, otherwise she ... she doesn’t know where the boundaries are, what her role is.”

The worries of the interviewees’ parents was not limited to them becoming mothers, but was also the case for their being visually impaired and for being able to function

properly as a visually impaired mother. The visually impaired women had to prove themselves to their families and their immediate environment. Júlia and her husband asked their parents' help not on account of their visual impairment but on their roles as grandparents (e.g. during their once-a-week sports day the grandparents keep watch over the children).

The fear of passing on the visual disability was also evident in the interviewees' families, the relatives having mixed feelings in reaction to the news of the coming child: “[They reacted with] joy and fear, whether my child would inherit my disability or not, so I felt their fear, which came out as a family member asking ‘So you’re giving it a go?’ to which we replied ‘Why wouldn’t we?’” [Anita].

The reactions of the grandparents were negative in all the cases in which the child was disabled in some way (one child’s visual impairment came to light during pregnancy, while in the case of another child a different disability [not wishing to make the child easy to identify we left the specifics out of our analysis] came to light during early childhood). At that time, the interviewees recounted that the grandparents were “completely beside themselves” with grief [Anita], but there was encouragement to have an abortion in the case of the visually impaired child [Rita].

The suggestion of an abortion was not only made then, but also upon finding out about the pregnancy, totally denying the mother her parental competence: “I was told to get rid of him since I wouldn’t be able to care of him anyway” [Sára], while in Gabriela’s case, to her mind, at that time her parents made their suggestion based on her young age, not her visual impairment, but still left it to her to make the final decision. After this, the expectation for visually impaired women

to have children similarly to sighted women can seem controversial, yet in the interviews the mother-in-laws’ desire to have grandchildren came up multiple times, and there was pressure on the would-be parents to comply with this. Based on the interviewees’ accounts, fear of the unknown and anxiety were initially predominant, yet standing their ground and proving themselves capable dispelled most of these reservations and fears from within their environments.

Healthcare and social welfare system – “I immediately fall out of the competent parent role”

Mention of healthcare, which was shown to have an extremely paternalistic attitude, was inevitable when discussing the visually impaired mothers’ experiences, since experiences of pregnancy or childbirth were an integral part of the discussion about motherhood. Mothers with a visual impairment typically have bad experiences regarding the healthcare system, the doctors and the supporting network, and they feel that the system disregards diversity and that their situation in the healthcare system is completely unsatisfactory.

Prenatal care and childbirth – “A blind mom, who sure-as-hell needs help”

“My gynaecologist cannot fathom how we live, or how we do it, at all” [Júlia]. “It hasn’t even occurred to him that the baby and I are at home together, and we are managing our lives perfectly well, thank you very much. Again, what did he see? He didn’t see a mother with her child but a blind mom, who sure-as-hell needs help” [Júlia].

The interviewees described the healthcare employees (obstetricians, gynaecologists, midwives and nurses) as being uninformed regarding visually impaired women and trying to deny them their role of competent parents. The interviewees ran into many obstacles in the obstetrics department. Due to the positioning of her room during labour Rita could not access the bathroom (she was put into the farthest delivery room), the midwife did not provide adequate care during labour, and it was the doula who helped her get through the difficulties. In Júlia's case, the nurses were flexible, they gave her baby without swaddling blanket, as she had requested, and she thinks that it was due to her mother's collegiate relationship that she did not receive the usual treatment given to other visually impaired mothers: you cannot put your child next to you on the bed, the two of you cannot be left alone etc.

Certain types and degrees of visual impairment justify the use of a C-section (e.g. in the case of Anita), although it is not mandatory to use it for all patients with visual impairment. "I gave birth with a C-section, which was pretty stupid, since my other two children came out through my vagina," but the doctor said, "I don't need a note about your eyes" [Rita]. They were preparing for a C-section because in the 35th week the baby had not moved into the proper position, but even after it did the examination still lacked professionalism: "Can you see or not? [...] How many fingers am I holding up? Ok, you can see. I'll write the paper then goodbye!" Naturally he wrote C-section on the paper."

