



## Visual functioning of an individual with progressive vision loss – a case study

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The aim of the article is to present the subjective perspective of a person with congenital low vision who experienced gradual vision deterioration up to total loss. The case study method was used, in which the narrative biographic interview was the main technique of collecting data. In the analysed narratives, certain milestones were identified in the process of coping with the consequences of progressive impairment. Those were the situations when the subject was no longer able to perform a specific task, which she had earlier performed under visual control. They made the subject realise the progressive nature of the disease and inevitably confronted her with the acquisition of permanent severe impairment. Those situations caused temporary disruption of her psychological balance and increased her demand for emotional support. With time, however, they also motivated the subject to use previously rejected rehabilitation devices and techniques. Lack of knowledge of functional implications of eye conditions (including reduced acuity and contrast sensitivity, field defects, light/dark adaptation problems, etc.) among family members and other people hindered the process of providing optimal instrumental support to the subject.

**KEY WORDS:** vision loss, progressive vision loss, functional implications, case study, narrative interview

## Foreword

Disability is considered to be a multidimensional, complex and internally diversified phenomenon. Thus, in order to describe and explain the life situation of disabled persons, it is necessary to take into consideration a number of different factors whose interconnections change dynamically. Apart from individual features, such as: age, sex, health condition, race, cognitive functions, personality and temperament, lifestyle, individual hierarchy of values and life goals, etc., the sociocultural context conditioning the quantity and type of resources that help cope with a dysfunction are crucial for this group of persons<sup>1</sup>. One factor that to a large extent determines the direction of analyses is – alongside the type and degree of dysfunction – the nature of disability (congenital vs. acquired), which generates different educational and developmental needs and possibilities and at the same time differentiates the demand for support (habilitation vs. rehabilitation).

Congenital disability concerns a minor part of the discussed population. Although medical and legal criteria for classifying disabled persons differ significantly between countries, an analysis of statistical data clearly shows that appr. 97% develop a dysfunction as a result of injury, disease and/or age<sup>2</sup>. According to domestic surveys, less than 20% of disabled persons suffer from congenital disability and the others developed disability mainly as a result of long illness, mostly in adult age and especially elderly age<sup>3</sup>. Thus, because of demographic changes taking place in contemporary societies, acquiring the disability status is a process that lasts a num-

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<sup>1</sup> S. Rudnicki, *Niepełnosprawność i złożoność*, „Studia Socjologiczne” 2014, No. 2(213), pp. 49–50.

<sup>2</sup> D. Goodey, *Disability Studies. An Interdisciplinary Introduction*, MPG Books Group, Bodmin and King's Lynn, London 2011, p. 1.

<sup>3</sup> J. Bartkowski, *Położenie społeczno-ekonomiczne i jakość życia osób niepełnosprawnych w Polsce*, [in:] *Polscy niepełnosprawni. Od kompleksowej diagnozy do nowego modelu polityki społecznej*, ed. B. Gąciarz, S. Rudnicki, Wydawnictwa Akademii Górniczo-Hutniczej, Kraków 2014, pp. 51–52.

ber of years and in this process, the progress of the disease gradually leads to loss of ability in a given area.

As the number of chronic and deformity diseases that gradually lead to disability increases, special needs education and health sciences are more and more interested in subjective perception and evaluation by adults of their life situation. As dysfunction slowly progresses, former goals become irrelevant and the vision of future existence transforms, while a new system of values develops. The significance of a disease is determined by the consequences experienced and evaluated by a person in specific life circumstances<sup>4</sup>, thus research should provide for the natural context of experiences to make it possible to thoroughly describe and understand a given issue<sup>5</sup>. Analysis of personal experiences of individuals and groups described in autobiographical stories shows what the process of a disease and acquisition of disability means for respective individuals and reveals the subjective dimension of their difficulties, needs, expectations and coping strategies. The narratives of individuals who develop disability may have a different character and different objectives. Some self-narratives focus on the causes of a disease and its daily consequences, whereas others relate changes in personal and social identity, enabling a person to understand the changes taking place within their own self. Narratives may also show the relationship between what a person experiences and the cultural and social connotations of health and disease, ability and disability<sup>6</sup>.

