

The dynamics of the coping process of families of children with severe multiple disabilities¹

Dynamika procesu radzenia sobie w rodzinach dzieci z poważnymi niepełnosprawnościami

Abstract:

The paper explains the specifics of the dynamics of the coping process of families with children with severe multiple disability (SMD). The realised study was of a qualitative design and was based on the thematic analysis and interpretative content analysis of case studies of families with a child with SMD. Data were collected using 11 semi-structured interviews and case studies of families. Among the analysed themes were hearing the first news of the diagnosis, making the decision to keep the child at home, the losses related to the disability of the child, general thoughts about the life experience and worries related to future. Data was interpreted on the basis of the model of loss created by Ross and discussed in the context of other models. Specific conclusions were found mainly in the dealing process with the first news of the child's diagnosis, the decision process to keep the child with the family, indefiniteness of the disability and integration of the losses.

Keywords: Family, multiple disability, coping, Kübler-Ross, loss.

Abstrakt:

Artykuł wyjaśnia specyfikę dynamiki procesu radzenia sobie w rodzinach z dziećmi z poważnymi niepełnosprawnościami (SMD). Przeprowadzone badanie było projektem jakościowym opartym na analizie tematycznej i interpretacyjnej analizie treści przypadków badawczych rodzin z dziećmi z SMD. Dane zebrano na podstawie 11 częściowo ustrukturalizowanych wywiadów i przypadków badawczych rodzin. Analizowane tematy obejmują: pierwsze wiadomości o diagnozie, podjęcie decyzji o zatrzymaniu dziecka w domu, straty

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związane z niepełnosprawnością dziecka, ogólne przemyślenia na temat doświadczenia życiowego i obaw dotyczących przyszłości. Dane zinterpretowano na bazie modelu straty utworzonego przez Ross'a i omówiono je w kontekście innych modeli. Konkretnie wnioski wyciągnięto głównie w oparciu o proces radzenia sobie z pierwszą wiadomością o diagnozie, proces podejmowania decyzji o zatrzymaniu dziecka w rodzinie, nieokreśloność niepełnosprawności oraz integrację strat.

Słowa kluczowe: *Rodzina, poważna niepełnosprawność, radzenie sobie, Kübler-Ross, strata.*

1. Introduction

In special pedagogic research there is a rising focus on individuals with multiple disability. This group had, until recently, been marginalised in pedagogic and medical fields due to their extensive institutionalisation in social care facilities. A similar situation had been prevalent for many years in western countries. Some foreign studies had even recommended placing individuals with multiple disability (MD) into a prolonged full-term institutional care in order for their families to live „a harmonious and balanced way of life“ (Farber, 1962). Such recommendations were later strongly criticised after the recognition of the children's rights to live with their family. Examinations of various aspects of family care of children with MD were initiated in order to make the system of professional family support more effective. The birth of a child with MD is an especially difficult situation for parents and siblings. Internationally published studies highlight the issue of managing multiple roles (Scorgie, Sobsey, 2000), a difficult time management of care (Heaton et al., 2005), managing mentally difficult complications of health status (Iversen, Graue a Clare, 2009), health complications of care-givers themselves (Brehaut et al., 2004) and many other themes. However, besides handling such specific tasks the respective members of the families are also coping with the disabled child's presence as such.

2. Models of the coping process with child's severe multiple disability

Several theoretical models exist that describe the dynamics of the coping process with the child's multiple disability. The most influential is probably the model by E. Kübler-Ross (further only Ross) often cited in Czech and foreign expert literature (e.g. Frye, 2015, Harčaríková, 2011, Vítková, 2006). The

model was created based on a prolonged experience with dying individuals. Based on empirical observations Ross described the stages of denial, anger, bargaining, depression that lead to the acceptance of reality as a definitive state (Ross, 2003). The respective stages are well-known since the impact of the model on other fields such as nursing was substantial (Newman, 2004). The Ross model is also being applied in expert literature to groups of people with serious diseases, after injury and to the issue of families of children with health disability (e.g. Bigge, Best, Heller, 1991) since there are similarities in the way these groups of people cope with the sadness and loss typical for dying people and their relatives.

