

# FIZJOTERAPIA PHYSIOTHERAPY

Official journal of the University School of Physical Education in Wrocław

ISSN 1230-8323

**2016**

volume 24  
number 1

Akademia Wychowania Fizycznego we Wrocławiu  
Polskie Towarzystwo Fizjoterapii

FIZJOTERAPIA / PHYSIOTHERAPY

Quarterly

vol. 24, number 1, 2016, pp. 1-44

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ISSN 1230-8323

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## The problem of obesity in adolescent primary school students from rural and metropolitan areas

DOI: 10.1515/physio-2016-0005

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### Abstract

**Introduction:** Obesity and overweight are health problems that particularly increase the risk of metabolic diseases, being a disease entity itself. It is confirmed that nutritious mistakes and hypokinesia constitute the basic threats in alimentary obesity.

**The aim of the study:** An attempt was made to evaluate the frequency of prevalence of obesity due to consumption habits and motor preferences of children aged 12-13 residing in the Tąrlów Commune representing a rural area and children from the Primary School in Wrocław representing a metropolitan area.

**Subjects and methods:** The scope of the study covered 148 children from both rural and metropolitan areas. The children were divided into 4 groups of 37 based on gender and place of living. BMI indicator and centile charts prepared in OLAF studies for the Polish population were used to evaluate the level of obesity. Custom surveys concerning consumption habits and children motor activity were used to evaluate lifestyle habits. The results of the study were subjected to statistical evaluation using Statistica v. 10 software.

**Results:** Within the studied group of children aged 12-13 obesity and overweight occurred among 30% of girls and 25% of boys, whereas a tendency for more frequent occurrences of overweight was observed within girls (26%) and obesity within boys (5%). Everyday diet among the studied group depends on their place of living. Girls from a metropolitan area more frequently ate high-fiber products, unsaturated fatty acids and vitamins relative to girls from the rural area. Differences in preferred forms of physical activity based on gender were shown.

**Conclusions:** There is an urgent need to implement education and preventive or health promotion programs in the field of obesity prevention in rural areas, with special attention to physical activity and modification of consumption habits.

**Key words:** obesity, lifestyle, rural area, metropolitan area, percentile

### Introduction

According to the World Health Organization since 1980 the number of overweight and obese people has doubled. Currently, it is estimated that 65% of global population is exposed to the risk of death due to obesity and its complications [1]. Relations between prevalence of obesity among adults and excessive weight in childhood were confirmed [2-4]. It was also indicated that obesity complications described for the population of adults (hypertension, disorders of carbohydrate metabolism and lipid metabolism, metabolic syndrome or emotional disorders) occur already in early childhood [5].

According to the Report by the International Obesity Task Force (IOTF) 20% children in Europe were obese in 2005. Poland was one of seven countries where obesity and overweight concerned 20% of the population of young people aged 13-17 [6]. While in the USA over the last 20 years a two-fold increase in the number of obese people aged 6-19 was observed. The prognosis for 2015 assumed that the number

of overweight people in the USA will increase to 75%, including 42% of obese people [7].

However, latest reports suggest certain positive changes in prevalence of obesity worldwide, although certain differences are observed. Estimated forecasts differ depending on ethnic group, economic status of a country or a region [7-9]. During the International HBSC Studies (*Health Behavior of School Children*) a plateau effect in prevalence of overweight and obesity in 25 European countries, in Canada and in the USA was observed [10]. However, other studies [11] also indicated a decrease of overweight in nine countries worldwide among children and youth aged 2-19. The tendencies were different depending on sociodemographic conditions. An increase in overweight and obesity was registered more frequently among youth from wealthy families of Western Europe as well as Central Europe. In the HBSC studies conducted in the countries of Central and Eastern Europe, including Poland, a constant growth of overweight and obesity among children and youth was observed regardless of

Table 1. Centile measures for assessment of obesity for boys and girls aged 12-13 based on the Polish OLAF assessments

Gender	Age	Underweight		Normal weight		Overweight		Obesity	
		Centile	BMI kg/m <sup>2</sup>	Centile	BMI kg/m <sup>2</sup>	Centile	BMI kg/m <sup>2</sup>	Centile	BMI kg/m <sup>2</sup>
Boys	12	< 5	< 14	6-84	14-21.9	85-95	22-25	> 95	> 25
	13	< 5	< 15	6-84	15-22.9	85-95	23-26	> 95	> 26
Girls	12	< 5	< 14	6-84	14-20.9	85-95	21-25	> 95	> 25
	13	< 5	< 15	6-84	15-21.9	85-95	22-26	> 95	> 26

the sociodemographic status. Recently in HBSC Report for Poland (2015) a certain reversal of the tendency is observed, as it was demonstrated that the number of overweight and obese children and youth is currently decreasing (in the group of boys by 1.6% vs. 3% in the group of girls) [10].

Excessive fat tissue is related to unhealthy behaviors considering diet and sedentary lifestyle [12]. Potential differences in prevalence of obesity depending on the continents and countries were indicated. Among children aged 5-17 in Greece, the USA and Italy one in three children had excessive weight (while in the OECD countries one in five). While in China, Korea, and Turkey overweight children constituted approximately 10% of the population. Boys had higher indices of overweight and obesity than girls in most countries, however, a reverse dependency was observed in Scandinavia (Sweden, Norway, Denmark), Great Britain, Holland and Australia. The growth of obesity was reduced initially in France, then in England, Korea and the USA [13, 14]. A different approach to obesity depending on the cultural context is indicated in papers [15]. The OECD Report (2015-2016) emphasizes more frequent prevalence of obesity among populations with a lower educational level, in particular referring to girls and women [16]. In Poland varied prevalence of obesity depending on the region was confirmed. [17].

Therefore, the objective of our paper was the assessment of potential differences in obesity among children during early adolescence depending on the place of residence in comparison to selected lifestyle elements.

## Materials and methods

### Research material

In the studies implemented from September to December 2015 148 children aged 12-13 participated; they attended 5th and 6th grade of primary schools from rural and metropolitan areas. Children from rural areas were represented by 37 boys and 37 girls attending the Secondary School Complex in Tarłów (pre-school, elementary and junior high school). Children from metropolitan areas (37 boys and 37 girls) attended the No. 34 Primary School which belongs to the No. 6 School and Pre-School Complex in Wrocław, ul. Gałczyńskiego 8. Legal guardians of the children and heads of the educational institutions gave permission to the participation of the children in the survey.

### Research methods

#### Anthropometric studies

In our paper assessment of prevalence of overweight and obesity among children aged 12-13 from two different areas was undertaken. Applying the anthropometric methods in the case of studies concerning children and youth, dynamics of changes of the studies parameters are taken into account based on centile charts which are created for particular developmental age populations [3, 18]. In the paper, the OLAF as-

sessments were implemented upon consent of the Commission of Bioethics at the Medical University of Białystok for a group of 17,573 children and youth from 416 primary and secondary schools from all over Poland. The authors of OLAF study created a set of centile charts for the Polish population aged 7-18, referring to the WHO recommendations for 2007 as well as the population of Warsaw and other studies from 1990-1999 [19, 20].

Measurements of height and weight were performed using a medical scale with the stadiometer (CE Class III). The obtained results were used to calculate BMI, and then they were applied to the centile charts developed during OLAF population assessments. The criteria to assess underweight, normal weight, overweight and obesity for boys and girls aged 12-13 were presented in Table 1. For each group, appropriate BMI values (kg/m<sup>2</sup>) corresponding to centile measures were provided.

### Surveys

Surveys were conducted applying the PAPI (*Paper and Pen Interview*) method using two original survey questionnaires to assess selected behaviors in the field of nutrition and physical activity. In our article, we answer the survey questions concerning nutritional habits, such as a quality structure of products eaten for breakfast, a frequency of consuming products containing protein, fruits, vegetables, fiber and products with a high content of saturated fatty acids and monosaccharides in diet were used. The physical activity questionnaire contained questions about frequency of undertaking physical activity, expectations of the form of a physical activity implemented within classes at school and motivation to undertake physical activity during free time as well as positive effects of physical activity in the children's self-assessment.

### Statistical calculations

For nominal variables, the percentage value and cardinality were provided. Normal distribution of the studied continuous variables was assessed using the Kolmogorov-Smirnov test. Differences in the frequency of selected lifestyle elements and overweight and obesity in the studied groups were assessed using the  $\chi^2$  test. The level of  $p < 0.05$  was assumed as statistically significant. In the paper, Statistica v. 10 was used.

## Results

In the studied population of children during early adolescence, an average value of BMI in the group of boys was  $19.619 \pm 3.25$  and in the group of girls –  $18.607 \pm 3.43$ .

Prevalence of overweight and obesity in the studied population taking gender into account was presented in Fig. 1.

Most studied boys (70%) and girls (64%) presented BMI appropriate to gender and age. Overweight was more frequent in the case of girls than boys (26% vs 20%). While obesity was more frequent in the case of boys than girls (6% vs 3%). Excessive weight, i.e. overweight and obesity, was the-

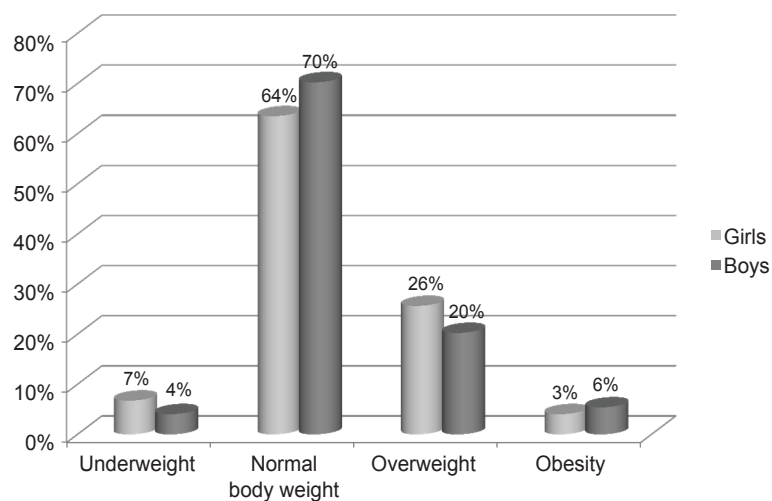


Figure 1. Prevalence of overweight and obesity in the studied population according to gender

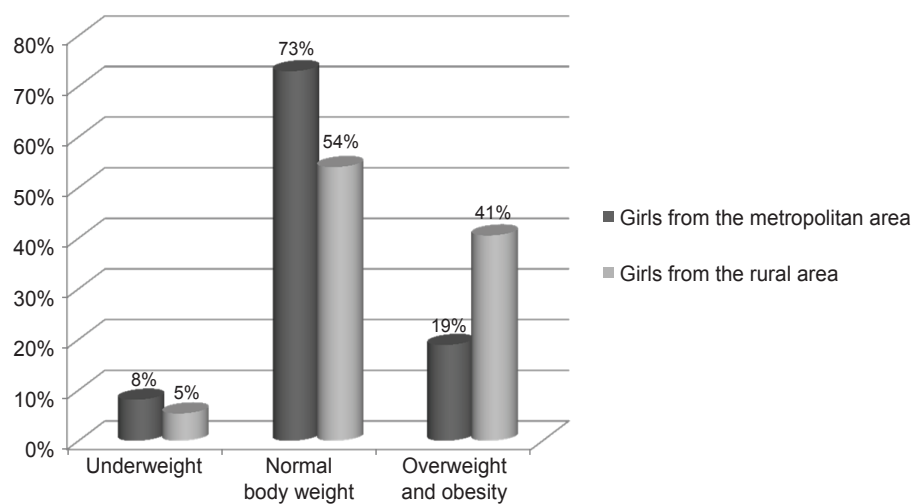


Figure 2. Prevalence of overweight and obesity in the studied group of girls depending on the place of residence

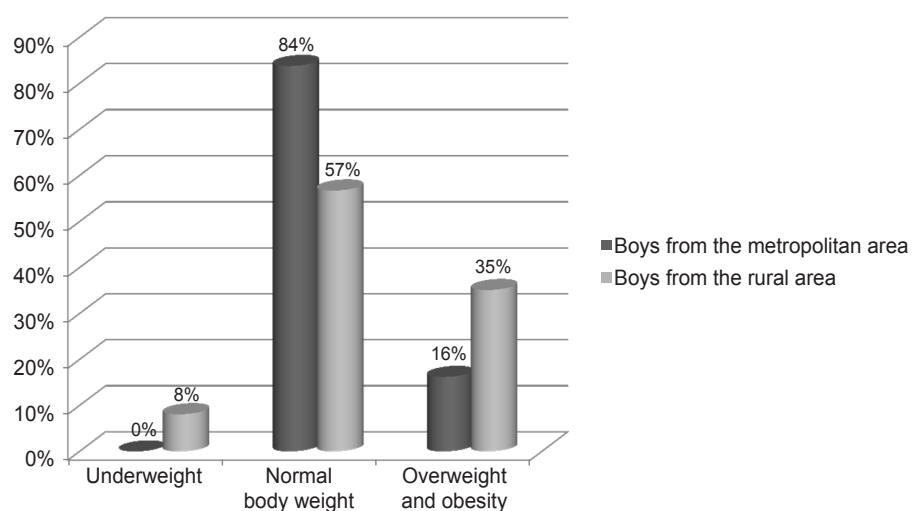


Figure 3. Prevalence of overweight and obesity in the studied group of boys depending on the place of residence



refore observed in 29% of girls and 26% of boys. Differences in the prevalence of overweight and obesity between genders were not statistically significant ( $\chi^2 = 3.131$ – $p = 0.372$ ).

Overweight and obesity were more (Fig. 2) frequent among girls from the rural area (41%) in comparison to girls from the metropolitan area (19%). The differences between groups received  $\chi^2=5.800$ ,  $p= 0.055$  but did not reach statistical significance. A similar analysis was performed in the case of boys (Fig. 3).

The differences between boys were respectively 35% vs 16% (boys from Tarłów vs boys from Wrocław) and were statistically significant ( $\chi^2 = 9.857$ ,  $p = 0.007$ ).

Alimentary obesity is related not only to the quantity structure, but also to diet quality. Children and youth should derive energy from food in 5 meals according to the hygiene recommendations. This recommendation was declared more frequently by children from Wrocław (49% of boys vs 41% of girls), while in the case of children from the school in Tarłów it was 28% of boys vs 19% of girls. Eating breakfast is one of the important health behaviors. This behavior was more frequently declared by children from Wrocław regardless of gender (68% of boys vs 71% of girls), while the frequency of eating breakfast by children from the rural area was respectively 51% of boys vs 56% of girls. Girls from the metropolitan area most frequently indicated products with a high content of monosaccharides (pastries), fruits and high-protein products (yogurts, eggs) as the basis of the first meal. While girls from the rural area also indicated high-protein products eaten for breakfast, however, the source of protein was different (milk, milk soup) and it was supplemented with bread with a low fiber content (wheat bread). While boys from the school in Wrocław preferred high-protein products for breakfast (hard cheese, eggs) and bread with a high fiber content (brown bread) and raw vegetables. Boys from the rural area preferred white bread, pastries and high-fat meat products (smoked meat).

