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*Special Education Research*

# Perceptions of Body Image of Women with Blindness

**Edina CSERNÁK,**
**Judit GOMBÁS**
Institute for the Methodology of Special Education
and Rehabilitation, ELTE Bárczi Gusztáv
Faculty of Special Needs Education
Budapest, Hungary
Email: gombas.judit@barczi.elte.hu

***Novel Research Idea***

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## Abstract

**Introduction**: Body dissatisfaction is a general concern from teenage years onwards, and is especially characteristic in the population of young women all over the world.

**Objectives**: This qualitative research sought to find answers to how young (aged 18-30) women with congenital or acquired blindness perceive their body image (BI), and how they get information about the appearance of others.

**Methods**: Semi-structured interviews were conducted with twelve blind women, aged 18-30 years. Verbatim interview transcripts were analysed independently by both first and second author, following guidelines of constructivist grounded theory (CGT). Coding was conducted in accordance with Strauss and Corbin's (1998) procedure: transcripts were analysed with open, axial and finally with selective coding.

**Results**: Findings confirm that feedback from important others, especially negative feedback, greatly influences young women with blindness in developing their BI, and that for many it is a concern to what extent they should internalise negative remarks which are related to their appearance.

**Conclusion**: Since feedback and verbal information from others are essential for women with blindness in trying to understand what they and others look like, it is important for professionals, parents and for the women themselves to understand how vulnerable they may be to the criticism of others.

*Keywords:* blindness, body image, constructivist grounded theory, important others

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Corresponding address:
**Judit GOMBÁS**
Institute for the Methodology of Special Education and Rehabilitation
ELTE Bárczi Gusztáv Faculty of Special Needs Education
Budapest, Hungary
Email: gombas.judit@barczi.elte.hu

## 1. Introduction

During teenage years, we all experience tremendous bodily and mental changes which are often hard to accept. Adolescent body dissatisfaction is a typical phenomenon which may not end as we transition from adolescence to young adulthood, but may increase, negatively affecting the individual's psychological well-being and self-esteem (Bucchianeri et al., 2013; Pukánszky, 2018;

Fernández-Gustos et al., 2019; Dittmar, 2021). The perception of body image (BI) is a popular field of research, which has been studied from various psychological, sociological and cultural perspectives. According to Grogan (2017), concerns with BI have become an epidemic all over the Western world.

The term BI was first used by Paul Schilder (1935), who defined it as a representation each person develops of his/her own body. The development of BI is a dynamic process (Burychka, Miragal & Banos, 2021), and it is influenced by various factors: psychological (e.g. self-esteem) (Sundgot-Borgen et al., 2020), physical (e.g. body shape and size) (Grogan, 2006; Bould et al., 2018; Gruszka et al., 2022), socio-cultural (e.g. the definition of beauty in the given culture) (McCabe et al., 2011), or social media and mass media (Muschetti, Schimmenti & Corsano, 2021; Pedalino & Camerini, 2022). Grogan (2006) defines BI as 'a person's perceptions, feelings and thoughts about his or her body', and is usually conceptualised as incorporating body size estimation, evaluation of body attraction and emotions associated with body shape and size." (Grogan, 1999 in Grogan, 2006, p. 524). Although there is a wide range of BI research worldwide, and the literature of the various aspects of BI is enormous, less attention is paid to the BI of individuals with disabilities, and relatively little is known about how individuals with blindness or visual impairment (BVI) develop their BI. This research investigated how young Hungarian women (age range 18-30) with congenital or acquired blindness perceive their own BI, and how they get information about the physical appearance of other people. We believe that understanding the latter is crucial in understanding how women with blindness construct their own BI, because comparing ourselves to others is fundamental in what we think of our own body (McComb & Mills, 2021; Pedalino & Camerini, 2022; Laker & Waller, 2022). This research focused exclusively on the experience of women with blindness, and included neither participants with a moderate VI, nor participants with a mild VI (see WHO, 2021). This inductive qualitative research sought to find answers for the following initial research questions:

RQ1: How do young women with congenital or acquired blindness construct their own BI?

RQ2: How do young women with congenital or acquired blindness get information about others' physical appearance?

