

Kasper Sipowicz, Ph.D.*, <https://orcid.org/0000-0001-7384-2899>

Marlena Podlecka, M.A.***, <https://orcid.org/0000-0002-2213-374X>

Associate Professor Tadeusz Pietras***, MD, PhD, <https://orcid.org/0000-0003-1771-3819>

**Department of Interdisciplinary Disability Studies
The Maria Grzegorzewska University in Warsaw*

***Department of Neuroses, Personality Disorders and Eating Disorders
Institute of Psychiatry and Neurology in Warsaw*

****Department of Clinical Pharmacology
Medical University of Lodz*

A child with disability as a value - motherhood in a noetic perspective

Dziecko z niepełnosprawnością intelektualną jako wartość - macierzyństwo w perspektywie noetycznej¹

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Abstract: The paper attempts to embed the experience of being a mother to a child with intellectual disabilities in a noetic (spiritual) perspective of human functioning. According to the noo-psychotheoretical assumptions (Popielski, 2018) constructed on the basis of Viktor Frankl's concept of logotherapy (2009), finding and fulfilling the meaning of life is the highest human need and a kind of metamotivation. The suffering resulting from motherhood is seen as a borderline experience, in which the existential situation so far is revalued and the meaning appears to be the acceptance of an attitude of moral heroism towards the inevitable fate.

Key words: intellectual disability, motherhood, meaning of life, suffering, noo-psychotheory, logotherapy

Streszczenie: W niniejszym artykule podjęto próbę osadzenia doświadczeń związanych z pełnieniem roli matki wobec dziecka z niepełnosprawnością intelektualną w perspektywie noetycznego (duchowego) wymiaru funkcjonowania człowieka. W myśl noo-psychoteoretycznych założeń (Popielski, 2018) konstruowanych na gruncie koncepcji logoterapii Viktora Frankla (2009) odnajdywanie i wypełnianie sensu stanowi najwyższą ludzką potrzebę i swoistą metamotywację. Cierpienie wynikające z macierzyństwa rozpatrywane jest jako doświadczenie graniczne, w obliczu którego dotychczasowa sytuacja egzystencjalna ulega przewartościowaniu, a sens jawi się jako przyjęcie pełnej moralnego heroizmu postawy wobec nieuchronnego losu.

Słowa kluczowe: niepełnosprawność intelektualna, macierzyństwo, sens życia, cierpienie, noo-psychoteoria, logoterapia

Introduction

Motherhood is understood at the most basic level as being a mother. However, this wording is enigmatic in some way. The concept of mother includes not only the woman who

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gave birth and raised the offspring, but above all the rich universe of meanings built up from the original biological level, through the mental and spiritual dimensions, ending with a symbolic area embedded in culture.

The vast majority of scientific literature explores the phenomenon of motherhood from the perspective of acting as a mother providing care and carrying out educational tasks for the child. However, the mother-child dyad can take on a much less asymmetric character, as at the metaphorical level both the mother gives birth to the child and the child gives birth to the mother. Thus, motherhood can be understood as a treasury full of experiences, from which the mother draws throughout her own personal development.

The thesis presented above seems to be particularly relevant in the case of motherhood marked by suffering at its root. When a child with intellectual disabilities is born, a woman faces the challenge of verifying previous notions of acting as a mother and, above all, of her entire existence. The suffering involved is a special kind of experience of motherhood and parental love. In Viktor Frankl's concept of logotherapy (2009), the noetic perspective of motherhood marked by suffering can paradoxically be a unique value in the life of the mother, promoting her personal growth.

1. Motherhood and suffering – a child with intellectual disability in the family

At the level of research exploring the psychosocial situation of the nuclear family, a child with an intellectual disability is seen primarily as a stressor (McConnell, Savage, 2015). This conclusion has an unpleasant taste for reductionism, the pejorative character of such reasoning can be questioned depending on the degree of remoteness of the researchers from the crux of salutogenic orientation. The concept of a stressor is so broad that it covers both unambiguously negative and positive experiences. A stressor is defined as any stimulus to which a person does not have a ready-made response algorithm. The stressor therefore arouses a state of tension, which can turn into either stress inducing a reduction in the individual well-being, or can be discharged with a positive effect (Antonovsky, 2005). Therefore, it is clear that in a purely theoretical sense it is neutral and logically right to assign the role of stressor to a child with intellectual disability. However, at a practical level, the research perspective is often limited to identification of the negative consequences for the psychosocial well-being of parents raising a child with intellectual disability, moving away from the assumptions of salutogenesis. Thus, the assumption is generated that a child with reduced intellectual potential is a source of stress for parents, with negative health consequences for them.