The studied children also indicated food products consumed as part of their daily diet. In the assessment products with a confirmed positive impact on health were distinguished, i.e. milk and dairy products, vegetables, fruits, bread with a high fiber content and animal products with a low content of saturated fatty acids. The second group included products with a confirmed negative impact on health, i.e. sweets, products with a high content of saturated fatty acids and bread with a low fiber content as well as sweet drinks.

Milk and dairy products were most frequently consumed by boys from the rural area (46%) vs boys from the metropolitan area (32%). Also, girls from the rural area consumed milk and dairy products more frequently in comparison to girls from the metropolitan area (38% vs 32%). A characteristic feature was that both boys and girls from the metropolitan area equally often declared consumption of milk and dairy products. Vegetables and fruits were more frequently consumed by girls from the metropolitan area in comparison to girls from Tarłów (81% vs 54%). This dependency was similar in the group of boys (51% vs 19%). However, in the consumption structure, vegetables and fruits were more frequently present in the diet of girls than boys. Bread with a high fiber content was more frequently consumed by girls from Wrocław than boys (35% vs 27%), while the tendency was similar regarding gender, frequency of consumption of this kind of bread was lower among the rural population (16% of girls vs 2% of boys).

Consumption of sweets in daily diet was most frequently declared by girls from the rural area (97%), while girls from Wrocław similarly to boys from the rural area declared daily consumption of monosaccharides 57% of the time. It should be emphasized that the consumption level of sweets was

from 49% among boys from Wrocław to 97% among girls from the rural area. Animal products with a low content of saturated fatty acids were most frequently consumed by girls from the metropolitan area (27%) and boys from the rural area (10%). While animal products with a high content of saturated fatty acids were most frequently consumed by children from the rural area (43% of boys vs 35% of girls).

Girls and boys from the rural area preferred bread with a low fiber content (65% vs 58%). However, children diet concerned nearly half of the group of boys (49%) and 27% of girls. Daily consumption of highly sweetened drinks was more frequently declared by children from the Primary School in Tarłów (68% of girls vs 72% of boys). While, pupils from Wrocław declared consumption of these drinks less frequently (36% of girls vs 38% of boys), as they chose mineral water more often.

The subject of the research also involved the preferred way of spending free time according to the place of residence and gender. Comparison of these preferences in the group of girls indicates a low frequency of undertaking physical activity in free time. Only 17% of girls from Wrocław and 9% of girls from Tarłów prefer such an activity. In the group of boys physical activity as a form of spending free time was declared by 29% of boys from Wrocław and 17% of boys from Tarłów.

The authors analyzed causes of undertaking physical activity in free time. Girls from the metropolitan area most frequently indicated improvement of physical condition (54%), while girls from the rural area – reduction of body weight (51%). Furthermore, boys from the metropolitan area are motivated most frequently by improvement of physical condition (46%), and reduction of body weight (51%) than boys from the rural area.

About 42% of boys from Tarłów and 38% boys from Wrocław declared undertaking physical activity for 45 or more minutes daily. While among girls it was only 16% in Wrocław vs 23% in Tarłów.

What beneficial effects of undertaking physical activity are observed by students was also analyzed. Girls from the school in Tarłów most frequently indicated aesthetic effects regarding their body (28%), while girls from Wrocław believed that improvement of wellbeing is a beneficial effect (21%). Boys most frequently associated effects of undertaken physical activity with benefits in somatic health (26% of boys from Wrocław vs 23% of boys from the rural area).

In the reported studies we observed the diversity of expected forms of physical activities implemented within school classes. Girls from Wrocław the most commonly declared swimming (18%), while girls from Tarłów – dance classes (20%). Boys were mostly interested in team sports, especially football (26% of children from Wrocław vs 22% of children from Tarłów). It should be emphasized that boys from the rural area also indicate elements of strength sports (20%) and martial arts (17%). Boys from the metropolitan area were more interested in team sports in comparison to individual sports in the case of boys from Tarłów.

## Discussion

Overweight and obesity affects more than 33% of children [21]. Epidemiology of obesity is diverse depending on the country and area of residence. In countries with high prevalence of obesity among adults, obesity among children is also more frequently observed [8]. Relations between obesity and an increased risk of metabolic diseases were indicated [22]. Etiology of obesity is multifactorial; great significance of environmental factors is also indicated [15, 23]. Within the studies

conducted among children aged 12-13 residing in the rural area and metropolitan area at the same age it was indicated that overweight and obesity is more frequently observed in the group of girls (30%) than boys (25%). Similar studies were conducted between 1986 and 2006 among schoolchildren from the Podlasie Region. Overweight and obesity were presented more often in the boys group (15.8%) than the girls group (11.9%) [24].

Different prevalence of obesity in our study may be a result of another age of the group and earlier time of the research. In our studies, overweight and obesity were demonstrated more frequently in the rural area which was statistically significant. Other authors also indicated that more obese people live in rural than metropolitan areas regardless of age [25, 26]. We confirmed that obese girls and boys more frequently represented the rural area, 41% vs 35%, respectively. Another studies between children aged 13 in Wrocław in 2004 concluded that obesity was more frequent among girls (22.6%) than among boys (16.9%) [23], which confirms our results. Furthermore, 30 years of observation (1971-2000) among young people in Kraków showed an increase in obesity and overweight (7.5% boys vs 5.3% girls) [27].

Differences between voivodeships in Poland were observed earlier among adults and children [17]. These studies concerned many years of observations of adults and children from Lower Silesia, Lublin and Łódź areas. Our results are also confirmed by other authors [24], explaining the difference by promotion of healthy lifestyle in metropolitan areas.

In many papers, relations between obesity with the unhealthy nutrition model were indicated [5, 8, 12]. Moreover, unhealthy nutrition model was observed more frequent among children from the rural area. The quality analysis of food model showed that girls from the metropolitan area consumed products with a high fiber content, unsaturated fatty acids, and vitamins more frequently than girls from the rural area, but we didn't exhibit an association between the number of nutrition mistakes and BMI (results were not included). Similar conclusions were drawn by authors of another paper concerning teenagers aged 13-15 from Lubartów [28].

One of the important behaviors regarding diet is eating breakfast. In the studied group of children aged 12-13 eating breakfast is more often declared by children from Wrocław regardless of gender (68% of boys vs 71% of girls), while the frequency of eating breakfast by children from the rural area was 51% of boys vs 56% of girls respectively. While the studies on the risk factors concerning obesity and overweight conducted in 2003 by Veugelers and Fitzgerald involving 4,298 children and their families from New Scotland confirmed that children who do not eat first breakfast at home, purchase second breakfast at school instead of taking food from home, do not consume meals with their family members and consume meals in front of the TV or computer are more at risk of abnormal body weight [29].

Therefore, it confirms the fact of a more frequent prevalence of excessive body weight among the rural population, as these children eat breakfast less frequently. The structure of daily diet of pupils analyzed in this paper indicates that children from the Primary School in Tarłów consume products with a high fiber content and a high content of unsaturated fatty acids less frequently than children from the Primary School in Wrocław.

A high frequency of eating fruits and vegetables is typical for the group of girls from Wrocław. In studies conducted by

other authors, girls consumed whole wheat bread more frequently (80%) in comparison to boys (65%). In the case of consuming vegetables and fruits, authors highlighted a higher frequency of consuming these products by boys (88%) than girls (70%) [28]. In the current studies, the structure is different as approximately 65% of girls and 35% of boys consume fruits or vegetables every day.

Undertaking daily physical activity for at least 45 minutes a day was declared by 42% of children in Tarłów and 38% of children in Wrocław. However, in the case of girls, it was only 16% in Wrocław vs 23% in Tarłów. Other authors indicated that a higher BMI was observed in children whose physical activity was less frequent than twice a week, who traveled to school longer than 30 minutes and who did not have educational classes about healthy lifestyle at school [29]. The analyzed preferences in the selection of the forms of physical activity were also diverse depending on gender and place of residence. Girls from Wrocław most frequently indicated volleyball, cycling and horse riding, while girls from Tarłów – volleyball, cycling and swimming. In the group of boys from Wrocław the most frequently chosen forms of physical activity were football, cycling, and basketball, while boys from Tarłów preferred football, cycling, strength training and swimming. Results of this part of the studies can be considered to be an initial diagnosis of the local health promotion program.

The analysis of dependencies between obesity and mental wellbeing in Korean children indicated that obesity is related to low self-esteem, negative assessment of their own appearance and symptoms of depression [30, 31]. It is an important indicator for people implementing health promotion programs. Studies conducted on the German population from 1975-2001 showed that a higher economic status is a factor protecting children from excessive body weight [32]. It was also indicated that people with a low economic status less frequently prefer spending their free time actively [33]. Studies showed that the lower the economic status of citizens, the higher the risk of frequent prevalence of overweight and obesity [34].

An abnormal BMI in childhood increases the risk of overweight and obesity in adulthood [26, 35]. This statement can constitute the basis to undertake actions to prevent obesity and to promote health among young people considering preferred forms of physical activities.

## Conclusions

1. Prevalence of overweight and obesity was higher among children from the rural area regardless of gender.
2. Overweight was observed more often in the group of girls and obesity in the group of boys.
3. Children from the rural area consumed fewer meals a day than recommended in comparison to children from Wrocław regardless of gender. Also eating first breakfast was more frequently declared by children from Wrocław.
4. The structure of the daily diet in the studied groups depended on the place of residence. Girls from the metropolitan area consumed products with a high fiber content, unsaturated fatty acids, and vitamins more often than girls from rural areas. While children from the rural area more frequently preferred consumption of simple sugars regardless of gender.
5. The study concerning the preferred form of physical activity was diverse depending on gender and the place of residence of children.



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**Submitted:** VII 2016

**Accepted:** VIII 2016

## Autobiographical reports in research on people with disabilities

DOI: 10.1515/physio-2016-0001

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### Abstract

The article looks at assumptions of research where the central role is played by a source of data (autobiographical report), means of application of descriptive categories (flexibility, sensitization, bridging) and the method of arrangement of particular dimensions of autobiographical reports (mapping). The reflections are divided into several parts, where the most important reflections are related to a sensitising nature of the category of everyday experience and scientific description and the relationship between the lifeworld (*Lebenswelt*) of people with disabilities and the method of mapping actions of their socialised bodies. On one hand, research procedures embedded in ethics are to free researchers from closed formal categories. On the other hand, scientific descriptions based on non-stiffening “transfers” of specialist discourses, but dynamic mapping of *milieu* of people with disabilities, enable a better understanding of the lifeworld of those people.

**Key words:** autobiographical report, disability, *Lebenswelt*, phenomenology, sensitising concepts, maps

### Introduction

The absence of clear specification of the power and direction of impact of psychosocial factors on the function of people with disabilities does not undermine the fact that such stimuli are very significant for effects of rehabilitation [1]. Agnieszka Kumaniecka-Wiśniewska believes that in case of people with mild or moderate intellectual disability, specialist qualifications “are not very relevant to forecasting social function” [2], and they are not directly transposed into every-day and interactive function of such people in various social circles.

This has important consequences for the representatives of social science and humanities who face a challenge of accessing experiences in the least invasive way possible and of ethical analysis and understanding of such experiences, and secondly, of working on the phenomenological assumptions of research concerned with experiences which are considered to be too obvious, touchy, private to discuss them on an everyday basis and recount them without a sound reason in an interactive study (e.g. during face-to-face interview) [3]. Seeing that “every language exchange entails a potential act of power, even more so if entities who adopt asymmetric positions in distribution of appropriate capital are involved” [4], particular attention should be given to autobiographical reports (personal documents), including those which are “artificial”, in a way written upon request of research teams, and those created spontaneously that come from the heart, concerned with various subjects, written on sometimes more and sometimes less regular basis. The phenomenological approach based on analytical multi-sequencing of facts, argu-

ments, descriptions and accounts [5], although, importantly, for application of economical [6] and simple explanations in everyday life, enables a better Understanding (*Verstehen*) and creating descriptions of the lifeworld (*Lebenswelt*) of people with disabilities that are closer to the reality.

The presence of analyses of social experiences associated with disabilities in literature is well-justified. They refer to, among others, the issues of value [7, 8], sports [9, 10], control over the body [11, 12], education and professional life [13]. Nonetheless, there are very few research studies based on autobiographical reports [14]. The value of such reports for the authors themselves as well as for other people who struggle with greater than usual resistance of the body: therapists, students, researchers – basically anyone who is interested in the essence of autobiography, cannot be overestimated [15]. An autoanalysis (self-understanding) of the past, related specifically to difficult experience in non-evident contexts, shifts accents to present emotions. Thus, it has the power to direct thoughts towards horizons other than the subjective horizon, “the effort associated with recalling the past brings us closer to others” [15]. Written autoanalyses have the potential to become one of the tools applied in integrating people with disabilities into the spheres of Understanding as an interactive practice of cognition of the “Significant Other”.

The nature of involvement of these people in overlapping spheres (fields) of common and expert knowledge (e.g. law, medicine, social work) makes one, if not shift the point of gravity of the analysis from people to these spheres, at least consider these spheres to be specified tools in a cognitive “tool box” in charge of the analysis and, as a consequence,

adequate and precise description of the lifeworld of people with disabilities. In research practice it means that the leading role is assumed not by methodologies of particular disciplines, but the following transdisciplinary problem areas that can reveal a specific type of “data”: type of autobiographical report, means of application of concepts [16] and descriptive categories (flexibility, sensitization, bridging) and the method of arrangement of particular autobiographies and their elements (mapping). These three issues form a conceptual axis for the reflections presented in this article.

### **Sensitizing nature of concepts in everyday experience and scientific description**

Intentional recording of experience, whether in the form of some “loose” notes or regular correspondence or record of one’s personal memories (diary), including electronic records (e.g. video blogs), has a lot of significance for common spheres of significance (e.g. daily living, education, arts). Information carriers (paper, page in a text editor) help to retain in memory the present self for the benefit of the future self. With reference to reflections of Phillipe Lejeune one should emphasise that they are instruments of action, specific “laboratories of introspection” and the recorded dialogue with self can affect the future words and acts of the author as well as other people [17]. The report is an element of self-perception and self-understanding. It enables “a start from empirical entity and reaching a subject, an auto-reflexive actor who is willing to be a subject” [18]. The special role of writing is associated with involvement of individual history with interactive contexts of group history (e.g. within families, friend and professional circles, clubs). It refers to biographical memory, which is “an effect of narration created by others and under this meaning the others become its co-authors, by sharing at least a portion of the story and incorporating it into their own biographical memory” [19]. Unlike in the context of an interview, the author of reports can turn specific fragments of biography into the subject of everyday conversations with family and friends, by using, e.g. photo albums, old letters and postcards, family documents, diplomas, diaries and “loose” notes [20].