There were differences between each doctor's attitude towards visual impairment and visually impaired persons. In Gabriella's case, her male doctor "ignored" her visual impairment when she first gave birth, while

on the following occasion she felt privileged, because her female doctor was "very proud to be working with such a mother and child [...] she categorizes her patients, those who are close to her heart and those who aren't, and I happened to be among those she liked".

The possibility of abortion was suggested by the doctor when they found out that the child would be born with a congenital visual impairment. The doctor added after the interviewee's rejection of the possibility "Ohhhh, not mentally disabled" [Rita]. The interviewee felt uncomfortable during the following medical check-ups and pregnancy due to the doctor's attitude towards persons with disabilities.

The typical experience was that the obstetrician or gynaecologist disregarded the pregnant woman's wishes, and the parents were also unhappy with the proceedings during childbirth, although some of these experiences were not attributed to visual impairment by them (e.g. Rita felt that the obstetrician was in a hurry and tried to speed up the process because of this, not due to some medical issue).

Health visitor and paediatrician – "The health visitor has no idea what I find problematic"

"On our first visit to the paediatrician, everyone there was obviously surprised. [...] We were odd-balls, and I certainly felt like one. 'Hey, look at that, she can do it, wow!' they said. So were, really were odd-balls but in a different way" [Júlia].

The interviewee thinks about the odd-ball effect in a positive way because her doctor and health visitor found her to be a compe-

tent, caring parent: “up until now, everywhere we’ve gone they’ve been nice to us, they didn’t treat me like incompetent, our health visitor and our doctor are really cool... with the doctor saying things like, ‘I don’t know how you do it, mommy, but I know that you can do it’”.

However, Sára found that her health visitor and doctor treated her in an impersonal way, aiming to be of assistance but generally treating her as a visually impaired person:

“The blind woman living in the next street does it this way [...], well, what do I care how she does it? I don’t know the other blind woman from the next street. She is herself and I am me. They can’t tell the difference because [to them] one blind person is just like another [...] my problem is measuring out the baby formula when I cannot see the 100 millimetre mark on the side. [...] Funny. It’s just that the visitor has no idea what I find problematic. She doesn’t even care, but... because if someone comes into the apartment asking, ‘Do you have any questions?’ and then there aren’t any, she leaves after five minutes. [...] So I’m downsizing these people, because they are more of a hassle than a help, really.” [Sára]

Sára feels that she is not being given any suggestions for possible solutions to her questions, nor even enough time or attention, so it has not been possible for her to feel any basic trust.

Being a mother of two other children, Rita said that after telling doctors that she had three children they considered her to be less incompetent, so she now has a tactic that she tries to use when she needs to diffuse

a tense situation: “by now I have developed a routine with which we can pretty quickly finish these rounds, to get them to treat me like a fellow person, but for this to work I did need the third child, since they did not always treat me as such, even though my vision was better”.

Due to the doctor’s condescending tone, she considered seeking the services of a private doctor whose first question was, “But how will you get here?”, so the expected attribution of competence was still left wanting.

Based on their experiences they can state that the professionals make them feel as if they are not providing the best environment for their children, and that because of their visual impairment their children may be disadvantaged: “while a health visitor, to this day, tells a visually impaired married couple to ‘put the child into a nursery as soon as possible, to learn what colours look like’... well, this is preposterous, I am dismayed, as well as appalled” [Anita].

It is often the case for both the doctor and health visitor to disregard the visually impaired mother and discuss the matters regarding the child with a visually able person who is present there:

“[As for] the health visitor and the doctor, there have been many cases, when after the first few sentences I had to correct them. [...] For example, I felt like they were only talking to the dad, but hey, I’m also here, and I should be told, because I want to remember. My partner loses any kind of paper given to him, he should never be given a prescription, by the time we get it, it will be gone [...]” [Anita]

Júlia also said that “they speak with the person accompanying me, because [maybe] he

can keep eye contact... or I don't know why." When accompanied by a visually able person to the doctor, "I immediately fall out of my competent parent role," she said, thinking that "to be taken seriously as a mother, I have to make sure that I take my child to the doctor".