Scholarly literature on the matter of coping with severe loss offers various alternative models. It is e.g. the model of loss and adaptation by M. Horowitz (1997), stages of sadness by G. Engel (1964) or the model of „6 R’s“ by T. Rando (1993), the J. Bowlby model (1980) and others. In Czech scholarly literature M. Vágnerová (2000) offers an adaptation of the Ross model that includes the stages of surprise, denial, anger, sadness and guilt, and the stage of balance and reorganisation. These alternative models had also been designed based on research of populations other than families of children with MD.

We may also encounter a critique of the theoretical consistency and the possibilities of using these models (Newman, 2004). In connection with the Ross model, for example, the continuity of the respective stages became less important since the described stages do not always occur or they do in a different order (Pomeroy and Garcia, 2008). There is a great inter-individual variability in the coping process with a severe loss. R. Kastenbaum’s (1998) and other critics’ main argument is based on the fact that Ross’ model of stages was not backed up by clinical research and what is more important, Ross does not describe a linear process but clusters of various psychodynamic reactions in a specific life situation.

The character of the loss in the case of families of children with MD is significantly less definite compared to the loss of a partner (in death or divorce). In scholarly literature we find suggestions of terms such as ambiguous grief (Boss, 2009) or nonfinite loss (Bruce and Schultz, 2001). Understanding of the implications of life with a child with MD unfolds throughout the years. The sorrow felt by these families is described as “frozen” since it persists even after children reach adulthood (Bruce, 2009). The final stage of acceptance typical for dying people is hardly applicable to the families of children with a health disability. In this case, the feelings that arise instead of acceptance are more of uncertainty, anxiety and fear of future times when parents won’t be able to take care of the child. It is just to assume that there are many more differences between tradi-

tional models of accepting loss in the form of the death of a close person and the birth of a child with MD. Understanding the coping process with MD by family members is complicated by the fact that there is no internationally accepted theory primarily designed for this population.

In the current scholarly literature two distinct tendencies in regard to the interpretation of the coping process with a child's disability are discernible: the traditional models of loss (especially the Ross model) and alternative views of the process. It is obvious that traditional models are incapable of adequately describing the experience of families of children with MD. Insofar however, there are no research-based alternatives to these models despite the fact that several authors sympathise with some existing theories. To state one example, author Cantwell-Bartl (2009) finds the model of double coping process with the loss of a close person (Stroebe and Schut, 2010) a possible alternative that better relates to the specific characteristics of families of children with MD.

For professionals working with families of children with MD there is no other option but to accept the traditional models while being aware of their limited validity for the group. The double aim of the realised study the methodology and results of which are described in the next subchapters to enable a closer understanding of some specifics of the coping process with the birth of a child with MD (1) and to suggest variations of traditional models (2) is meant to close, at least partially, this gap in current knowledge.

2.1. Methodology of the study

The aim of the study is to interpret the experiences of families of children with SMD related to the coping process with the disability as such using current theoretical models and to determine which aspects of the models are relevant to the families' experiences and which are not. The process of interpreting the experiences of the families consists of searching for falsification moments indicating differences between the existing theory and the reality as described in the textual material of the case studies. In such cases it is necessary to consider revising the theory, its expansion or alteration in order to make it more compatible with reality it represents.

Due to the great number of models describing coping with loss the Ross model was chosen for this study due to its high citation and prevalence in domestic literature focused on the issue of health disability. For this research data collected from the research of lived experience in five families with children with SMD were used (Kantor et al., 2015). These families altogether consisted of 11 members: 5 mothers, 3 fathers and 3 siblings. The original research of lived expe-

rience focused on the process of coping with the disability as one of the factors that transforms the life of families.