Reflexive and subjective embedment of reports in group histories can be considered an example of one of the assumptions of phenomenological work of Natalie Depraz, “life of practice calls more for mixing, composition and hybrids than purity and exclusivity” [21]. Therefore, important qualities of phenomenological descriptions include “hybridity” and “incompleteness”. The categories of first-person affective reporting (e.g. story, testimony) are not characterised by tight demarcations. The principal objective is to give testimony of “phenomenological experience in its uniqueness” [21]. The hybridity of everyday life and the inability of the act of reporting to “unglue” from the described content result in inward-oriented contemplative nature of the descriptive language. Eventually, it inevitably leads to the truth. Depraz, with reference to Ricoeurian reflections, sees it as something more than epistemic certainty “about descriptive knowledge, but trust of ethical nature that can be placed in an individual engaged in testimonial” [21]. The ethical means of embedment of truth in an internal order of equity [21] of people, which cannot be interpreted outside everyday reality of a group, applies to special circumstances (e.g. fighting for survival, one’s own life or life of next of kin) and elsewhere. It also applies in the context of social research, specifically research on people with non-standard body features, which they experience intrinsically and instrumentally.

The reference to ethics is supposed to de-objectify the subjects by freeing their description from formal categories, which are conclusive in themselves. By building categories of

opposing nature the researcher is protected from interference with originally established structures of autobiographical report which constitutes a non-reducible whole. Non-conclusive categories are a bridge “between theoretical reasoning of sociologists and practical reasoning of people who deal with the objective sphere [...]”. A sociologist learns that he has a ‘sense’ of everyday reality of situations, whereas an individual in a situation learns that he can control and handle theory” [22]. This bridging nature is based on research categories which have to be, first, abstract enough to determine qualities of concrete beings, and not beings per se [22]; secondly, they have to be flexible to become a general guide to changing situations of daily living. Finally, they cannot be devoid of the “sensitising” character: they have to specify the general, initial, “working” area of search; not the thing that should be seen, but the direction in which one should look so as to be in constant and direct contact with empirical reality and thus conceive an adequate picture of the phenomenon [23].

Although Herbert Blumer points to many important and still relevant problems associated with the use of autobiographical reports (personal documents), this “sensitisation” is indispensable to distance researchers from clear-cut concepts and formal definitions in favour of application of a description “which covers a considerable picture evoked by an apt illustration which enables one to see ties in terms of one’s own experience” [23]. For the research to be adequate and for the description to be good, one has to make a careful selection of empirical cases and work on congruence between concepts and phenomena in an in-depth manner. A meticulous description of cases and an analytical insight into their nature enables constant and close contact with the natural lifeworld [23]. The proximity enables the recipient (researcher, interpreter) to make repeated adjustments, to purify and test used concepts. The work results from the changing nature of concrete manifestations of everyday reality which is a reason why “what we assume [in research – W.D.] is not expressed in itself in a specific way” [23]. A number of concepts of social theories fail to precisely designate their empirical equivalents, they only bring their identification closer [23]. In the countless nuances of daily living the consequences of having, e.g. no palm, hand (hands) are different from those which are incidental to having no foot, leg (feet, legs), although specialist definitions may generatively “stiffen” (“transfer” – more in further sections) these features under an identical “overcoding structure” of specialists’ theory. Seeing that the principal objective of autobiographical research is the description of structures of the lifeworld, where the priority is given to the act of recording, the interpreter (recipient) “sensitises” himself to development of collections of language categories out of elements such as: diversity and frequency of forms of reports, (re)configuration of descriptive, argumentative, dialogue, factographic elements, language of emotion, first-person narrations, introspective and contemplative descriptions, elaborations and intimisation, abundance of specialist terminology, development of new techniques of body use and its exteriorization.

### **From the lifeworld to mapping socialised body**

The lifeworld is a basic category of phenomenological approach where a description of reality is more important than its construction: “The whole world of science is constructed on the basis of the lifeworld and if we want to think about science in an accurate manner, evaluate its sense and reach, we must first awaken that world experience whose secondary expression it is” [24]. Science as a symbolised determination of the world has a different existential sense than a world seen “as geography in relation to landscape which taught us first what forest,



meadow or river are" [24]. The world is primordial in relation to every activity that subjects it to analysis and, as a consequence, people are "a thorough attitude to the world" [24]. Only through processes of conceptualisation and categorisation one can really understand people's actual involvement in the world. Maurice Merleau-Ponty stresses (in the context of awareness) that "experiencing self, that awareness which we are, and that experience are a measure of all language meanings and it makes language have a meaning for us" [24]. Ultimately, it is about the content of the experience, because as opposed to thoughts, the experience builds the world. Being "a thorough attitude to the world", people are "doomed to sense" which in phenomenological world "glimmers at the point of intersection of my experience and at the intersection of my experience and the experience of another human being, at a point where they overlap" [24].

From the very beginning of existence, people have shared this world with others (fellow human beings) who, just like them, are in a biographically unique situation. Everyone has structured significance systems that mark out direct (close, intimate) and indirect (remote, indefinite) areas of influence. The bodies of all of them are a specific "zero point" which determines the current and potential reach of the temporary "here" and "now". From the cultural perspective, it is an arrangement of coordinates which determines points and areas of orientation in the surrounding fields of knowledge. Bodily involvements define individual pragmatic motives to experience the world on an everyday basis as a centrum that is spatially and temporally ordered around a human being [25].

The multitude of structures of the lifeworld and the possibility of multidimensional description of such structures makes the means of reconstruction of a system of elements of experience the primary task of a researcher. There, a substantial role is played by mixing of concepts related to observation and theory, which account for knowledge about the world, characteristic of social science, humanities and others [26]. The immersion of individuals and groups in areas of knowledge with various degree of "density" and elaboration (including non-dense areas of ignorance) can be reconstructed with a cartographic approach. According to Jean-Claude Kaufmann, mental maps, supported by memory that is close to physicality of objects, help organise one's intimate surrounding and have a direct impact on our everyday choices, behaviour, judgements [27]. Such maps give a sense of continuity of "me in the world", predictability and control, coherence with the surroundings. The immersion in knowledge, such which is biographically certain and used "at hand" on a daily basis, and such which is vague, connected with prior insignificant number of "entries" and "exits", reminds a system of contour lines: "a topographic map which reflects ground elevation with lines that join points of equal elevation. Peaks and valleys, hills and slopes extend on such a map in an infinite number of configurations" [28].

More inspiration in this context can be found in reflections of Gilles Deleuze and Félix Guattari. Based on their reflections, one can assume that the division into a field of reality, field of presentation (e.g. report of a memory) and field of subjectivity of the author of a written account of experience (the act of recording), disappears. A person with disability together with their topographic surroundings of the situation of recording (milieu), can be considered an auto-reconstructing dynamic system (network, plexus) where the "multitude" of cartographically separated areas work in parallel under material, social and semiotic flows [29]. Under such a system, an element of an expert system (e.g. a researcher, official correspondence, social campaign), which for many reasons (usually non-existential reasons) focuses on (analyses) its operation, can sometimes come to the fore. This dynamic sys-

tem is fuller and more complex than that pointed out by Kaufmann, "Absolute exteriorisation displaces exteriority. An explanation of this curiosity is based on a socialised body with changing shape which extends to an object" [27]. Becoming used to attributes of disability (e.g. a prosthesis, a cane, a wheelchair) and, in consequence, controlling them, change the people who use them but also the objects which, with time, become invisible, imperceptible, they "blend in with" the body [27], "getting used to a hat, a car or a cane is like moving into them, or reversely, incorporating them into the resources of one's own body" [24].

Deleuze and Guattari point to the positive, "non-stiffening" aspects of application of principles of cartography and decalomania in research on the above-mentioned system. For them a transfer is an element of a visible system of expert knowledge, a type of "a radiogram which starts with the choice and isolation of the things it intends to reconstruct by means of artificial measures, colorants or other instruments of force" [29]. A copy which works by isolating (stiffening) stabilises the picture, which is dangerous, because "a transfer reproduces only itself, in a belief that it reproduces something else" [29]. Being governed by generative and structural patterns, a transfer reflects something which is "already made, based on over-coding structure or supporting axis" [29]. Transferring seen as "verticalization", "stiffening" (like a structure of a "tree") entails a risk of immobilisation of maps whose essence is action, openness and susceptibility to practical modifications, a large number of "entries" and "exits" and vast possibilities of constant updating. To avoid a dual opposition of "theory" and "practice" one should, according to the researchers, always apply the transfer onto a map, never the other way round [29]. Mapping is primordial, perhaps also with reference to "observable data", and surely towards "non-interfering" language description. They refer to Fernand Deligny and write „create a map of gestures and movements of an autistic child, juxtapose numerous maps for the same child, for many children" [29]. Such means of operation of a map is absolutely open and it exhibits the experimental nature of the everyday reality of people who face the risk of hierarchical involvement in "stiffening" instruments of dictatorial power of an expert, "general Freud" [29]. The open character of the maps questions the hegemony of "significant": "in children, the semiology of gestures, facial expressions, play, etc. regains freedom and frees itself from "transfer", that is, the prevailing lingual competence of a teacher – a microscopic event disrupts a local balance of power" [29].

In the area of social functions of the language of scientific descriptions transfer-like actions and map-like actions concern the possibilities of communicative reproduction of the lifeworld either through "pure" copying of tradition or through breaking with the tradition [30]. The latter one activates a problematic issue which has been mentioned above next to Deligny's reflections – it is not about building many maps by researchers specialising in many branches of science, but about the ability to superimpose one on the other in such a way as to ensure that authentic details of everyday life of an autistic person can be still recognised in a collection (set) [3]. Thus, it is about building a transdisciplinary social theory in such a way as to ensure that it will not "transfer" nor "stiffen" and it will not remind a "tree", i.e. it will not be based on a "transferring" radiogram – "a theory of disability". It is easy to see a vertical direction of movement and the absence of horizontal lines on a tree diagram. For as long as "social theories" bear a similarity to "trees", there will not be many theoretical statements and theories – in the precise meaning of this word" [26].

The one-way movement of theories "stiffens" biographies usually along the timeline. The fragmentary and non-linear



nature that make for the spatial non-continuity of biographical stories point to a description and explanation "oriented towards a multitude of concurrent events" [31]. The multidirectional coincidence of existential involvements of people with disabilities in a way also forces mapping of scientific "ideologies" embedded on mental maps. Mapping process itself (cartographic diagrams) may fail to supply comprehensive explanation, but through the possibility of disclosure of a model of discursive universe of such "ideologies", it will sensitise theorists as well as practitioners to the above-mentioned autobiographical multi-contextual trans-subjective "glimmers of sense" in a milieu of people with disabilities.

## Conclusions

Reporting as a method of experience, work, communication, both in general and scientific contexts, should be considered in terms of elements of Olson's "world of paper" of Western culture. An autobiographical record of experience is not only a feature of communication. As we learn to write and read it becomes a pattern to be followed by spoken language and, in consequence, as a method of experiencing reality, it is an accepted cognitive perspective [32]. By reinforcing community and identity processes [33], an autobiographical report has a power of aesthetic multiplication of the reality [34] specifically in contexts of "redoubled effort of living" and resistance of a disabled body [14].

A transdisciplinary nature of procedures of autobiographical research on people with disabilities, always based on phenomenological assumptions, enables non-invasive (non-interfering) interpretation of the lifeworld, defending the interpreter in everyday life against attitudes of power characteristic of specialist language. Thus, Gadamer's assumptions, according to which reader's interpretation cannot take the place of an interpreted report, are proven. Since it is a language-related event, the purpose of interpreting concepts "is to disappear beyond things they verbalise thanks to interpretation" [35]. Interpretation is an element of comprehended content, not only a means of understanding. It means that its principal purpose is to "give the floor to the thing described by the text" [35]. On one hand, it protects the reader, a researcher from overinterpretation, on the other hand, he becomes open to use of informal, flexible categories. Sensitisation of a researcher to introspectiveness of autobiographical reports emphasises the value of ethical foundation of the truth in first-person affective descriptions.

The lifeworld of people with disabilities, to which a researcher gains access through autobiographical reports, constitutes a type of a network (plexus). An important role here is played by the fact that a "body in action" immersed in a *milieu* exists in material, social and semiotic flows which exist in unison and in parallel. It is directly related to the possibility of describing that unison and parallel, i.e. with the procedure of creating maps, which protect the researcher and the subject from hierarchical stiffening by discourses of expert knowledge systems.

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**Submitted:** VII 2016**Accepted:** VIII 2016

## Linguistic record of suffering in pain disease (Wallenberg syndrome) in “The Diary without vowels” by Aleksander Wat

DOI: 10.1515/physio-2016-0002

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### Abstract

The elaboration is rooted in the humanities, it constitutes a so-called case study and it suits the discussion on the significance of psychosocial, biographic and axiological factors in the study of people with disabilities. The Diary by Aleksander Wat, a poet and intellectualist constitutes an extraordinary and the only such mature testimony of suffering written in Polish, a linguistic record of pain in Wallenberg syndrome. Raising awareness and the holistic approach to disability is particularly important if rehabilitation is almost impossible. Apart from physical pain, mental pain is equally significant, and a physiotherapist with their compassion and understanding can significantly alleviate suffering of the patient and their loved ones. In the elaboration significance of the humanistic coefficient is highlighted, the application of which in the rehabilitation interaction protects both sides of the contact from the asymmetry of power relations.

**Key words:** Aleksander Wat, personal document literature, diary, Wallenberg syndrome, suffering in a pain disease

### Introduction

The elaboration addresses the issue of linguistic and biographical empowerment of the patient with a pain disease. The approach of a humanist is important and inspiring for physiotherapists, as presentation of the biographic side of suffering of the patient through linguistic communication allows their compassion and holistic approach to the disabled to be built. The elaboration draws attention to the humanistic and individual dimension of not only somatic suffering, but also mental pain which occurs in the face of a terminal disease, helplessness of medicine, new social, legal and professional contexts, among others, related to the experience of disability. Discussion of this subject is related not only to the ongoing discussion in “Physiotherapy” on humanistic and social aspects of rehabilitation, but also with personal experience of the author, the sense of helplessness in the face of suffering of another person (taking care of a person dying of cancer and of a husband with a back injury).

Intimacy of the records in the Diary allows the recipient (reader, physiotherapist) to better understand the nature of suffering and highlights an extremely important role of people from the closest surrounding of the poet, Aleksander Wat, whose experience of his disease constitutes an axis of presented considerations. Therefore and first of all, the text joins the discussion about an important role of psychosocial and humanistic factors in defining and describing some effects of rehabilitation [1, 2]. Second of all, it will be useful for therapists who deal with terminally ill patients and if medicine is helpless, physiotherapists involved with the axiological sphere of the patient (the patient and their family, friends, neighbors)

can alleviate mental pain with their involvement, understanding and compassion through a non-medical response to the needs of the patient dealing with biographic relations with the surroundings. Third of all, it highlights the importance of biographic studies [3] and axiological studies [4] with the application of memoirs, the cognitive status of which turns out to be different than data obtained as a result of various types of depth interview. The record from the phenomenological perspective “should be treated as a tool of internal discourse, an element of self-perception and self-understanding [and therefore – H. J.-R. created a “game” of reflexivity and subjectivity of the studied person” [5].

