



Original research article

The lifestyle of mothers of individuals with a disorder/illness formed in the perinatal period

Aneta Witzanyová^{1*}, Miloš Velemínský²¹ University of South Bohemia in České Budějovice, Faculty of Health and Social Sciences, České Budějovice, Czech Republic² University of South Bohemia in České Budějovice, Faculty of Health and Social Sciences, Institute of Laboratory Diagnostics and Public Health, České Budějovice, Czech Republic

Abstract

A newborn child always brings a great change to its family. If the newborn child has specific needs, its mother mostly experiences not only a great change but also a different organization of her future life. A different lifestyle has its advantages and disadvantages.

The goal of this study was to ascertain the lifestyle of mothers of children with disorders, the changes to this lifestyle and whether there is a risk of social isolation. Social isolation is associated with the effort to ascertain the impacts of the place of residence on a mother's lifestyle. The research used a qualitative strategy and the data was analysed using the embedded theory technique.

We learned that the lifestyle of mothers of children with a disorder significantly changes in many areas – family and work life as well as personal life, where the most frequent reaction is a change of personality and especially values. We also learned that the place of residence significantly affects their lifestyle, specifically regarding the approach to services. Living in a village or a small town is very restricting for these mothers regarding the approach to services. These changes and facts usually do not lead to a negative approach to life with a disabled child. The research showed that these mothers usually have a different but quality life.

Keywords: Child disorder; Life changes; Lifestyle; Mother; Place of residence

Introduction

The birth of a child with a disorder is usually considered as one of the most significant critical situations in life. It is important that these people are provided with the broadest multidisciplinary help possible regarding all personality areas (Slaný et al., 2017). It is also necessary to know the areas in which these families need help and support. The goal of this article was to ascertain the lifestyle of mothers of children with disorders, its changes and whether there is a risk of social isolation. Social isolation is closely related to the effort to map the impacts of the place of residence on such a mother's lifestyle.

Disorders formed in the perinatal period are such disorders that are formed between the 26th week of the foetal period and 4th postnatal week (A Great Medical Dictionary, 1898–2017). According to Slowík (2016), the causes of perinatal disorders most frequently include lack of oxygen – hypoxia, asphyxia, infections, and mechanic injuries of the child or other complications. These perinatal causes usually cause health disorders that are related to the diagnoses, such as poliomyelitis, mental retardation, intracranial bleeding, injuries of the central nervous system, skeleton and many other parts of the body (Slowík, 2016; Valenta and Müller, 2013; WHO/IHIS, 2014).

Accepting a mother's role is a significant life process which lasts for a certain period. According to Van Wyk and Leech (2016), in cases of mothers of children with disorders, it is usually very difficult because the mother must bring the child-care and special needs and possibilities into accord.

Such situations are very difficult for a mother because she must usually sacrifice a part of her life (Vágnerová et al., 2009). The field of psychology describes managing an overlimitary stressful situation as "coping" (Jankovský, 2006). Parenthood and a mother's role are mostly a climax in life regarding the fulfillment of one's needs. If such parents have a disabled child, their needs do not have to be fully satisfied (Vágnerová et al., 2009). It is obvious that the mother of a child with a disorder has an extremely strong personality, which is also reflected by Velemínský (2011) in his book. In such a case, social support is necessary. This can be emotional, assessing, informational and instrumental (Mandincová, 2011).

Lifestyle and its social impacts

According to Diderot (1996), lifestyle can be defined as a way of life that develops from reproduction characteristics, industrial relations, leisure time, social interactions, traditions and human values, and also a person's economic and social circumstances. Considering the fact that a disorder affects all personality, life and family areas, the lifestyle of mothers can change in many areas (Jankovský, 2006; Velemínský, 2011).