Social welfare system – "They'd rather fight on their own"

"I think that visually impaired mothers won't budge. If it's about creating a group and talking or about ... They'd rather fight on their own and keep repeating the same things over and over individually." Sára believed that the adequate advocacy and grouping was missing. She would prefer taking a common stance, seeing this as possible way to make progress. "A group of sighted mothers, who maybe have visually or in any other way impaired kids. Also not sighted mothers but with sighted kids, so a mixed group. And they all have contact with health visitors." Sára was the only interviewee who spoke in detail about the shortcomings of the social sphere and the lack of proper professional help. From the possible solutions she would prefer the creation of a bottom-to-top organized, diverse, inclusive group, which she would link into the health advisor system, instead of the inclusion of social aid professionals.

DISCUSSION

During our analysis we identified the attitude of the broader environment, gender role expectations and stereotypes, the healthcare and social system and the micro-environment as master themes. Maternal identity, experiences of motherhood, the coordination of roles, the contribution of the husband/fa-

ther, micro-communities, family's attitude, prenatal care and childbirth, health visitors and pediatricians and the social welfare system were all identified as emerging themes.

The interviewees typically have an identity of strong motherhood, and regard motherhood as an important part of femininity apart from pregnancy and breastfeeding. The disparity between the identity perceived by the interviewees and that perceived by other people was prominent in the interview. While the interviewees primarily defined themselves as mothers when introducing themselves, the broader environment, based on the feedback they received from them, denied them that, viewing them primarily as visually impaired and robbing them of the role of competent mothers (cf. Fine and Asch, 1988). In the interviews it appeared that not only the broader environment but, during pregnancy, the micro-environment also robbed them of the role, yet it was still a fundamental element of their self-definition.

The interviewees chose to have children after having overcome mostly reticent, slightly hostile attitudes of the broader and micro-environment towards them. They informed themselves of their opportunities and the procedures and techniques of baby care prior to and during pregnancy. They thought that their fears were no different than those of sighted mothers. Moreover, they were less afraid of the new-born phase, since they already had all the required knowledge at hand. The phase that caused them to have mixed feelings was when the child would already be mobile but still unable to speak. The fears regarding childbearing were mostly voiced when it came to transportation; for example, the fear of running into something while carrying the baby in a sling. The fears concerning childbearing and childraising

had less to do with visual impairment and more with motherhood.

It is important to mention that motherhood was an identity that was emphasized among all those mentioned during the interviews. It is an identity that is currently the most defining factor in their lives, and requires a few temporary sacrifices on their part. The feeling of having to perform well at the same time not only as mothers but also in other roles was a defining part of their narratives. Cultural stereotypes view childraising mainly as the mother's role, yet in the case of the interviewees a division of labour could be seen not only regarding childraising but also housekeeping, when the visually impaired woman had a visually able man for a husband (cf. Wołowicz-Ruszkowska, 2016). In the interviewees' families the fathers also have a determinative role in family life, and they regularly take part in child-related tasks.

The family also plays an important role in the visually impaired mothers' quality of life (based on Nagy, 2011), the women viewing family as an important immediate safety net (Gregor and Kováts, 2018). Not even the interviewees' immediate environment could unconditionally and automatically accept them in the role of caretaker, and the fact that they could be both giving and receiving care, supporting and being supported at the same time (Wołowicz-Ruszkowska, 2016; Wendell, 2011) was difficult for them to imagine.

The results show that the families' reaction to the pregnancy and their views and expectations regarding childbearing and childcare have a significant effect on the interviewees' self-esteem and their expectations of themselves. The negative feedback coming from immediate family members, which questions their suitability for motherhood and their abil-

ity to fulfill the role of caretaker and robs them of a sense of competence, was clearly present in the interviewees' accounts, and this affects their everyday lives. Only by standing their ground and continually proving themselves could they overcome their families' prejudice regarding their role as mothers. In most cases, the interviewees experienced a great sense of satisfaction when their environment became convinced of their competence and revised their earlier attitudes, doubts and opinions concerning the interviewees' capabilities.