Analysis of how a person gradually developing disability constructs the reality is of high cognitive value for special needs education, as the content and scope of the support provided in such situations are determined not only by the dynamics of the disease but even more importantly by the individual's needs and expectations,

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<sup>4</sup> M. Blaxter, *Zdrowie*, translated by M. Okła, Wydawnictwo Sic!, Warszawa 2009, pp. 88–89.

<sup>5</sup> U. Flick, *Jakość w badaniach jakościowych*, translated by P. Tomanek, Wydawnictwo Naukowe PWN, Warszawa 2011, p. 14.

<sup>6</sup> M. Bury, *Illness narratives: fact or fiction? "Sociology of Health and Illness"* 2001, No. 23, pp. 267–280.

which must be properly recognised and understood. Accordingly, the purpose of the article is to present narratives that express the subjective perspective of an individual experiencing gradual loss of vision, focusing in particular on the sense, significance and value associated with specific experiences in the context of acquiring the status of a person with permanent disability.

### Specificity of gradual loss of vision

Functional consequences of developing visual disability depend on a number of factors, the most fundamental of which are considered to be the following: stage of life, how the vision loss happens (suddenly vs. gradually), degree of vision loss (total vs. partial), personal resources, including personality features, lifestyle and interests<sup>7</sup>. In the case of gradual vision loss, traumatisation of the process is affected by such factors as, for example: the diagnostic process, unfavourable prognoses, duration of the disease, sense of loneliness due to long periods of hospitalisation and repetitive surgeries or medical procedures, etc.<sup>8</sup>. Also the way in which a dysfunction deepens (continually or abruptly) has a direct effect on the degree of disorganisation of mental structures. Less emotional burden causing moderately negative emotional reactions is observed, if a disease progresses gradually and the effects are hard to notice in daily life. On the other hand, sudden and significant deterioration

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<sup>7</sup> T. Majewski, *Tyflopsychologia rozwojowa. Psychologia dzieci niewidomych i słabo widzących*, Polski Związek Niewidomych, Warszawa, 2002, pp. 18–19; I. Chrzanowska, *Pedagogika specjalna. Od tradycji do współczesności*, Oficyna Wydawnicza Impuls, Kraków 2015, p. 186; M. Zaorska, *Tyflopedagog wobec problemu aktywności życiowej – zawodowej i prozawodowej osób dorosłych z niepełnosprawnością wzrokową*, Wydawnictwo Edukacyjne Akapit, Toruń 2015, pp. 24–26.

<sup>8</sup> See K. Devine, B. Reed-Knight, K. Loiselle, N. Fenton, R. Blount, *Posttraumatic growth in young adults who experienced serious childhood illness: A mixed-methods approach*, "Journal of Clinical Psychology in Medical Settings" 2010, No. 17, pp. 340–348.

of vision, making the existing difficulties much more acute or producing new symptoms of the disease, are associated with a condition of strong distress. The predictability of things is shaken, the sense of control and agency is lowered, decisional autonomy is reduced, the fear of total blindness intensifies, former life goals seem to become unattainable, and these factors combined may lead to a strong emotional crisis undermining the sense of one's existence.

The difficulties experienced by a person suffering from progressive vision loss in all aspects of daily life, especially spatial cognition and mobility, living on one's own, doing things that require precision or maintaining interpersonal contacts increase anxiety, fear, uncertainty and a feeling of helplessness and dependence<sup>9</sup>. Non-acceptance of the changes as well as lack of help and social support may lead to depression<sup>10</sup>. It should be noted that social support may effectively protect persons suffering from vision impairment from becoming radically dissatisfied with their own life as well as reduce their typical daily problems<sup>11</sup>. The effectiveness of support strongly depends on whether its scope and content are relevant to the specific situation and satisfy the person with visual impairment. Too much or insufficient help or help focusing on the wrong area of a person's functioning is not only ineffective in coping with difficulties but, even more importantly, has negative consequences that may affect the mental condition of a person in a crisis situation<sup>12</sup>. In the case of gradually progressing visual disability, typical social reactions are based on being sympathetic and showing

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<sup>9</sup> E. Stanikowska, *Psychologiczne aspekty słabowzroczności*, „Kontaktologia i Optyka Okulistyczna” 2008, No. 3(19), p. 20.