* **Author for correspondence:** Aneta Witzanyová, University of South Bohemia in České Budějovice, Faculty of Health and Social Sciences, J. Boreckého 27, 370 11 České Budějovice, Czech Republic; e-mail: witzaa00@zsf.jcu.cz
<http://doi.org/10.32725/kont.2019.010>

Submitted: 2018-07-27 • Accepted: 2019-01-22 • Prepublished online: 2019-04-03

KONTAKT 21/2: 172–180 • EISSN 1804-7122 • ISSN 1212-4117

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A disorder significantly affects the level of harmful stress in the family and mostly increases its emotional, psychological, temporal and financial load (Majnemer et al., 2012). The increased need for medical care and the necessity of commuting to medical facilities often cause significant technical and financial problems (Van Wyk and Leech, 2016). A disorder often has an effect on a mother's mental condition because she sacrifices herself for her child (Vágnerová et al., 2009). Studies show that some socioeconomic, cultural and biological factors may lead to a worsened health condition of the mother (Kimura, 2018). From the beginning, the care seems to be an unmanageable load, which can come through social isolation and very frequently end in burnout syndrome (Kallwass, 2007; Vágnerová et al., 2009). Such trauma can force a person to change their view on life, gain new knowledge and change their values (Preiss, 2009; Vágnerová et al., 2009).

A mother's economic situation is also affected. *"The mother becomes the main, often the only carer who takes on most responsibilities for the future development of her child. She loses the freedom to decide about herself... She becomes financially dependent on her partner, family or social support"* (Vágnerová et al., 2009, p. 37).

The changes regarding leisure time are individual and depend on the mother's possibilities, as well as her personality (Vágnerová et al., 2009). Leisure time, how it is spent and the right way of relaxing may prevent burnout syndrome.

Social isolation and burnout syndrome

Social isolation is the condition when a person feels alone in their environment and has no friends or acquaintances. It is usually connected to a new environment due to their change of employment or place of residence etc. (Výrost and Slaměnik, 2008). Mothers of children with disorders experience social isolation especially due to their feeling of inferiority and the feeling that nobody understands their situation, nobody will help them and that the people around them look at them as inferior (Vágnerová et al., 2009).

Burnout syndrome is a condition in which a person feels that they are not able to live as they have up to the moment and they feel overloaded and physically and mentally exhausted (Stock, 2010). Burnout syndrome in mothers of children with disorders is mostly caused by persistent stress and the necessity to permanently provide care without the possibility to leave (Kallwass, 2007; Kebza and Šolcová, 2003). If all energy is put into a child without the possibility to rest or do a different activity, a frequent consequence is depression, lack of energy, fatigue, reluctance to perform daily activities, somatic problems and the absence of a meaning of life, especially when a child's condition worsens or does not improve (Kallwass, 2007; Vágnerová et al., 2009).

The treatment of burnout syndrome is long and does not need to be totally successful. It is better to prevent it. It can be prevented by measures that prevent social isolation, give the mother the feeling of being needed or at least the opportunity to rest from worries and constant care. Preventative strategies include the use of various relieving services. They help carers to have time for themselves and their hobbies and relax. The best prevention is a holiday or return to at least a part-time workplace, where the carer can concentrate on themselves and their needs (Kerrová, 1997).

Materials and methods

This research dealt with the issue of the lifestyle of mothers of children with disorders, its possible changes and the threat of

social isolation. The second goal was to ascertain the impacts of the place of residence on the lifestyle of such mothers.

This research used the method of qualitative analysis of data, specifically the technique of embedded theory. This is a set of systematic inductive approaches which lead to the creation of a theory. The main benefit of this method is the stimulation to think about the studied phenomenon differently, especially due to the use of coding techniques (Lewis-Beck et al., 2004). The data from 7 medium structured interviews were assessed using a three-level coding from the simplest to the most complex (Hendl, 2012). From the open coding, over 300 codes arose, which were categorized. Based on the axial and selective coding, we created embedded assertions which theoretically summarize some research results. Graphic outputs in individual categories were processed using the ATLAS.ti 8 software. The programme enabled the data to be classified and the resulting codes to be graphically presented, so the research was supplemented by interesting charts (Frieze, 2014). The selection of respondents for interviews was carried out using the "snowball" method. The first respondent was selected intentionally. Another significant selection criterion was the size of the place of residence (municipality/small town × city). A municipality can be defined as a statutory unit which has its own local authority office (Institute for Spatial Development, 2017). A town can be defined as a municipality with a population no larger than 30,000 (Institute for Spatial Development, 2006). A city is a municipality with a population larger than 100,000. Four respondents lived in a city or its outskirts. The rest of them lived in a municipality or town with a population of up to 30,000.

