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PHENOMENOLOGY OF VISION LOSS

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Abstract

The present paper covers numerous issues that are subject to research by neuroscientists, philosophers, psychologists, clinicians, as well as special education teachers. The main objective of the study is to achieve a deeper understanding of the phenomenon of vision loss in human beings as a changing phenomenon. One of the goals of the study is further development of a research study published as 'Perception in a Person with Visual Impairment in the Context of Imagination Specifics'. How does the phenomenon of perceptual experience and imagination in a person change in the situation of vision loss? The phenomenon of gradual vision loss is highly specific, and its characteristic features cannot be summarized quantitatively. The qualitative study focused on the participants' life stories. Research data were collected by means of written and oral questionnaires. The data were supported by a review of relevant documents. The data evaluation process was based on a description of the phenomena, development of clusters, recognition of patterns, and identification of associations. The final part of the study is a result of a comparison of the participants' subjective experiences. Elements of triangulation were used and a qualitative approach was followed. This study helped develop the authors' previous qualitative research. The above mentioned publication presents a comparison of cases of persons who underwent various stages of vision loss from low vision to blindness. In the present research project (Ref. No. IGA_PdF_2017_013), the authors focused on persons with gradual vision loss, i.e. those with residual vision.

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1. Introduction

According to the World Health Organization (2014), there are as many as 39 million blind people and 246 million people with low vision worldwide. In total, this amounts to some 285 million people with visual impairment. The majority (82%) of the total number of persons with visual impairment are adults over 50 years of age. Vision loss need not necessarily mean complete blindness. Depending on the etiology of visual impairment and the overall development of an individual, the phenomenon of vision loss is accompanied by various person-dependent specifics. The text below presents two cases of individuals who in the course of their lives experienced several turning points including progression of their medical condition. The background of the research will be used to describe the cases of vision loss.

2. Problem Statement

The term vision loss is usually understood by the general public as complete blindness. Blindness is then combined with free associations such as perception of darkness, white stick, guide dog. Apart from congenital complete blindness, vision loss is rather a developing process. Although special education of persons with visual impairment considers impairment a state, it should be noted that vision loss may be a state but also a situation that changes in the context of internal as well as external conditions. Vision loss is a phenomenon just as vision is. As added by Petrů (2007), if we want to understand a phenomenon, firstly we need to examine its 'disorders'. Examining differences can help formulate hypotheses about the hidden functional organization of a system.

A qualitative description of vision loss is based on a holistic and phenomenological concept, while it is important to focus on specific experience of an individual. A person with visual impairment is not merely an interpretation of an aspect of visual impairment, a number, a term or definition, but is a human being, and the invariability of the condition or situation caused by the visual impairment is a matter of attitudes and interpretation (Majerová, 2016). According to Barash (2013), the attitude to visual impairment depends on what people believe in and what the interpretation of blindness means to them. At the same time, a holistic and eco-holistic approach to human beings needs to be emphasised.

Although holistic issues have always existed, these approaches started to be considered for the purposes of structurally complex objects and processes – computers, programming languages, development of numerical methods, development of new measuring methods, theories of limit states, new ways of information processing (Přemysl, Marek et al., 2013). For a modern scientist, thinking about any scientific issue should involve consideration of the whole context in order to be able to define the direction which is the core focus of the scientist. First of all, an individual with visual impairment should be considered in a comprehensive bio-psycho-socio-spiritual context. Yet, the traditional holistic approach deals primarily with social and humanity-oriented aspects with a minimum focus on eco-holism. But focusing on environmental issues should be as important as deeper understanding of some phenomena, one of which is globalization. Clapp, Dauvergne (2005) add that globalization is a multidimensional process characterized by restructuring and integration of world economies, institutions and the civil society. Today, we could use terms such as globalizing political economy or social and structural origin of environmental degradation; these terms would aptly portray the current setting of the

civilization (Kutting, 2004). The planet Earth and the civilized society cannot be separate forms, but form a single life cycle. At the same time, the development of the civilization, the environment, and the speed of scientific progress are greatly influenced by political and economic structures. And it is the ethics of research in all scientific fields that should take into account the issues mentioned above.

Regarding the above mentioned theoretical background and with respect to the aspects of qualitative research, Majerová (2016, p. 20) states that ‘an individual with visual impairment is not a technical term but rather a person characterized by a certain condition of the visual analyser and methods of information processing.’ The current status of the visual analyser can have an ophthalmological, biological, but also socio-psychological or spiritual dimension. Similarly, vision loss as a process has the same dimensions, as shown in Table 01. As added by Růžičková, Kroupová, Lopúchová (2016), the issue is closely correlated with various perspectives, consequences and determinants of quality of life of the target group.

