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Autonomy and participation (IPA) in Polish research on people with physical disabilities

Abstract: This article focuses on the phenomenon of autonomy of people with physical disabilities, which has been relatively little described in the Polish literature to date. The undertaken considerations are of a review nature and present a theoretical approach towards the issue of autonomy and participation from the perspective of International Classification of Functioning, Disability and Health (ICF). They are supplemented by the presentation of the results of the selected empirical studies. The article is based on literature review, in which the Polish adaptation of the IPA Questionnaire was used for the study, and concerns the nature of autonomy and physical disability. As a result of the conducted analyses it can be inferred that autonomy and participation of people with disabilities is to the greatest extent shaped by contextual factors (personal and environmental ones). There is also a positive relationship of the analysed variables with life satisfaction and its quality, adaptation to disability as well as wisdom and a negative relationship with secondary health complications and mobility limitations.

Keywords: autonomy, participation, , self-realisation, physical disability, ICF.

Introduction

Autonomy is a fundamental condition for participation and an important determinant in shaping a sense of quality of life of people with disabilities. It is also one of the fundamental rights of persons with disabilities. In fact, it is more and more often associated with its high level and self-rated health, indicating that people with disabilities perceive their lives as satisfying when they can decide for themselves and their environment (Lundt et. al, 2007; Li, Cheng, 2019). The issue of autonomy is deeply embedded in the tradition of subjectivity. Participation in society, understood as a commitment to action in accordance with a self-determined decision, is strongly linked to a sense of quality of life (Levaseur et. al., 2009). It manifests itself in the fulfillment of one's own goals, intentions and assumption of social roles that are entrenched in a certain social context. The autonomy of a person is emphasised by the participation in a variety of activities pivotal to this person. The increase of limitations in both the perceived autonomy and participation are, unfortunately, part of the long-term consequences of living with disability. As a conceptual model, the ICF illustrates interrelationship between health (disease or disorder), body (represented as body functions and structures) as well as individual's participation in society (represented as autonomy and participation). Autonomy is a basic prerequisite for the participation in society and is understood as the ability to make decisions about both oneself and one's environment. Participation is expressed in the achievement of the goals set and in taking on social roles according to one's own decision (Cardol et al., 2001). Therefore, autonomy is a fundamental prerequisite for participation and an essential determinant in the perceived life satisfaction of people with disabilities, thereby negating a stereotypical perception of this group as having no control over their fate. An important factor consists in the changes to the perception of disability. The evolution of the disability paradigm addresses the needs of these people, shifting focus towards broadly understood independence in activities in all the relevant spheres of functioning. This trend is referred to as disability studies, highlighting self-determination and life activity.

The objective of this paper is to present a theoretical approach to the phenomenon of autonomy of people with physical disabilities. The presented research review draws on the results of studies pertaining to a sense of autonomy, where the framework of the International Classification of Functioning, Disability and Health (2001) was applied as a theoretical model. Additionally, an overview of the selected foreign and Polish studies on autonomy is presented in order to demonstrate the validity of psychometric properties of the scale used in Polish research.

Autonomy – Definitional Approach

Autonomy is the subject of research in many scientific disciplines, ranging from political sciences through sociology, medicine and law to human and social sciences, which results in it being differently defined. Nonetheless, one thing that all these approaches have in common is that autonomy pertains to all the people regardless of background, age, gender, health condition or the degree and type of disability. Suppression of autonomous aspirations of people with disabilities is an assault on their fundamental rights, as it is an inherent part of any considerations about humanity and its subjectivity. The issue of autonomy of people with intellectual disabilities has been raised quite extensively in the field of pedagogy (Meininger, 2001; Ćwirynkało, 2010), while few positions draw attention to the perception of autonomy by the people with diverse physical disabilities. An interdisciplinary approach integrating psychological and social approaches, with account taken of a temporal perspective, is of paramount importance in research on the autonomy of people with disabilities. Thus, a person's autonomy can be considered in different dimensions of its functioning.