The elaboration is a reconstruction in the aspect of cultural and literary study of the manner in which the subject talks about his suffering and laboriously builds the axiological spaces of autobiography. The analysis presents how a man with an extraordinary linguistic sensitivity, an artist who loves life and is enchanted by it, a man – a husband and a father – deals/does not deal with suffering and how he domesticates it through linguistic expression. *The Diary without vowels* is a kind of linguistic sublimation of suffering and emotions related to it. It is a testimony of destruction and rescue of a man, his lack of consent to be imprisoned in the impotence of his own body, a portrait of a man crushed by pain and constantly undertaking not only a linguistic fight so that suffering does not destroy what is his and exceptional, to avoid accepting the sense of nothingness.

*The Diary without vowels* by Aleksander Wat [6] is a completion of a memoir *My age*. *The spoken memoir* [7] consists of three parts. *Moralia* from the 50s, *The Diary without vowels* from 1963-1965 when the poet was in Paris and Berkeley,

and finally *Papers in the wind* written in the last years of his life – 1966–1967. The title of the book may be misleading, as *The Diary without vowels* was not written on a daily basis which is a genre requirement. It could not be written in such a way as Aleksander Wat in 1953 went down with an incurable, exhausting pain disease which determined further life of the poet. Neurology determines this disease as Wallenberg syndrome. The disease was presented for the first time by a physician from Switzerland – G. Viessux during a symposium for surgeons in Geneva in 1808 as his own case. At the beginning of the 20<sup>th</sup> century Adolf Wallenberg described the disease from the neuropathological perspective. The cause of Wallenberg syndrome was closure (as a result of a embolism or blood clot) of the posterior bottom artery of the cerebellum, its small branches or the vertebral artery itself. There are various clinical types of the syndrome, depending on the extent of damage. Symptoms include among others severe neck pain, headache, cranial nerve palsies, transient loss of consciousness and coma. In literature we can find descriptions of single cases [8], and authors highlight that the prognosis is different – from complete resolution of symptoms and recovery, through long-term escalating pain, lack of effective possibilities of pharmacotherapy and physiotherapy. Consequently, the patient requires palliative care in which the deciding role is played by intimate and empathic features of direct contact, e.g. communication. Records of suffering as a result of Wallenberg syndrome finished with a defeat (the poet committed suicide) are found in *The Diary without vowels* by Aleksander Wat [9].

### What is destructive

Wat took advantage of temporary improvements of health to work. When he did not feel pain, he rushed to write, note and record all he could. He wrote the Diary, even though it was not his most important work. It was created alongside when he worked on *My age*, a kind of summary of experience and thoughts related to communism. Painful and constant attacks of the disease slowed down the creative process, caused anxiety, frustration and almost made him give up the work of his life. Alongside this huge creative effort and fighting pain, he created *The Diary without vowels*. Several years after the poet's death, Ola Wat deciphered his work with the editor and therefore, his notes being a testimony of his fight with the disease, his great experience, thousands of subjects, motifs, ideas, the poet wished to develop, undertake and leave after himself, became public.

The disease of Wat is a source of almost everything that is written in the Diary. It is a principle constituting the narration: the objective of the poet, the subject of his fight – and finally what he is internally. It is actually a trait typical for his poetic creativity and some critics speak about it directly: "his poems constitute a transcript of suffering; the poet could not raise above the subject of his own experience, the source of which is physical pain" [10].

However, can it be different if each written verse or sentence is accompanied by inexpressible physical suffering? It seems that describing it using metaphors, a literary attempt to deal with it is not just a manner to distance it from oneself, but a fight so that it does not dominate you, not to lapse into it completely. The disease and pain related to it are associated with prison, a tight and suffocating imprisonment in the cell of one's body where we cannot allow ourselves for freedom of thoughts, to live daily life normally. The disease rules the entire human body, it is a weakness, thinness, dematerialization: "I have a physical sense of gradually losing weight, I become thinner, dematerialized, I have an extraordinary sense of lightness when walking which would be pleasant if it was not

a weakness, as well" (DS, 96). What is worse, weakness penetrates the mind which results in the lack of productivity, barrenness of thought, lack of discipline and diligence, and consequently causes despair, lethargy, a sense of defeat and failure: "Discipline, will, diligence, focus on one sentence. It is so difficult for me, who every morning after waking up, must raise himself from falling into despair and inertia. So that I do not fall apart for the entire day" (DS, 167). A frequent metaphor of the disease as powerlessness is "my bed of sorrow at Niemcewicza Street" (e.g. DS, 183), slavery (medications), vileness: "For several days I am excessively overwhelmed by a note in *Christian Science* that percodan is heroin and it is very addictive! Therefore, I am threatened by enslavement and vileness of a morphine addict" (DS, 169–170) and finally a philosophy: "It is a puzzling matter to speak of the disease which for me is a fascinating subject and a mother of philosophy (...) – it is astounding how difficult it is for people who do not suffer to understand what chronic physical pain is, what a disease is" (DS, 222).

It is different in the case of the beloved ones, e.g. Ola, however there is another problem – the difference in understanding the disease and its importance by the patient and his wife. The poet is fully aware of that. For him his lethal disease means godsend, realization of dreams about the imminent end of suffering, on the other hand, for his wife, cancer, and therefore death, means the end of hope, tragedy, break down and the end of remaining physical strength: "Ola's pain when she sees my pain is based on a thorough belief that my life is not at risk. The thought of cancer would break her down. (...) It is opposite for me. A selfish bastard (...). She, the thought of cancer and close death, she healed me from unbearable depression (...). Therefore, I will not go to the doctor and because of Ola – if I have cancer, and because of me – if I do not have cancer and a desert of many years of suffering is awaiting me" (DS, 96).

The poet determining and explaining his disease to himself, draws handfults from literature, in particular from the Bible. This way, his disease begins to bear signs of sin. "If the disease is a symptom of a sin of the soul, then how sick, how sinfully sick my soul is" (DS, 93). It is also Cain's stigma "...literally pressed on my face" (DS, 188). In his reflections, Wat comes to the conclusion that he is cursed, his disease is a curse from God in whom he cannot believe. Such a punishment and a kind of possession by a demon "Sathan" (DS, 173), or even by a horde of demons in his head which dispel thoughts like papers in the wind. The patient, an old man, struggles with young devils who make it impossible for him to work and function normally, making him insane: "What a shameful possession, and there is no faith, and there will be no patroness nor exorcist to save me from the devil's captivity. As I absolutely and completely do not believe in the existence of the devil, although I believe that I am possessed by devils" (DS, 173–174).

Direct symptoms of Wallenberg syndrome, which were experienced by Aleksander Wat, were chronic headache, neck pain, paralysis of cranial nerves, paralysis, clumsiness and problems with feeling. The entire Diary is a record of fighting with pain, battles which were won sometimes, but more often lost completely. Aleksander Wat, a poet and master of words, applies numerous euphemisms, epithets, he describes the shape and he gives names to pain. Pain is his hell and a wish for eternal non-existence, a freezing wind. Personalized pain is "Furies, Erinyes – are devouring me" (DS, 218). You can try games with pain: "Now he was lying still and numb. He must be pretending to be dead. I know this from my experience: when pain is unbearable, I do the same, cleverly to deceive it. <You can see: I am dead anyway: why would you bother me?> It works sometimes" (DS, 228).

Pain is intransigent and Wat thinks that it talks to him: "You cannot doubt that we will stay with you till the end, till the



very horrible end" (DS, 216). Pain is a wall, "it does not leave space for any sublimation, for any hope, for any indulgence towards oneself" (DS, 165). Pain is loneliness, despite the greatest efforts of his family, the poet is left alone with pain forever: "Here, in the circle of physical pain, no one will follow. Not even my faithful wife" (DS, 229). Suffering finally brings him into the sphere of mysticism: "I have sought rescue in baptism, I strongly believed, I wanted to believe that the sacrament, even though it will not release me from my pain, it will give me mercy and strength, and joy to deal with it" (DS, 231). Unfortunately, Wat was rejected; God did not give him the mercy of faith alleviating pain.

For the poet a very important consequence of the disease is creative infirmity. A horde of devils in his head cause constant waves - alternating waves of weakness and short-term waves of euphoria ruling the patient's mind. The poet works with difficulty. He feels as if a rubbish bin is growing in his head which he cannot deal with. On one hand, pain and suffering cause the sense of infirmity, on the other - an internal command prompts him to express the truth - registered by Miłosz - as a witness of the era, a communist disappointed before the war, a Jewish intellectualist, a person who used to be an avant-garde poet, Wat wished to present his experience of "a skeptic and scoffer who found God at the bottom of a dungeon" [11], faith which helped him survive the time of separation from his family and a shocking attempt to force him to accept a Soviet passport. While, work depended on temporary freedom from pain: "When the demon of pain fell asleep for a moment due to oblivion or fed with nembutal, its victim made a dash on a piece of paper and rushed to write - along, across and on any empty centimeter - the most important thoughts recovered from the depths of the sore mind. Some records were encoded in a peculiar record without vowels due to rush - hence the title of the entire work" [11].

This way the Diary was created; it is full of subjects commenced and then given up mid-word, obsessive thoughts - a testimony of a constant battle with a mental block. "I am constantly in a panic state of soul and intellect, distracted, I lose time due to my despair, I have not done anything positive in two months. Time flies and I will waste my chance again, but maybe it is not so?" (DS, 145). This style of work causes the darkest thoughts. After leaving for America, which was supposed to change so much in his life, awareness of numerous moral and life obligations - towards his protectors in the USA - exhausts him. "Projections, illusions, deceiving myself and others again. I cannot do anything anymore" (DS, 181). So that he does not fall into poverty, good friends obtain favorable helpers, however it only causes shame and humiliation. Wat hates his powerlessness and lack of productivity, he feels dependent, he calls himself a cripple, a bankrupt. Even more because he found himself in a society which - as he describes accurately - is afraid of pain and disease, and separates useless individuals "(...) with American logic of ruthlessness towards themselves and others. Sorted, sifted. As I belong to the world of the useless (...)" (DS, 183).

All these issues arising from the disease, and striking the most important part of Wat's ego - his creativity - cause fear from which he cannot escape. "(...) none of our fears disappears, all are rooted in my soul, old age is a bag of fears and then you find out that all, all the fears were a prefiguration, a mask and a substitute of one fear: death" (DS, 129). There was only one efficient remedy for this fear: culture and literacy. It intertwines in the Diary with descriptions of his creative intentions, it is a basis for intellectual fascinations. Extensive reports on his reading are naturally combined with experiencing everyday life and memories: "Ola bustling around us at home of the siblings from Magdala, beautiful, joyful, cautious, calm and me, Lazarus, who has died and been resurrected so

many times. I am aware that writing about it, I introduce literature, that huge doses are contained in the act of my experience and also in the act of my perception (...). This belongs to my secondary nature (...). I am a cultural man" (DS, 126).

However, this also must be destroyed. As noticed by Wojciech Ligęza "...*tempus edax rerum* in Wat's creativity is audacious to the greatest extent" [12]. Myths, beliefs and symbols, sophisticated words are buried here - all fictions of his ending life. There is nothing left from illusions of the inherited culture. "I am a naked old man now", says Wat.

The last important and dramatic consequence of the disease for Wat is suffering of his beloved ones which seems more horrible than his own pain and inability to write. The fact that he burdens his wife, causes her sadness with his behavior, coldness, the fact that his son "starts to be afraid of him" constitute additional torture. The disease becomes a cause of arguments, conflicts.

"My greatest concern with Ola. When I feel better, tension of her energy weakened, she was gaunt, tired and annoyed, and this sight, my God, caused my anger which was impossible to control. It is me who suffers in my own body and if I have enough strength to survive, she should, too" (DS, 102). Difficulties in communication, the sight of his wife who goes out to crowded streets of Berkeley not to cry after her husband, and her complete mental exhaustion drive Wat to despair. Additionally, a difficult financial situation, a complete lack of certainty about the future torment the poet. Due to his disease he does not have any influence on his life anymore. "I leave everything unfinished, my wife, my son and my so-called heritage. Unfinished. Unfinished. Confusion, disorder. (...) The last wave of my night despair about Ola (...) that I will leave everything so unfinished in such an extreme chaos" (DS, 219).

Disease changes not only a human being, but also the world around them which becomes hostile, alien and without understanding. Despite tangible beauty around the poet, he falls into himself, he does not belong to this world anymore. The patient is subjected to melancholy and he cannot believe that his soul which used to be rich in experience and content, now has become indifferent to anything that is not pain and suffering. He cannot afford to cry any longer, all human reflexes have been taken away from him. This causes a sense of real misery - final destruction of internal life, rule of the sick body over the mind.

## What survives

Death - there is nothing else the narrator analyzes more profoundly. Many times on the pages of the Diary he speaks about it with yearning, it is nearly a reward for him which will end his misery and suffering. However, analyzing this motif in the course of days and years of writing the diary, we can observe significant changes. Initially, death means liberation from suffering, a desired end of everything, but without despair of the beloved ones. The specter of death introduces the sense of finality, the end of misery: "The thought about cancer brought order, serenity, renewed willingness and ability to work, consent to everything, and even willingness to live, a taste of life (if only short-lived!), goodness, gentleness to everyone and everything. Goodness of farewell" (DS, 96).

Writing his diary, Wat admits that he masks his fear of death. Even though he has been living with a belief that he is not afraid of it, is it really possible? Finally, three years before he died, in 1964, he wrote: "I know now that I was mistaken: we cannot fear death. (...) It is fear" (DS, 214). The author speaks about his battle against death many times and at the same time he brushes with it. Death is "the fear of fears" and also a wish: "It means that none of our fear disappears, all of



them are in the soul, old age is a bag of fears and then you find out that all, all these fears were a prefiguration, a mask and a substitute of one fear: death, all of them led to it" (DS, 129). Fear needs to be tamed, pain must be endured. There is someone to do it for. However, struggles must continue because of the beloved person: (...) no pain without hope was strong enough to exhaust the memory, the sight of Ola to whom I cannot do it (...). Then, for so many years, for twelve years of the disease, I was the master of my life and death, every night I prayed and I believed and I did not believe (...), asking and not asking for death, I dreamed about it, it was for me, in my thoughts and in all my wishes, it was a summary and the idea of goodness, it was understanding. Death was given, sent, however not death taken by force, not my bad will of death" (DS., 216).

The vision of death seems to come from beyond, it occurs like fate. Wat speaks about the stigma of death, that he was born dead and this determined his life. He tries to reconstruct his imagined death. If some time ago he imagined that during agony pain will disappear, he will die calmly, serious, focused, now just before dying he is not so sure about it anymore. He sees an image of dramatic death he saw, death is not so poetic anymore. It is frightening. However, a sudden growth takes place. The dying person needs awareness of death. „I cannot waste it, my death cannot be wasted" (DS, 220). One needs to face death with courage like throughout life. Death, despite being terminal in nature, highlights the value of the entire life. It cannot be annihilated. This way the narrator wishes to face "the opponent or brother". "(...) I will die standing, I am an old wrestler, if needed, despite all softness, intelligent oversensitivity, my jaw is a jaw of a boxer (...). I will experience great harm if I die in dullness, passively, feeling impotent" (DS, 220).