Having control over their own lives is a key motif in the interviewees' lives: rather than control being transferred due to the pressure exerted by the environment they gain their own personal control and acquiring autonomy is one of the aims of visually impaired mothers (based on Yamaguchi et al., 2005 control orientation). In the event of direct control not working, self-enlargement can still be asserted by expanding the visually impaired mothers' group, as collective control can be an effective tool for self-assertiveness (for example, if the visually impaired mothers can act together in a synchronized way with family members and helpers in order to create a group such as that mentioned by the mothers in their interviews).

Apart from the micro-environment's initially negative attitude, the broader environment has also denied the interviewees their role as mothers, as typically they could only view the visually impaired mothers as needing to be taken care of (cf. Garland-Thomson 2002; Hernádi, 2014). They recounted many situations in which they were faced with discrimination, prejudice and marginalization (based on Palombi, 2012). They experienced the contradiction of the dominant social group's gender stereotype, which asserts that reproduction is the women's obligation, and

the fact that this stereotypical expectation is not applied to women with disabilities (based on Fine and Asch, 1988), so in their case the discourse of motherhood has become complicated (Vaidya, 2015).

The members of the dominant social group deny the interviewees the ability to meet traditional female role expectations, questioning their competence as mothers and seeing them solely in the role of persons requiring care (based on Garland-Thomson 2002; Hernádi, 2014). The denial of their having a caretaking, supporting role and the incredulity of others towards their capacity for childbearing has openly arisen in several interviews (the “Where are your parents?” question in O’Toole and Doe, 2002, being the equivalent of “Wow, such a cute child! Is it yours?”).

This powerfully negative attitude can also be seen in the family members’ initial reaction to the news of pregnancy, which included voicing their doubts. The dominant social group’s concept of ideal motherhood (based on Limaye, 2015) also appeared in the immediate relations’ expectations. Fear of the lack of care and parental competence as well as the passing on of the visual impairment (Saxton, 2000; Frederick, 2014) was present in the visually impaired mothers’ recollections. They feel afraid due to their environment’s reaction and the pressure it seeks to exercise on them with regard to childbearing and the possibility of passing on their disability.

Apart from the attitudes of family members, those of healthcare employees also reflect skepticism regarding their parental suitability and sometimes, similarly to the family members, having an abortion may be suggested. The healthcare employees mainly focus on the risks and dangers of pregnancy

(Hankó, 2018), as well as the possible passing on of the disability (Hernádi and Köncezi, 2017), which is evident in the interviews. Consideration of personal needs and the giving of appropriate information as well as being given answers to their questions with the appropriate care (based on Hernádi, 2014; Wołowicz-Ruszkowska, 2016) were rarely experienced by the visually impaired mothers.

In healthcare institutions, the visually impaired women’s questions regarding the layout of the examination room and the delivery room were disregarded, equal opportunities for access were not guaranteed, and the interviewees could not meet their personal needs and expectations regarding the use of space (based on Becker et al., 1997). Apart from being able to secure sufficient usable space as well as the typically distant and occasionally negative attitude of obstetricians or gynaecologists, the interviewees also mentioned positive delivery room experiences, when the nurses accommodated their needs regarding the baby’s care and nursing. It can be said that the attitude typical of healthcare employees mirrors that of the social majority.

Our results reinforced the notion that in the Hungarian society of today, the place of those mothers who do not meet the health expectations of social stereotypes, is not guaranteed (cf. Stenhouse and Letherby, 2011). The struggle against those prejudices that would deny them their femininity takes centre stage in the lives of women with disabilities (Lloyd, 2001), and some of the interviewees felt it to be their duty as well as a small everyday success to make a stand for the group, to educate the dominant social group and to appear as a representative of their group. The coping mechanisms that they have developed (Hernádi and Köncezi,

2013) provide an adequate response to the stigma of the dominant social group and to its rejection of diversity.