Table 01. Subcategories of vision loss in the context of perception and imagination (adapted from Majerová 2016)

Vision loss	Perception	Imagination
Ophthalmological context	Residual vision, visual perception, visual experience	Imagination and imagery in dreaming
Self-evaluation (how individuals perceive their own visual impairment)	Other senses (hearing, touch, smell, taste, echolocation)	Mental representations (verbal, visual)
Visual experience from the past	Self-perception – perception	Self-perception – image
Awareness of vision loss and associated emotions	Perception of the surrounding world (social, psychological, biological, spiritual)	Effect of experience on imagination (vividness of images, colours, etc.)
Self-perception in a situation of vision loss (emotionally difficult situation)	Mental space mapping (reference points, elements in current vision and previous vision, in residual vision)	Fantasy content
Emotional context and coping with the difficult situation of vision loss		Mental space mapping (with respect to perception, experience, progression of the impairment)

Regarding the above mentioned aspects of the issue, a person with visual impairment is a coherent entity with many dimensions of being, numerous dimensions of quality of life, a human being working with information, an active part of the society. The objective of the society should be to maintain an active approach in the life of each member and to provide the conditions necessary to facilitate the changes of the approach to an individual with impairment.

3. Research Questions

Vision loss is a difficult life situation that influences not only visual perception and its transformations, but also changes the internal dimension of the person, including the perception of oneself. Mental conditions, qualities, processes and emotions associated with vision loss are by far not the only aspects influencing this process. Adaptation to a new life situation takes place in the context of consciousness, unconsciousness and meta-consciousness. On the one hand there are modalities in the

consciousness of an individual, on the other hand there is awareness of vision loss (consciousness and awareness are not identical terms). Awareness of impaired perception and the transformation of internal images cause the individual to turn inwards, stay in solitude, and meet oneself and the new reality. All this in order to, after the change takes place, be able to go ‘out’ again – back to life. Throughout the whole transformation process, the perception and imagination of an individual changes in the context of the progression of visual impairment. From this perspective, the process of transformation includes not only the way of the person’s perception and the images that the person develops (Majerová, 2016). The transformation – the phenomenon of vision loss will be further analysed in the context of the author’s research. The research part builds on a qualitative research study presented in a publication entitled ‘Perception in a Person with Visual Impairment in the Context of Imagination Specifics’. In the publication the author presents ‘stories’ of research participants and the transformation of their perceptual experiences in the context of imagination. The author proceeds from etiological aspects of the participants’ visual impairment and their recollections to everyday life. The main focus is on the perception of the participants in the conditions of vision loss, their imagination, dreams and mental representations. The path follows a hermeneutical spiral, as shown in the situational map below (Figure 01).

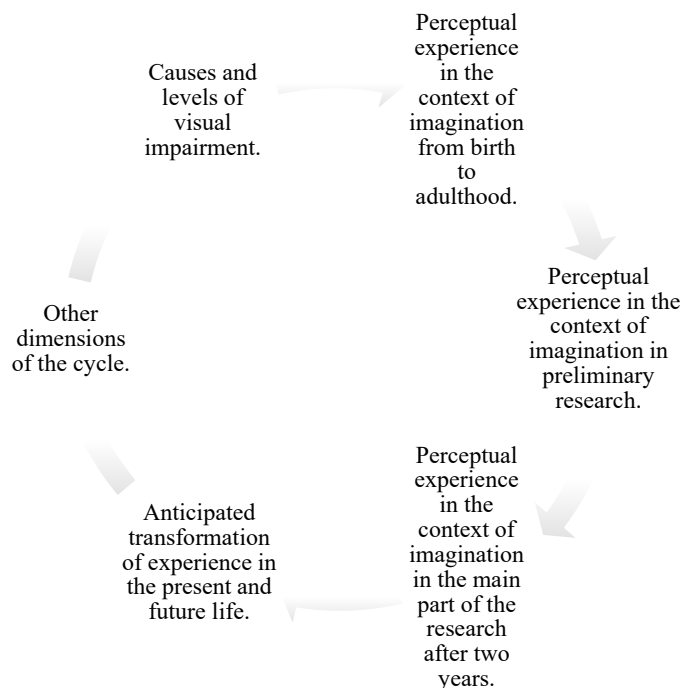


Figure 01. Cycle of the transformation of perceptual experience in the context of imagination

The qualitative study presented in the mentioned publication focused on a target group of persons after vision loss. For the purposes of the research, Majerová (2016) uses the category of vision loss, i.e. persons with previous visual experience. In the present paper, the existing research was complemented with other cases. Following the previous research, the main research question of the present study is as follows: How does the phenomenon of perceptual experience and imagination change in persons with vision loss?