As foreseen before, understanding of death by the patient and his beloved ones is extremely different. Only in one place in the Diary these differences fade. When Wat arrives to America, he observes: "It is easy for us to talk about gas being at comfortable conditions: Ola finally said the word which is stuck and plays in my brain for such a long time since we decided that we will not go back to the bed of agony at Niemcewiczka Street. We survived, she said, there have been such and such misfortunes that we can say enough. It is easy to say, gas, however with our crazy wish to live and appreciation of life and about life, in life and with life!" (DS, 147).

Life saves, disease and death disappear before the passion of experiencing events, people, works of art and beautiful landscapes. Feeling life through awareness of weakening of the body sharpens. The poet wants the world and he cannot refrain from joy when he experiences relief from pain. He appreciates his wife, their 40-year struggle with life, beautiful, extremely difficult memories. As it is the past and memories which reappear that relieves fear, ensures certainty of continuous cycles of life – all will finally lead to the current moment as it is, as it should be. Images coming to the poet's head from literature and culture he lives with, are found around him, in his wife, in simple events in life. Such a sense *du déjà vu, du déjà vecu* (DS, 126) ensures a sense of safety, "what I need (...) is to know that what I experience now, has been experienced before (...), that it is in human power, in my power, to survive it. While it does not matter whether it is dangerous, common, easy or cliché" (DS, 126).

Wat rescues himself from annihilation in the disease, therefore he says who he is and why he writes. Hence, the fragment concerning the past – the poet believes that everything that happened in his life has a deeper meaning, confirms some values which played an important role in constituting his person. Everything that took place in the past is arranged logically, events are kinds of components of the entirety of the current

moment. He explains the world and himself to himself, trying to embrace things in a broad context. Such a generalization is an escape from himself, from the obsession about himself, "there is no other rescue apart from the thought about a brother rather than about myself" (DS< 220).

Indeed, what most efficiently motivated the man tortured by the disease to fight with pain, with himself and his weaknesses, was love. Wat speaks a lot about his wife Ola. He does it in an unaffected, delicate and subtle way. He also mentions their years of marriage, moments of forced separation, life under extreme conditions (labor camps, interrogation, exposure to starvation), complete consent and understanding of their common ideas regardless of the price to be paid. In suffering Wat, Ola was the only loyal, faithful and committed person. He describes his wife as a pure, calm and strong woman. Their unity of thoughts, bravery and fortitude of his wife led to compete fusion of two people: "However, in my all misfortunes I found strength in myself as our life was so close that none of us can say they are only themselves. In each of us we both are" (DS, 221).

Treatments and toil of his wife were the most effective remedy for the disease even tough at the end of his life they turned out to be ineffective and they cannot ensure rescue. As long as the author had strength, apart from love, in a natural way, also work and literature supported and rescued him.

### Le moi haïssable – Self (is) hateful to me

Between what destroys and rescues, there is the narrator. Constant, internal fight of oppositions causes Wat to determine himself as *le moi haïssable*. "I do not like writing about my life as I am one of the people for whom 'self' is *le moi haïssable*. If Pascal could have defined it so beautifully, it certainly means that there has been a species since the beginning of the world" (DS, 188). Demons, the disease and life, identity and nothingness, beauty and destruction, live and hate torment the author to insanity. Wat calls himself using numerous extreme terms. He is multiplicity, multitude as there are numerous thoughts and subjects which come back obsessively, demanding development. In the Diary the narrator is a prisoner, a poet "oversensitive and insufficiently tamed horse which is pricked by a spur and whipped by an incapable rider" (DS< 189). He determines himself as a bankrupt, Jewish, Pole, coward, and an old wrestler. He feels old and naked. He is a bursting and dying volcano, Lazarus and a man constituted by literature. He speaks of himself that he was born dead and oscillates between the offender and the follower. Contradiction is everywhere; everything becomes a space for battle between antagonistic forces. Multitude of identity dilemmas increases with progress of the disease – there is less and less time and so many questions the poet did not have time to answer. Dramatic internal contrasts constitute the entire image of *le moi haïssable*. "Hateful self" comes from one side of the body, its powerlessness, load, and from another side from beyond self. "Wat tried to think with his body: "He looked for hidden relations between what we feel and what thinks and feels in us". He was interested in an attempt of extra-personal seeing. Perception of self as a third person, from a distance. His own fate was interpreted as an example of general law. Taking care of details, he skillfully highlights analogies" [13].

Freeing oneself from writing about oneself is not possible – a sick and indifferent man must fight for himself, for his thoughts, memories which create him. If they disappear, there will be no man. This mental compulsion, a requirement from oneself brought a piece of work as a result – papers. Piles of paper, as determined by Wat, "papers – which is where a whim of a coincidence meets a whim of the mind which serve itself, and not me, and goes where it wants to go and

when it wants. (...) Whims, sets of whims, and not a piece of work" (DS, 180). Wojciech Ligęza will define the form of the Diary in a different way. In his opinion it is a record of a testimony, however not literature. This private document, if it was not for the disease, could be arranged, however, it was impossible and therefore "an original mixture of words must be between < pretentiousness and commonplace>" [12]. It is a form suspended between poetry and prose, poetry of a fragment which is most suitable to present bitter and scattered meditations. There is a "principle of a miserable sum deprived of any illusions about cruelty of life and time, in which fear and fate are mixed" [14].

It is worth looking at the form of writing *the Diary without vowels* at the end. Partially it was written without vowels, hence the title of the work. A question remains why Wat wrote in code, what is the significance of it for the text. As noticed by Ola Wat, reconstructing and preparing the diary for printing: "...I found more than a hundred pages written in code – with words without vowels (...) I cannot clearly solve this mystery, however I think that it deserves attention in the context of my husband's biography. A vowel is light, breath, life of words, its pulse. And therefore, pages filled with consonants must show suffering. Coarse, rough and crushed words were a symbolical and very particular expression of his condition at the time" [14].

Following this path, we can say that the code is another proof of Wat's struggle with the disease and pain, or a proof of increasing sinking in suffering of the author. Artur Stęplewski agrees with such an explanation. He believes that it was a conscious process to return to the author's roots. Wat, being a son of a Jewish tsaddik, knowing Jewish philosophy profoundly and struggling with his identity as a Jew-Pole-Christian, finally at the final stage of the disease, he pays tribute to the Jewish nation. "The nation with which he has always wanted to be connected after death at the Christian cemetery in Erec Israel>" [15].

It can be also assumed that giving up vowels was a dramatic attempt to extract primary meanings of works. Struggling with the lack of understanding from friends and associates, Wat saw how difficult it was for them to believe in words – a testimony of his pain. "He seeks [a friend] these non-verbal signs on my face which he normally associates with pain. And the need of confirmation with scream, groan or mimics indicates how little trusted words are" (DS, 241). Maybe that is why the form of writing was shaped as an escape from words "into the world of characters logically related in the mathematical analysis which cannot be falsified" [15].

## Conclusion

*The Diary without vowels* is a set of fragmentary notes which through their form and content give testimony to a dramatic nature of time when they were created. Extraordinary multiplicity of meanings of the statement, its multiple function: testimony, disclosure, trust, rescue, collection of moments and images, a draft of works which have never been written down, and finally a confession, auto-reconstruction, autobiography. In his narration Wat perfectly present the nature of the opponent with whom he fights – the disease. He constructs battle fields on which the eternal struggles with it take place, acknowledges it as necessary to construct himself – from the beginning, against all odds to stand to fight. Finally, he presents the object of his fight – what he must protect, what he struggles for. And all this closes in himself. The disease is in him, it is his integral part. This way the Diary is "a kind of dialogue with oneself, a dialogue about people, about God, about politics, Stalin and poetry. It is a record of unanchored and chaotic thoughts, which are contradictory sometimes. Everything in him arises from

pain" [13]. Wallenberg syndrome in the case of Aleksander Wat is a chronic disease, incurable, impossible to treat with pharmacotherapy or physiotherapy. It is only possible to alleviate pain with increasing doses of narcotic drugs. At moments of pain there is an important place for a physiotherapist who accompanying the suffering family, through his presence and compassion has a chance to alleviate pain and at least partially eliminate fear and trembling, anxiety due to what is inevitable, anxiety about the fate of the loved ones.

Long-term pain and the influence of medications in combination with literary rationality and Wat's reflexive mind constitute "unitas multiplex". His record without vowels does not exist without the author, similar to its content – without many associations of Wat to literature. The author and people from his surroundings, objects and events in which he is involved do not exist independently from one another. This multi-element combination is a research challenge as in the scientific analysis there are numerous biographic details, as well as in the area of social rehabilitation, as the common discourse rooted in scientific discourses (e.g. medical, legal) opposes and re-orientates the policy of disability [16]. Establishing reasonable borderlines intersecting various territories of daily life of the Wats is not possible. Like Wat who plays with pain, the researcher, guardian, rehabilitant are also forced to play, however not according to the principles of a discourse of power relations and a scientific discourse, with their boards, pawns and movements, but the game of Wat with his pawns and according to his principles. Wat's autobiographic records are like boards with complementary principles, it is "a system of values in which specified components constantly create a network of relations, dependencies and interactions between one another and the system as a whole" [4]. The boards bring to mind the issues with mapping elements of the system of values, constituting the world of a sick person: "another 'map of text' is created by its author, another by a common recipient, and another by a professional researcher" [5]. In rehabilitation practice, the use of a multiplicity of interpretations and in particular selection of what's best – authentically in the sense of "real" and adequately nuanced – cannot eliminate the "depth" and authenticity of human experience.

Reading and creating literary descriptions with love to his wife is a remedy for Wat to his painful daily life in which associations with the past co-define current choices and assessments. Trusting the word of Wat as a testimony of an internal compulsion to write the truth regardless of contradictions and existential dilemmas is the most important objective of a researcher, rehabilitant and other disabled people. Therefore, the meaning of the humanistic coefficient is highlighted which "makes it possible to become familiar with the reality of the disabled in specified contexts of their functioning, frequently incomprehensible for able-bodied people and disabled people remaining beyond these contexts" [4, 17]. This trust protects both sides of the direct rehabilitation contact from the asymmetry of power relations hidden in social conventions of using linguistic expressions [3]. At the same time it allows both parties of the interaction to discover nonlinearity of symbolical relations between the past, the presence and the future of their trans-subjective experienced world (*Lebenswelt*). An effect of such narrative trust is the need for constant interactive development of existential justifications to exclude consequences of acting with a partner in the areas of *Lebenswelt* of the patient by the patient and the rehabilitant. In the common area of existential justifications, the value of trust dominates the indicator of which is "an agreement between units not to undermine authenticity of features which appear on this common field/area" [3].

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Submitted: VII 2016

Accepted: VIII 2016

## Disability as desubjectification. Autoethnography of depression

DOI: 10.1515/pysio-2016-0004

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### Abstract

Disability is a label and a significant 'identity marker'. The objective of the article is a response to an autoethnographic question: how is disability constructed socially. The main character is Irmina who fulfills the definition criteria of disability as she is mentally ill. Irmina writes her diary at a mental institution where she stays during her treatment. She makes notes systematically and guides us through her mind (disabled?) describing situations she comes across. She refers to the matter of medicalization, bio-authority, standards, normality, illness, sexuality, desubjectification by disability and aspects of being a person. The elaboration makes physiotherapists sensitive to the issues of the world experienced (Lebenswelt) by people with various types of depression.

**Key words:** autoethnography, disability, depression, bio-authority, desubjectification, standards, intersectionality of disability

### Introduction

The category of disability is sometimes oppressive: indeed, it indicates privileges entitled to a disabled person, but it also stigmatizes. On one hand, it is a social issue, on the other – a power relation through a medicalized discourse. The objective of the elaboration is to analyze the social process of constructing disability in the context of clinical depression. I use two types of sources. First of all, I will refer to works by Michael Foucault [1] and his interpreters, such as Thomas Lemke [2] or Ewa Bińczyk [3] as well as to the definition of disability [4-6]. Secondly, to the diary of Irmina [7], a mentally ill person, for whom writing is a form of therapy. The first set of the main research questions concerns the manner Irina constructs her identity as a disabled person. What language she uses experiencing herself? Does she find herself to be a disabled person and how her appearance may impact her understanding of disability? In my elaboration, I use original fragments of Irina's diary which are written in italics. I also ask the question of how the care of Irmina can be used in rehabilitation work. Answering this question, I will start with considerations about the definition of disability to move to the exemplification of mental disability and conclusions.

### Several methodological comments

I started working with Irmina's diary two years ago. My methodological struggles are described step by step in the text *Piszę więc jestem. Stawianie się podmiotowości w tekstach* (I write therefore I am. Appearance of subjectification in texts) [7]. For the analysis, I chose a fragment of the diary which

was written between May and June of 2012 during her stay in a psychiatric hospital. I applied the autoethnographic method which is based on the assumption that "writing is a testimony of the situation and experienced emotions and a method to discover and analyze *ego* in the context of daily experience. We speak of autoethnography when a researcher comes out the framework of the traditional scientific writing, e.g. enriching the research material with a description of a subjective perspective of an overview of the studied phenomenon" [7, 8]. Autoethnography entitles the researcher to assume a strategy of colliding the author's own narration with the narration of the studied person. I have been doing it since the beginning of my work with the diary as in light of the WHO definition I am a disabled person. I do not describe my experience, but my research reliability involves the revealing of my personal commitment in the subject of the studies. Irmina's diary is a living example of the experienced world in which illness/health, disability/ability, normality/abnormality were confronted with my – as a researcher - perspective of an overview.

Considering the fact that we deal with an intimate nature of data [8], it is worth presenting the Reader with the process of reaching the source of experience in Ricoeur's understanding of the interpretation, i.e. "explain this type of «being in the world» extended before the text" [9]. I chose autoethnography, i.e. an analysis through writing about Irmina although it is a controversial method which is marginalized sometimes [10]. However, in nuanced contexts of experiencing disability (e.g. linguistic, rehabilitation, medical, legal) it is one of the most interesting options to describe multidimensional relations between an individual and a broader social and cultural context in which a significant role is played by an insight into the ex-



perienced world (*life-world*, *Lebenswelt*) mediated by writing [11]. Consequences of such an insight must be included in the body of the “technicised” discourse, i.e. medical and legal, about the manner of understanding, supporting and activation of disabled people as well as each time applied interactively in direct contact between patients and physiotherapists.