The interviews took place in January and February 2018, mostly on a neutral ground with the absence of children and a partner. Five interviews took place in a café and two in the respondents' household. All respondents knew the purpose of the interview and they were assured that it would be absolutely anonymous. All respondents confirmed that the interview was voluntary. Before the beginning of the interview, the respondents were asked to agree with voice recording. Some respondents asked what would happen with the recording after the transcripts of the interview. They were all assured that the recording would be deleted. Unfortunately, despite being assured, two respondents refused to be voice recorded due to an uncomfortable feeling. Considering the sensitive topic and work ethics, we respected the refusal. We took notes, which were transcribed into text.

The validity of the research was insured by external validity, specifically using literary comparison and comparisons with other researches with similar topics. Considering the low number of respondents and the selected strategy, the results cannot be presented as generally valid facts. They are a valid testimony on the solutions of issues and problems of individual respondents regarding their life situation.

Results and discussion

We used the analysis of the gained data to create these basic categories:

- *Identification data* – information that characterizes the respondents, e.g. from the point of view of age, education, gender and their child's age, place of residence or profession.
- *Type of disorder* – this category shows the respondents' children's disorder and other possible health or other complications.

- *Pregnancy and delivery* – this category summarized the data about the respondents' pregnancy and delivery.
- *Family relationships* – this category especially deals with the impact of the disorder on the relationships in the family, specifically with the husband, between siblings and with a child's grandparents.
- *Lifestyle* – the most extensive and perhaps one of the most important categories describes the respondents' lifestyle, e.g. regarding changes in life, hobbies, problems, leisure time etc.
- *Compensatory strategies* – this category shows the ways that helped the respondents to cope with their child's disorder.
- *Social recourse* – this category shows the resources where the respondents gained help and strength to live with the disorder.
- *Social support* – this category shows the support system and assessment from the state.
- *Life with a disabled child* – another important category points out the risks of living with a disorder; it also contains the assessment and a view on life and parenthood.

The research included 7 middle-aged women who had at least one child with a disorder. The respondents were between 35–54 years old. Their children were mostly boys and their age was between 7 and 33. Almost half of the respondents were married, one was a widow and the rest were divorced.

Almost half of them were religious and the rest did not have a religious creed. The respondents' place of residence was in a city or its outskirts, a village or a town.

The most frequent disorder was a combined one. It mostly concerned an individual with different forms of poliomyelitis. It was very frequently supplemented by mental retardation on different levels. Most disabled individuals had other problems that affected their life and health condition; the most frequent supplementary complication was epilepsy.

Most respondents assessed their pregnancy as trouble-free at the beginning. Some respondents had certain complications in their pregnancy, which led to a risky pregnancy.

The deliveries were much more complicated. Most respondents had a natural birth but the delivery was usually very complicated. Prenatal problems of some respondents caused the necessity for a Caesarean incision.

Family relationships

A child's disorder always affected family relationships. The impact of a disorder on the respondents' marriages varies because every person is an individual and has their own way of coping with difficult situations. In some cases, the disorder strengthened the relationship between the partners and sometimes it caused a divorce. One respondent gave a different opinion: *"Our son's disorder certainly affected the relationship with my husband; I think that it is the reason why we did not separate much earlier."* The results of the study correlate with Vágnerová et al. (2009).