<sup>10</sup> Por. R. Casten, B. Rovner, *Depression in age-related macular degeneration*, “Journal of Visual Impairment & Blindness” 2008, vol. 102, No. 10, pp. 591-599.

<sup>11</sup> See S. Steuden, *Z psychologicznej problematyki zdrowia i choroby*, [in:] *Jak świata mniej widzę: zaburzenia widzenia a jakość życia*, ed. P. Oleś, S. Steuden, J. Toczolowski, Towarzystwo Naukowe Katolickiego Uniwersytetu Lubelskiego, Lublin 2002b, pp. 35-36.

<sup>12</sup> C. B. Wortman, *Posttraumatic growth: Progress and problems*, “Psychological Inquiry” 2004, No. 15, pp. 81-90.

pity, which leads to overprotectiveness. This type of reaction, the same as avoiding contact and distancing oneself from the problem, may be caused by lack of competencies to assist a person who loses vision. Also, the visual possibilities of a person suffering from progressive vision loss change dynamically, which means that the assistance provided must be modified accordingly. Thus, of key importance is the ability of a visually impaired person to accurately define their current visual competence and clearly communicate their individual needs and expectations. On the other hand, the society and in particular the family must constantly develop their ability to provide appropriate assistance. The basis to identify the current possibilities and needs of a person gradually developing visual disability is updated functional assessment of vision and knowledge of the consequences of a given visual disorder in daily life.

Among the most typical functional consequences of eye diseases are: reduced visual acuity, contrast sensitivity disorders, vision field loss, light sensitivity disorders, problems with adapting to changing light, twilight vision disorders, colour perception disorders, nystagmus, etc.<sup>13</sup> Reduced visual acuity is one of the basic medical and legal criteria to classify vision disorders. Visual acuity is understood as the ability to see items and their internal elements, and reduced acuity has serious consequences for the ability to perform activities that require precision, such as reading, writing, drawing, measuring or other activities associated with learning processes based on watching, imitating or working with visual materials<sup>14</sup>. In advanced stages of a disease, visual acuity is usually reduced so seriously that it negatively affects not only the ability to correctly identify and

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<sup>13</sup> The abovementioned consequences are discussed in detail e.g. in M. Walkiewicz-Krutak, *Stabowzroczność w aspekcie klinicznym i funkcjonalnym*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej*, ed. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2015, pp. 198–219. This article briefly describes only those functional consequences that are relevant to the case study presented here.

<sup>14</sup> R. Walthes, *Einführung in die Blinden- und Sehbehindertepädagogik*, Reinhardt Verlag, München 2005, pp. 50–54.

distinguish small items and their properties (e. g. distinguish letters or faces) but also hinders all the aspects of a person's functioning, making spatial cognition and independent mobility difficult and causing problems in effective performance of daily tasks and social contacts. The importance of visual acuity for a person's functioning is proven by the results of research conducted among cataract patients, according to which persons with objectively better acuity esteem more highly the quality of life in general as well as the quality of life with the illness<sup>15</sup>. Similar research conducted among glaucoma patients proves that improving visual acuity corresponds to a higher esteem of the quality of life in general, better realistic self-assessment and a desire for interpersonal contacts. Moreover, improved visual acuity in subjects was accompanied by alleviation of such clinical dimensions of the disease as: sense of hopelessness, sense of loneliness and fear perceived as a condition<sup>16</sup>.

Deteriorating visual acuity is often accompanied by contrast sensitivity disorders, causing numerous difficulties in distinguishing adjacent items that differ only slightly in terms of illumination and colour intensity, also in distinguishing items from their background. Contrast sensitivity, the same as visual acuity, strongly affects the quality of vision.

