

Body as a value in the experience of a disabled person: an axiological analysis of a text published on the website [niepełnosprawni.pl/wszystko o niepełnosprawności](http://niepełnosprawni.pl/wszystko_o_niepełnosprawności)

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Abstract

The objective of this elaboration is to perform an axiological analysis of an opinion of a person with a stoma published on the website [niepełnosprawni.pl/wszystko o niepełnosprawności](http://niepełnosprawni.pl/wszystko_o_niepełnosprawności). The analysis will show how the author experienced her own body in various contexts during several years of her disease, e.g. in her family, peer group, sport, hospital, professional work, and moreover – how this kind of narration can be used in the therapeutic process.

Key words: axiological analysis, system of values, disabled person

In the experience of people with disability, the body plays an important role, as it can impact their system of values constructively and destructively [1-4]. From the axiological perspective, experience of the body may vary depending on the type, form, content, location and function implemented by it [4]. This multidimensionality of experience reflects a complex network of relations the body enters with other values, e.g. life, health, physical fitness, education, professional work, etc. It constitutes a value which fundamentally impacts the experience of the world by the disabled as well as needs and purposes implemented by them¹.

Disabled people can experience their body as an autotelic and instrumental value [4]. Autotelic values constitute an objective themselves, therefore they are not implemented due to any other value. Instrumental values are used as a tool in implementation of other values [9]. However, one must remember that enthusiasts of instrumental values often undermine the legitimacy of autotelic values; it is done among others by pragmatists. In their opinion, the primary fault of autotelic values is assigning transcendental existence beyond empirical reality available in the research process to them [10].

As a value, the body may assume numerous forms, e.g. subjects fulfilling needs of an individual, beliefs, approaches,

existential opinions, cultural symbols, etc. It depends whether it is treated as a sociological, psychological or cultural phenomenon [8, 11, 12]. The body may also assume various contents, e.g. hedonistic, utilitarian, vital, spiritual, cultural, moral, religious [13]. Moreover, it may take the central or peripheral position in the system of values of disabled people. Some researchers, instead of the position of values, analyze their intensity [14]. However, regardless of the fact whether the subject of the study is the position or intensity of values, in both cases the definition of central and peripheral values is fundamentally identical. As a central value, the body significantly impacts functioning of individuals, organizing their life around itself, while other values are pushed to the peripheries of the axiological system. While the body as a peripheral value does not have a significant impact on the functioning of individuals, it does not organize other values around itself which would have such an impact [11, 15].

In systems of values of disabled people, the body may implement various specified functions. In literature on the subject, most frequently the cognitive function is listed – through their bodies, individuals get to know themselves and determine their status in society; the motivational function – through their bodies, individuals plan specified actions as well as select methods and techniques to implement these plans; the educational function – through their bodies, individuals learn particular approaches and behaviors; the expressive function – through their bodies, individuals manifest their emotional states [8, 15].

The presented possibilities of the axiological approach of the body have not been exhausted as systems of values are characterized by dynamism, and therefore particular values can change depending on the current context [11]. Furthermore, they can simultaneously assume various forms, con-

¹ In this elaboration I do not deal with ontological issues of values. I do not discuss the subject of objective, subjective or emotive existence of values undertaken for many years by researchers of various disciplines [5-7]. I assume that values exist as an element of the cognitive system of each rational and conscious individual, therefore they are meaningful in the perception of the experienced world as well as an motivational factor controlling behavior in certain daily practices [8].

tents or functions. Particular values can also complete and strengthen one another, as well as exclude and weaken one another. They can initiate appearance of subsequent values or block them, preventing their formation [15, 16].

In the methodology of quality studies, the axiological analysis is an important element in interpretation of written texts. Such texts, e.g. memoirs, diaries, letters, blogs, are selected and carefully thought threads of authors' life to which authors applied a relevant axiological rank [17]. This way, a kind of autobiography is created. From the perspective of significant events, e.g. disease or disability, authors describe their own stories.