Autonomy not only defines the rights of an individual, but also his duties and accountability for the actions resulting therefrom. „The state of autonomy requires from a person both wisdom and courage to responsibly and consciously create good living conditions for the fulfillment of needs and goals of an individual and the community, while maintaining the distance from oneself and others, in addition to the ability to defend oneself against the harmful domination of others" (Michałowska, 2021, p. 38). The value of knowledge was emphasised by W. Sak (2017, p. 456), who stated that „the essence of autonomy consists in obtaining such kind of information which ensures independence in a certain area. From the subject's point of view, such kind of autonomy is significant which allows for the provision of well-being, healthy action and harmonious life".

Autonomy of an individual usually boils down to a sense of independence. These are not the same concepts, though they are semantically related. According to PWN, the Polish Language Dictionary, independence means non-subordination to someone or something, deciding about oneself, while autonomy means self-reliance and independence in decision-making. Although these words are often used interchangeably, the understanding of autonomy is not always linked to non-subordination, but rather to an independent, value- and principle-driven decision of a self-determining nature, which is connected with the context of a given situation. Autonomy is the ability to make decisions in all the spheres important for a person without coercion, but in compliance with the accepted system of values and principles governing functioning, e.g. social functioning. „Autonomy is not a function of what one can do for oneself and by oneself, but rather acceptance of responsibilities and making decisions for oneself in the context of social connectedness" (Crittenden, 1990). It is acting in accordance with one's own sense of identity (Meininger, 2001, p. 246), whereas engagement in action, which is consistent with the self-made decision, is strongly associated with a sense of quality of life (Barclay et al., 2016). It is a fluid category, viewed from the perspective of an individual, as its existence is subjectively decided by him. This means that understanding of autonomy may differ among individuals – the number of spheres it concerns and the extent thereof depends solely on the judgement of an individual. Thus, the extent of one's autonomy is the result of the choice of an individual, his own autonomous decision as to the degree in which he is able to pass on a specific scope of dependence to others. Something that constitutes the basis for maintaining autonomy for one person may not be of such a value for another, hence the analysis of this concept in the case of people with disabilities entails recognition of the specificity of individual situations. „Therefore, in practice, there will be different faces of autonomy, as different as these persons are different" (Zawiślak, 2008, p. 45). Furthermore, autonomy is not a state of total independence, but it lies on a continuum between total dependence and independence, so it is dynamic in nature. Dependence does not exclude autonomy. That is why it is pivotal to identify the conditions sustaining it. An ambiguous understanding of the concept of autonomy has also given rise to its types. According to R. Michael and J. Attias (2016), in the cognitive approach the emotional and behavioural autonomies are distinguished, while the relational and decision-making autonomies in M. Cardol's approach (2001), where the latter autonomies are most frequently used to describe disability adherent to the ICF assumptions (2001).

In the light of developmental psychology, the process of acquiring and realising one's own will is a developmentally desirable function, which was underscored by E. Erikson in the capacity of a pursuit of autonomy (Witkowski, 2000, p. 129). Autonomy as a process is the acquisition of „the ability to an independent choice and critical judgement, to being a distinct person, responsible for the conformity of one's behaviour to the accepted universal ethical principles, and simultaneously acting for the good of communities" (Kwieciński, 2019, p. 43). It follows that the achievement of the autonomy during this period is the result of upbringing process. In the case of people with physical disability, it is important to analyse the process of acquiring autonomy in terms of both the cause of acquisition of the disability and its temporal aspect. As for the acquired disability, a sense of autonomy was shaped in line with the standard or had already been shaped, however, due to the acquisition of disability it is very crucial to redefine it, along with the progressive process of adaptation and adjustment to disability. As for the congenital disability, autonomy was shaped in certain specific conditions and it is subject to change over time.