Most respondents had more children. The age differences between the siblings varied and there were different reasons for this. The respondents whose first child had a disorder were frightened that the second child would be disabled as well, which is also pointed out by Velemínský (2011). Another research shows that a child's disorder does not affect its mother's reproduction (Wehby and Hockenberry, 2017). However, in Japan, the researches show that mothers often decide against having another child due to the obstacles caused by the disorder (Kimura and Yamazaki, 2017).

Regarding the relationship with grandparents, the respondents mostly mentioned their own parents. The relationships were positive and the respondents often said that their parents were an important source of social support. The conciliation of the father's parents with their grandchild's disorder was often very difficult. Jankovský (2006) says that it is a different form of coping programme.

Lifestyle

The lifestyle of mothers of children with a disorder is different in many ways than that of the rest of the population. The birth of a child with a disorder changes the life of a whole family, mainly its mother's, which is shown in Chart 1.

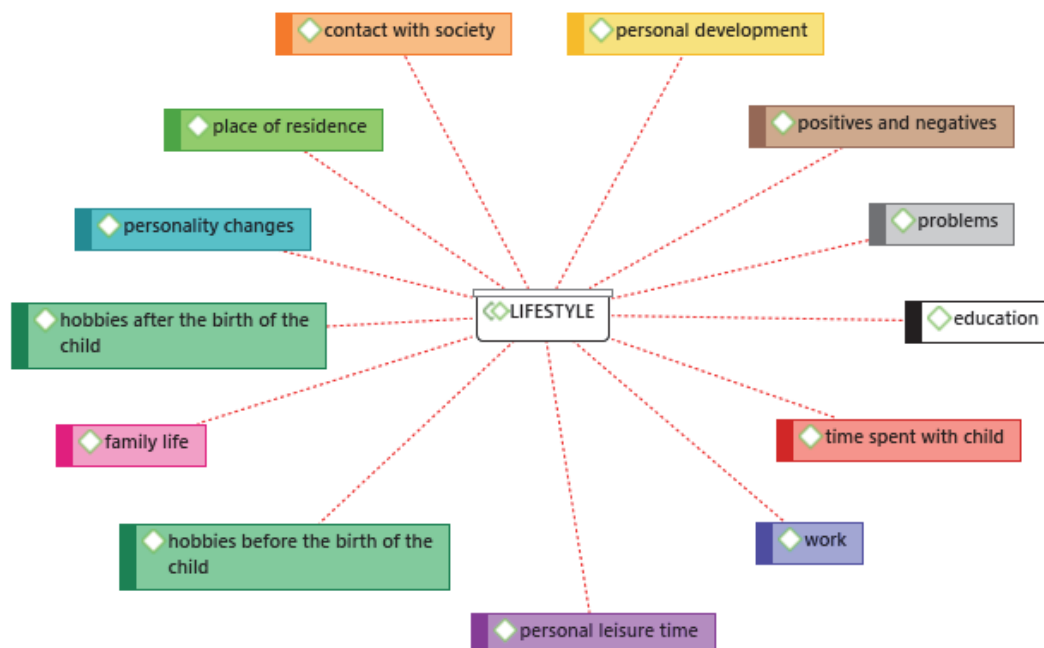


Chart 1. Lifestyle

The changes in the lifestyle of mothers have mostly affected their employment, personality, family life, hobbies, personal leisure time, education, personal development, contact with society and the time spent with the child. The lifestyle of such mothers is also closely related to their place of residence and the problems that the disorder brings, which brings many positives and negatives.

Lifestyle changes mostly affect employment because almost all respondents ended their maternal leave to give up their jobs and they stayed at home to take care of their child. In time, some mothers managed to work part-time. The respondents were mostly enabled to work due to the improvement of the child's condition or help from their family. It is interesting that one of the respondents started caring for such children professionally.

Personality changes of the respondents were individual. Most of them stated that having a disabled child made them change their values and health became the most important. They also felt fear and emotional reclusiveness.

The respondents were divided approximately in half regarding their place of residence. Those who lived in a village or small towns stated that they were limited by their place of residence regarding leisure time. On the contrary, those who lived in a city or its outskirts did not complain about the accessibility of services and social life.

