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DIANA AKSAMIT
The Maria Grzegorzewska Pedagogical University, Warsaw

Existential experiences of single mothers raising children with severe intellectual disability and their psychological, social and pedagogical determinants

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Self-relations of mothers raising adult children with severe intellectual disability constitute a documentation of motherhood diverging from an established role model of a mother and a woman. The narratives show that this group of women struggle with many difficult experiences and emotions related to their own existence. The aim of this paper is to analyse existential experiences of interviewed mothers in terms of reflections on the meaning of life and future, as well as questions such as 'Why me?', often asked by the interlocutors. I will make an attempt to identify determinants of these experiences.

KEY WORDS: motherhood, existence, meaning of life, future, disability

> *To love is not enough.*
> *One must embrace this love with both hands, and carry it along through life.*
>
> K. I. Gałczyński

Introduction

Both Polish and foreign scientific literature concerning families raising children with severe intellectual disability is quite extensive. It appears that most of the research focus on parents[1] and siblings[2].

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[1] See. A. Twardowski, *The Situation of the Families with children with disabilities* (*Sytuacja rodzin dzieci niepełnosprawnych*), [in:] I. Obuchowska (ed.), *A Children with Disabililty in a Family* (*Dziecko niepełnosprawne w rodzinie*), Warszawa 1991, pp. 18–53; R. Butkevičienė, *Šeimų, auginančių vaikus su negalia, adaptacijos modelis*. "Tiltai" 2001, nr 4, s. 83-91; L. Woolfson, *Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems*, 'British Journal of Health Psyhology' 2004, 9 (1), pp. 1-13; L. Bakiera, Ż. Stelter, *Parenthood from the angle of parents of child without and with disability* (*Rodzicielstwo z perspektywy rodziców dziecka pełnosprawnego i niepełnosprawnego intelektualnie*), 'Yearbooks of the Sociology of the Family. Interdisciplinary Sociology Studies' ('Roczniki Socjologii Rodziny. Studia Socjologiczne i Interdyscyplinarne') 2010, XX, pp. 131-151; H. Liberska, M. Matuszewska, *Models of Families with Children with Disability* (*Modele funkcjonowania rodziny z dzieckiem niepełnosprawnym), 'Polish Psychological Forum' ('Polskie Forum Psychologiczne')* 2012, 17 (1), pp. 79-90; Ż. Stelter, Roles of a Parent of a Child with Intellectual Disability (*Pełnienie ról rodzicielskich wobec dziecka niepełnosprawnego intelektualnie),* Warszawa 2013; Ż. Stelter, *The Ways of Parenting the Child with Intellectual Disability* (*Sposób realizacji roli rodzicielskiej wobec dziecka niepełnosprawnego intelektualnie)*, 'Polish Psychological Forum' ('Polskie Forum Psychologiczne') 2014, No. 1, pp. 87-109.

[2] A. Sidor, *Psychological and Social Aspects of the Ways of Functioning of Young Adults with the Siblings with Intellectual Disabilities* (*Psychospołeczne aspekty funkcjonowania młodzieży mającej rodzeństwo z niepełnosprawnością umysłową,* Lublin 2005; E. Pisula, *Parents and Siblings of the Children with Development Disorders* (*Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju)*, Warszawa 2007; A. Wojciechowska, A. Cierpka, *Family from the Perspective of Siblings of Persons with Intellectual Disability – Comparative Analysis* (*Rodzina w percepcji rodzeństwa osób z niepełnosprawnością intelektualną – analiza porównawcza*, [in:] E. Pisula, D. Danielewicz (red.), *Family with a Child with Disability* (*Rodzina z dzieckiem z niepełnosprawnością),* Gdańsk 2007, pp. 101-122; A. Cierpka, *Family from the Perspective of Siblings of Persons with Disability* (R*odzina w percepcji rodzeństwa osób z niepełnosprawnością)*, [in:] H. Liberska (red.), *Family with a Child with Disability – perspectives and limits of development* (*Rodzina z dzieckiem niepełnosprawnym – możliwości i ograniczenia rozwoju),* Warszawa 2011, pp. 235-256; A. Żyta, *A Life with Down Syndrome. Biographic Narratives of Adults with Down Syndrome, Their Parents, and Siblings (Życie z zespołem Downa. Narracje biograficzne rodziców, rodzeństwa i dorosłych osób z zespołem Downa)*, Kraków 2011.