## 2. Method and sample

As the research had a Constructivist Grounded Theory (CGT) design (see details in subsequent sections), in the initial research phase, only a brief literature review was carried out. As various authors say (Glaser, 2005; Hallberg, 2010; Burns et al., 2022), in GT, a preliminary literature review contextualises the research, but no detailed literature review should be conducted before qualitative data collection, so that researchers could remain open-minded and could avoid preconceptions. A comprehensive review of the literature was therefore carried out, and compared to the emerging theory, only after data had been analysed. This article is written reflecting the CGT research design, this is why the literature review may be read only in the discussion. Participants were recruited with purposive and snowball sampling techniques, both of which are efficient tools for recruiting research participants in hard-to-reach communities (Valerio et al., 2016). The 12 participants' age range was between 18 and 30 years (M=26,08, SD: 3,118). Eight participants were congenitally blind, while four participants had acquired blindness (all of them lost their sight between the ages of 13-18). By blindness, a visus equal to or lower than 3/60 is understood (WHO, 2021). Table 1 contains participants' age and ophthalmological status. All participants were middle-class, white Hungarian women, five of them had a BA or MA degree and seven participants were, at the time of recording the interviews, college/university students in a town or city in Hungary.

**Table 1**

*Participants' age and ophthalmological status*

| | Age | Ophthalmological Status | | Diagnosis |
|---|---|---|---|---|
| R1 | 23 | congenital blindness | | ROP |
| R2 | 27 | congenital blindness | | ROP |
| R3 | 26 | acquired blindness | blind since the age of 14 | Glaucoma |
| R4 | 25 | congenital blindness | | ROP |
| R5 | 30 | congenital blindness | | ROP |
| R6 | 27 | congenital blindness | | ROP |
| R7 | 22 | congenital blindness | | unknown |
| R8 | 23 | congenital blindness | | Retinitis pigmentosa |
| R9 | 29 | acquired blindness | blind since the age of 13 | Cataracta, Glaucoma |
| R10 | 22 | congenital blindness | | ROP |
| R11 | 30 | acquired blindness | blind since the age of 13 | unknown |
| R12 | 28 | acquired blindness | blind since the age of 18 | Retinitis pigmentosa |

## 3. Ethics

This paper introduces findings of the first author's BA thesis research project. The research plan was approved by the thesis consultant (second author). The complete thesis was assessed in a two-step process, in accordance with the thesis assessment rules of ELTE Bárczi Gusztáv Faculty of Special Needs Education: it was read through and marked by the consultant and an independent opponent, and was then presented verbally to an exam committee of three academics for assessment and ethical approval. Students at ELTE Bárczi Gusztáv Faculty of special Needs Education are not required to have a higher level ethics committee approval. Despite this, there was a careful consideration of all ethical issues.

Interviews were recorded online by the first author. The interviewer had contacted each participant prior to the interview, and inquired which online platform was most accessible for her. Based on answers, Facebook Messenger and Google Meet were used. Interviews were sound recorded on the interviewer's phone in order not to be stored online. Apart from the interviewer, only the thesis consultant/second author had access to the recordings. A short description of the research was read out loud to each participant before recording. Participants were informed that their participation was voluntary and unpaid, they could withdraw from the interview or the research any time, and that researchers would take all measures to protect their personal data.

Before starting the recording, participants gave informed consent, and were asked if they gave permission to the recording; their verbal consent was recorded. In the thesis and in this paper, all participants are referred to anonymously, with a corresponding number. Interviews were on average 45 minutes long.

## 4. Data gathering and data analysis

Since CGT acknowledges that researchers and research participants co-construct theory on the basis of their personal experience (Charmaz & Thornberg, 2021), data was gathered via a set of semi-structured interviews, in which subsequent questions closely reflected on the participants words. Face and content validity were established by the two researchers, and by three young women with blindness with whom the first three interviews were recorded. Qualitative data, gathered during the interviews, supports the understanding and interpretation of participants' lived experience (Creswell & Poth, 2018).