## Are we all disabled?

One of the most important inspirations for this elaboration is a social campaign entitled „We are all abnormal” where it is indicated that “one is a workaholic, another one counts steps, another does not eat bread or irons tickets. Kasia has down syndrome. Everyone is different. We are all abnormal” [12]. Abnormal and disabled are categories which in everyday language oppressively divide people. As constantly functioning labels they cause a stigma and simultaneously enter the world of “hurt identity” [4]. Its ‘treatment’, social rehabilitation depends on numerous factors, e.g.: hurt identity – ego, interaction of social surroundings, starting from cultural patterns which jointly impact evaluation of reality and therefore some characteristics of disability cause a marginalization effect or even exclusion. Analyzing the subject of disability, one of the most important questions concerns its social consequences. We can state that disability is a lack or excess of something in the body or mind of a human being. The body is understood here as a category constructed culturally and socially as well as biologically. The mind concerns activity of the human brain which is a mediator in perceiving the world and oneself. Let us consider situations of granting retirement pension to disabled people or those “claiming” to belong to this category. In a way, it depends on interpretation of physicians/officials in the deciding committees. Therefore, in certain documents there are stories about how ill people try to pretend to be even more ill than in reality as they are afraid to admit that they manage and live normally, i.e. like healthy people, despite what they must deal with on a daily basis. Such an institutional “mask theatre” is a common response to the needs of being granted a label by an official authority. Therefore, in this elaboration my purpose is to balance the center of gravity of disability from the perspective of power relations, medicalization, definition of health and illness, normality and abnormality. Irmina’s case will be helpful as well as the discourse about women as disabled people.

As there is no one and only definitions of disability [13], a more important task seems to be to indicate relations which are applied. In probably the most popular definition of disability, according to the World Health Organization, the mentioned excess or lack is in the body or mind, it is noticeable as impairment is “any loss of ability or abnormality in the structure or functioning of the body in the psychological, psychophysical or anatomical aspect” [14]. Or it is “disability as each limitation or inability (resulting from disability) to lead an active life in a way or to a scope considered to be typical for a human being” [14]. They are also “limitations in fulfillment of social rules (handicap) – an infirmity of a person resulting from disability or impairment, limiting or making it impossible to implement the social role corresponding with age, gender and compliant with social and cultural conditions [14]. Therefore, are Natalia Partyka or Oscar Pistorius disabled? Or is a person without dentition who cannot chew their meals on their own disabled? Or are we, who are ailing due to various mental or somatic reasons, such as migraines, back pains, mild depression, neuroses, abled or the opposite? Or maybe it means that in numerous cases disability is a label which someone gives us or we give ourselves. If so, analyzing disability, one needs to take into account the approach towards the person

who was labelled as disabled. In this context, as well as within the discussion in “Physiotherapy” about social and humanistic consequences of functioning of people with disabilities the analysis of Wojciech Doliński [5] can be considered; he postulates that disability as a notion of ‘logic’ classification (in the scientific theory) was not simultaneously a category imposed from above on biographically established everyday life. It is an important element of the experienced world and Partyka, Pistorius or Irmina do not have to feel that way, and this has an important impact on the construction of their identity. Disability can undermine humanity of a human being who is not qualified within the framework of normality. Therefore, a person with a label of a disabled person who feels that way or not, has ‘hurt identity’ [4]. Erving Goffman was interested in managing hurt identity in daily social relations as “shameful distinctness” [4]. In order to see that, one needs to study situations with which people considered to be disabled struggle. Also transgender, homosexual, bisexual people as well as people discriminated due to racism, prejudice and sex are characterized by shameful distinctness [6]. These are all cases of abnormality, and therefore they can be considered as a disability. Hence the postulates of the reparative therapy of LGBTQ people. If disability is a spectrum of features, then does it not mean that we are all disabled?

I do not perceive the category of disability as unnecessary as it would be an excessive simplification to determine all people as disabled. In spirit “all, so nobody” would be a category saying little about the issue of disability. Analyzing social consequences of disability, I lean more towards Doliński’s approach who doubts the definitions proposed by expert systems (e.g. medical), qualifying people with above-standard feature set. In other words, he does not believe that Partyka or Irmina mentioned at the beginning whose example I will describe below were disabled as “only in situations in which I cannot interact with another person (only with oneself?), (...) «real» – social – disability should be sought” [5]. Doliński moves within a relatively relational disability by distinguishing “a scope of control” which concerns individual, daily and practical aspects of feeling able despite all [5]. Therefore, ability can be marked on the axis determined with a minus on one side and a plus on the other. Between these poles there are various scopes of the category: physical ability concerning different body parts as well as mental and psychological abilities.

## Gender, authority and disability

The issue presented in such a way is not an exaggeration, as Colin Barnes and Geof Mercer [6] state that what creates sense in disability depends on the culture in which it occurs and they provide a definition of disability in a deep meaning penetrating the hidden social and cultural relations. In other words, creating sense takes place based on values which are considered and implemented in given society and they generate social divisions and power relations. One of the sources of these divisions is disability. Barnes and Mercer [6] write that if you are a disabled person and a woman, you deal with “double oppression”. A woman is often a victim of sexism and discrimination due to her impairment, i.e. the fact of being a woman. Moreover, “American and British experiences confirm a high degree of social exclusion felt by disabled women on the labor market. And therefore, disabled women are in a worse situation both in comparison to disabled men and able-bodied women. Thus, disabled women are neglected or presented as passive victims in the feministic discourse: «able-bodied women, perceiving disabled women as childish, helpless and persecuted, exclude them from the community of women, as they promote strong, competent and attractive



icons of femininity»" [15]. Therefore, gender here is an oppressive power relation as it desubjectifies women labelled as disabled and women who strive to be 'attractive icons of femininity' – women striving to fulfill social and cultural expectations and therefore deprives them of the possibility to have the right to seek oneself on their own.

How about Irmina? How does she construct her 'hurt identity'? How are overlaps of various features which qualify Irmina as a disabled person or – the opposite – as fully able shaped? As I mentioned before, the correct approach to define disability is the analysis of its relations. Such a point of view consequently leads to acknowledgement of intersectionality of this notion.

### Intersectionality of disability

Doliński states that ability is a broad "set of features worth developing [related – A.K.] with control of one's own body and its parts in various interactive situations (including imagined situations towards generalized other self)" [5] which means that each of us has goals to achieve, such as learning to read, to write, to analyze, to philosophize, run long distances, jump with a parachute or manage a fear, stress, sense of chaos in life. He believes that achieving ability concerns not only so called healthy, able-bodied, 'normal' people. It is sufficient to answer the following question: who of the able-bodied can be more able than a disabled basketball player in a wheelchair? [5]. Or what happens with our body and spirit when we take care of them? Therefore, based on his considerations, it is justified if we ask a question whether disability is a category characterized by intersectionality? It would mean a phenomenon of crossing, overlapping of various social categories which could hide marginalization of people or accentuate it. When I speak of intersectionality, I mean feminist critique which discusses these issues. However, the matter involves that the theories concern the subject of exclusion, marginalization, oppression, discrimination of women whose femininity has something of disability. However, they are not discussions dealing with disabled women as women without e.g. a leg, a breast or blind women [16].

Without going into details, I wish to notice that intersectionality involves overlapping of the category of age, disability, race, gender, identity of minorities such as sexual orientation, ethnicity, etc. and creating an exclusion identity. Irmina's diary constitutes a proof for the existence of this intersectionality: Irmina is a homosexual, but she is not in a relationship with a woman. She experiences clinical depression, and preparing herself to divorce her husband, she is concerned for her material status and the possibility to take care of her child as she wishes to be a single mother. However, she does not know whether she will be permitted to do this by the courts.

### Irmina's story

In Irmina's features we can see intersectionality and disability. Does Irmina consider herself to be disabled? She does not describe herself as disabled in her diary, however she believes that she is ill, i.e. she does not reach subjective well-being typical for a healthy person. According to the definition by WHO Irmina fulfills the criteria of disability. Hence, another question appears: how can we recognize in a certain and authorized way that Irmina is disabled?

First of all, a proof of Irmina's disability can be a biographic note about her: Irmina is an author of a diary which has been kept since 2011 till now. Receiving the research material, I selected a fragment in which Irmina particularly experi-

ences her trajectory keeping a diary in her PC concerning her hospitalization in a psychiatric hospital [7]. Writing is a form of understanding herself and the world around for her. The diary structure is determined by subsequent days during six weeks of spring in 2012. Irmina is 37 years old and after years of marital life she admits that she denied being homosexual. This short characteristic of Irmina shows intersectionality of various features indicating disability in the form of the fact of being a biological and cultural woman, a homosexual person, a mentally ill person (clinical depression is a mental illness while less severe forms of depression are considered to be mental disorders). We can see that the direction of narration is related to the processes of exclusion and inclusion. A psychiatric hospital is supposed to be a connector with the normal world, a kind of transition between worlds of various daily lives – before and after hospitalization.

Second of all, a strong fragment of the diary confirms this where Irmina writes about herself that she is ill. The category of illness appearing in the narration is an indicator of disability as it is something that causes a lot of suffering to Irmina. She writes: "I am badly ill. How can I shake off dementia caused by pain which penetrates my guts and brain. If the head is ill, it is impossible to endure life. An ill mind puts a cage on independence and independence becomes a simulation of life. The illness makes my life a disguise because I breathe only when someone is looking. And truth be told, I am running out of air which gives life as what I feel is bad" (29-05-2012, Tuesday, at 16.18)".

This is a significant fragment which indicates that being mentally sick you cannot really live. You can live, but only on the surface. Can we say that disability means living on the surface? In some aspects – yes. They are immersed in the daily consequences of a medicalized discourse which leads to interference in the most intimate spheres of life, biopolitics and distribution of power practices.

### Disability as biopolitics versus the hidden voice

Michel Foucault [1] was interested in a question how modern people have been and are changed by the fact that „we are exposed to public view" of human sciences with which we deal in psychiatry, psychology, sexology, criminology and pedagogy as well as institutions related to them [3] involved in practices of power through knowledge. History speaks a lot about the ethics of activities justified by medicine. According to Foucault the theory of power-knowledge understood in such a way is a theory of society which indicates the phenomenon of knowledge and rejects the classical dichotomy between what we believe as social, i.e. power mechanisms and what is discursive, i.e. knowledge, truth. Simultaneously, it is an indication that knowledge is a reverse of power [3]. Therefore Irmina lives in a "poisoned" life in the above quotation and what she feels *is bad*. It suits a medicalized discourse which provides ready calques of meanings to treat and understand oneself. She writes in a different place:

"I do not know how it is to speak my voice out loud. I have a voice, but it is inside me. No one can hear it. I can barely hear it. It is me. But I do not know what it says as it is very quiet. It is quiet as it is afraid. Being afraid is so horrible that it is not possible to get rid of it. It is better not to enter, as then you die. I speak about it with doctors a little. However, I do not know if they hear me. I do not know if they respond. Maybe they hear something totally different. But I do not know that. They only tell me to treat myself and they do not know how long it will take. Maybe even years. And I do not know how I can survive all these years in bad life. Every day I cry for

help. But it is a cry inside me. I cry inside me and I am very torn in blood. As when I try to cry I start to choke. And then someone must help me survive as I am very close to death. haHaHA what a pathos! Death is close uuuuuuu, be afraid. As death is serious and I am very serious now, as well. One needs to be unserious so that death does not bother them. How to do this when it hurts and when I am afraid? [30-05-2012, Wednesday, at 13:16]".

"Crying" is an attempt of Irmina to say something. Something what will be heard by the external environment. Something others will treat seriously, very seriously, i.e. they will hear there is a human being. A subject. A feeling person. How can others notice Irmina if she does not cry, she cannot cry? Therefore, they perceive her as a mute medical case which suits the power scheme or not. The metaphor of Irmina's *bad life* is a good example how biopower operates. Biopower (or biopolitics) uses expert specialized language to describe the case. The case of a human being. Arising from state mechanisms, biopower reaches very deeply into our alcove. The objective is that as little as possible escapes its control [1]. The biopolitical approach makes people a mass, a statistic group and simultaneously it desubjectifies them as a human being becomes a disabled individual, a cripple which needs to be treated consequently. And here a normalization discourse appears concerning knowledge and e.g. it organized campaigns to teach hygiene and medicalization of people [1]. Briefly speaking, standards succeed as they have the power to exclude and authorize. All exclusions of disabled people and labelling them constitute a biopolitical mechanism (Nazism is a very clear example of that).

### Desubjectification through disability

A question appears whether today's institution of a psychiatric hospital as an element of biopower desubjectifies or subjectifies its patients? The response is not clear. Today's psychiatric hospital treats disability in a different way than it is described by Foucault in his "The Birth of the Clinic" [17]. Indeed, fastening belts are still applied, medications about which the patients often knows nothing are still administered and it is justified by the placebo effect, but simultaneously there is an institution which gives consent to treatment. This is subjectification of the patient. But is it really? Does it not mean that if consent is signed, it is simultaneously an illusion and consent to submission to biopower which will conduct normalization experiments? On one hand, it is certainly that, as among doctors there are a lot of officials, however to honestly answer this question, we need to complete the previously quoted fragment of Irmina's diary which indicates that:

"I run from the Standards. I am a diagnosed fugitive from the Standards. As I stay with the abnormal. But I do not do anything wrong. I have only fallen seriously and fatally ill. Fortunately here in hospital there are people who understand – I think – that what I feel is real. Very often I do not know whether the situation I am in is real. I do not know whether it is normal. I am used to it as it has been so many years. Normal, real, right, healthy, but not free. This I know. Even though I stagger and I am not strong enough to raise my eyelids – I know this much. I know that the Standards are not free, but quick to improve in truth. If a man cannot have his truth, it is a thing. And if in hospital they do not allow me to have my truth, I will be a dirty thing. But here no one wants to be a dirty thing. Even when someone strokes their roommate and they do not want it. There is a truth coming out their whose? head. As truth is something hidden deeply inside us. Therefore, I do not cry, I only cry inside. As it is too deep. If I cried, I could scare you all. And I do not know what would happen. The end

of the world. I do not want to scare you, I do not want to cause death. Therefore, I am silent which hurts me. Truth hurts me. My own. Do not scream at me, I want to be pure (at 13:45, Thursday 21-06-2012)".

Irmina is subject to the normalized discourse again. She keeps the façade as stated by Goffman [18], determined by the institution. This means that even in a psychiatric hospital, one needs to know how to behave as there are rules of normality. Irmina does not want to be perceived in a bad way in the hospital. The last sentence refers to her fear related to the potential lack of acceptance, and therefore the standards constitute a tool of social exclusion.