The axiological analysis of written texts allows to penetrate into the author – intention – experienced world relationship taking into account not only the textual sphere, but also everything that is written between the lines. The axiological approach allows to present feelings and emotions which accompanied the author when he/she was writing the text, which in the text itself were not written directly. Such silenced issues constitute an extremely important guideline for the researcher that the author of the text has specified reasons to behave in a certain way. Therefore, subsequent spaces for interpretation occur and they are rooted not in the text itself, but in the context of its creation, e.g. historical moral, economic, political, etc. However, the main objective of the axiological analysis seems to be to establish the fundamental values based on which authors construct their experienced world. Description of this world created by evaluative judgments, reflecting the state of implementing such values in a given time and space context [13]. However, one must remember that these values are not identical to the fundamental values occurring in society or they have a different form, content as well as space than in society. Despite the fact that individual values are sometimes very dynamic and difficult to grasp methodologically, they constitute a rich source of information about the state of consciousness of the author of the text for the researcher.

The objective of this elaboration is to perform an axiological analysis of an opinion written by a person with a stoma², published on the website [niepełnosprawni.pl/wszystko o niepełnosprawności](http://niepełnosprawni.pl/wszystko-o-niepełnosprawności) [18]. The character and simultaneously the author of the narration is Paulina Kszuba-Krzepicka (approx. 30 years of age) who has been functioning with this type of disability for several years. The analysis will show how the author experienced her own body in various contexts for several years, among other in the family, peer group, sports, hospital, professional work, and moreover – how this type of narration can be used in the therapeutic process.

Up until the age of 9 Paulina functioned relatively normally. She treated her body instrumentally as a material subject being a carrier of pleasure ensured in various forms of activity: "(...) I was a small spark impossible to extinguish. I was full of energy and I trained artistic gymnastics: I was one of three best athletes, I succeeded as a daring freestyle skier, interested in the world, loving people, sport and animals. I climbed trees as a small risk-taker, cheeky and hot-tempered. I loved the company of children – always as a loud leader. I broke hearts as a spontaneous brown hair girl with brown eyes".

In the girl's life, her body had a central position, therefore her fundamental activity was focused around it, among others artistic gymnastics, skiing, climbing trees, playing with kids, breaking hearts of her peers. Her body also allowed her to implement the cognitive function as entering into relations

with other values, e.g. sport, entertainment with peers, it constituted a source of knowledge about her own personal features (out-going, loving, risk-taker, cheeky, hot-tempered), as well as social features (an athlete, friend, leader). However, from the fragment above we can also conclude that thanks to becoming familiar with her own body, the girl also become aware of her attractiveness ("a spontaneous brown hair girl with brown eyes") which allowed her to enter into new social roles, e.g. "a heart-breaker". Undoubtedly, in this context the body allowed the girl to implement the educational function, too.

As the instrumental value, the body most frequently assumes the vital, hedonistic or utilitarian content [19]. Such was the case of Paulina, for whom the body is most of all a carrier of life energy and pleasure, as well as a tool to achieve sports success. Implementation of these goals may lead to values which are much higher in the hierarchy of values, e.g. cultural values. Nonetheless, in the attitude of the girl, hedonistic values dominate most of all as even in the situation when she mentions her trips to Disneyland and London, as well as skiing trips to Austria with her parents, she speaks about it mostly in the context of taking pleasure from the trip itself and attractions related to it, and not in the context of becoming familiar with culture of the visited places.

However, sport can be listed as a cultural value, as the author was successfully involved in it. Apart from clearly hedonistic experience, sport brings a certain ethos of an athlete and competition which belong to cultural values, e.g. a symbol of victory, fair play, respect for opponents. Such values shape not only attitude of the athlete towards their body, but mostly attitudes towards other individuals embedded in specific social roles, e.g. opponents in sport, referees, activists, organizers of tournaments, spectators, etc.

However, after turning 9, Paulina's childhood started to be disturbed with increasingly severe health problems: "(...) at the age of 9 I am admitted to an isolation hospital in Gdańsk with suspected salmonella poisoning. I went through a nightmare, as nurses were rude, I was not able to go out to the corridor, I was forced to eat disgusting food. I screamed and cried. My mum could not bring me any food. They did not respect me or my needs and they did not acknowledge that a child has their favorite flavors, needs and customs". During the disease, the girl treated her body as an instrumental and central value, responsible mostly for physical fitness (vitality) and experiencing pleasure (hedonism). Unfortunately, implementation of these values in hospital was significantly impeded as the young patient was not allowed to go out to the corridor, and therefore she could not implement her natural need to move. Moreover, nurses forced her to eat tasteless meals which was perceived by the author as a lack of respect of her needs.