There is no doubt that raising a child with intellectual disability differs significantly from the well-established routines of mothering and entails the need to adapt one's existence to the specific needs of the child. Research indicates that the occurrence of behavioral

problems is the most difficult aspect of raising a child with intellectual disability (Morse et al., 2014; Baker et al., 2002; Baker et al., 2005, Blacher et al., 2005) such as aggression, self-injury, hyperactivity, destructiveness, stereotyped mannerisms, other socially unacceptable behaviors (e.g. smearing feces over the body, constant vocalization, public masturbation), etc. (Emerson, Einfeld, 2011). It must be understood, however, that such problem behaviour, although most stressful, is only a part of the everyday landscape of the life of a mother of a child with intellectual disability. The reduced intellectual potential, which at the semantic level is equated with intellectual disability, does not constitute an isolated deficit, because it is associated with unharmonious development in all areas of functioning (communication, gross and fine motor skills, emotional, volitional and social spheres, etc.). The sum of the experienced difficulties results in a decrease in the scope of self-sufficiency in daily life and adaptive behavior, which is somewhat a reflection of the child's level of functioning (Combed, 2012). The detailed description of the daily experiences of the mother of a child with intellectual disability is so extensive that it could be the subject of an extensive monograph in itself. A superficial presentation of the peculiar disorders of the child's functioning outlines the form and extent of the difficulties faced by the mother. These include, in particular, the care and education-related activities at a level inadequate to the child's age, such as feeding, bathing, dressing or hygiene training (Plant, Sanders, 2007; Tomanik et al., 2004); financial problems (Singh, 2015); difficulties in carrying out the mother's professional duties; reduced satisfaction with marriage (Noor, 2003); stigmatization and social isolation (Green, 2003; Emerson, 2003). The consequences can be observed in the emotional and interpersonal, social and economic spheres.

The maternal attitude towards the child's disability is an issue extremely sensitive and at the same time fundamental to the phenomenon of motherhood. Achieving the right level of acceptance is an extremely complex and long-lasting process, often permanently open. Emotional responses of mothers confronting the diagnosis of the offspring's intellectual disability most often include guilt, denial, shock, anger, sadness, embarrassment, depressiveness, withdrawal, ambivalence, disappointment and anxiety (Gogoi, et al., 2016). The following stages of emotional adaptation to the child's disability can be distinguished: the shock phase, the emotional crisis phase, the stage of apparent adaptation to the situation and the phase of constructive adaptation to the situation (Twardowski, 1991). The first stage refers to a strong emotional shock, which is a direct response to the diagnosis of intellectual disability in a child and is associated with a growing sense of hurt, hopelessness and helplessness. The phase of emotional crisis includes more subdued and chronic conditions, with predominant despair and depression. The period of apparent adaptation to the situation oscillates around the defense mechanisms, enabling the transformation of the image of reality into one more corresponding to the ideas about motherhood. The final stage is the achievement of full acceptance of the child's disability with all its consequences.

A child with intellectual disability, appearing in a crisis atmosphere, is undoubtedly a stressor for each member of the system, which is the nuclear family, causing a state of severe tension. No one has automated reactions to the spectrum of cognitive deficits and abnormalities in the adaptive behaviour of a child with reduced intellectual potential and their psychosocial consequences developed in advance. This state of tension can turn into stress that causes long-term health problems, but this is not the rule.

Numerous studies indicate that mothers of children with intellectual disabilities experience stress, anxiety and clinical depression up to 2-3 times more frequently than women raising typically developing children (Emerson, 2003; Lee, 2013; Singer, 2006; Hastings, Beck, 2004). The results of studies conducted by V. Totsik et al. (2011) demonstrated that up to 60% of mothers raising children with intellectual disabilities do not experience emotional problems of clinical severity.