Vágnerová (2009, p. 17) sees a disabled child's and its parents' lifestyle as follows: "A disabled child is a complex burden for parents ... Such parent's life brings many limitations and loss of the possibility of choice and it predestines the content of their life up to a certain point, which, at least at the beginning, they see as a total loss of positive alternatives and a growing number of problems." The results of our study show that the mothers of disabled children do not see their life so negatively. They assess positives and negatives but they have mostly discovered a new way of life and, as some of them said, new horizons opened to them.

Coping strategies

The interviews showed that almost all mothers experienced a coping programme and coping phases regarding a difficult situation. The ways are shown in Chart 2. The most frequent were family support, sharing emotions and time. Time and frustration tolerance are the most individual factors that help to cope with a disorder, which is confirmed by Kerr (1997). One mother denied coping phases and strategies. Nevertheless, it is common that parents feel sad or pity due to their child's condition and diagnosis several years after the diagnosed disorder or impaired development (Bouzek Mattasová, 2017). Bouzek Mattasová (2017), who dealt with a similar topic, showed various options of coping with a child's disorder.

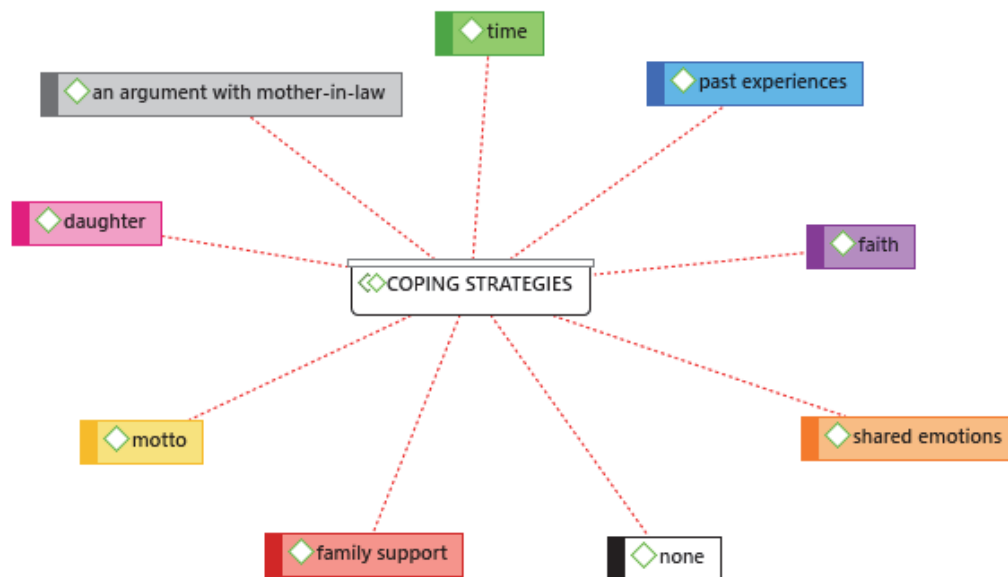


Chart 2. Coping strategies

Social support

All respondents had their own sources of social support that gave them strength, energy and help in tense situations. The respondents stated that it was mainly emotional support. Informational support was very important as well. Slaný et al. (2017) see the importance of such support mainly during the early stages of care.

The most frequent sources of social support are the mother's parents, husband and children (Chart 3). The analysis of the statements showed that social support mostly did not consist of "mere" words of comfort, but included help with babysitting or the possibility of relying on another person.

Social welfare

Disabled individuals and their families in the Czech Republic are provided with different types of help from the state (various services, financial support), as shown in Chart 4.

The analysis of the interviews showed that the possibility of using relieving services mostly depends on the place of residence. The research showed that such services are very good and necessary. They can be unavailable for some families due to their place of residence or finances and, in some cases, such facilities have a low number of vacancies. Brožová (2017) also reflected this issue in her research. She studied the lifestyle of mothers of healthy children on maternity leave in smaller towns and villages. They are mostly temporarily in a similar situation to mothers of disabled children.