A fundamental change in Paulina's approach to her own body took place when she got back home from hospital: "After two weeks I got back home with hope that I will never go to any hospital again. Then, for a year when I went to the toilet, I was losing a lot of blood. I withheld it as I was afraid of going to hospital again, but my mum discovered my secret one day. To my great despair she took me to be examined and it turned out that I had severe anemia and acute inflammation. I was diagnosed with Colitis Ulcerosa – chronic ulcerative colitis". In this case, the girl also treated her body as an instrumental value, however not central any more – but peripheral. Through her body, the author got to know herself (cognitive function) and even though the knowledge was frequently disturbing ("for almost a year when I went to the toilet I was losing a lot of blood"), she "pushed it away" into the peripheries of the axiological system, being afraid of going to hospital where – as she believed – her fundamental needs were not respected.

² The body of patients with a stoma cannot control the process of defecation, and therefore defecation takes place into a colostomy bag, normally placed next to the abdomen.

The secret concerning her body was discovered by her mother who took Paulina to a doctor. After examinations, it turned out that another hospitalization was required as the patient was diagnosed with chronic ulcerative colitis.

Hospitalization was another traumatic experience: "Friends from hospital died before my eyes. I was not a child any more. I grew up quickly and I became very humble. Twice a year I had IV drips, parenteral nutrition, acute relapses, especially in autumn and spring. I spent two months in hospital a year. My body was injected, I was exhausted, sore and worst of all – very often bedridden". The disease limited Paulina's physical activity more and more often and it impeded her from experiencing pleasure, e.g. eating favorite meals. Such experiences caused that the girl become prematurely mentally matured and she became very humble regarding her physicality. This fact made her focus more on matters unrelated to the body directly in the vital, hedonistic and utilitarian aspect, but concerning moral matters: "In hospital I became a small psychologist for patients. This gift and strength of my character were noticed by doctors, and they helped me turn my attention away from myself and my problems".

After being discharged, Paulina still marginalized her body, trying to replace her previous physical activity (sport, travel) with other types of activity (writing poems, playing with animals, meetings with friends). The girl modified her previous system of values, distancing herself from values directly related to health in the biomedical approach (vitality, hedonism) and focusing on cultural, social and moral values around which she started to organize her life: "I adapted to new conditions, I started drawing, I wrote a diary, poems, I played with Lego, puzzles, I made dolls of paper and I designed clothes for them. I played with my dog and cat. I had a few friends who visited me after being checked whether they are not sick. They did not eat any chocolate bars, fruits, ice-creams in my presence, as they knew that I can't eat them (my mum did everything so that I was not sorry for myself). She and my dad made my diet diverse. (...) I did not eat for 6 months. I had IV drips into the stomach through so called gastrostomy. I connected these bottles, visualizing my beloved pizza, chops, toasts with cheese and tomatoes I remembered from the past".

The girl seemed to recover; so did her daily routine. Although her previous level of physical activity was not achievable, in the author's system of values new interests appeared which allowed implementation of previously unknown passions. Unfortunately, it turned out that even a strict diet and parenteral nutrition did not protect the girl from further health complications: "(...) I was admitted to the Child Health Centre where I had surgery. This was the last moment as I almost had perforation, i.e. rupture of the large intestine. As a 13-year-old, I underwent total colectomy, in other words - removal of the large intestine. A few days were removed from my life, as I was lying in intensive care. After a month I was discharged home where I experienced «another most horrible time» in my life. I was running to the toilet all the time, I did not sleep at night, I cried as I could not sleep because of my wounds – my eroded body due to permanent diarrhea. I survived, gritting my teeth in pain, and despite all that I managed to smile and enjoy small things. After six months, further complications appeared and my stoma was revealed. I was terrified. I wanted to die. I remember how loudly I cried for that. I had abscesses on the buttock and fistulas which made me insane due to pain. I was threatened with sepsis". Removal of the large intestine, further health complications, revealed stoma, depression were sequences of events which caused Paulina's existential collapse. In such a situation two options seemed most probable: give up and wait for death or rebound and start fighting to recover. The previous hierarchy of values

of the author ceased to be applicable and her independent creation of a new one seemed beyond her strength. However, her beloved ones supported her at her darkest moments: "Sometimes I wanted to die, but my mum did not let me (for which I am very grateful and I love her so much!), so I fought for my life...".

