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Challenges of Polish families related to caring for a disabled child at home: a cross-sectional study

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A family with a disabled child has major changes and challenges. The difficulties experienced by the whole family are of various natures and relate to emotional, psychological, caring, and financial problems. The aim of the study is to learn about the challenges and involvement of Polish families in caring for a disabled child in the home environment. A cross-sectional pilot study was conducted in a group of 103 parents of disabled children. The proprietary questionnaire and a standardized scale for the Generalized Self-Efficacy Survey (GSES) were used as a research tool. The material for the study was collected online, using Google Forms software, and statistically processed. Emotional contact with a disabled child turned out to be the most difficult aspect of care for almost half of the respondents (42.7%). The vast majority of respondents (75.7%) described the level of difficulty in caring for a disabled child as much higher than the level of difficulty in caring for a healthy child. Most parents (87%) spend between 10 and 20% of their family income on the treatment and rehabilitation of disabled children. A significant relationship was noted between the assessment of the family's economic situation and place of residence ($\chi^2P = 27.32$; $p < 0.0001$; Vc 0.51). Parents of children with disabilities who live in rural areas and have less education are less well off financially. The average GSES score was 24.54 and was in 4 sten. The biggest care challenge for parents of disabled children turned out to be emotional contact with the child. The GSES index for parents of children with disabilities is lower than the average values obtained in Polish studies, which translates into worse coping with problems.

Keywords Disabled child, Parents, Siblings, Caring challenges

Abbreviations

GSES	Generalized Self-Efficacy Survey
WHO	World Health Organization (WHO)
SUWS	The generalized self-efficacy scale
CP	Cerebral palsy
Me	Median
IQR	Interquartile ranges
rS	The Spearman rank correlation coefficient
M	Mean
SD	Standard deviation
r_{xy}	Pearson's correlation coefficients
α_C	Cronbach's alpha coefficient
Vc	Cramer's V

Background

The World Health Organization (WHO) defines a person with a disability as being totally or partially unable to perform activities considered normal for a human being, resulting from a congenital or acquired physical and/

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or mental impairment[1]. It is estimated that there are almost 240 million children with disabilities worldwide[2]. There are several types of disabilities in children, including sensory, intellectual, behavioral (reduced social and communication skills) and physical disabilities. Reduced sensory (sensory) skills are characterized by impaired vision and/or hearing. Intellectual disabilities are associated with skill deficits and can be congenital or acquired. Behavioral disabilities are manifested by emotional imbalances and reduced communication skills. Physical disabilities, on the other hand, are found in children with congenital or acquired dysfunctions of the musculoskeletal system caused by damage or diseases of various organs[1,2]. Globally, the most common cause of physical impairment in children is cerebral palsy, affecting 2 to 2.5/1000 live births worldwide. Children with this condition may have complex care needs due to sensory, intellectual, and communication impairments[3].

The concept of disability is a complex issue, and interventions to overcome the disadvantages associated with it are multifaceted and vary depending on the circumstances. In the context of a child, this condition makes it difficult for them to go through the next stages of development, both in the area of physical and psychosocial functioning. Therefore, a child's disability requires special treatment and rehabilitation, constant monitoring of development, and multidirectional care[1,3].

Disability in children may have a somatic or psychological basis, or may occur in combination[4,5].

Intellectual disability in children is a heterogeneous group of developmental disorders characterized by a significant reduction in the level of mental ability[3].

A child with a mild intellectual disability is characterized by reduced motor coordination, slowed speech development, low independence of thought and weakened control of emotions. They may also have problems with learning due to difficulty concentrating or remembering information. In turn, a child with moderate intellectual disability has significantly delayed motor development and impaired speech development. The child also has great difficulties in learning due to limited concentration and slow pace of knowledge acquisition. He also has problems understanding and following social norms. However, children with a significant degree of intellectual disability often have defects of the sense organs and various internal organs. They may have mobility disabilities. They have difficulty communicating, controlling emotions, showing feelings and following the simplest commands. The last, profound degree of intellectual disability in children is characterized by serious neurological and physical defects and significant sensory impairment. These children have little ability to communicate and great difficulties with learning and remembering[6].

In Poland, there are approximately 300 thousand children with a disability certificate. The percentage of children and adolescents with disabilities in particular age groups, in relation to the entire population of children, ranges between 3.4% (0–4 years) and 5.4% (9–14 years)[7]. The degree of disability of a child up to 16 years of age is determined for a specified period. However, due to moderate or severe intellectual disability, children follow a different core curriculum at school than other children of the same age. The educational goals of disabled children must be adapted to their functioning abilities. Moreover, due to disabilities, there are certain benefits and entitlements for parents who care for such children[4,5].

The presence of a child with a disability in a family influences the relationships between its members, poses new tasks, and the need for cooperation and mutual support[6]. After receiving information about a child's disability, resulting from an illness, injury, or congenital defect, parents experience very difficult emotions. These include fear, despair, anxiety, anger, guilt, loneliness, and exclusion. Parents' negative emotions can also cause an unfavorable attitude toward their disabled child[8]. The burden of caring for parents and their diverse emotional states also adversely affects healthy siblings. Attending to the healthy siblings is often neglected by parents, who usually devote less attention and involvement to it than to a disabled child[9,10].