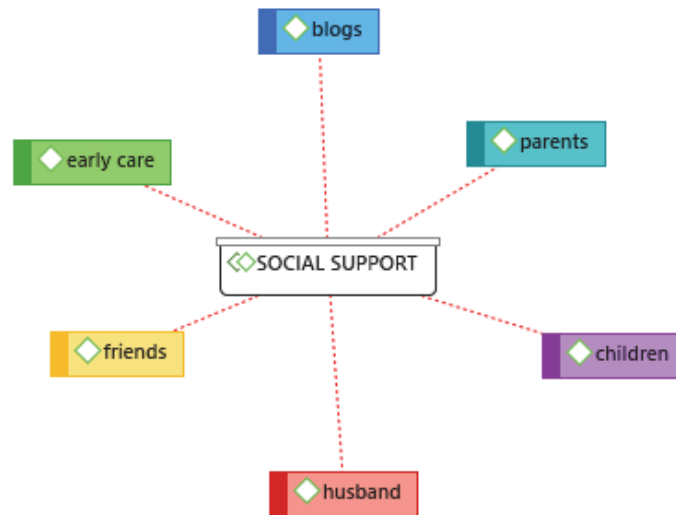


Chart 3. Social support

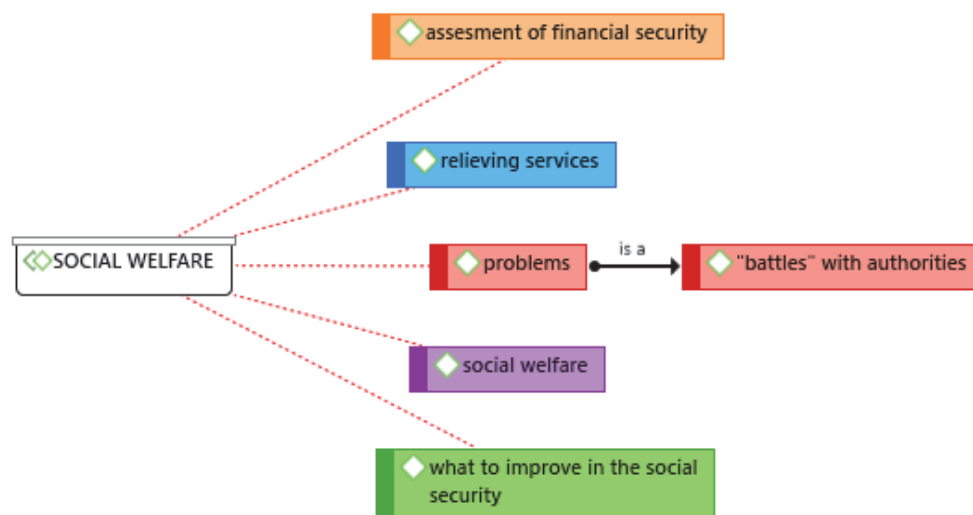


Chart 4. Social welfare

Significant support from the state is social welfare. All respondents got financial support on different levels and all of them got mobility support. Some respondents were provided with special aid support and the support for buying a vehicle. Unfortunately, none of the respondents were satisfied with the financial support from the state. Social support is praiseworthy but it can be very ambivalent. Vágnerová et al. (2009) state that mothers often face envy in their environment because of social welfare, which does not cover life needs, and they begin having financial problems. The respondents would solve this problem by increasing financial support and changing the concept of social security. The largest problem was “the battle with authorities”.

Life with a disabled child

Life with a disabled child includes various problems. Most frequently, it is fear of securing future care because the mothers are afraid for their children (Küçük and Küçük Alemdar, 2018). One of the significant problems is burnout syndrome, which

can be prevented. Most respondents agreed that the main prevention involved spiritual purification, whether it was leaving the environment for several hours or doing an activity where they could concentrate on themselves. The results of our research (Chart 5) correlate with other authors on the ways of preventing burnout syndrome (Kerr, 1997; Vágnerová et al., 2009).