4. Purpose of the Study

The main objective of the study is to achieve a deeper understanding of the phenomenon of vision loss in human beings as a changing phenomenon. One of the goals of the study is further development of a research study published as 'Perception in a Person with Visual Impairment in the Context of Imagination Specifics' (Majerová, 2016). The phenomenon of gradual vision loss is highly specific, and its characteristic features cannot be summarized quantitatively. Qualitative research provides an opportunity to view vision loss as a 'live' experience. The study focused on the participants' life stories. This approach enabled a closer look at this phenomenon, which is still under development.

5. Research Methods

The main data collection methods included a qualitative questionnaire, in-depth interview, study of documents and other resources. Regarding the issue and its dimensions, the data analysis was carried out by means of a descriptive approach (comparison, development of clusters, identification of patterns, comparisons, searching for associations). The key approach in the present study was to focus on the cases by means of triangulation (theory, resources, data, explicit), including the application of the hermeneutical spiral principle.

For more efficient and easier data handling the RQDA project (software programme) and Adele Clarke (Clarke, 2015) approach were used. The publication by Clarke (2010) entitled 'Situational Analysis: Grounded Theory after the Postmodern Turn' addresses not only the situational analysis, grounded theory and postmodern turn. The book provides modern researchers with a variety of interesting suggestions on data handling.

In the present research, data sections were classified by means of three types of maps – messy maps, situational maps and positional maps. Some of these projections will be mentioned in this paper, although it only includes a partial selection. The present text cannot cover all data material contained in the researcher's journal.

6. Findings

The following part of the text focuses on a comparison of cases analysed in the context of the follow-up research. The comparison also uses existing data materials published in the scientific book mentioned above. The cases are compared in terms of their specifics regarding the phenomenon of vision loss. The cases are compared in the following four areas: origin of the vision loss; specifics of perception regarding the vision loss; imagination, visualization, dreams; coping in everyday life.

6.1. How did the vision loss occur?

The vision of participant 1 (22 years old) is currently on the border of low vision and practical blindness (residual vision). The etiology of the visual impairment was identified by the physician as microphthalmia. Regarding the participant's vision loss, an important turning point was around 13 years of age, when the left eye was affected by complete retinal detachment with subsequent vision loss in this

eye. Between fifteen and eighteen years of age, the participant’s vision further deteriorated (flashes in the visual field), with subsequent eye inflammation. Until adulthood, participant 2 (38 years old) did not know that she suffered from Stargardt disease. She was prescribed glasses to correct vision when she was 12 years old. When she was 24, she still wore glasses for short-sightedness. After her child was born (24 years of age), the participant had a bicycle accident, after which her vision began to deteriorate. At the age of 36, the participant was also diagnosed with elevated intraocular pressure and glaucoma. Now her visual acuity is 0.1. From a developmental perspective, the participants’ recollections of their visual experience from childhood to the present can be compared using the following situational maps.

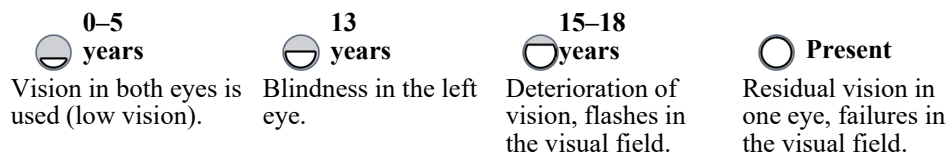


Figure 02. Participant 1

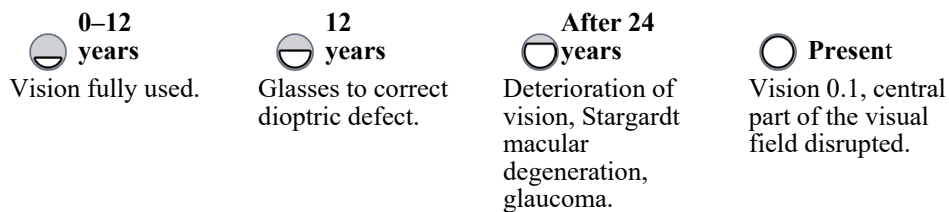


Figure 03. Participant 2

Although in terms of etiology the two cases differ, both individuals have visual experience and a limited ability of visual perception, which they use. The question for a longitudinal survey is how these cases are going to develop in the future.