For decades, a default paradigm has been developed in this research area, according to which motherhood, when confronted with intellectual disability, should be seen solely in terms of suffering, and the child as a stressor exceeding the woman's resources. However, many researchers look at the reverse of negative experiences, looking for both the positive aspects of raising a child diagnosed with intellectual disability (Horsley, Oliver, 2013) and the mechanisms of effective coping with maternal stress (McConnell, Savage, 2015). One of the resources that allows mothers of children with intellectual disabilities to cope with difficult experiences and suffering is the spiritual (noetic) dimension of existence (Gray 2006; Durà-Vilà et al., 2010).

2. In search of the meaning of motherhood marked by suffering

Experiencing motherhood in the face of a diagnosis of intellectual disability can be seen in terms of the borderline situation. The associated experiences are located at the limit of adaptability and defense, disturb the mental balance and routine ways of functioning, eliminate inauthentic identities and relationships. However, the experience of anxiety and internal chaos is not unequivocally pejorative, as it broadens self-awareness, forcing to confront the fundamental issues (Mundt, 2014). Whether suffering becomes existentially disastrous or if it proves to be a value depends on the attitude taken towards it. The birth of a child with intellectual disability does not necessarily mean the personal end of the world - paradoxically, it can give a new meaning to life.

In the generally accepted psychological sense, the broadly understood spiritual area of human life is taken into account as one of the mechanisms for coping with stress (Heszen, 2019) which, from this perspective, can allow to maintain the relatively high mental well-being of mothers raising children with developmental disabilities, or as one of the well-being criteria (Steger and Oishi, 2004). However, reducing human spirituality to the function of

a mechanism regulating the level of tension seems to be an oversimplification. It has even been proposed to include spirituality as the fourth pillar of health (in addition to the somatic, mental and social ones) (Heszen, Sęk, 2007; Oman, Thoresen, 2005).

A special approach to the spiritual dimension of humanity is presented by noo-psychotheory (Popielski, 2018), which is a modern direction in existential psychology and psychotherapy, constructed on the foundations of Victor Frankl's logotherapy (2009). According to the noo-psychotheoretical concept of existence, the bio-mental dimension is only its basis, being an initial, but subjectively unformed manifestation of the basic functioning processes. A spiritual dimension, here referred to as noetic or noological, gives to this existence the shape and quality (Popielski, 2018).

A special property of a human being is the capability of self-detachment, which allows, in a sense, detachment from oneself, and thus the adoption of an attitude towards somatic and mental conditions and determinants. The human existence is not limited to the bodily existence governed by mental mechanisms. The possibility to go beyond the somatic and mental phenomena implies the existence of a higher dimension – the noetic one. This transcendence, in a sense, forces man to take a stand against himself and seek answers to questions of an existential nature. "Man enters the noological dimension whenever he reflects on himself or, if necessary, when he rejects himself, makes himself an object, or questions himself, it turns out that he has self-awareness or that he has a conscience" (Frankl, 2018, p. 30). Thus, the prospect of a particular kind of freedom to shape his character, responsibility for who he will happen and discover his own meanings opens up to the man. According to Frankl, it is the ability to take an attitude towards ourselves and our own destiny that makes us human (Frankl, 2018).

Freedom and responsibility are two noetic qualities (Popielski, 2008) describing aptly the position of a man endowed with the ability to look at his own existence (self-transcendence). Freedom expresses the vastness of capacity, and responsibility entails the need to make a choice. Human existence is not suspended in a vacuum, it is realized in constant entanglement in the surrounding reality, which, despite its objective existence, requires individual understanding and interpretation on a trans-subjective level. Frankl (2018, p. 89) stresses that the modern man trapped in moral relativism lacks an axiological compass – "at a time when the commandments of the Decalogue have lost their indisputable value in the eyes of many, every day we must keep the ten thousand commandments resulting from tens of thousands of unique situations (...) and with respect to them we have a duty to rely on our conscience". Conscience, on the other hand, is to be understood here very broadly as an intuitive ability to see the meaning of specific circumstances of life (Frankl, 1984). Frankl strongly disagrees with Jean Paul Sartre, who claims that the man himself is the creator of ideals and values (Webber, 2009). According to Frankl's concept of man and the underlying philosophy of life, the man transcends his biopsychic being by