What is positive is that almost all the respondents assessed their life positively. Despite having a very different life to mothers of healthy children, they were able to find a positive side to it. The area of parenthood was more ambivalent but even here the negative opinions did not dominate. Such findings are very positive and it is necessary to support life optimism in these mothers.

Paradigmatic model from the point of view of a lifestyle

We used axial coding for data classification and created a paradigmatic model. Its use is very effective because it enables thinking about data differently, in other contexts and inter-

connecting them (Strauss and Corbin, 1999). However, it is difficult to distinguish individual categories because everything is related to everything and everything affects everything else. It is sometimes difficult to distinguish cause and context or strategy and consequence.

The paradigmatic model enables a synoptical understanding of relationships and helps to connect individual categories. The result is a “central model” because all categories are closely related to a phenomenon and they are mutually influenced (Chart 6).

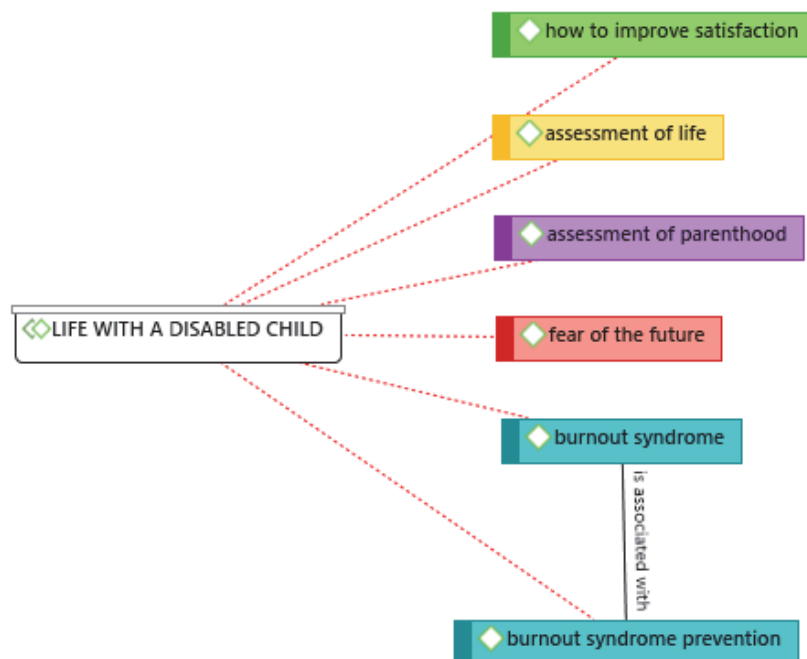


Chart 5. Life with a disabled child

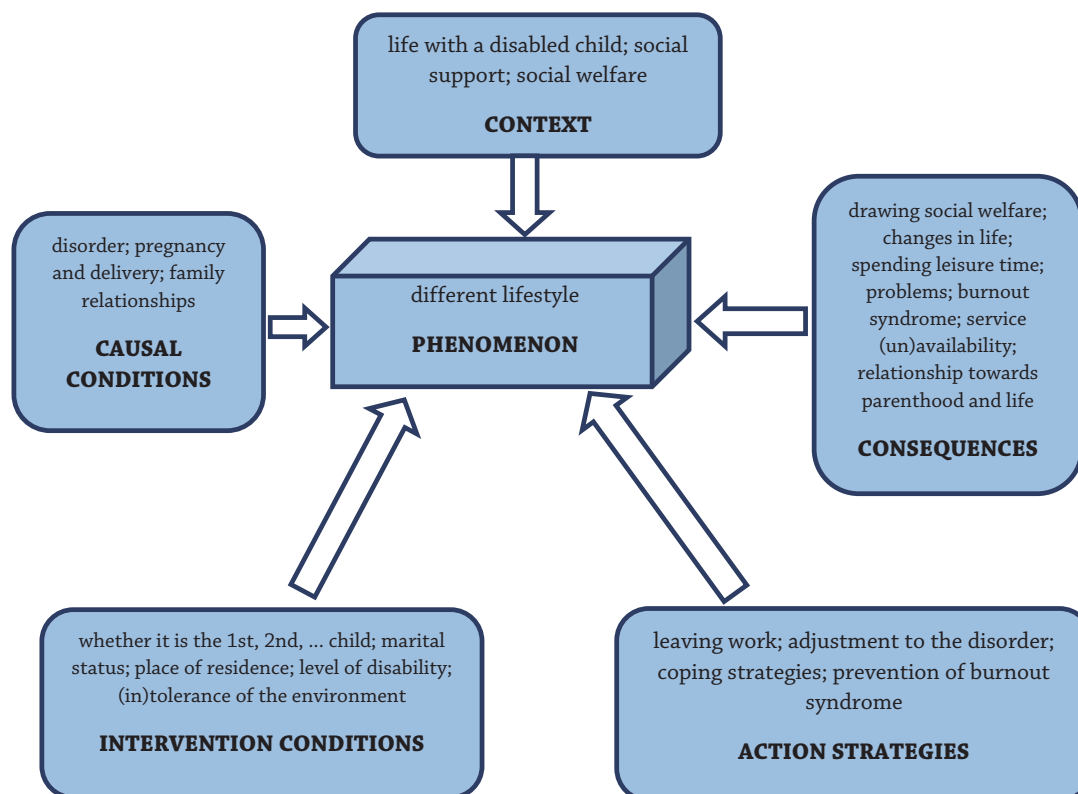


Chart 6. Paradigmatic model

a better approach from the authorities and better social security, or a simple tolerance of existence. The strength of their personalities lies especially in the ability to live a common and happy life, although it is different, and they love their children despite a difficult fate. They try to see their differences as an advantage and they see many positive facts in their life. One respondent said the following: *“Being a mother of a disabled child is destiny and sometimes a huge test, but everything has a meaning and everything is as it is supposed to be...”*