A brief characteristic of respective families may be found in Table 1. It gives details of the medical condition of the children (Dg.) and the family characteristics (Ch). As part of the data collection we obtained information about the disability of the child, his or her functional condition, age and characteristics of the family (number of family members, completeness of the family, demographic and other specifics). The article uses abbreviations: M for mother, F for father, B for brother and S for sister coupled with a number indicating the family.

Tab. 1: Characteristics of children with severe multiple disability

Eva (family 1): female, 19 years old	
Dg.:	Microcephaly, severe psychomotor retardation, epilepsy, severe hypotonia, paroxysmal syndrome, progressive kyphoscoliosis, progressive pulmonary fibrosis, signs of significant fluctuations of attention and focus, astigmatism, hypermetropy, exotropy, central visual impairment (practical blindness). The level of mental ability is impossible to test clinically in the range of profound mental retardation.
Ch:	Incomplete family, parents divorced. Eva lives with the mother (M1). She has an older brother (B1). They live in a 3+1 apartment, 1 st floor, not suitable for her disability, however, due to financial situation there is no other possibility.
Adéla (family 2): female, 20 years old	
Dg.:	Down syndrome with severe mental retardation with the presence of behavioural disorder (F71.1) and affective disorders (Mood Disorder Due To Known Physiological Condition F06.3) - anxiety. Communication: dyslaly, echolaly. Atypical autism, limited vision, decreased level of frustration tolerance and decreased pain threshold.
Ch:	Incomplete family, parents divorced. Adéla lives with her mother (M2). She has an older sister (S2) who has a 1-year-old daughter. The father lives alone (F2). They live in a 2+1 rented apartment with little furniture on 6th floor without an elevator (this is due to little finances).
Marcel (family 3): male, 17 years old	
Dg.:	Combined spastic and dyskinetic form of cerebral palsy and a mild form of severe mental retardation. Psychomotor development is uneven. Low vision, dysarthria, and hypersalivation. At the moment, the major problem is dysphagia and food intake problems, which results in a secondary failure to thrive (also because of reflux).
Ch:	Complete family (M3, F3). The boys live with both the mother and the father. The family lives in a two-generation house on the upper floor. This year the house was made barrier-free (elevator, ceiling lift, barrier-free bathroom and toilet, etc.).
Daniel (family 3): male, 17 years old	
Dg.:	Daniel is Marcel's brother, combined spastic and dyskinetic form of cerebral palsy and a mild form of severe mental retardation. Psychomotor development is uneven. Low vision, dysarthria.

Kristýna (family 4): female, 13 years old	
Dg.:	Mental retardation, atypical autism (low-function type) and behavioural disorder, hidden epilepsy. Kristýna has strabism and is after an operation.
Ch:	Incomplete family. Kristýna lives with her mother (M4) and her mother's partner. They live in a rented apartment 2+1 on 1 st floor. The apartment is nice and suitable to the special needs of the daughter.
Magdaléna (family 5): female, 16 years old	
Dg.:	Central muscular hypotonia, mental retardation, and speech disorder.
Ch:	The family is complete. Magdalena lives with her father (F5), mother (M5), older brother (B5) and two younger siblings. They live in a barrier-free family house, which is adapted to enable the free movement on a wheelchair.

Data were collected using case studies of families of children with SMD via qualitative semi-structured interviews with family members and the study of various documents about the families and the children (school documentation containing medical reports, family history, etc.). The data were transcribed and edited into a form suitable for analysis.

For data analysis a combination of thematic analysis by van Manen and interpretative content analysis of case studies was used. The purpose of the thematic analysis was to identify basic themes and categories occurring during interviews. Thematic analysis was an important element of the research process since it highlights specific designations, checking and recording patterns (themes) in the data set (Braun and Clarke, 2006). The themes are essential for the description of the examined phenomenon, they relate to the research question and become categories for analysis. Van Manen (1997) lists three steps for the identification of thematic statements: those are a detailed reading of the text, selective or interpretive approach and holistic approach to reading the text.