moving towards the meanings that exist outside of him objectively and are not a projection of the human “ego”. Meaning is therefore a phenomenon that man can seek and find, or that he can miss or lose, but he is not in power to invent it. The question of the meaning of life is never absolute – by its very nature it must always be addressed *ad personam* and *ad situationem*. For, assuming that the meaning of life is the same as the man’s realization of his own being, it becomes clear that every individual person and every particular situation fulfills an unique meaning (Frankl, 1984). Therefore, it can be said that the sense of meaning of life is fulfilled in the face of a multiplicity of partial, particular meanings. The borderline experience of having a child with intellectual disability should be interpreted in this context as another life situation awaiting the discovery of its meaning.

At the biopsychic level, a person is “pushed” by the urges regulating vital activity. However, the pressure of somatic and mental resources energizing the existence is not sufficient for human existence to take on a fully subjective character. The entropic force of life (*elan vital*), unless given meaning and value, evokes existential dissonance only (Popielski, 1987). Ordering of the chaos of these forces and their proper orientation is achieved by discovering and fulfilling a meaning that, in a sense, “pulls” the man towards what is desired. A life that does not rise to meaning remains merely an unaccomplished potential – a beauty that is dead at its core.

The basic premise of logotherapy concepts is the belief that there is no meaningless life, and that striving to discover and fulfill the meaning of life is a natural and innate property of man. The man fills his existence with meaning by implementing values, which can be accomplished through three paths: (1) creative work or action; (2) experiencing the world and interpersonal relationships and (3) an attitude towards unavoidable suffering (Frankl, 1984). The first two ways are somewhat compatible with each other, because they include what the man achieves, what he will accomplish, how he shapes the world around him, as well as the assimilation of beauty, goodness, truth – by immersion in nature, culture, deep relations with others. Motherhood is usually achieved through both of the aforementioned paths. In biological, mental and noetic areas, the mother is both a donor and a recipient - she bestows life, feeds, supports in growth, bestows love and is loved by the child, experiences moral beauty. However, being a mother of a child with intellectual disability, differs significantly from the simple paths of finding the meaning in shaping and experiencing, because it is associated with suffering. As Frankl points out (1984), the of “creative” and “experiential” values are, in essence, limited and as such can easily be exhausted, as is particularly evident in the set of functional and psychosocial difficulties faced on a daily basis by a parent of a child with intellectual disability, as indicated in the first part of this paper. The birth of a child deviating from the norm becomes a breakdown of the life line for the mother and undermines the meanings previously known to her. However, at the noetic level, the retreat from the values that are no longer possible is at the

same time a step towards the highest values and the meaning hidden in every suffering. A child with an intellectual disability, in whom the mother's suffering is located, crystallizes itself as a value related to the attitude that the mother will take towards him/her. The value of human suffering is hidden in the heroism with which the man overcomes it, thus shaping his own inner landscape.

Adopting an attitude towards motherhood full of suffering requires facing the freedom to decide for oneself and to accept personal responsibility for who an individual will become. Frankl (2009) deals with the genetic environmental determinism in the understanding of personality, claiming that at the noetic level man is capable of shaping himself. "The man must manage what the fate has decreed" (Frankl, 1984, p. 290), and he does so by taking a fully conscious attitude towards such circumstances, thus finding meaning with the highest moral value. The borderline experience of motherhood facing a child's intellectual disability can become both a disappointment and a source of personal triumph depending on the axiological transformation of the mother. Suffering, to a certain extent, ceases to be suffering, as long as it is found to have a specific meaning – because it is devoid of the tragic element of absurdity.

As emphasized by Frankl (1984), realizing the meaning of life by adopting an attitude towards suffering is associated with the implementation of the most difficult category of values. The ability to suffer is not innate, otherwise it would be rather apathy towards fate. Everyone learns to perceive the meaning of suffering during their life, which often turns out to be a task beyond their strength. Hence the need to support and reinforce internal aspirations in the realization of the noetic dimension of personality in the face of adversity.