One of the subjects of interest is the question of social assistance[3]. Discussed studies are but a sample of the wide range of research on this subject, and they mostly concern families raising children with mild, moderate and severe intellectual disability, with autism, Down syndrome, or sensory disability. Although the number of research and studies on severe intellectual disability is not that impressive. It is caused chiefly by the fact that this particular disability is a complex phenomenon, difficult in terms of early and precise diagnosis, as well as therapeutic work. For years, education, training, and even rehabilitation have not been, in common opinion, associated with severe disability. A long-term practice of placing persons with severe intellectual disability in group homes or care homes has transformed this field into a kind of a taboo. Families raising children or adult children with severe intellectual disability have been taken care of by social and medical sector. It caused many existential problems which mothers of now adult children still contend with, despite many upturns in the system of social assistance, and introducing the policy of inclusion in education. In this research paper I will describe and analyse chosen existential experiences of an examined group of women. I will also make an attempt to identify determinants of these experiences.

Theoretical framework

Women who, unaided, raise adult children with severe intellectual disability, especially children above the age of 24, who are often deprived of the opportunity to attend to rehabilitation centres due to their condition, shortage of places, or distance from dwelling

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[3] L. Gvaldaitė, *Šeimų savipagalbos veikla socialinio kapitalo perspektyvoje*, ‘Acta paedagogica Vilnensia’ 2010, Np. 22, s. 43-53; A. Naess, L.P. Grue, *Habilitering som koordinerende tiltak. Erfaringer fratre brukergrupper*, “Nova: Rapport” 2012, No. 4, s. 14-31; B. Kreivinienė, J. Perttula, *Subjective representations of families who have a child with severe disability on the place of social work help within the lawful social support system*, ‘Special Education” 2011, No. 1, pp. 42-52.

place – these women lead a life filled with constant search and growing expectations toward themselves as mothers. The ways of dealing with reality in which examined women exist are reflected in major assumptions of philosophy and psychology of existentialism: 'A human can always become more than they already are'[4]. Families constituted by these women and their children diverge from the established model and image of a family unit. Nonetheless, interlocutors indicate family as a *locus sensus*[5] for their experiences of existence. As Kazimierz Popielski remarks, it is family, where 'parents and their children, on their way of co-existence, can experience and discover a very natural and primal meaning and meaningness of life'.[6]

This is why experiences of mothers raising children with severe intellectual disability have been reflected upon and analysed using chosen questions of philosophy and psychology of existentialism, derived from existentialism of Søren Kierkegaard (19th century), Martin Heidegger, and Karl Jaspers (20th century)[7]. Major assumptions of existentialism concern existence of a human being, and a key to understanding it is their existential experience. Existential experiences of the examined group of women were analysed in various situations, breakthrough moments in their life, when they were, to the utmost, experiencing their personal existence inextricably interwoven with their children, in symbiosis between 'me' and 'you'.

The fundamental existential questions most often revolve around issues regarding: identity, meaning of life, death, freedom, suffering, faith, and are conditioned by intra- and inter-psychical

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[4] P. Szczukiewicz, J. Olszewski, *Existential Attitude in Psychology and Psychotherapy – Opportunities and Limitations* (*Podejście egzystencjalne w psychologii i psychoterapii – możliwości i ograniczenia), 'Psychology Horizons'* ('Horyzonty psychologii') 2014, Vol. IV, p. 105.

[5] K. Popielski, *Family as Locus Sensus* (*Rodzina jako lokus sensus),* 'Pelpin Studies' ('Studia Pelplińskie') 2002, No. 33, pp. 511-523.

[6] K. Popielski, Family*…, op. cit.*, p. 522.