6.2. Perception specifics

According to participant 1, the most important sense is still vision, the second is hearing, then echolocation and touch. Smell and taste are ranked last. By contrast, participant 2 claims to have well developed smell, which she ranks in the first place: ‘I recognize people by their perfumes and odours. In the shop, when I meet an older person, I can sometimes smell the typical odour.’ The remaining senses are ranked by the participant as follows: touch, hearing, vision, taste, and finally echolocation. During the interview she admitted using her residual vision, although vision is not ranked in the first place. In this respect, there is a significant difference between the participants.

When the participants commented on their residual vision that they use, some individual differences were observed. Participant 1 described his ordinary visual perception as follows: ‘I see flashes in my visual field, flickering, small black spots, and colours in case of strong lighting. On the right side of the visual field I see something like a moving spider web. In case of strong light I can see light spots in the middle and lower part of the visual field. The stronger the light and contrast, the better I can see, but you need to be cautious with light. For me, low light is the same as dark.’ Participant 2 also described her

visual experience by having losses in the visual field, although the overall picture is somewhat different: 'I can see around the middle part of the visual field, in the centre the perception is significantly out of focus. When shopping I cannot see price tags. I have losses in the visual field, I can't see traffic lights. After a night shift and in the evening my vision is much worse, for example when car lights shine in my eyes I am photophobic.' The general description of the participants' perception through residual vision also includes working with a text and seeing at a short and long distance. At a short distance, participant 1 can read enlarged texts; the ideal size of a sans serif font is 24. By contrast, participant 2 can read a text at a distance of about 15 cm from the paper; her desirable font size is 20. She further adds: 'the text becomes wavy if not large enough.'

6.3. Imagination, visualization, dreams

The type of perception can also be projected to the form of imagery while being awake or while dreaming, and to the visualization ability. Participant 1 describes his imagery in the form of visual or hearing representations; according to him they can also be spatial, locomotor or verbal. According to the participant, touch, smell and taste are ordered last in terms of the development of mental images. The participant described his dreams as follows: 'The images in my dreams mostly consist of how I saw and perceived the place. They are stripped of details; significant objects such as people or furniture remain. What is placed on the closet is not projected in the image anymore.' According to the participant, his visualization of images in the awake condition is similar: 'they are colourful, a lot simplified – in the form of shapes or they are made of a single colour.' Participant 2, as in the case of her perception of the content, prefers smell for the purposes of imagination. After that, mental images are developed by means of vision, hearing and touch. According to participant 2, the specific form of images is out of focus: 'I can't see them clearly,' she adds. Her dreams are lively and visual: 'I was directly in the dream.'

To obtain more detailed information, the research focused on how the individuals cope with learning new things in the context of imagination. In terms of learning, the man admitted being rather an auditory type. By contrast, in learning new things the woman still prefers the visual path. Despite the fact that she also tries the auditory method, this sort of information is insufficient: 'I have a programme in my computer, which reads out a text, but that's not enough for me. It's difficult for me to learn, I have enlarged text in Word, I try to memorize it – what is at the top, what is at the bottom.' According to her, it is helpful when she writes a large text and 'puts it in her eye'; hearing is supplementary.

The fact that participant 1 is competent in information technology has an effect on his visualization abilities. According to the participant, he can precisely and easily recall (in addition to things of daily use) numbers or geographic locations (if known). Participant 2 can easily recall light, objects, and things learned in childhood: 'When I hear an actor's voice, I can recall the face from the past when my sight was better.' For this participant it is more difficult to imagine concepts that she is not fully familiar with. A similar response was given by participant 2: 'When the level of abstraction of the learning content makes it impossible to use examples – I can hardly imagine that.' And learning is not the only area of everyday life; in the following section the cases will be compared in terms of everyday activities.