One of the first researchers to draw attention to relational autonomy was B. Wright (1965, p. 337), who believed that autonomy cannot exist without dependence. She pointed out that „independence as a goal has the weight of an axiom", which may be the reason for the problems with the formation of autonomy. Too strong emphasis on independence and extreme individualism can contribute to an unintentional isolation and a sort of psychological burnout as a consequence of inability to accept help and support. Autonomy is the freedom of choice according to one's own needs, hence acceptance, agreement and readiness of the person oneself are important for decision making. Too much emphasis on the training of independence can trigger negative consequences in the course of adaptation and adjustment to disability, while the assumption of full human independence is a kind of utopia. „By looking for resources rather than staying focused on defects, personalising support strategies as well as balancing realistic expectations and possibilities, in the relational autonomy model the activities for the benefit of independence of people requiring more intensive and specialised support are embedded in the existing realities" (Podgórska-Jachnik, 2018, p. 63). It refers to a situation in which, even with limitations, a person is ready to make decisions and perform certain activities independently. As a result, autonomy is based on respect for other person's thoughts, will and decisions (Hammar et al., 2014).

Autonomy of People with Physical Disabilities – ICF Perspective

The importance of autonomy is highlighted by the contemporary model of disability, with its essence being expressed in the integration of biological, individual and social dimensions, thereby changing the narrative of disability, where capabilities and limitations constitute an integral concept of life, and yet presenting a complex nature of the relationship between body functions and structures, activity and engagement as well as contextual factors (ICF, 2001). These dimensions characterise disability as a complex and an ambiguous phenomenon determined by a multitude of various factors and, as a consequence, they present diversity in its formation and experience. According to the assumptions of the International Classification of Functioning, Disability and Health (2001), it is coping with the challenges of everyday life, participation in family and social life as well as broadly understood autonomy of an individual that are the keys to describing the functioning of a person with physical disability, whether acquired or congenital. In this sense, the

ICF emphasises the level of successful overcoming of difficulties, deciding for oneself and shaping one's own life in accordance with the set objectives, shifting focus from limitations in the functioning to the opportunities of using the potentials inherent in both the person and his immediate environment, in line with the real image of the disability, and putting emphasis on autonomy and engagement of people with disabilities. „The change of perspective transfers support measures towards the enhancement of autonomy and promotion of activities in all the spheres important for a person, which are modelled by a number of factors ingrained in the environment and in the person himself, and which are referred to as the contextual factors in accordance with the International Classification of Functioning, Disability and Health model" (Duda, 2022, p. 96). The environmental context, in addition to personal factors, plays a crucial role in a sense of autonomy, as through the environment it is either supported or limited. The approaches centred on the person and based on functioning are aimed at enabling people with disabilities to gain control over their lives. Effective rehabilitation of people with physical disabilities is oriented towards the achievement of autonomy and a high level of participation in society. The attention should also be drawn to the fact that each individual is entangled in a number of conditions that shape a sense of autonomy, which is in turn shaped through these conditions.

Reflections pertaining to autonomy continue to be a problem because of its ambiguity, especially in the field of empirical studies. This stems from the difficulty regarding operationalisation of the concept. Autonomy should solely be measured with the use of tools based on self-report, on account of its specificity. The Impact on Participation and Autonomy Questionnaire (IPA) was developed by M. Cardol, J. R. de Haan, G. van den Bos, A. B. de Jong and I. J. M. Groot, the Dutch researchers, in 1999 (Cardol et al., 1999), and it is one of the most common research tools used to measure autonomy and participation of people with disabilities. The advantages of the usage of this tool encompass, first and foremost, high conceptual consistency with the ICF model of disability, satisfactory psychometric properties in both language versions (in the original and Polish versions) and subjective assessment, which is based on the perspective of people with both acquired and congenital disability (Byra, Duda, 2020). It is worth mentioning that autonomy and participation as well as limitations connected therewith are the best indicators of the functioning of a patient from his standpoint. Even though the IPA scale involves self-assessment of the respondents' sense of autonomy (Perenboom et al., 2003), it is an objective indicator of the psychosocial functioning of an individual (Li et al., 2018).