Another serious functional consequence of eye diseases and damages that hinders the planning, executing and controlling the precision of numerous activities is reduced visual field (scotoma). Its direct effects depend on the size and area of the disorder. If the central part of the visual field is damaged, a visually impaired person mainly experiences reduced visual acuity and finds it hard to

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<sup>15</sup> P. Oleś, M. Oleś, *Poczucie jakości życia u pacjentów chorych na zaćmę*, [in:] *Jak świata mniej widzę: zaburzenia widzenia a jakość życia*, ed. P. Oleś, S. Steuden, J. Toczolowski, Towarzystwo Naukowe Katolickiego Uniwersytetu Lubelskiego, Lublin 2002, pp. 104–105.

<sup>16</sup> S. Steuden, *Poczucie jakości życia u pacjentów chorych na jaskrę*, [in:] *Jak świata mniej widzę: zaburzenia widzenia a jakość życia*, ed. P. Oleś, S. Steuden, J. Toczolowski, Towarzystwo Naukowe Katolickiego Uniwersytetu Lubelskiego, Lublin 2002, pp. 128–129.

distinguish colours, and if the disorder concerns the peripheral parts of the visual field, the basic problem is spatial cognition, especially in unfamiliar surroundings, noticing obstacles and perceiving large objects. Multiple scotomas, i.e. defects in multiple areas of the visual field, are typical of some diseases<sup>17</sup>.

The numerous functional consequences experienced by visually impaired persons in daily routines include light sensitivity disorders, typically hypersensitivity to light (photophobia, glare) or increased demand for light. In the case of hypersensitivity, inability to control the intensity of light may cause major discomfort or pain, or may even make it impossible to see altogether. Similar problems are associated with glare, which means sudden and relatively short reduction of visual acuity caused by light reflected by a smooth surface or coming directly from its source<sup>18</sup>. Both hypersensitivity to and increased demand for light mean that the quality of vision depends to a large extent on the current conditions in physical surroundings, which may change frequently and abruptly, making it difficult to control them, especially in open space. Changing light is also problematic for those visually impaired persons who have difficulty adapting to light and darkness, which usually means that more time is needed to get used to new conditions or, in extreme cases, causes functional blindness.

These and other consequences of eye diseases are one group of factors determining the use of vision by visually impaired persons in education, work, entertainment and daily routines. Being aware of them and understanding their specificity enables the person gradually losing vision and other people to select the right coping strategies, this way reducing the sense of helplessness and lack of control. If the family of a person suffering from progressive visual

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<sup>17</sup> B. Golemba, *Dostosowanie otoczenia do potrzeb dziecka słabo widzącego*, „Niepełnosprawność i Rehabilitacja” 2007, No. 2, pp. 72–73.

<sup>18</sup> M. Walkiewicz-Krutak, *Słabowzroczność w aspekcie klinicznym i funkcjonalnym*, [in:] *Tyflopedagogika wobec współczesnej przestrzeni edukacyjno-rehabilitacyjnej*, ed. K. Czerwińska, M. Paplińska, M. Walkiewicz-Krutak, Wydawnictwo Akademii Pedagogiki Specjalnej, Warszawa 2015, pp. 213–214.



impairment know the person's visual possibilities and potential problems associated with a given activity and specific external circumstances, the risk of either overprotectiveness or insufficient support is minimised.

## Functioning of an individual with progressive vision loss – a case study

The main purpose of the research was to study the subjective perception of progressive vision loss in the course of life. The research uses the case study method. The method is recommended for analysing the life cycle of individuals, especially if the explored area is multidimensional and complex, and insight into a given phenomenon requires direct reference to specific contextual factors<sup>19</sup>.

The basic data collection technique was biographic narrative interview conducted according to the model proposed by F. Schütze, i.e. it consisted of three stages: main story, internal questions and external questions<sup>20</sup>. It should be noted that the main part of the interview was very elaborate – the narrator related in detail her life experiences associated with progressive vision loss, she described the events that were the most important in her opinion, trying to account them in chronological order, and she presented the socio-cultural context, including political and economic situations, in which the events took place. Most probably the reason why the narrator remained very open throughout the procedure was the comfort associated with certain familiarity with the researcher; she seemed to feel safe and confident, because she frequently repeated the statement: “I can confide in you”. The narrator's positive atti-

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<sup>19</sup> R. K. Yin, *Studium przypadku w badaniach naukowych. Projektowanie i metody*, translated by J. Gilewicz, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2015, pp. 36–49.