### Standards as a tool of social exclusion

Standards push themselves anywhere with Panopticon's precision [19]. But something else can be seen here: according to Michael Foucault in the 19<sup>th</sup> century hygiene enters the daily life sphere. This impacts the approach of people to their body. Cleanliness appears as well as a requirement to be physically clean, not just spiritually, in a Christian way. Power enters the body in a new way. There is also "medical valorization of sexuality" which means the beginning of the theories of perversion and degeneration which facilitate crystallization of social standards. Since then, standards are supposed to be used as a tool of social exclusion. Foucault states that biopower facilitates expansion of racism, and therefore elimination of entire populations. Apart from that, biopower was "a necessary element for development of capitalism – it could survive only for the price of pressing bodies into the creative apparatus and adjusting population phenomenon into economic processes" [3, 20]. Can a disabled person adjust to economic processes and fulfill conditions of efficiency, usefulness and rightness? Standards, e.g. a neoliberal standard, being a derivative of capitalism says 'no' to disability. Being disabled is a stigmatized identity which must prove that the life of the disabled has a value. It means to constantly prove that it needs means to live in a situation when it is not able to undertake work. This causes that people must be qualified – whether they function in society as able-bodied or disabled. Is there anything in between? I ask this question as in practice patients develop their own biographic skills and strategies of obtaining independence, abilities as well as maintain appearances – Irmina writes about "life in disguise" which may mean that it is life to show society, i.e. trying to prove to the system of power to be normal:

"Sometimes we talk that if we were in a psychiatric hospital tens of years earlier, obligatory electroshocks would make us vegetables. And maybe it is good that I cannot cry even though it is exhausting to hold it inside, as because of that I do not have strength to live and I am a vegetable on my own wish. However, something tells me that I know that if I didn't endure, I would not be able to work, I would not have friends who are actually not fully normal, either, however they know how to move within the system very well. And this is not why they are very valuable. They are valuable because that try to walk on the grass, and not only on specified paths. When they came to visit me, I was forbidden to accept them (at 13:45, Thursday, 22-06-2012)".

Therefore, it turns out that this "life in disguise" mentioned by Irmina is not only pretended, but careful. The primary value in life in disguise is professional work in her opinion, as it is a guarantee of normality, i.e. of the fact that she fulfills requirements of biopolitics. She is productive despite her disability. Another important point of reference are friends who "are not fully normal, either", however it is an indication of the value of being able to use the system for one's own purposes.

We can see here that the context of functioning of disabled people where valuable skills matter is extremely important.

### Values and being valuable and a person, as well

Pezdek and Doliński [21] raise the matter of disability in the axiological context where values create a system which indicates significant spheres of life. It happens because "values may assume a form of objects, ideas, motivations, purposes, physical and mental states, etc." [21]. It involves the systems of subjective rather than objective values. It means that they are considered in the context of a person, group, institution, society rather than system properties, i.e. the subjective side [21]. The authors write that it is undoubtful that functioning of disabled people "is determined by the system of values which constitutes a plane to determine needs, choices, assessments or purposes" [21]. And therefore, they can be values related to a form of spirituality, even though in the case of mentally ill people, if we talk about values, it may often mean not only certain purposes, but also self-esteem, their own dignity.

If we talk about the role and meaning of a value as a sense of one's dignity, a question appears whether and when disability deprives a person of being themselves? Pezdek and Doliński [21] quote a definition of a person according to Peter Singer which highlights that a secular definition is different than religious understanding. "In secular concepts a person is a man who is rational, conscious and autonomous" [22, 23]. Therefore, infants and adults suffering from permanent disturbances of consciousness are not people [21]. Mental illnesses, not mental disorders which are definitely more frequent than illnesses, mean that patients experience various disturbances of consciousness. A question appears whether mentally ill patients can be considered according to this definition to be people? The answer is: they should, however it is not always the case. In this text I consistently use a term of person/people determining disabled individuals. I do this as I wish to highlight that disability is a deeply relational feature of human beings. Irmina does not feel disabled, but she feels ill as she is in hospital. However, the medicalization discourse indicates that Irmina is disabled as she suffers from disturbances of consciousness. The moment of being admitted to hospital in her diary is a turning point. Irmina believes that what happens to her is not mild depression which is treated as mental disorder, but as clinical depression which severely changes her perception of the world. Hospital is a place where she discovers and starts to acknowledge her illness. It results from the fact that the illness impairs her daily life, making it impossible. Does Irmina stop being a person? How to assess clearly that Irmina experiences disturbances of consciousness which disqualify her as a person? In her diary Irmina also considers her desubjectification. I write and I call this 'desubjectification' phenomenon as the disturbances of consciousness and assumptions who has the right to be a person indicate these kinds of processes. Desubjectification is an opposition of subjectification. Both these phenomenon occur in a psychiatric hospital as well as in our daily lives. Not only mentally ill people struggle to be a subject – and therefore, a person. Irmina writes:

"They look at me like at a case, even though they want me to say what I feel. What does a case in a psychiatric hospital feel? Or what does an ill case feel? There are interns here. They ask questions. I don't say anything to them. Fear. I feel a lot, but it is all bad. A bad life, as it is wormy and it is better not to open the plum. I like plums, but one might be afraid of the worm inside. And I do not know the worm inside me. It does not speak. It tears me from inside. So, if I say something

it may happen that no one will believe me that I am real. The plum will be disposed of. I talk about it a little, but only here. When I write. Fear. I try to be normal at the therapist's. How is it possible that they can see that there is something wrong? Is it the fact that I am being torn inside, that I must cut myself, even though I am not a teenager who does it to show off. Fucking fear. They check how I look. I do not have anything sharp anyway. But recently I have cut my arm with a stone. A blunt stone. Blunt. A nurse slapped me, she punished me her eyes filled with pity and sanitizing the wound, she said that it is my own fault and now it should burn a lot. She sprayed it. I felt stupid. I am ashamed of myself, but I calmed down a little. I directed my fear to my wound (29-05-2012, Tuesday, at 14:50)".

It is a fragment accompanied by fear. Sometimes it is so strong that consciousness is disturbed. Additionally, there are creative symptoms which involve seeing various creations which increase confusion. Irmina writes about it on subsequent pages of her diary. Does Irmina stop being herself when she experiences disturbances of consciousness? Maybe it happens if we consider the fact that she loses the ability to consciously see the situation and she is subject to creative symptoms. As I mentioned before, broadly understood ability and experience of dealing with one's own life constitute an important element of not being defined as a disabled person. On the other hand, did Virginia Woolf, Vincent Van Gogh or James Joyce stop to be people? How about Irmina who like other patients tries to live in society as we can see in the quoted fragments. She writes a lot about the fact that she has troubles with standards as she does not understand her own motifs and therefore she hides this worm in the plum very deep. She is afraid that someone will dispose of her because of it and what we know about the worm is that it is bad.

### Summary

In order to show intersectionality and relationality of disability, I used Irmina's example who despite being mentally ill and perceived that way does not consider herself to be disabled. I chose the fragment of her diary written at the institution of psychiatric hospital which concerns experiencing the illness as experiencing disability because it is time of biographic suspension, a kind of pause from external daily life in a closed place of seclusion. The first important conclusion concerns the fact that mentally ill people frequently do not see themselves as disabled, but rather as desubjectified by their illness which does not allow them to be reliable for other people and causes imposed loneliness. Thus, disability is constructed in various ways and it is not necessarily called disability. Disability is a process of labelling which penetrates biographies of people as a trajectory for many years or even their entire life. It is also a process of becoming conscious of one's identity, as symptoms of disability impact how we construct knowledge about ourselves. It can be seen in the fragments of the diary where Irmina tries to overcome the illness. In her diary, she describes reality as if she explains who she is, how she lives, how she breathes, how she meets people, how she fulfills her needs. Irmina builds relationships with others, subjecting them to reflections, also in writing, and therefore her experience means that disturbances of consciousness do not disqualify her as a person.

Irmina's diary also constitutes a very good example of overlapping of biopower and construction of hurt identity which we can grasp only by an in-depth analysis of detailed cases. The purpose is also to show people from their direct surroundings, including physiotherapists and guardians that some mentally ill people cannot be treated statistically. Some



common features, e.g. features of behavior, can be noticed, however it is not the most important element. Each depression, schizophrenia, bipolar disorder or personality disorder has its own individual nature rooted in group stories (family, friends, neighbors). Often depression occurs in conjunction with back injuries or inability to walk and other diseases. It occurs in the case of cancer, which is spoken of by the Amazons. Depression can be a reaction to a life trajectory which is difficult to overcome and which builds hurt identity of sick patients. For the areas of physiotherapeutic knowledge, the process of communicating/understanding the patient suffering from depression is important regardless of whether they define themselves as such or not. In such direct contact, it is not only about efficient application of specialized theoretical and practical knowledge (e.g. medical), but also about communication skills, negotiation skills and skills which allow physiotherapists to better understand not only how the patient's body functions, but also what is the biographic situation of the body (socialized body). Each person who appears in the intimate surrounding of the patient even for a short period becomes an important element of their world (*Lebenswelt*). In this world, the patient and the physiotherapist must find existential justifications so that rehabilitation is without conflict, not to mention so that it is completed with a mutual sense of success. Consequences of such a sense are rooted in linguistic practices with an institutional [24] and media [25] nature. Success will be experienced by both partners of the rehabilitation process if they achieve the state of mutual trust

indicated by "an agreement between individuals not to undermine authenticity of features which appear on the common field/area" [5].

Irmia's example also shows that sexuality, and therefore gender, sexual orientation, sexual desires are one of the cruelest factors of oppression. Discrimination concerning professional or educational relationships is something different. Sexuality, as mentioned by Barnes and Mercer [6], is frequently a silenced area among disabled people and a strong source of stress as "unexpressed desires". The analysis quoted by the researchers highlight that sexuality of the disabled constitutes an area which "provides proofs to underestimate problems of «sexuality, human relationships and patients' own identity»" [6]. Therefore, disability is a desubjectifying factor, i.e. depriving the right to be a person. On the other hand, there is a question what being a healthy person means. Because sometimes even people suffering from schizophrenia, but remaining in remission, are considered to be healthy. Therefore, a theoretical as well as a practical challenge is that the scientific, common and media discourse about disability does not stigmatize and commemorate inequality as each of us has physical and mental barriers in a way. A huge value of features related to some types of disability is in the fact that they constitute positive points of reference and areas of similarities of experienced ability. In such areas, we should seek existential and methodological arguments to co-experience daily life (e.g. related to physical or sports activity [26]) of people with various scopes of control of their body [5, 16].

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**Submitted:** VII 2016

**Accepted:** VIII 2016



## 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)

DOI: 10.1515/physio-2016-0003

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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 them<sup>1</sup>.

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-

<sup>1</sup> 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 stoma<sup>2</sup>, 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.

<sup>2</sup> 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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**Submitted:** VII 2016

**Accepted:** IX 2016

## Physiotherapy in the first three months after allograft face transplantation – case report

DOI: 10.1515/physio-2016-0006

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### Abstract

**Objective:** The aim of the study was to present physiotherapy procedures of the patient with von Recklinhausen's disease in the first three months after allograft face transplantation (PT).

**Methods:** During hospitalization lasting 2.5 months intensive functional rehabilitation was conducted. It ran in two stages: early (up to 30 days after surgery) and recovery (1 to 3 months). In physiotherapy the method with elements of PNF (Priprioceptywne Neuromuscular Facilitation) was used. During 2 months from PT an electrostimulation of orbicularis oris muscles was included. Physiotherapists did not focus only on rehabilitation of the face transplant, but also paid attention to functional problems caused by von Recklinhausen's disease. When planning therapy, they took into consideration personal, physical and emotional features. In therapy we used exercises in different starting positions, such as rollers, elastic bands, balls and sensory rings were employed. Lymphatic drainage of the face and neck was performed.

**Results:** During three months of the rehabilitation an improvement of upper and lower limbs' muscle strength was achieved; cervical spine range of motion increased, pain and discomfort caused by scar restrictions were reduced. There was also an improvement of the overall functionality of the patient. However, due to short time after PT no improvement in the functioning of facial expressions and sensory feeling was noticed, nevertheless the patient accepted the new face. In our opinion, rehabilitation is an inevitable element after face transplant (PT). The use of an individual and comprehensive program of physiotherapy, and it's early and systematic implementation allow to achieve an improvement of the patient's physical function after PT. Continuing rehabilitation is necessary to achieve full facial functionality and maintain physical capacity.

**Key words:** neurofibromatosis type I, face transplantation, rehabilitationn

### Introduction

In this article treatment proceedings in the first three months after allograft face transplant in a female patient with a diagnosis of neurofibromatosis type I were presented.

Neurofibromatosis type I (von Recklinhausen's disease) is a disease from the phacomatoses group (Greek "phakoz", i.e. marked at birth); it is genetically determined, and autosomally and dominantly inherited. It occurs once in every 2,500-3,500 people with identical frequency in both sexes and all races. The course of disease varies in different patients. Anomalies of the skin and subcutaneous tissue, the central nervous system, within the musculoskeletal system, endocrine, ophthalmic and cardiovascular disorders, and anomalies within the gastrointestinal tract are typical for this group of patients. In the patients there is also an increased risk of malignant tumours of soft tissues [1]. Typical symptoms include brown

spots (color: coffee with milk) spread on the skin of the trunk and limbs, and freckled spots with a 2-3mm diameter in the area of armpits and groins. In young people and adults subcutaneous nodules, which in the histological examination show hematoma or neurofibroma tissue, are also observed. In 30-50% of patients skeletal disorders, most frequently bone loss due to the oppression of neurofibroma, scoliosis, and congenital bent long bones disease are observed. Epilepsy occurs in 10-15% of the patients, and delayed psychomotor or mental development – in 15-20%. In approx. 70% of patients optic nerve gliomas develop; brain and spinal cord meningioma, as well as astrocytomas can also occur [2].

An indication to perform allograft face transplant includes serious, complex facial deformations or trauma in cases where it is not possible to apply any other treatment methods restoring lost functions, aesthetic appearance and well-being of the patient. The procedure of allograft face transplant requires principles of microvascular surgery and organ transplantation to be combined as well as application of immunosuppressive therapy the aim of which is to prevent transplant rejection.

### Abbreviations:

PT – allograft face transplantation

The first successful partial facial transplant was performed in 2005 in France [3]. Within the last 9 years thirty-two facial transplantations in 25 men and 7 women were conducted throughout the world. The amount of transplanted tissue varied: in 16 cases it was partial transplantation, and in the remaining 16 cases the entire face was transplanted.

During the initial post-surgery period, due to transplantation of muscle, vascular and nerve structures, the patient does not feel the new face. Within the transplant exteroceptive sensation is disturbed or suppressed, and the brain still “sees and remembers the old face”, it does not reflect the new one [4-6]. Long hours of surgery, anaesthesia procedures and immobilization in bed decrease overall fitness and exercise capacity of the patient. Additionally, pain and swelling disturb patterns of movement and motor control throughout the movement system.

A key element of treatment of the patient after facial transplantation is rehabilitation, an important component of which is physiotherapy [7, 8]. The ultimate goal of rehabilitation is to restore optimal physical, mental and social functioning of the patient. Regarding physical functioning the goal is to restore the following functions: chewing, swallowing, and smell, speech and facial expressions. It is equally important to restore and maintain the highest possible level of functioning of the entire body, to eliminate or decrease unwanted movement patterns and other effects of immobilization, to support healing of tissue in the area of the transplant. Obtaining the proper performance and physical fitness positively impacts the mental condition of the patient which translates into improvement of their quality of life.