Verbatim interview transcripts were analysed independently by both the first and second authors, following guidelines of CGT (Corbin & Strauss, 2008). CGT was implemented in this inductive research in order to deepen the poor understanding of blindness on BI and on perceiving the looks of others (Corley, 2015). Constructivism is a paradigm which states that there is not a single objective reality, but there is a plurality of realities, which are 'social constructions of the mind', and there exist as many subconstructions as as there are individuals (although many constructions will be shared)" (Guba & Lincoln, 1989, p. 43). CGT phylosophycally acknowledges that knowledge is incomplete and unique to both the researcher and the participant (Charmaz, Thornberg & Keane, 2018), and that meaning is co-constructed by the researcher and the research participant. Consequently, the evolving theory is grounded on researcher's and participant's subjective life experience (Mills, Bonner & Francis, 2006; Burns et al., 2022). The two researchers had different lived experience. The first author was a sighted, qualified psychologist, preparing her BA thesis to become a qualified teacher of individuals with visual impairment. The second author was a blind academic, specialising in BVI. The reason why the research was carried out in line with CGT methodology was that in this framework, researchers, together with our abundant subjective personal knowledge, are acknowledged to be co-producers of the research content (Charmaz, 2006; Charmaz & Thornberg, 2021).

Coding was conducted in accordance with Strauss and Corbin's (1998) procedure. Transcripts were analysed with open coding (first step of coding), axial coding (connections were shought between codes) and finally with selective coding (categories of axial coding are connected in a final theory). Initial codes were determined on the basis of the first three interviews, which facilitated the development of more focused questions (Charmaz & Thornberg, 2021). For example, during open coding, the labels 'subjective definition of BI", 'own physical appearance" and 'emotional attributes to own physical appearance" were determined. Categories which emerged during axial coding were 'feedback from others", and 'senses and BI", which was broken down into subcategories of 'touch", 'smell",'voice and speaking"; 'describing myself', 'visual memories;'mass media and blindness". Data gathering and data analysis were carried out parallelly, so researchers discussed emerging topics and determined further themes and subthemes. Memos were written after each interview, which helped researchers identify similarities and differences, form new questions, and develop focused codes (Charmaz, 2006; Charmaz & Thornberg, 2021). A review of the literature was then carried out, reflecting to the emerging theory and the results of the research.

## 5. Results

### 5.1. 'Participants' subjective definition of BI"i

As BI is greatly determined by visual feedback, respondents were asked what the concept of BI meant to them. All respondents defined BI along visual characteristics, such as body shape, body size, length and colour of hair. '*The way people see themselves and others, all characteristics we can see." (P (participant) 10).*

Four participants added that a personal experience of the body, the way we think of our own body, is an important element of the concept of BI: *„It is a subjective idea of how I imagine my own body. It is a subjective image, which may differ from reality." (P9).* As a result, the sub-category of 'discrepancy between real and imagined body" emerged.

### 5.2. 'Own physical appearance"

When describing themselves, all young women mentioned characteristics which could be perceived in a tactile way, such as body shape and hight. It is however conspicuous that they all mentioned visual characteristics, for example the colour of the eyes and hair. When describing themselves, nine participants added personal, emotional remarks to the objective description: '*I like, well, others also tell me… So, I like that I'm not a hundred kilos. I like the size of my hands, they are small. To me small hands are feminine." (P4).*

Eleven of the 12 participants said that feedback from sighted people, especially feedback from sighted relatives and friends, was essentially important in shaping their opinion about their looks, so the category of 'feedback from important others" was created. *'They often explained to me what to wear, that I should know it, no matter that I'm blind." (P4). 'I don't search for information on the internet, but I just hear things, when I chat with my sister and with friends." (P5).*

When speaking about feedback from sighted people, 41,6% of participants also mentioned how harmful feedback from sighted people occasionally felt: *'There were times when my parents kept telling me to exercise, because so many blind people don't do* *sports and become obese. As a result of their constant comments, there were days when I had just a small sandwich during the day. My dad said being fat was ugly… It was like blindness equals fatness. And all blind people are fat, don't be fat." (P1)*

### 5.3. 'Components of BI"

Two thirds of respondents said their BI was influenced by their feelings and impressions of their own body, and a third of respondents emphasised the importance of the tactile experience they had of their body: '*I can say that my hair is long and dyed. People say my face and shape look good, I know that I'm not very thin but fat either… About my body I mostly concentrate on things which mean something to me, too."(P1)*