Experiencing the meaning of motherhood marked by suffering can be extremely difficult for a woman. Therefore, it is advisable to propose a range of supportive actions in the form of, among others, psychotherapy, coaching, psychological support, or appropriately targeted counseling. Frankl's logotherapy, which is, in fact, psychotherapy focused on meaning, seems to be particularly adequate in this case (Dezelic, Ghanoum, 2015). The suffering associated with raising a child with an intellectual disability may be associated with experiencing existential frustration, and thus induce the occurrence of the so-called noogenic neurosis (Popielski, 2018). In this case, logotherapy makes it possible to rediscover one's own axiological universe, thus acquiring the ability to experience a new quality of meaning in life.

The hypothesis that the mother of a child with intellectual disability may feel happy adapting to her role has emerged relatively recently in research in this area (Horsley, Oliver, 2013). The perception of a child with intellectual disabilities exclusively as a source of suffering dominated this current of research, creating a picture of motherhood worthy of compassion. To date, few explorations in this area have represented a psychological rather than a noo-psychotheoretical approach, integrating the noetic dimension of human

functioning into mental mechanisms. Nevertheless, they have provided interesting empirical data.

R.P. Hastings and H. Taunt (2002) have pioneered the themes of positive perception themes, most important in this area to date which are as follows: (1) finding pleasure/satisfaction in looking after the child; (2) perceiving the child as a source of happiness and joy; (3) doing one's best for the child resulting in a sense of accomplishment; (4) sharing love with the child; (5) the child as a challenge or opportunity to learn and develop; (6) strengthening the family and/or marriage; (7) finding a new or increased sense of purpose in life; (8) developing new skills, abilities, or finding new opportunities for career; (9) self-improvement (becoming more compassionate, less selfish, more tolerant); (10) becoming a stronger or more confident person; (11) expanding social and community networks; (12) increased spirituality; (13) changing the perspective on life (e.g. developing the awareness of what is really important in life, awareness of the future) and making the most of each day; (14) living at a slower pace. Among the distinct motives (Hastings, Taunt, 2002) the paths of fulfilling the meaning of life through action and shaping of the world (care, upbringing, rehabilitation, improving one's own skills and qualifications, etc.), experiencing the world (joy and satisfaction from contact with the child, experiencing love, strengthening family ties and social relationships, etc.) and adopting an attitude towards fate and inevitable suffering (becoming a better person, increased personal strength, etc.) can be found easily. Motives related to the development of spirituality, reevaluation of, or an increase in the sense of purpose can be regarded as the general dispositions for the perception of individual meanings.

It is also noteworthy that there is some interest in pursuing parental roles towards a child with intellectual disability in a neo-psychotheoretical perspective among Polish researchers. A study using the Purpose in Life Test (PIL) has demonstrated a high level of meaning in life in a group of parents of children with intellectual disabilities (Stelter, 2015). Research conducted using an interview questionnaire designed by the author (Barłóg, 2017) shows that 90% of parents of children with intellectual disabilities consider their lives to be meaningful and of particular value. Although 24% of respondents admit that they have experienced a crisis in the meaning of life in connection with the birth of a child with a disability, 56% say that this event involves finding an additional meaning in life. None of the subjects claimed to have lost their previous meaning of life as a parent of a child with a disability. While the studies presented are scarce and carry some methodological weaknesses, they should be seen as the basis for a noetic perspective on motherhood for women raising children with intellectual disabilities.

Conclusion

Giving birth to a child with intellectual disability is undoubtedly a borderline experience for the mother, undermining her mental balance and well-established ways of functioning. The multiplicity of difficulties associated with raising and rehabilitating a child with developmental disabilities disrupts the course of life, forcing to confront existential issues. The suffering felt by the mother can lead both to deep disappointment with motherhood and to the discovery of hidden values in it. Thanks to self-transcendence and heroic attitudes towards the experienced problems, a woman can discover in her motherhood a new meaning of life with a unique moral value.

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