The original version of the scale has satisfactory psychometric properties (Cardol et al.,1999). The proposed tool takes into account multidimensional understanding of participation and autonomy. The questionnaire consists of 32 items, which are divided into 5 subscales: autonomy indoors, autonomy outdoors, social life and relationships, family role, work and education, and it is based on self-assessment. The additional advantage is that the tool can be used in foreign research, as it has been translated into nine languages so far: English (Sibley et al., 2006), Swedish (Larsson Lund et al., 2007), French (Poulin, Desrosiers, 2010), Persian (Fallahpour et al., 2011), Danish (Ghaziani et al., 2012), Thai (Suttiwonk et al., 2013), Finnish (Karhula et al., 2016), Chinese (Li et al., 2018) and Polish (Byra, Duda, 2019). The IPA questionnaire in the Polish adaptation is characterized by satisfactory psychometric properties. Factor analysis confirmed the 5-factor model consistent with the original version of the scale. This provides an opportunity for the conduct of international research and comparison of results.

Autonomy and Participation of People with Physical Disabilities – Polish Perspective

The Polish adaptation (Byra and Duda, 2020), similarly to the original version, has satisfactory psychometric properties: the reliability coefficients of the individual subscales fall within the range between 0.87 and 0.96 (Cronbach's alpha), whereas correlation coefficients (Spearman's r) prove stability of the tool, reaching the values of 0.90-0.97, which means that the tool can be successfully used in the studies on people with disabilities and other somatic conditions as well as in the studies on the elderly. The results of the studies with the use of IPA questionnaire in the Polish population are noteworthy. The IPA questionnaire has been used in the studies on different populations: in a group of people under social care (Duda, 2022), people with long-term physical disabilities (Byra and Duda, 2019; Duda, 2021) and people with spinal cord injuries (Byra, 2020). Relevant articles were identified from Scholar database for approximately the period 2015-2023, cross-indexing "physical disability", autonomy", "participation", "ICF" and "IPA".

Autonomy in making everyday and life-significant decisions as well as in performing a variety of social roles, plus in the way and the extent of participation in particular activities of social life shows a correlation with higher life satisfaction. Respondents (N = 98) experiencing additional secondary health conditions are characterized by significantly higher limitations in autonomy and participation, while early acquired physical disability correlates with higher perception of autonomy (Byra and Duda, 2019). A study on long-term paraplegia patients (N = 166) found that higher post-traumatic growth was related to higher resilience and participation, both of which were associated with wisdom (Byra, 2021). Research results concerning people with long-term physical disabilities (N = 78) revealed that satisfying social relationships and autonomy outdoors promote a high quality of life (Duda, 2021). Autonomy and participation of people under social care (N = 98) can be explained with three personal factors referring to disability: level of independence, mobility, age of disability acquisition (disability onset) as well as two sociodemographic factors, i.e. age and place of residence (Duda, 2022). The presented studies have proved that the IPA questionnaire is a tool of high validity. They confirm relevance and usefulness of the tool in research. The empirical findings cited above provide solid reasons to believe that autonomy and social participation can play a significant role in explaining high quality of life, commitment to goals, high social activity, life satisfaction, higher post-traumatic growth and resilience. Autonomy, through its function, contributes to a person's sense of psychosocial well-being.

Conclusions

In rehabilitation practice, the consideration of a sense of autonomy of people with physical disabilities primarily individualises activities and increases their effectiveness, while prevention is aimed at suppressing people with disabilities from being withdrawn from physical, mental and social activities. Therefore, the need arises to study its nature and resources necessary for the development and exercise of autonomy. This will allow for the provision of knowledge enabling the reduction of the consequences of disability. The IPA questionnaire seems to be a well-fitted and structured tool to study autonomy. The results of research based on this questionnaire constitute an important source of knowledge about autonomy and participation in social life. There is value in further research with the use of this tool to measure autonomy and participation of people with physical disabilities of various etiologies. Indirectly, however, the emphasis of the importance of autonomy itself fosters its promotion and combats the stereotype of dependency, weakness or helplessness of people with disabilities.

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