6.4. Coping with everyday life

When participant 2 spoke about her everyday life, she mentioned various situations that she had to face as a result of vision loss. According to her, one of the most difficult is shopping: ‘When I go shopping I always buy meat products. When I ask what they have the shop assistant is surprised that I don’t see it. My eyes look healthy.’ At the same time the participant admitted avoiding people as a result of her vision loss: ‘Today we have a reunion of classmates from technical school, I’m dreading it.’ At other times, she struggles with a gradually changing perception, her own uncertainty and low self-esteem: ‘When I go for a lunch with my friends, sometimes an embarrassing situation happens. For example I say – look, what kind of animals are there, and they are people you know.’

On the contrary, participant 1 mentions study-related situations: ‘Throughout the course of the study we were given an assignment to produce a presentation. Unlike the other students it’s not easy for me to read out my presentation, a piece of paper or an electronic text (this would hold me back and longer pauses would occur). Therefore, it was usually better for me to learn the content of the presentation by heart.’ In this context, the participant mentioned some aids that were necessary, such as a magnifying device, notebook with special software, tablet, mobile phone with special software. His everyday life includes not only study but also leisure activities such as music: ‘I’m an active member in a band, which consists mainly of persons with visual impairment.’ The participant also helps develop and administer the website of an organization for the visually impaired. Similarly to the young man, the woman is a student in a combined form of study. In the future she would like to change her profession. In the past she graduated from mechanical engineering in a technical school, now she focuses on special education – adult education. She uses some aids such as a hand magnifier with a light, enlarged computer and mobile phone environment, anti-glare sunglasses.

The following table shows a comparison of the role of senses in everyday lives of the participants. We asked how and where they use the senses.

Table 02. Senses and their roles

Sense	Participant 1	Participant 2
Hearing	Orientation, learning, communication, entertainment, relaxation.	People’s voices, listening to the radio, more sounds together – traffic orientation. Hearing is used less than residual vision.
Touch	Writing on the computer, playing on the keyboard, orientation, automatic tactile activities.	Identification of materials – fabric, foil. Cannot read the Braille at the moment.
Smell	Smell in a shop, for example a bakery. Smoke – smelling smoke can be a warning.	Fragrance, odours, perfumes – identification of people. Very good smell.
Taste	Identification of food.	Food, types of wines. Less developed sense, sometimes cannot identified saltier food, only oversalted food.
Vision	Residual vision (orientation, learning, entertainment).	Residual vision (study, work, leisure).

It is obvious that hearing plays a key role in the orientation and communication in the participants (people’s voices). Yet their residual vision is still important. Smell and taste function as a safety device (smoke, salty food), but also for the purposes of orientation (orientation on the way according to smell of

a specific shop, identification of people according to their perfumes). Their touch is of equal importance, whether it is for the purposes of orientation, work on the computer, or playing a musical instrument, identification of materials, reading the Braille, etc.

‘Live experience’ of an individual cannot be summarized by means of numbers or statistics. The above mentioned comparison of the cases of individuals affected by vision loss is part of the personal histories of persons affected by visual impairment. It provides an insight into the everyday life of persons with vision loss. The cases study illustrates how the phenomenon of perceptual experience and imagination of a person with vision loss transforms. This issue is also clarified by the participants’ recollections from early childhood to the present. |

7. Conclusion

|The perceptual process provides an opportunity to complete the perception with an image or picture from the past. A sighted individual completely relies on the current perception, while a visually impaired person (with residual vision) uses perception in the context of imagination. This system works as long as the person has some residual vision. This stage is followed by individual development, during which the ability of visualization changes. Renowned publications, such as a study by Sacks (Sacks, 2011) or autobiography by Hull (Hull, 2013) suggest that the visual cortex can be activated after complete vision loss together with an ability to generate adequate images, or can be completely suppressed without any possibility of producing visual images in the mind (in which case other functions are taken over as a result of the plasticity of the brain). In an individual with vision loss the activity of the visual cortex is not weakened, on the other hand it is more sensitive and active. The visual cortex, which is denied visual perceptions, requires new functions – in some individuals space is provided for imagination with rich visual elements, in others perception is shifted to other than visual perceptions and images. The world of persons with severe visual impairment might be rich in inter-sensory meta-modal states, i.e. certain “inter” states, which cannot be described by any common language. As a result, a person in a situation of visual impairment might have the ‘ear of mind’, ‘nose of mind’, and perhaps even ‘vision of mind’ (Sacks, 2011). The above mentioned comparison of the two cases showed the development of the phenomenon of gradual vision loss throughout several years. The question that remains is how the cases of our participants will develop in the future. |

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