[7] P. Szczukiewicz, J. Olszewski, *Existential…, op. cit.*, p. 104.

factors. Existential experiences of examined mothers have been mostly related to reflections on the meaning of life and future, and questions such as 'Why me?', often asked by the interlocutors. They all fall into existential psychology paradigm of Karl Jaspers[8], who claimed that we can talk about existential experiences of a human being in boundary situations of their life or in time of exceptional challenges they encounter: both conditions occur every day in the life of the examined mothers. Existential psychology is based upon a concept of four dimensions in which people exist: spiritual, social, psychological, and physical dimension. It appears that, for women raising children with severe intellectual disability the spiritual dimension of their life is the major one. Spiritual dimension is referred to as noetics (*Latin*: of or pertaining to the mind or intellect, originating in or apprehended by reason)[9]. Existentialists point out that thinking of problems related to human existence only in psychological or social dimension is flawed, as it does not allow to get through to the essence and complexity of the matter. Given the above, I examined and analysed existential experiences of interviewed women in terms of those four dimensions, with particular attention to the spiritual one.

Methodology of own research

Research material presented in this paper is based on thirteen interviews with women from all over Poland (the research is in progress). The aim of this research is theoretical, empirical and practical analysis of various motherhood experiences of women raising, by their own, young adults with sever intellectual disability. In this paper I focused on identification and analysis of existential experiences of the mothers, trying to answer the following research questions:

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[8] K. Jaspers, *Philosophy of Existence* (*Filozofia egzystencji)*, Warszawa 1990.

[9] K. Popielski, *Noetical Dimension of Personality* (*Noetyczny wymiar osobowości),* Lublin 1994, p. 49.

- What are the existential problems that examined women encounter?
- severe intellectual disability above the age of 24. Study subjects were recruited using a snowball sampling method, through social institutions, charity associations and non-profit organisations, as well as via internet blogs and websites. Primary technique used in this research was the in-depth interview technique. Respondents were asked to tell about some parts of their life or to tell the story of their whole life in terms of their experience of motherhood. Acquired information was analysed in terms of procedures used in grounded theory (GT) methodology[10], with particular attention to main assumptions of existential psychology.

Analysis of own research outcomes

Experiences of single mothers raising adult children with severe intellectual disability

Aloneness of a mother and a sever intellectual disability of her child are connected on the basis of a deep emotional existential relationship. Other scientific research shows that women often see their own parenting from the angle of their children's achievements and evolvement.[11] This kind of motherhood is bound up with permanent care of an adult child, and is often called by some researchers a 'hipermotherhood'[12]: as the interviews indicate, it involves deep

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[10] B. G. Glaser, A. L. Strauss, *Discovering the Grounded Theory. Strategies of Quaitative Research* (*Odkrywanie teorii ugruntowanej. Strategie badania jakościowego).* Kraków 2009.

[11] A. Maciarz, *Motherhood in the Perspective of Social Changes* (*Macierzyństwo w kontekście zmian społecznych)*, Warszawa 2004, p. 16.

[12] A. Palęcka, H. Szczodry, *Hipermotherhood: The Mothers of Children with Intellectual Disability* (*Hipermacierzyństwo – na przykładzie matek osób z niepełnosprawnością intelektualną)*, [in:] A. Palęcka, H. Szczodry, M. Warat (ed.), *Women in Polish Society* (*Kobiety w społeczeństwie polskim)*, Kraków 2010, pp. 17-42.

existential problems. The examined group of women consisted of mothers who lived through many events which have determined their existential experiences, and have shaped their reflections on the meaning of life and future, as well as formulating questions such as ‘Why me?’.

The ‘Why me?’ question in self-reflection of the examined mothers

Women varied in the ways of describing their motherhood. Some of them told their stories chronologically, describing events following in succession; others pointed out crucial moments in parenthood. Referring to the beginning of their motherhood, they often recalled the question ‘Why me?’. In opinion of most of them, the beginning was the most difficult moment, filled with spiritual experiences. They felt that it was related to many difficulties which they must have encountered in spiritual and social aloneness.