For young women with acquired blindness, their visual memories of their body served as a point of reference:'*My memories of my face when I was around 13-14, well, I remember that. But all the changes that my face has gone through, I just can't integrate that into the picture." (P3) 'All my knowledge from my sighted past serves as reference." (P9)*

### 5.4. 'Getting information about others' physical appearance"

As regards sighted people, comparison to others may greatly influence BI. An important goal of this research was therefore to understand to what extent young women with blindness were interested in what other people look like, and how they gathered information. Participants confirmed that touch, voice, speech, odour, and any verbal information about the person's looks which arises during conversation, is included in the mental picture they shape about someone's appearance. All respondents mentioned that they used various senses when trying to construct an image about someone:

*'If someone smells good … I always imagine good-smelling persons have nice bodies, even if in reality it's not so." (P4)*

*'Voice is really important, and how somebody shakes my hand. That tells me a lot about the person's looks, too – height, if he or she is young or old, even the personality, whether he is determined or uncertain." (P9)*

In relation to touch, one third of respondents mentioned that while it is a common stereotype among sighted people that individuals with blindness may feel a need to touch other people's faces, respondents believed this was intrusive and far too intimate: *'For me, it's absurd to ask you if I can touch your face. A nice chat gives me so much more anyway than to know what your nose is like." (P11)*

Respondents with a congenital blindness agreed that personality was much more important for them than information about physical appearance. Three respondents believed that the lack of visual impressions helped them be more open with others, because their impressions about the personality were not influenced by looks: *'If someone has lots of tattoos, well, if I could see them, it'd perhaps activate stereotypes in my head. but I can't see tattoos, so I'm simply open with the person." (P11)*

Visual information proved to be more important for young women with acquired blindness. One respondent said she used her visual memories for categorising people: *'I meet a guy for the first time, and he tells me he is Steve Smith. I have a 'Steve schema". What does this mean? I met a Steve before I was 13 (age of losing sight). So whenever I meet a 'new Steve", I put this Steve face on him. This face may change over time. … But at least there's a face I can associate this Steve with." (P9)*

### 5.5. 'Influence of mass media"

The lack of vision appeared as a protective factor against harmful effects of mass media: *'I'm lucky because all these ideal things can be seen on photos, they are everywhere, but I can't see them. I read and hear about them, but it's easier to ignore it all." (P10) 'I'm grateful I can't see. There are so many things, plastic surgery, and people want to look like their idols because they think they are less worthy. I think, blind people are less influenced by all this, just think of all the media." (P4)*

## 6. Discussion

The construction of BI and the high prevalence of body dissatisfaction have an abundant, evidence-based literature, which shows that the prevalence of body dissatisfaction is the highest among young women (Jacobi et al., 2011; Manaf, Sarabanan & Zuhrah, 2016; Mental Health Foundation, n. d.). In order to elaborate effective prevention strategies, it is essential to understand how body dissatisfaction develops. Related research among young women with blindness is rather poor, and science has no detailed understanding of how people with congenital blindness construct their BI. Various research on blindness and body dissatisfaction (e.g.

Vandereycken, 1986; Bemporad et al., 1989; Kocourkova et al., 2011; Simeunovic Ostojic & Hansen, 2013) agree that body dissatisfaction is as much present in the population of young women with BVI as in the sighted female population. Research findings on the extent of satisfaction among young women with blindness with their body are however contradictory, and an important reason for the contradictory findings may be the lack of a standardised instrument with which perceived BI could be assessed in this particular population. Morgado et al. (2013) tested two and three-dimensional body rating scales, both adapted from the Stunkard Figure Rating Scale, and found that while the 3D version was clearly more suitable as a haptic instrument than the 2D tactile adapted figure rating scale, validity indexes of the 3D scale were not satisfactory for men and women with blindness likewise (Morgado, Ferreira, Campana & Rigby, 2013).