A detailed reading of the text has been applied by multiple reading and considering the meaning of each sentence or group of sentences. The meaning was initially captured by setting keywords. Similar passages in each interview were grouped before passages were identified that characterized the overall impression of the conversations and which emerged during repeated reading of the text. This procedure is already part of the second phase of thematic analysis, i.e. the selective and interpretive approach. Here, the researcher searches for those statements that best reveal the nature of the examined phenomenon. Statements were then grouped according to more specific subthemes and broader themes. In the next phase the statements were grouped into similar categories and the categorisations kept changing. In the third stage of the analysis a holis-

tic approach to the text was also applied. In this process the researcher perceives the text as a whole and searches for the phrases concealing the essential meaning of the text.

The methodology of interpretative content analysis applied to case studies is described by Ženka and Kofroň (2012). The aim of this approach is to interpret case studies according to already known theoretical concepts rather than creating a new theory. The respective themes, categories and subcategories created using thematic analysis are subsequently interpreted by the Ross model. These were sought during interpretation:

Similarities or moments in case studies that may be interpreted based on this theoretical model.

Differences compared to theory described by the model. These are so called moments of falsification that point to inconsistencies between data and theoretical framework. These instances suggest that the theoretical framework needs to be revised or modified to better reflect reality it represents.

2.2. Themes of the coping process with disability

The thematic analysis uncovered the following themes related to the process of coping with disability: receiving news about diagnosis and the decision to keep the child, the disability of the child as a multiple loss, thinking about the life experience and fears of the future. Other related inconsistent statements were identified (these statements were important for the second part of the data analysis). The themes will be described briefly here.

The stage of receiving information about the child's diagnosis was the beginning of the whole life experience for each family, however, it is not necessarily chronologically related to the process of finding out the diagnosis of the child. In the case of a child with MD the diagnostic process is prolonged and parents get information about various serious diagnoses gradually. Although the interviews clearly show the parents were at first hearing of the diagnosis shocked, they obviously had to face repeated diagnostic findings regarding the medical state of their children. The process lasted several years in some cases. To state one example, M1 describes the unfoldment of the diagnostic process of her child:

Case M1: Pregnancy (without serious problems); birth (complicated but child considered healthy by doctors); 0,5 year-old (diagnosed with visual disability); later, time not specified in interview or documentation (diagnosed with physical and mental disability); 1,5 year-old (diagnosed with epilepsy); later, not specified (diagnosed with pulmonary fibrosis).

Although parents describe receiving news about some of the diagnoses casually upon hearing the whole interview it is obvious it was a very difficult stage of life with many stress inducers including the repeated unpleasant information about the medical condition of the child: „Pregnancy with Eva was planned, we were expecting her and happy... The birth of Eva was difficult, the shoulders were wider than the head, it took a long time to push her out, her skin was blue, she didn't cry and inhaled some amniotic fluid. Her medical record stated she was alright and I naively trusted the doctors... We found out about Eva's disability when she was 6 months old – the visual disability, later also physical and even later mental, then also epilepsy (she was about year and a half) and at last the pulmonary fibrosis – the disease that is so limiting to Eva... When Eva was born at first we were shocked, later adjusted and fought the situation. The doctor's and medical personnel wasn't very pleasant... But the confirmation of Eva's disability brought me despair, I was unhappy, I didn't want to live. I lost my life purpose, I could not imagine ever being happy with a disabled child. I collapsed but later I started to live for children and fight for happiness.”

An important part of the diagnostic process is sharing the information with the partner if he is not present at the doctor's office and the decision to keep the child with SMD in home care. Family no. 2 experienced it this way: “When I was in hospital I was in a really bad mental state. I could not bring myself to tell my husband that our daughter was born with a disability. I wrote him a letter asking him to decide whether to keep Adélka or put her in an institution. Fortunately, he categorically replied that we keep her” (M2).