> Agnieszka[13]: *The beginning was the hardest time – you have to come to terms with so many things… A lot of different questions was coming up somewhere inside of me: ‘God, why me?’. Today I know that everything I lived through back then strengthened me as a human being; it showed me that I am strong, but it also left a mark.*
>
> Nela: *I went through a crisis from the start. ‘Why me?’ I asked myself: this question was overpowering. I couldn’t resign myself to this, I somehow understood it was time to forgot about myself. I don’t know, I live with it for 30 years now, I think I’m strong.*
>
> Barbara: *First, I didn’t know how it would be, I was afraid it was the end of my life, that I would not handle it. I asked so many questions… But I managed, I think so.*

The crisis which puts severe limitations on a life of a family as well as an individual, changes the ways of social and emotional

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[13] All names have been change to protect the identity of respondents.

existence.[14] Looking back at it some years later, the mothers notice that these experiences revealed for them their existential potential. Asking themselves the question 'Why me?', the women tried to search for an answer in many different ways: submitting their children to medical tests, comparing themselves with other mothers, reviewing their own existential values. Some of them still have not found the answer. Deep analysis of every single word has shown that, despite the passage of time, the mothers have not fully come to terms with the state of affairs, and that this is a result of the 'silent self-blaming' for a child's disability. Mothers are often blamed by their immediate family, as a result of social prejudice. This applies to the group of examined women.

> Nela: *I was always living with the question 'Why me?'. 'Why did it happen to me?'. That's why I gnawed at any tests there were. I have never answered myself to this question, and it torments me to this day. I have waited for this answer, waited for too long.*
>
> Beata: *I thought of the fact that it happened to me as something natural, and I assumed that it's something I had to come to terms with. I had these values inside of me that in a way shaped the answer for the question 'Why me?'.*
>
> Aleksandra: *I could have felt that many people thought it was my fault, cause you know – a mother is a mother. I often think that I actually am to blame, that somehow, I did something wrong, during my pregnancy, or afterwards…*
>
> Barbara: *It's true, I sometimes compare myself to other mothers. Once in a while you think that other people have it easier in their life. But I don't want to complain, it could have really been worse.*

As the above statements show, the question 'Why me?' was mostly asked in the first period of motherhood. It is worth mentioning that despite the passage of time, the question accompanies the

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[14] M. Sekułowicz, *The Problems of the Functioning of Mothers and Fathers of Children with Disabilities* (*Problemy funkcjonowania matek i ojców dzieci z niepełnosprawnością*), [in:] Z. Palak, A. Bujnowska, A. Pawlak (ed.), *Edukacyjne i rehabilitacyjne konteksty rozwoju osób z niepełnosprawnością w różnych okresach ich życia*, Lublin 2010, p. 47.

life of the mothers with varying degrees of emotional intensity. It can be assumed that the main cause of theses existential experiences, such as asking the questions 'Why me?', was the mothers' powerlessness toward the situations that required many transformations and sacrifices of them. It was also related to a different idea of parenthood they had.

The sense of the meaning of life

Questions about the meaning of life are present in human existence for centuries. The answers to these questions are searched for in various life areas: family, work, dreams, life goals and achievements. These dilemmas were prevailing in mothers' narratives as well.

> Nela: *In the past, I didn't really wonder what I lived for, I didn't search for the meaning of what I was doing. But then, along with my son's disease, it came to me by itself, I began to think about it. It was more often back then… When my husband left us, for a long time I didn't feel as anything meant something, it was all so sudden… And you lose this sense.*
>
> Alicja: *Sometimes I think: 'God, what do I live for?' But I know what for – for children, so they can feel they matter, because they are in the centre of my life, they give a meaning to my life…*
>
> Grażyna: *I often wonder about my life, but I know she needs me and I should not let myself have these thoughts. Sometimes they would come to me, because I am alone in all this, well, maybe not totally, but you know what I mean. I lost my job, it was horrifying because i didn't know what to do, how would I provide for us, there are expenses.*

Questions about the meaning of life came up along with the information about the child disability, and they tend to come back in critical moments in women's' life – at the time of divorce or job loss. Mothers point out that, with time, these dilemmas tend to change direction into the question of taking care of an adult child and the specificity of their severe intellectual disability. Living and achievements of their children have become the meaning of their own existence.