The complex process of coding lead researchers to the theory that touch and verbal information, provided by sighted 'important others", are both primary determinants of what women with blindness think of their own body or about the appearance of others. Two thirds of respondents said that their feelings, impressions, emotions determined how they thought of their body, and these were greatly influenced by others' feedback. This finding confirms that BI is a multidimensional concept, composed of perceptual, attitudinal and affective components (Striegel-Moore & Franko, 2002), and women are different in which of these components are more influential for them in shaping their BI. Various former research findings had highlighted (e.g. Bemporad et al., 1989; Kaplan-Myrth, 2000; Kocourkova et al., 2011; Simeunovic Ostojic & Hansen, 2013; Pierce & Wardle, 1996; Yager et al., 1986) that feedback from parents and peers had a huge impact on the BI of women with blindness, and negative feedback could also lead to the construction of a distorted BI. Almost half of the participants in this research mentioned their uncertainty; not knowing to what extent they could trust feedback from important others and to what extent they should internalise it. This is an undoubtedly problematic issue, because it is really personal what body shape, fashion style etc. one finds attractive, while another person finds less attractive. Blind persons should therefore be very careful whose opinion they count on. One must not believe however that negative feedback, or any feedback arriving from a less important person, may be fully neglected. Women with blindness, like anybody else, are different in how much importance they pay to other people's remarks. But while sighted women have 'first-hand feedback" through their own eyes about their own looks (even if it may be distorted by their brain), and they have an opportunity to compare this visual image to other women's appearance, women with blindness must rely on 'second-hand" information. Kaplan-Myrth (2000) emphasised that while sighted people could directly compare their body to others, individuals with blindness had to evaluate their physical appearance on the basis of vague and indirect comparisons. We may therefore conclude that women with blindness are vulnerable when trying to construct a realistic BI.

A third of the young women said that they constructed their BI primarily on the basis of their tactile experience of their own bodies. For respondents with an acquired blindness, the last visual memory of their appearance served as a point of reference, to which they could add the changes of their body over time. Several research participants underlined that thanks to blindness, they were able to avoid the influence of mass media on their appearance. In their research projects, Baker, Sivyer and Towell (1998) as well as Ashikali and Dittmar (2010) found that women with congenital blindness were more satisfied with their body than women who lost their sight later in life or members of the sighted control group. Ashikali and Dittmar (2010) pointed out that sighted women's lower satisfaction with their body may prove the powerful impact of visual media on sighted individuals. While mass media may harmfully influence sighted women more than women with blindness in shaping their BI, our findings show that important others' remarks may be equally harmful for women with blindness who have limited points of reference to compare their bodies to.

## 7. Limitations

The sample consisted of 12 middle-class women with congenital or acquired blindness, aged 18-30, and all of them had a degree or were studying at college/university at the period of data collection. In order to have a more general picture of how women with BVI perceive their own BI and others' physical appearance, it would be useful to repeat data collection with a more numerous and more heterogeneous sample. Interviews conducted in this research were coded by first and second authors. No independent coder was involved due to a lack of funding.

## 8. Conclusion

All results of this research, in which 12 young women with congenital or acquired blindness were asked about how they perceived their own BI and how they got information about other people's physical appearance, show that since so many components of BI are of visual nature, individuals with blindness need advice and support from important others in understanding visual aspects of physical appearance, and in constructing their own BI. In this process, it is crucial to have information about other people's looks. The lack of vision increases the vulnerability of young women with blindness in constructing their own BI, because they must rely greatly on sighted people's opinion and feedback. Feedback which does not reflect the real looks of the person with blindness, but is, for any reason, distorted by the sighted person, may end in negative BI or body dissatisfaction. We believe that women with blindness could benefit from professional support concerning their BI. Organisations of individuals with BVI could arrange regular peer group discussion in the topic for those interested. The same organisations could provide appointments with a style consultant, a colour consultant, a hair dresser, a beautician, so that women with blindness could ask for professional and impartial advice about their looks, which may increase their confidence. Furthermore, a standardised figure rating instrument should be created and adapted to the unique perception of people with BVI. Finally as research of men's BI is much less frequent, interviewing blind men about how they perceive BI would enrich scientific knowledge of BVI.

## Conflict of Interests

Authors have no conflicts of interest.

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