## Case report

A woman, age 29, suffering from neurofibromatosis type I since her birth with advanced destructive craniofacial changes: head and neck external surfaces were covered in full by neurofibromas, came to the Department of Oncological and Reconstructive Surgery of the Oncology Institute. The patient was visually impaired and she had troubles moving independently. Due to large tumours, deformities of the face and mouth the patient had problems with breathing, talking, eating and drinking. The patient did not have an active movement of closing her mouth. It was impossible to evaluate the facial muscles due to deformation. The size and severity of changes caused compensatory setting of the shoulders in elevation, large muscle tension of the shoulder girdle manifested in activation of trigger points of the levator scapulae muscle and trapezius muscles of the ridge.

Earlier the patient underwent many surgeries of her facial soft tissue which were not performed by the Oncology Institute. She underwent 36 plastic surgeries involving partial resections of deformed facial external surfaces which did not result in the expected functional and aesthetical effect (Fig. 1).

Because it was not possible to apply conventional reconstructive surgical methods improving the patient's quality of life, in October 2013 she was qualified by the Team for Facial Transplantation of the Oncology Institute in Gliwice for allograft face transplantation (PT).

The surgery (PT) was conducted in December 2013. During surgery which took 23 hours resection of the affected soft facial tissue at all levels (skin, blood vessels of muscles and nerves) was performed with concurrent reconstruction through allogeneic multi-tissue whole face transplant collected from a dead donor in the same scope. Microanastomoses of the external carotid arteries of the donor with the facial arteries of the recipient as well as facial veins with internal carotid veins were performed bilaterally. Additionally, on the right

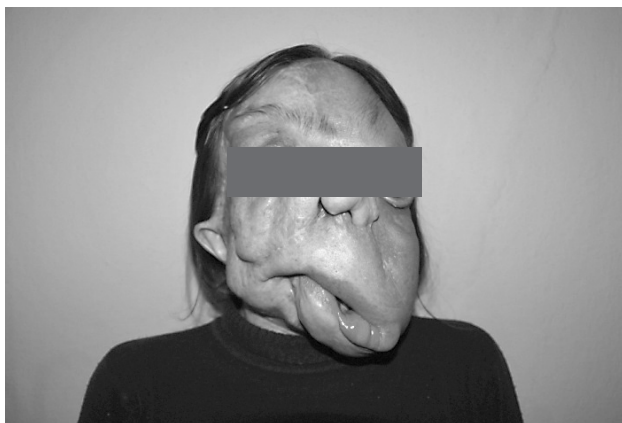


Figure 1. The patient's face before transplant

the retromandibular vein was connected with the external jugular vein. Also the nasal cartilage frame of the donor was connected with the margin of the recipient's nose. Bilaterally the facial nerves were micro-combined within the branches, and mental nerves of the donor with the great auricular nerves of the recipient.

After surgery the patient was hospitalized for 2.5 months, during which intense functional rehabilitation took place consisting of two stages: early stage up to 30 days after surgery and recovery stage from 1 to 3 months. The treatment program is presented in tables no. 1 and 2.



Figure 2. Exercises of the upper and lower limbs and the torso using three dimensional resistance – transferring tension (irradiation) on the facial muscles



Figure 3. Exercising control of proper setting of the head

Table 1. Physiotherapy program in the early period after the face transplant

Early rehabilitation (1-30 days)	Goals of physiotherapy	Applied therapeutic techniques
	Preventing negative effects of immobilization	<ul style="list-style-type: none"> <li>– Changing positions (active and passive)</li> <li>– Breathing exercises: through the chest and diaphragm, tapping</li> <li>– Assisted exercises of the upper and lower limbs</li> <li>– Active exercise of the upper and lower limbs</li> </ul>
	Transplant protection	<ul style="list-style-type: none"> <li>– Active learning to change positions by the patient from lying on the back to lying on the stomach with head compensation and returning to the initial position – learning to protect her face</li> <li>– Learning to protect her face, including touch (the patient delicately touched her new face)</li> </ul>
	Verticalization	On the fifth day after surgery the patient started to learn to sit <ul style="list-style-type: none"> <li>– Exercises described above were continued</li> <li>– Learning to change from the position of lying on the side to sitting with lowered legs and returning to the initial position</li> <li>– Exercises restoring proper setting of the pelvis, head, shoulder girdle when sitting down</li> <li>– Exercises stabilizing the torso in the sitting position</li> </ul>
	Facial sensorimotor re-education	<ul style="list-style-type: none"> <li>– Exercising physical memory within facial muscles (the patient received recommendations to imagine her facial expressions occurring in the case of expressing feelings and emotions, among others: joy, laughter, surprise, anger, smelling pleasant and unpleasant odours)</li> </ul>
	Re-education of gait	On the eighth day the patient started to learn to walk <ul style="list-style-type: none"> <li>– Exercises described above were continued</li> <li>– Active exercises of the upper and lower limbs in the position of lying on the back applying three dimensional facilitating resistance</li> <li>– Exercises of changing positions: from sitting to standing</li> <li>– Exercises of alternating axial loading of the lower limbs</li> <li>– Learning to walk forwards</li> </ul> On the fifteenth day the patient walked 1.5m for the first time <ul style="list-style-type: none"> <li>– Improving walking forwards, walking backwards and sideways</li> </ul>
	Learning active movement of closing the mouth Learning correct operation of the tongue and facilitating the swallowing function	<ul style="list-style-type: none"> <li>– Assisted and self-assisted exercises of temporo-mandibular joints: projecting the lower jaw forward, moving the lower jaw from side to side, closing the mouth.</li> <li>– Sensorimotor exercises of the proper setting of the lower jaw</li> <li>– Exercising the tongue using facilitating resistance with the use of a spatula</li> </ul>

Table 2. Physiotherapy program in the period of 1-3 months after the face transplant

Recovery period from the 30 <sup>th</sup> day – 3 months	Goals of physiotherapy	Applied therapeutic techniques
	Mobilization of the postoperative scar and reduction of swelling of the face	<ul style="list-style-type: none"> <li>– Fascial techniques, facial lymphatic drainage</li> </ul>
	Re-education of the functions of mimic muscles	<ul style="list-style-type: none"> <li>– Passive and self-assisted exercises within facial muscles combined with exercises of facial expressions occurring during communication, expressing feelings and emotions</li> <li>– Exercises of lower and upper limbs, torso using three dimensional resistance to transfer tension on the facial muscles (Fig. 2).</li> <li>– Electrostimulation of the orbicularis oris muscle using unidirectional current. Triangular impulses lasting 20 ms (muscle chronaxie was 20 ms) was applied with an interval of 1 sec. 3.5 cm/2.5 cm electrodes were placed on opposite edges of the mouth so that current passes along the orbicularis oris muscle. Concentration of 12 mA was applied which caused visible muscle cramps. Treatment time was 2 min.</li> </ul>
	Strengthening of the muscles of lower and upper limbs	<ul style="list-style-type: none"> <li>– Active and resistance exercises using elastic band</li> </ul>
	Body posture correction	<ul style="list-style-type: none"> <li>– Activation of the transversus abdominis muscle</li> <li>– Control exercises of the proper head position (Fig. 3)</li> <li>– Control exercises of the proper scapula position (activation of the lower part of serratus anterior and the descending part of trapezius muscle)</li> <li>– Exercises for the correct position of the pelvis</li> </ul>
	Preventing limited mobility of the cervical spine, contractures of muscles of the neck and shoulder girdle	<ul style="list-style-type: none"> <li>– Stretching and postisometric muscle relaxation: trapezius muscle – descending part, scapula levators, suboccipital muscles, scalene muscles, rhomboids, Sternocleidomastoid muscle (Fig. 4)</li> </ul>
	Strengthening of the deep neck flexors	<ul style="list-style-type: none"> <li>– Active exercises with resistance strengthening of the following muscles: longus colli muscle, longus capitis muscle, anterior rectus capitis muscle, lateral rectus capitis muscle, (Fig. 5)</li> </ul>
	Exercises of the tongue and learning to swallow	<ul style="list-style-type: none"> <li>– Exercises of the tongue with facilitating resistance using a spatula mobilization of the hyoid bone</li> </ul>
	Improving gait, balance, coordination	<ul style="list-style-type: none"> <li>– Balance and coordination exercises using sensorimotor cushions, balls, rollers</li> </ul>





Figure 4. Stretching and postisometric relaxation of the scapula levators



Figure 5. Active exercises with resistance strengthening of the following muscles: longus colli muscle, longus capitis muscle, anterior rectus capitis muscle and lateral rectus capitis muscle

Treatment commenced on the fourth day after surgery after disconnecting the patient from the ventilator, with stable cardio-respiratory parameters. Physiotherapy sessions took place twice a day and they took 30-45 minutes each. The sessions were conducted in the patient's hospital room due to her reduced immunity caused by administration of immunosuppressive drugs. Due to impaired vision the patient required constant assistance and support of a third person. In the initial period treatment was also impeded due to large swelling in the area of the transplant, lack of the movement of closing the mouth, and habitual compensatory settings of shoulders and trunk. Elements of the PNF (Proprioceptive neuromuscular facilitation) were used in the treatment procedure. Rehabilitation of the transplanted face was not the only focus, but also the use of the entire functional potential of the patient [9, 10]. Attention was drawn to positive commencement of the therapy through work without pain, and use of the strong parts of the body to stimulate the functional reserves of the patient. Planning the therapy physical and emotional features of the patient were taken into account. To teach movement the following were used: irradiation (transfer of the muscle tone from the strong parts of the body to the weakened parts), manual contract, verbal commands, facilitating resistance, relief (traction) and pressure (approximation) of the joint surfaces of limbs and torso.

In the therapy various starting positions were applied, using the force of gravity to facilitate or hinder movement. In exercises rollers, elastic bands, sensory rings and balls were used. Also lymphatic drainage of the face and the neck was applied as well as manual techniques on soft tissue. Two months after PT electrostimulation of the orbicularis oris muscle was additionally applied. The method of treatment was established based on electrodiagnostics results. The patient was also receiving psychological care.

Applying the described physiotherapy program during three months of rehabilitation the muscular strength of the upper and lower limbs was improved, the scope of mobility of

Table 3. Functional evaluation of the patient after 30 days and 3 months after surgery

	Evaluation of the functional condition of the patient after 30 days after surgery	Evaluation of the functional condition of the patient after three months after surgery
Muscle strength of upper limbs – Lovett's test	4	5
Muscle strength of lower limbs – Lovett's test	3+	4+
Facial muscles – Lovett's test	0 no sign of tension within the facial muscles	0 no sign of tension within the facial muscles
Mobility of the temporo-mandibular joint	lack of active movement of closing the mouth	incomplete active movement of closing the mouth
Range of motion of the cervical spine using CROM device: extension-0-flexion	40-0-30	60-0-45
Range of motion of the cervical spine: left side bow-0-right side bow	15-0-15	30-0-30
Range of motion of the cervical spine: counterclockwise rotation -0- clockwise rotation	25-0-30	60-0-60
Pain of the neck and shoulders (VAS 0-10)	7 at the VAS scale	1 at the VAS scale
30-second Chair Stand CS	Impossible to perform – the patient gets up from the chair helping herself with her hands	5 repetitions
Eating	The patient was fed though PEG (percutaneous endoscopic gastrostomy), additional oral ingestion - semi-liquid diet, eating 100ml of food takes 25 minutes	The patient was fed though PEG (percutaneous endoscopic gastrostomy), additional oral ingestion, eating 200 ml of food takes 15 min
Gait	The patient walks independently (due to impaired vision she requires assistance) difficulties with walking backwards and sideways	The patient walks forwards, backwards and sideways independently (due to impaired vision she requires assistance)

the cervical spine was increased, pain and discomfort caused by tightening of postoperative scars were reduced. Also the general fitness of the patient improved (Table 3). No improvement was observed in the functioning of facial expressions and exteroceptive sensation due to too short a time after surgery. In spite of that the patient fully accepted her face.

The patient with her family was educated in the field of exercise techniques and discharged with a recommendation to continue rehabilitation under outpatient conditions with periodical follow-ups and functional evaluation in the Oncology Institute.

## Discussion

Allograft face transplantation (PT) is a new achievement in medicine and rehabilitation giving hope to people whose face was deformed by disease, injury or as a result of congenital defects of development [11].

In literature there are no publications presenting detailed schemes of physiotherapeutic proceedings of patients after allograft face transplantation. Devauchelle et al. (2006) describing the first successful partial face transplant say that in the patient whose face was severely bitten by a dog, when she waited for her partial transplant, intense physiotherapy was applied in order to decrease scarring within the damaged area of the face and to prevent atrophy of facial muscles of the preserved part of the face. The authors say that physiotherapy was also applied after PT for four months after surgery as of the second day. Therapy took place twice a day and it involved: passive and active exercising of the face mostly aimed at restoring mobility of the lips and closing the mouth [7, 8].

Also Roche et al. (2015) point out the necessity to apply early and intense rehabilitation in patients after PT involving: speech therapy, physical activity and sensory re-education [3].

Siemionow et al. (2009) say that physiotherapy in the patient after the total face transplant was commenced after 48 hours after surgery and it was conducted once a day for six weeks, and then three times a week. Active and passive physical exercises, delicate massage, sensory re-education and learning to accept the transplanted face were conducted. Functions, such as chewing, laughter, speech, swallowing and facial expressions were evaluated [6].

In our opinion in the early period after the PT surgery in the patient with neurofibromatosis type I, apart from direct re-education of functions within the transplanted face, it is important to improve functioning of the entire musculoskeletal system of the patient and using strong parts of her body to facilitate mobility within the transplanted tissue. Application of the presented treatment program allowed improvement of the general fitness of the patient to be achieved and conditions for further rehabilitation within the transplanted face to be created. The achieved improvement motivated the patient and her family to continue therapy.

A face transplant is a significant venture requiring cooperation of surgeons, transplant specialists, physical therapists, speech therapists, psychologists, a nursing team and many other specialists.

In treatment of patients after PT it is particularly important that the transplantation team takes into account the needs to conduct complex rehabilitation after surgery, and consider the possibility to commence it before the planned transplant.

In order to achieve fitness in the field of facial functions and maintain the correct fitness and physical capacity application of an individual and complex physiotherapy program is necessary. Physiotherapy proceedings require numerous studies and an exchange of experience, which might be impeded due to a small number of this type of procedures performed in the world.

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Submitted: I 2016

Accepted: III 2016

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### AIMS AND SCOPE

**FIZJOTERAPIA / PHYSIOTHERAPY** (ISSN 1230-8323) is an international scientific peer-reviewed journal, published in both paper and electronic format by the University School of Physical Education in Wrocław, Poland. The original version of the journal is its paper issue. The Editorial Office accepts original papers on various aspects of physiotherapy and rehabilitation for publication. Manuscripts in basic science and clinical physiotherapy science are published at the highest priority. Letters to the Editor, reports from scientific meetings and book reviews are also considered.

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## *Jakość i styl życia w świetle nowoczesnej rehabilitacji*



**WYDZIAŁ FIZJOTERAPII  
AKADEMIA WYCHOWANIA FIZYCZNEGO  
WE WROCŁAWIU  
2017**

# *Jakość i styl życia w świetle nowoczesnej rehabilitacji*

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