The family in the decision-making process regarding the child's upbringing may be influenced by their social background including the medical personnel. M1 describes her experience with her wider family's pressure to “place the child in a facility” and the realisation that she is the one to decide the child's fate: “The grandparents with the exception of my mother had a very hard time accepting my daughter, they said when “it” (meaning Eva) won't be well to put her in a facility. ... I realised they would not tell me what to do in life and I, the mother, will be the one to decide in this case. Not them! I never for a moment considered institutional care since based on the medical diagnoses she doesn't have much longer to live and so I would like her to be with me until the end.” Social support of the families also include professional assistance. The diminished support of professionals is alarming in the experiences of some families, their pressure to place the child into institutional care, their insensitivity in bringing the news about diagnoses etc.

The process of understanding the disability by siblings is different, unless there is a great age difference between them. Contrary to the parents who find

out about the diagnoses, it is more accurate to describe the process as a gradual understanding of the diagnoses. The siblings are at first confronted with the differences in behaviour of their brothers or sisters with SMD and their understanding of the meaning of the disability unravels gradually: "When Eva was born I didn't understand it very much and I don't remember what I thought. I just know that my sister didn't respond to me, I thought it was strange, but I was 2,5 years old so I didn't dwell on it. Parents told me my sister was sick. Then I thought it was strange that my sister was at home all the time. I could not play or go out for walks with her" (B1). From the analysed data it appears the siblings' reactions are similar to the processes of outer and inner crises that had been described in individuals with a congenital disorder (Bigge, Best, Heller, 1991). A typical childhood theme of younger siblings of children with SMD may be fighting for parents' attention and acceptance of differences in their parenting approach.

The coping process with the child's disability related by the family members was connected to multiple losses mentioned by the families. The losses were categorised into four areas: into losses on a personal level (the loss of free time, loss of privacy and individual freedom), the losses in relationships to others (losses within families, losses of friends), the limitations of family activities (the family as a whole, respective members and activities of the disabled child) and the losses of perspectives (the losses of expectations, the losses in the development of the child and worries about the future of the child).

Further course of the coping process with the child's disability was only partially outlined in the stories. Therefore it was only possible to use fragments describing the coping process with the disability in analysis. Among the experiences of the respective family members are feelings of guilt, blaming, later forgiveness and redefining the view of the life experience (M2), feelings of despair, the mobilisation of strength and great demand of care, exhaustion and acceptance of the health condition of the child (M1), growing awareness of the child's condition due to negative reactions of others and a gradual desensibilisation towards such feelings (M2, M4, M5), etc.

"Before Eva started school upbringing had been very difficult. ... It was a hard period, I kept running towards a goal, trying to improve or change something. It is much more peaceful now. I know I cannot dramatically change the situation, I have accepted it, I am not competing for anything, I just want Eva to smile, not suffer, I want her to be happy and content and then I am also alright" (M1).

The concept related to the coping process with the disability is the participants' balancing their life experience. They compare their losses against benefits using phrases such as "On one hand..., but...", balancing losses and benefits,

measuring them etc. Balancing as it seems is one of the steps supporting the integration of the participants' experiences: "I definitely disagree with the saying that it is a gift to have a disabled child, rather I sometimes consider it a punishment and wish such children would not exist at all. But it has definitely changed me in the way I see the world, values and I also have a more intense relationship with Eva than with the healthy son. I wish for a different father to the children, for a healthy child, but if I have to keep the disability, I'd like to lose the pulmonary disease and epilepsy. Nevertheless, life with a disabled daughter brings me love, a feeling of fellowship but also many responsibilities and worries. It takes away my freedom and strength" (M1). Balancing in a less articulated form was identified also in siblings.

The remaining area that forms an inseparable part of the coping process with the child's disability is the parents' and siblings' pondering the future. The participants talked about the future matter-of-factly, focusing more on the practical questions of security in the future (e.g. choosing a proper facility, a person who might be able to provide further care) without expressing their own feelings related to the question in most cases. However, from other parts of the interviews it is obvious that care-givers think first of all about the child and the family focusing on practical aspects of their security and functioning in the future. Only after considering that matter they start focusing on themselves, their needs and feelings. The questions regarding the future of the child with SMD are important to the siblings who categorically stated that they would not place their sibling into an institutional care and that their need for a certain life flexibility influences their plans for the future, their choice of a partner, etc.