<sup>20</sup> E. Kos, *Wywiad narracyjny jako metoda badań empirycznych*, [in:] *Badania jakościowe w pedagogice. Wywiad narracyjny i obiektywna hermeneutyka*, ed. D. Urbaniak-Zajac, E. Kos, Wydawnictwo Naukowe PWN, Warszawa 2013, pp. 91–116.

tude towards the researcher helped reduce the preliminary procedure associated with establishing a positive relationship and encouraged the narrator: "Tell me about your life, because I want to understand the experience of vision loss you have gone through".

Analysis of data obtained through a biographic narrative may focus either on the biography itself and its structure or on selected content of the narrative<sup>21</sup>. When interpreting the narrative material from a transcript of the interview, it was not the researcher's intention to reconstruct the entire biography of the person suffering from progressive vision loss, but rather to analyse the factors<sup>22</sup> that explained the specificity of the process of becoming a visually disabled person. One of the directions of the analysis was determined by those parts of the narrative that answered the following research questions:

- What is the role of trajectory experience (developing visual disability) in the narrator's overall biography?
- Which events were the milestones in the trajectory of progressive vision loss?

The interview took 4 hours. The narrator was a 46-year-old woman suffering from the Marfan syndrome, i.e. a genetic disorder of the connective tissue characterised by considerable phenotypic variation. The disorder affects all the organs, especially the eye, causing short-sightedness, astigmatism, lens dislocation, corneal flatness, iris hypoplasia, increased length along an axis of the globe, retinal detachment, glaucoma or cataract<sup>23</sup>. The subject has suffered

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<sup>21</sup> E. Soroko, *Wywoływanie autonarracji w badaniach psychologicznych. Ocena (auto)narracyjności wypowiedzi*, Wydawnictwo Naukowe Uniwersytetu Adama Mickiewicza, Poznań 2009, pp. 50-51.

<sup>22</sup> One of the most interesting thematic categories was emancipation, which in this case involved developing a strategy to cope with oppressive forces linked with disability. This issue was discussed in greater detail in another article: K. Czerwińska, *Wątki emancypacyjne w biegu życia osoby stopniowo tracącej wzrok*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej” 2015, No. 10, pp. 127-153.

<sup>23</sup> For more information on the etiology, clinical symptoms and progress of the Marfan syndrome, see, for example: B.T. Tinkle, H.M. Saal, the Committee on Ge-

from health problems since birth, including eye problems, and she became completely blind in early adult life. She has a university degree in economics. At the time when the research was conducted, she worked in open market, on expert position, had been married for many years and childless and lived with her husband in a large urban agglomeration.

Biographical accounts of early childhood and adolescence are full of theoretical commentaries in which the subject expresses her own opinion concerning her ways of acting at that time, and which are highly reflective. She perceived her progressive vision loss, which was one of the consequences of the serious systemic disorder, as, to some extent, the pivot of her life path: it significantly affected her performance of school roles, determined her contacts with peers and in a way determined her relationships with family members and, last but not least, influenced her life plans and goals. At the same time, the subject notes that daily life was not dominated by her condition or constant fear of progression of her disease. Progressive vision loss was a slow and quite inexplicit process that spanned over many years. The issue of potential vision loss in the future returned during medical check-ups, numerous periods of hospitalisation and medical procedures. According to the subject, the milestones in the trajectory were the moments when she was suddenly confronted with the fact of reduced visual possibilities and inability to quickly, safely and effectively perform tasks that did not use to be problematic before.

