Autobiographical reports in research on people with disabilities

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Abstract

The articles 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 system 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 decalcomania 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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