2.3. Conclusions of interpretative content analysis

The data collected using a thematic analysis were interpreted based on the Ross model. Here, only those instances will be introduced in more detail that show differences between data and theoretical consistency in the application of that model. Due to the purposes of this study the falsification moments are more essential than similarities. It is these moments that determine in which areas of life experience of families of children with SMD the model is applied inappropriately and that make it possible to revise the current theory.

The falsification was related to these instances:

The period of receiving the news about the diagnoses (which according to Ross model is the phase of shock) that is in families of children with SMD characterised by several medical interviews informing of unpleas-

ant diagnoses and the decision to keep the child in the family or to place it in institutional care.

Indefiniteness of the experience of family members (according to the Ross model it is the phase of acceptance of disease).

There are other themes not included in the Ross model: balancing the losses against benefits of the life experience which we consider an inseparable part of the process of integration of losses into a holistic life experience.

It is only possible to consider the application of the Ross model in regard to the primary care-givers or parents since the siblings cope with the disability in a specific and very unique way (see previous sub-chapters).

Receiving information about the diagnoses

The Ross model (and other models of coping with loss) consider the period of receiving the information about the child's diagnoses into the phase of shock that typically occurs in various forms in reaction to a serious loss. As mentioned above typically in families with children with SMD the unpleasant diagnoses are unveiled gradually and the diagnostic information is received repeatedly. Therefore, the traumatic experience is not one, rather there occurs a whole series of repeated findings the gravity of which may even increase in time. Based on the acquired data in respective families it was not possible to determine whether the information was received with the same intensity or not (we suppose there are various individual variations). More research is needed to describe in more detail the course of receiving information about the diagnoses of the child. Part of this area is also the decision-making process of whether to keep the child at home. This theme is not included in the Ross model but is described by authors who deal with this phase in families of children with a disability, such as S. Sládečková and I. Sobotková (2014).

The ongoing life situation of family members

Some statements of this study's participants confirm the indefiniteness of the coping process with the child's disability. For example M1 says: "By the way, I will probably always suffer from Eva being born disabled. It is a lifelong pain. Everyone wants a healthy child. I would like to know what she would be like if she, for example, talked. I would like to see her wedding, I would like to see her children and so on. I will never cope with that..." Here is a big contrast between losing one's loved one and experience with a disabled child. In the case of

families of children with SMD in the final stage instead of acceptance it would be more accurate to talk about the difficult thoughts about the future that are characterised by uncertainty, anxiety and fear.

Other themes

Among other themes not mentioned by Ross there is the ongoing interaction between the processes of loss and reorganisation. These processes were in research data captured in the theme balancing the life experience and were put into contrast with the integration of the losses as unchanging life experiences including possible reframing of the views of these experiences, seeking out support and the application of other coping strategies.

The conclusions of interpretative content analysis: it is clear that a substantial attention is given to the period of finding out the diagnoses of the child. For further development of the life of families there is a wide range of possible scenarios: and because of that it is extremely difficult to compare the experiences of respective families and focus on the similarities in their great variability.

3. Discussion

As part of the qualitative data analysis some essential themes were identified that are related to the coping process with the SMD of the child. These are the period of receiving information about the disabilities of the child which also includes the duty to inform the partner and the decision to keep the child in the family and later a period that includes balancing the life experiences and pondering the future. The experience of parents with children with SMD may be characterised as multiple and gradual serious losses; according to the terminology of current professional contributions the losses are called cumulative or secondary (Bruce and Schultz, 2001). A typical feature of the losses is their orientation towards all three: the past, the present and the future. The experience therefore runs through the whole family life and is related to various types of unpleasant expectations and the impossibility to predict, regulate and control the losses.