I do not remember exactly how my vision changed, but I used to see differently even as a child. When I read or looked at pictures, I literally did it with my nose touching the paper. I looked at items from a very short distance. Later, after a few eye surgeries, I got glasses – a different kind than before, because those were plus-corrective, then I could look at things from a longer distance, but of course I could not see them well. It went on like that for a number of years, I did not see or register

any changes in my vision. Until the moment when, in secondary school, I got retinal detachment in one eye, but it did not cause any major deterioration in vision, only as if a "fringe". Later, I had surgical retinal repair and a long break from school, and when I returned to school a few months later, it turned out that event though I did not notice much difference in my vision, it was no longer the same. It suddenly turned out that although before I could see the board quite well from the first desk, now, even though I was sitting right under the board, if I did not follow the teacher's hand and was not listening to what she was saying, I could not read what she wrote. I attended normal school. In secondary school, it was the most evident at Maths lessons. The Maths teacher wrote a lot and very fast, so fast that I could not check what she was writing in my friend's notebook, but had to go on copying from the board all the time. It was a great shock for me after returning from the hospital. It made me understand that there was a difference, that my vision got worse.

In the narrator's retrospective evaluation, situations like the one described above played a major role in the process of getting used to the fact of developing disability. These events were immediately followed by periods of emotional imbalance of varying intensity, from short lowering of mood to a depressive episode in early adult life, which resulted in a year-long stay at the parents' house and total isolation from peers. However, in a longer perspective, having overcome emotional problems, the events stimulated the narrator into action and motivated her to learn useful rehabilitation techniques, which she had previously rejected as good for persons with less visual potential than her. The narrator mentioned around ten such situations, which in her opinion were milestones in the process of adapting to gradual vision loss.

These events are described in the narratives in a detailed, or even punctilious way, and the subject gives much room to describe them and explain her emotional experiences. She received kind support from her family in overcoming emotional crises and actively joining the rehabilitation process, and understanding of the problems she experienced in daily life due to her disorder. The narrator stressed the fact that she had received a lot of help and support

from others in the periods when her vision acuity deteriorated and she could not see the details she needed to be able to do things that required precision. Her parents and friends, using mainly popular and intuitive knowledge, tried to predict which activities could be problematic or even unattainable to her, and applied simple preventive or supportive measures, such as, for example, reading information on drug leaflets or using enlarged print on food products, or reducing physical distance during conversations, etc. Other functional consequences of the disorder that developed or intensified as the disease progressed turned out to be difficult to explain to others, which is why the assistance provided was usually insufficient or inadequate. Such functional consequences included: problems adapting to changing light conditions, twilight blindness and multiple scotomas.

Scotoma is not at all a dark spot. You do not register scotoma at all. The image around that gap in the visual field, around that scotoma, spreads to that scotoma, as if melting together. As a result, what I see is as if the surrounding background, I do not see the scotoma. I did not even know I had one until a small light spot from a candle positioned itself on the level of that gap and then I noticed that when I looked at it, it disappeared. Completely. It was probably because of this reason that sometimes I hit or bumped into something, but I did not associate it with scotoma, I did not notice it. Maybe because it was just one scotoma, a specific, small spot in the visual field, with time I got used to it and I realised that when I was looking for something, I automatically set my eyes to look below or above that scotoma, and that this is automatic and I no longer control it. I tried to explain it to my parents, but it is difficult to imagine for a seeing person.

(...) I was in a religious community where we read the Bible, we all took turns reading fragments, and luckily our leader knew I could not read such small letters in a poorly lit place, so she just skipped me. Nobody could understand why, because nobody explained that... It did not occur to me that I could explain it... It was embarrassing for me... For example, one time, when we had to move from one room to another, which was very dark, at least for me, because the others could see well, but for me it was completely dark, and I stopped and could not

walk, so they were surprised: "What is wrong with you?" and I told them I could not see anything. "What do you mean you cannot see", "I cannot, because it is dark in here", "But it is not dark in here". That was a problem for me. Once, I was on a trip and I kept close to my two friends, who knew that when we moved from sunlight to a room, I was completely helpless in that moment and needed to hold on to them to walk. but... the others did not know that. The rest of the group did not know that and they made fun of us, calling us, for example, lovebirds or the like. They did not notice that they were simply helping me because no one could tell I had this kind of problem. In general, I had mixed feelings, on the one hand, I did not want them to know but on the other hand, I was very stressed in situations when it became evident.