With support of her family and friends, Paulina recovered, learnt to function with revealed stoma which was not easy at the beginning. She also returned to her interrupted plans: "I graduated high school and I went to study in Italy. I never complained about the lack of success which made me aware that dramatic scenarios in my head could be a creation of my dark imagination. I studied Italian interior design, I learnt Spanish, living in Spain, I trained Brazilian martial arts, I danced flamenco, I went to discos with my friends, I fell in love and fell out of love, I travelled, skied and jumped with a parachute".

From the axiological perspective, it seems especially important that Paulina accepted her own body with revealed stoma and thanks to that it became her central value again – however, not the only one, as education, professional work and travelling also became her central values. One should remember that implementation of these values was possible only in a strict relation to the body – its expression and exposure. As a person with revealed stoma, the author realized her dream to work as a model and participate in a professional photoshoot: "My dream about modelling was realized 100% as I had a professional photoshoot, I became the face of a social campaign, I could show my body – with a beautiful bag and for a greater good".

Revealed stoma did not become an obstacle in implementation of the author's plans, it did not decrease her sense of physical attractiveness. The body as a material subject still constituted an instrumental and central value for her, most of all with the vital, hedonistic and utilitarian content. Through her body the author still implemented her cognitive, motivational and expressive function, manifesting her own physicality in subsequent contexts, e.g. participating in a professional photoshoot or entering into relationships with subsequent partners. In the system of values of the author, the body strengthened implementation of values such as education, professional work, travelling or friendship.

Despite traumatic experiences, the body turned out to be a value which fundamentally positively impacted the world experienced by Paulina. However, it was possible as she was able to modify this value depending on the context. Therefore, in the context of health her body was a central value around which she organized her life. Nonetheless, in the case of her disease she managed – thanks to support of her family and friends - to marginalize her body to a peripheral value and build a system of values around different central values, among others cultural, aesthetical, moral and social values. Interestingly, such a skill to modify the body within the instrumental value caused that the author of the narration did not treat her physicality as an autotelic value. Even at the most difficult moments, when she thought death is close, she did not experience her body in religious categories as a subject of salvation which has a value in itself. On the contrary, in the case of her disease and threat to life, she marginalized her body as a lower value and sought other forms of activities among higher values.

Knowledge about the fundamental values may be successfully used in the therapeutic process. It allows therapists to penetrate the world experienced by patients (through the analysis of the narration), to get to know the hierarchy of values as well as motivational factors controlling their behavior. Thanks to this knowledge therapists can increase effectiveness of the process of treatment and rehabilitation, adjusting

it to the needs and objectives of patients. When the system of values of patients is not coherent with the process of treatment and rehabilitation, it may impact its modification, giving new meaning to values or replacing values with other values. In the axiological system of Paulina, one of the fundamental values was undoubtedly her body, around which she organized her life. Therefore, at the beginning of her disease, therapists could motivate the girl to participate in therapy, referring to her achievements in sport, travelling with her parents and playing a role of the leader during her meetings with friends. Nonetheless, in subsequent stages of the disease, when it turned out that some physical practices cannot be implemented by the girl, referring to them could significantly impede her fight with the disease. In this situation, therapists could identify other values, implementation of which positively impacted the patient during the process of treatment and rehabilitation; it could be e.g. artistic activities. In the case of Paulina, these values allowed implementation of her own needs and objectives within other central values. However, after colostomy therapists could use the values related to ex-

posure of her body again, motivating the girl to accept her physicality in the context of her disability. Therefore, the axiological analysis orders the fundamental values which significantly impact construction of appropriate relations with therapeutic personnel based on understanding, trust and supporting self-realization of disabled people [20, 21].

However, one must admit that the therapeutic situation, especially in hospital, does not favor recording of patients' own experiences or analyzing such records by medical personnel. Nevertheless, there are numerous records in the form of blogs, letters, memoirs and diaries. Authors excellently described the fundamental values in them which could not be realized during their hospitalization [22-24]. Therefore, performance of such analyses could be taken into account in the programs of medical, physiotherapeutic and nursing studies, occupational therapy and others, as this way the meaning of the experienced world (axiological) in the therapeutic process would be presented, but – most of all – it would allow patients to be treated holistically which seems one of the fundamental postulates of modern medicine.

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