Data comparison has shown that siblings undergo the coping process with the disability in a different way characterised by a gradual development of an understanding of the seriousness of the disability. The siblings also suffer from multiple loss but the dynamics of the process seems to vary according to their age and many other factors. Although the issue of the siblings of children with disabilities

is being researched in many studies, the author is not familiar with a complex description of the dynamics of their coping process in literature.

Further, data were interpreted using the Ross model focusing on the differences between the model and the research data. There were these main themes: repeated information about unpleasant diagnoses, the decision to keep the child at home, the indefiniteness of the whole process and the presence of some special themes, such as balancing the life experience; it is not clear whether this stage is independent or is part of the process of integration of life experience. In some foreign scholarly contributions the indefiniteness of the process is especially highlighted; the situation is metaphorically named “frozen” (Bruce, 2009).

The findings may be used also in interpretation of the coping process with the disability using other models. Some models contain similar stages to the Ross model. E.g. Horowitz model contains four stages that are similar to the shortened variation of the Ross model: the outcry stage, the denial stage, the working through stage and completion stage. Thanks to the special situation of families of children with SMD and the questionable finality of the coping process the variation designed by M. Vágnerová (see above) may also be applied relatively well. The same is true of some stages of T. Rando’s model. This model avoids defining finality of the whole process: last stages are titled re-adjustment and new exploration (of the world, its possibilities and potential relationships). These stages might be accurate in the context of some types of serious loss characteristic of the life of family members of children with SMD, however, it is questionable whether the model may be applied to the whole life of the members. On the other hand, there are models of coping with loss that only distantly relate to the experience of families of children with SMD, e.g. the four-stage model of J. Bowlby and C.M. Parkes (expressions of insensibility, yearning and search, disorganisation and disorientation are more typical for disruptions of attachment in children rather than adults).

Reflecting on the current scholarly literature a question arises whether in the future it will be possible to describe the process of coping with SMD of the child as a holistic experience or rather we will have to limit the descriptions to defragmented segments of the experience by researching a set of partial themes related to the process (e.g. in connection to research of family resilience). By discarding the necessity of a linear view of the whole process and by respecting the significant individual variability (which increases with time) these models offer a certain vision of possibilities of unfoldment of psychodynamic reactions related to the coping process with the child’s disability. Such vision might be useful for professionals accompanying the families.

Pondering the validity of the findings we may highlight the lower number of participants in the research set, a lower homogeneity in the children's diagnoses and in the family characteristics. It is so because of limited availability of this population and some complications in data collection (the research is related to private family issues, including some family taboos, it is difficult to perceive the dynamics of family life, etc.). For these reasons even internationally significant studies in the field do not reach a proper homogeneity of the research set. On the other hand, the data collection in the study built on a prolonged and thorough knowledge of the families, a professional history with the respective families and research supervision (especially in the data interpretation phase). Majority of the findings find validity in conclusions of internationally published contributions as was made clear in the previous text.

4. Conclusion

The paper discussed the dynamics and the stages of the coping process with the SMD of a child. Using thematic and interpretative content analysis the dynamics of the coping process with a child's SMD was compared to the model designed by E.K. Ross (2003). The research findings suggest that contrary to the Ross model there is no final stage since parents are gravely worried about the future of their children throughout their whole lives. Similarly, the stage of shock, rather than being a one-time event, is experienced as a prolonged period of repeated receiving of adverse information about the diagnoses of the child. We also found that an important theme occurring in the families' lives is the balancing of their life experience and their losses. In the course of upbringing of a child with SMD multiple losses arise while some are oriented towards the future. This complicates perception of the continuity of the whole process and forces the families to consider the need to reorganise practical life and repeatedly integrate the respective losses into the life experience as a whole. The study also introduces some differences of the process in parents and in siblings of the children with severe multiple disability which is in the later characterised by a gradual unfolding of understanding of the impacts of the disability. The author argues that so far there exists no accurate model for the complex description of the experience of families with children with SMD. It is, therefore, necessary to use variations of traditional models of loss that were discussed in this paper.

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