The outcomes of this article can serve mainly as a support to the mothers of disabled children because, due to their positive attitude, they could serve as a confirmation that it is possible to live a satisfied life with a disabled child.

Conflict of interests

The authors have no conflict of interests to declare.

Životní styl matek jedinců postižených onemocněním vzniklým v perinatálním období

Souhrn

Narození dítěte v rodině je vždy velkou změnou. Pokud se však narodí dítě, které má specifické potřeby, pro matku to ve většině případů znamená nejen velkou změnu, ale i zcela jiné uspořádání budoucího života. Jiný životní styl má však jistě své přednosti i svá negativa.

Cílem studie bylo zjistit, jaký je životní styl matek dětí s postižením, jaké jsou jeho změny a zda hrozí riziko sociální izolace. Se sociální izolací úzce souvisí i snaha zjistit, jaké dopady má místo bydliště na životní styl matky. Výzkum byl realizován pomocí kvalitativní strategie a data byla analyzována technikou zakotvené teorie.

Analýzou a interpretací získaných dat bylo zjištěno, že životní styl matek se po narození dítěte s postižením značně mění v mnoha oblastech – jednak v oblasti rodinného a pracovního života, jednak v oblasti osobnosti, kde je nejčastější reakcí proměna osobnosti a především hodnot. Dále se ukázalo, že místo bydliště značně ovlivňuje životní styl, a to konkrétně v přístupu ke službám. Bydliště na vesnici či v malém městě je pro matku dítěte s postižením z hlediska dostupnosti služeb a dopravy velmi limitující. Tyto změny a skutečnosti však ve většině případů nevedou k negativnímu vnímání života s dítětem s postižením. Výzkum prokázal, že matky dětí s postižením často žijí jiný, ale ne nekvalitní život.

Klíčová slova: matka; místo bydliště; postižení dítěte; změny v životě; životní styl

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