> Agnieszka: *In this life of mine I just want to help her… I better have enough physical strength; psychologically – I don't even think about how I manage to live… If I don't manage, I will lose any sense of meaning. But as it is, this thought keeps me alive, the thought that I help, that I manage, that it matters.*
>
> Nela: *There is no choice or hesitation… I dedicated my life to him and that's that.*
>
> Maria: *It is not how I imagined my life would look like, is it? But without my daughter, I can't even talk about it cause I'll cry… I see the meaning of my life in her every achievement.*

Main assumption of philosophy and psychology of existentialism state that the sense of meaning is experienced in relation to something or someone, and that to be able to recognise and accept the meaning of life one has to acknowledge it in their experiences and consciousness. In opinion of the examined women, the experiences they had to face, made their life meaningful without them thinking of it or searching for it. During the years, the motherhood which the respondents have been bestowed with, strengthened their firm conviction about the meaning of their life. It has been reflected in the process of shaping personal and social identity of examined women. As can be seen, there is an importance of a relationship within the paradigm of existentialism – a person is turned toward another human being; they fulfil themselves by being with other person, by living and experiencing their own selves in terms of relation toward other individual. It can be assumed that this kind of belief strengthened the mothers spiritually, psychologically, and physically.

> Jolanta: *What can I say? Life's hard. But you don't think about whether it does or doesn't matter… You act in such a way as to keep your child well. This is where the meaning is.*
>
> Agnieszka: *I don't think in terms of the category of 'me' anymore, instead I think of 'us'. Because when she takes even a small step further, I feel I move forward too.*

> Zofia: *What truly gives me hope is my strong belief that she needs me, and that if it wasn't for me, she would just stop living. It is sad after all, but it is actually my only goal.*

The meaning of life is an aim of a constant striving within and for human existence, and it applies to mothers' lives. The sense of their own existence, their social and psychological identity are directly related to another human being. When talking about themselves, they usually relate to their own children. They are aware of the existential obstructions related to this attitude, but it is worth mentioning that as they have managed to live this way for years, they resigned themselves to the idea of sacrificing their lives for their children. However, it does not mean that they have come to terms with their sons' or daughters' disability or suffering.

> Nela: *The truth is, I don't have any life of mine anymore. When my son fell ill, I gave up thinking about myself. Different priorities. He became my whole life.*
>
> Maria: *She needs my support, and it's obvious it's going to be this way for the rest of her life. I actually live for her. Do you know how she suffers sometimes? I would swap with her and suffer just so she could be happy.*
>
> Beata: *Sometimes I feel like I'm going crazy, but she is what matters most, and this is just the way it has to be.*

Therefore, in the attempt to answer the question about the determinant of the meaning of life which has been revealed in mothers' narratives, we can consider it a reality in which the mothers have come to live in, identifying the meaning of life in another person. It has been shaped by various experiences and life events, which the women have encountered over the years.

The future

In the narratives about their motherhood, most of the women raised the issue of the future, although in a peculiar way, as in relating to the upcoming old age. When describing past events, they have not mentioned the vision of the future that they had back then. From what they said it appears that it begun to change when they started to notice that they grow old, both physically and psychologically. Reflections on ageing are the immanent part of human existence. They are present at various stages of life, concerning life recapitulation, and achievements. Old age in the narratives of interviewed mothers is associated with the lack of strength, physical and psychological exhaustion, but mostly with the concern for the child's future.