Instead of focusing on coping mechanisms aimed at concealment, as described by Wendell (2010), and escaping from their “rejected bodies”, the interviewees chose to emphasize their group identity, which in some cases can be interpreted as a consequent compulsion to additionally prove themselves to the dominant social group described by Wendell. They have to make an extra effort to prove their parental competence, to meet the public’s requirements and to free themselves from stigmatization (cf. Wołowicz-Ruszkowska, 2016).

LIMITATIONS

One of the shortcomings of qualitative research is that the researchers participate in the data collection and analysis. A distorting effect may also come into play when the researchers try to disregard their previous knowledge and preconceptions. Thus, in order to ensure reliability, we employed an independent encoder, who did not take part in any other phase of the research. Interpretative phenomenological analysis is not equipped to discover cause-and-effect relationships, as it typically analyzes processes and changes in personal experiences. The

results of the IPA analysis are not suitable for generalization, but this is not the aim of the method, but rather due to its explorative nature it focuses on the detailed examination of personal experiences.

CONCLUSION

In conclusion we can say that while the interviewees emphasized their identity as mothers when defining themselves, their perceptions reflect the opinion of the broader environment, and that of the dominant social group, which would typically deny them the role of caretaker and competent mother. This paternalistic approach is not only found among members of the social majority, but is also reflected in the attitudes of the micro-environment. Therefore, the concept of ideal motherhood, as determined by the dominant social group, has managed to slip through the holes of the family safety net, the micro-environment not formulating its notion of motherhood according to its personal acquaintance with the woman in question and her actual capabilities, but according to the attitude of the social majority. The healthcare and medical points of view require further changes, as visually impaired mothers need to be treated as well as advised on the grounds of their individual needs.

ÖSSZEFOGLALÓ

A LÁTÁSSÉRÜLT ANYÁK MEGÉLT TAPASZTALATA ÉS A TÖBBSÉGI TÁRSADALOM ATTITÚDJÉRŐL
ALKOTOTT PERCEPCIÓJA

Háttér és célok: A kulturális sztereotípiák szerint a fogyatékossgal élő nők alkalmatlanok a reprodukcióra. Jelen vizsgálat célja a látássérült nők anyasággal kapcsolatos megélt

tapasztalatainak, valamint a domináns csoport attitűdjéről alkotott percepcióiknak feltárása.

Módszer: A kutatás során 5 látássérült anyával vettünk fel félig strukturált interjút, amelyeket – a téma érzékenységre való tekintettel – interpretatív fenomenológiai analízissel (IPA) elemeztünk.

Eredmények: A látássérült anyákkal felvett interjúk elemzése során fő témaként azonosítottuk a tágabb környezet attitűdjét. A nemi szerepelvárások és sztereotípiák fő téma alatt kibontakozó témaként megjelent az anyai identitás, és az anyaság megélése, a szerepek összeegyeztetése, valamint a férj/apa szerepe. A mikrokörnyezet fő téma alá a kisközösségek és a család attitűdje altémák kerültek, az egészségügy és a szociális ellátórendszer fő téma alá pedig a várandósgondozás és szülés, a védőnő és gyermekorvos, valamint a szociális ellátórendszer tagozódott be.

Következtetések: A látássérült anyáknak jellemző élményük, hogy elsősorban fogyatékos személyként azonosítják őket a domináns csoport tagjai. A kompetencia kihangsúlyozása fontos szerepet tölt be az életükben, hiszen tapasztalatuk szerint a többségi társadalom tagjai rendszeresen megkérdőjelezzik annak meglétét, emellett a család attitűdjét is paternalista viszonyulás jellemzi. A családtagok mellett az egészségügyi szakemberek attitűdjét is a szülői alkalmassággal kapcsolatos kételkedés, a családtagokhoz hasonlóan pedig esetenként az abortusz lehetőségének felvetése jellemezte.

kulcsszavak: látássérült személyek, anyaság, a domináns csoport attitűdje, interpretatív fenomenológiai analízis (IPA)

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