The above account shows the narrator's strategy to conceal her eye problems in adolescence and early adult life, which she applied in many public situations, even if it exposed her to danger (e. g. walking on her own after dusk without the white cane) or prevented her from performing a given task effectively (e. g. not reading certain written texts because of her unwillingness to use the magnifying glass). From today's perspective, the subject interprets her behaviour as a manifestation of helpless resistance to the progress of the disease and denial caused by strong emotional barriers against accepting the status of a person with permanent and serious disability. She thinks that those problems were specifically manifested by her actively avoiding for a number of years movement techniques based on the sense of touch and hearing.

To think that I could take out a cane, well, that was a problem. I had a cane. I had got it a long time before, when I joined the Polish Association of the Blind. There was a trend back then that when you became a member of the PAB, you automatically received a cane. I remember that it was a shock for me, but even more for my mother, who was terrified, because back then, I could still see quite well, it was the beginning of my secondary school only. I joined the Association in order to join a library and borrow books, because longer reading was already a problem, and someone told me that they had tapes in that library,

so I thought it would make things easier for me. So I got that cane and put it deep inside a wardrobe, and my mother found it when she was cleaning the room and said: “Oh my God, hide it away”. The Association gave me the cane but there was no training in spatial cognition... I even went to two summer camps with the Association, and at one of them they taught me how to hold the cane... But back then, it did not seem like serious.

The problem mentioned by the narrator was discussed at greater length in Swedish interpretive research concerning learning processes and changes associated with acquired vision loss. It was concluded that the white cane, due to its identifying function, plays an active role in social interactions, because of which learning to use it in the context of spatial cognition and mobility should not be considered only in terms of technical support. It should be taken into consideration that learning to use the cane also involves certain changes in terms of personal identity, as in public space, a person with the white cane is a priori categorised in a specific stereotypical group rather than regarded as an autonomous individual<sup>24</sup>.

Interpretation of the interview reveals at least two kinds of attitude to practical work on the trajectory and attempts to control it<sup>25</sup>. The narrator tried to “tame” the trajectory in daily activities, although it took her a long time to accept the inability to remove the trajectory potential, and it was not a linear process. Objective difficulties caused by the advancement and type of the disorder were intensified by lack of professional informative support from vision therapists or other specialists that could help understand the consequences of the disease and assume a positive attitude towards the encountered problems. The narrator also tried to liberate herself from the trajectory mainly through rehabilitation that helped her reorganise and improve her living conditions. For example, she travelled abroad on her own in order to acquire new competencies.

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<sup>24</sup> I. Berndtsson, *Förskjutna horisonter. Livsförändring och lärande i samband med synnedsättning eller blindhet*, University of Gothenburg, Göteborg 2001, pp. 498–499.

<sup>25</sup> See M. Górecki, *Trajektorja*, [in:] *Encyklopedia Pedagogiczna XXI wieku*. Tom VI, ed. T. Pilch, Wydawnictwo Akademickie Żak, Warszawa 2007, p. 779.

## Summary

The narrator's accounts of the progress of the disease were elaborate and they focused mainly on the functional consequences of the disorder. The subject explained their character and gave examples of the difficulties they generated, and analysed their understanding by other people. Her focus on issues closely linked with visual abilities seems to obscure the process of identity transformation that must have taken place during subsequent stages of adapting to blindness. Developing and interpreting identity within the framework of the trajectory and beyond it remains in the background of stories about changing visual possibilities.

Progressive vision loss had numerous negative consequences that periodically reduced the narrator's subjective perception of the quality of life. Although the progress of the disease sometimes overburdened psychological control mechanisms and made it difficult to perform important social roles, and required prolonged treatment and rehabilitation, from today's perspective, the narrator notices the pro-developmental potential of the trajectory experience. In her opinion, her effort associated with the trajectory made her more resistant to difficult situations and more reflexive, and enabled her to appreciate the value of interpersonal relationships.

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