> Maria: *What is most difficult right now? Well… I suppose it's the fact that I'm old now and I just lose my strengths, I feel tired more often… I keep thinking what will happen with my daughter.*
>
> Renata: *I'm old now, and sometimes I'm exhausted, my arms ache.*
>
> Małgosia: *I would really want someone to take care of our problems. To be honest, I'm tired. I am just too old for all this.*

Thoughts on old age were mostly focused on the feeling of physical weakness, which in respondents' narratives was closely related to the fear of the perspective that a child would not get necessary support they now do. The women point out that their children have grown older along with them, and that means different, more absorbing and time-consuming kind of care.

> Agnieszka: *Now I can see the difference. My daughter grows older, I'm not young either, my back often hurts, it gets more difficult for me to bath her, all these duties…*
>
> Beata: *I'm afraid of that day, when I won't be able to take care of her anymore.*

Old age pictured by mothers is not related to their personal 'self', but to their physical and psychological exhaustion. The women consider the beginning of their parenthood the hardest time, as they must have dealt with difficulties they had a direct influence on. The ageing process it the stage at which they have to struggle with things they don't have any control of. Raising and caring for a child are an integral part of life in terms of the women's existence. It has a strong impact on their reflections on future events, when their children will have outlived them or, the opposite, will have gone first.

> Maria: *I cannot imagine my life without her, it would all become meaningless.*
>
> Nela: *I think about what will happen to me when my son dies, as he is severely ill now, he has got seizures more often these days. No one will need me then, I will be all by myself… I don't keep in touch with my family.*

For years, the have women lived in solitary, taking on many roles not associated to the traditional idea of a mother; they have built their own homes submitting themselves to their children's needs. Being aware of the fact that they might be the ones to leave first evokes a truly scary perspective of a care home or rehabilitation centres. Most of the women have already been looking for this kind of place. Mother's greatest fears concern their children's daily living: their habits, difficulties which the women are able to manage thanks to motherly love. In the respondents' opinion, even the finest rehabilitation centre would not provide this kind of care for their children. It can be assumed that women value highly their own way of caring for a daughter or a son, and this attitude helps them to not give in, both psychologically and physically.

> Maria: *This thought that she will outlive me, that I will have to go too… I will have to leave her, this is the hardest and most tragic thing of it all. Even if she is put in the best rehabilitation centre, the best you can imagine…*
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> Alicja: *All I really care about now is to finish this house refurbishment already. So, when we're gone, someone young from the family would take care of our children, and we leave them the house. Just so they take care of our children.*
>
> Agnieszka: *I consider a centre, a house for my daughter, where her sister can be close to her. I consider this option as well. I'm always joking though that for me the best way to go is to go together.*

For the mothers, future poses some kind of a threat for their children. The women are searching for various ways of securing their children's future. Some mothers reached for help within their families, but most of them lived in spiritual and social solitary. There are very few mentionings of the spiritual support for women in the research material. Therefore, in the attempt to answer the question about the determinant of the existential experiences in the reflections on future, once more we can consider it a difficult reality in which the mothers live; a life on the edge of burn-out, a state of a constant mobilisation, but also a lack of spiritual support and social acceptance.

Conclusion

The analysis of existential experiences of single mothers raising children with severe intellectual disability is an important area of research in terms of several sectors of social life. It develops foundations of creating a model of support for this group of families, which includes current trends in system legal and social assistance solutions. It is worth noticing that the current model does not include the spiritual support in a range which would suit women's needs. It has severe psychological consequences and may cause an existential vacuum. As the conducted analyses show, being a mother of a child with severe intellectual disability is associated with many existential problems, questions such as 'Why me?', and reflections on the meaning of life and future. They have different basis, although they all have a mutual determinant: the reality which, at the beginning of the motherhood, was full of powerlessness, a vision of unfulfilled parenthood, sacrifices, and transforming own 'self' into 'ourselves'. Life in constant exhaustion, every day care that requires from a woman some extreme physical and psychological strengths, provokes existential questions and experiences imbued with negative emotions. It is worth to notice that parents raising children with severe intellectual disability have a strong need of spiritual support. What is to be done:

- initiating institutional and non-institutional activities which aim would be to support mothers raising children with severe intellectual disability;
- organising a complex system of psychological and therapeutical activities, focused on supporting examined women who experience existential problems.

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