Most often, the main responsibility for caring for a disabled child is assumed by the mother, due to the special emotional bond that she has with the child. Often, the mother is unable to take up gainful employment and is forced to give up the development of her own professional career[6,11,12].

The presence of a disabled child in the family usually means higher costs of maintaining the child than that of healthy children. For many families, the rehabilitation of a sick child is a large amount, especially when the disability is, complex, coexisting with many disorders of the body. Financial issues are also an additional source of frustration between family members[4,8,12,13].

A child's disability also has an impact on his or her way of living in a society in which the ideal of a healthy, good-looking person, always ready to be active, is promoted. Children with disabilities are still often stigmatized and treated as disabled. Their contact with their peers is usually limited. The isolation of children with disabilities causes additional suffering for the whole family[14,15].

Support for a disabled child and his/her family, including by the health care system (primary care physician and nurse and various medical specialists), as well as social institutions, at various levels of functioning, can significantly facilitate their daily life. It is important that this assistance is targeted at the needs of the individual family and its members. Proper identification of health, educational, and communication problems can significantly facilitate the development of appropriate forms of assistance for disabled children and their families by both medical professionals and social institutions[16–18].

The aim of the study is to learn about the challenges and involvement of Polish families in caring for a disabled child in the home environment.

The way parents deal with a crisis situation resulting from a child's disability is very individualized and depends on the parents' personal resources as well as social support from family, friends and acquaintances. Institutional psychological help, provided systematically over a long period of time, to both the child and the entire family, is also very important. It turns out that comprehensive psychological support is one of the most important factors determining the quality of life of both people with disabilities and their family members. It allows them to better adapt to the situation, deal with stress constructively, and strengthens their self-esteem and self-esteem. It also enables the experience of positive emotions that strengthen the readiness to take actions supporting the development of a disabled child. Efforts should be made to provide professional psychological assistance to all family members of disabled children. Healthy siblings also require special psychological care to limit the consequences of childhood trauma caused by the presence of a child with a disability in the family[10–12].

Parents of children with disabilities experience various difficulties, and the process of adaptation to the changed life situation they find themselves in depends mainly on time, availability and quality of the support received. Research shows that there are large disproportions in access to various forms of assistance for parents of disabled children. In line with parents' expectations, an integrated system should be created to manage a package of services to help families raising a child with a disability. Parents need comprehensive support, primarily in the psychological, financial, educational and medical areas. Therefore, helping parents of disabled children is one of the most important challenges of the state's social policy, which builds parents' sense of security and contributes to improving the quality of life of families with a disabled person[8,9,11,13,15].

Materials and methods

A pilot study was conducted among parents of children with disabilities. The research tool used was the author's questionnaire (part A) and a standardized scale for the study of Generalized Self-Efficacy in the Polish version from 2009, adapted by Zygfryd Juczyński (Generalized Self-Efficacy Scale – GSES; Part B)[19]. This scale determines the level of a person's general view of the effectiveness of coping with difficult situations.

The author's survey questionnaire was developed based on a review of current scientific literature on various aspects of caring for a disabled child. It consisted of characteristics of the demo-graphic data of the surveyed parents, which are presented in Table 1 and questions about the specific functioning of a family raising a disabled child in the home environment, including, above all, in-formation about the division of responsibilities in the family and the time allocated by various family members to indirect care and direct care of a disabled child. Questions were also included regarding difficulties in raising a disabled child, the impact of the presence of healthy siblings on bonds and relationships in the family, and the family's use of psychological support.

The material for the study was collected online, using Google Forms software. The research tool was posted on the website: https://docs.google.com/forms/d/e/1FAIpQLSdK1c0DbujQ1YwI2JWe1y1PZ1X3e2D7dGzkynleE3Ol6c15wA/viewform?%20fbclid=IwAR01wBXPpQmRLAc6kmalPaWqLP7EEPeSapzW1av1S2I6LTs9sYnAnIUKiJw for the period from March 13 to May 10, 2023.

The link to the questionnaire in parts A and B was made available to members of several different groups on the Facebook platform, such as: Center for Support of Families of Disabled Children, Association of Families of Disabled Children "Our Chance", Association of Parents and Guardians of Children Disabled people "To Our Children". Information about the availability of the online survey for this study was also provided using the snowball sampling method, which in-volved recruiting parents of disabled children through other families with a similar health problem. It took parents about 40 min to complete the questionnaire. The research was conducted exclusively online.

Parents of children with disabilities, after agreeing to participate in the study, had the opportunity to complete the questionnaire and the standardized scale remotely, without having to leave their homes. The information included a request to respondents to complete and submit the survey once. Ethical approval was granted by the Bioethics Committee at the Medical University in Lublin (Decision No. KE-0254/67/2022), and the study was conducted in accordance with the Declaration of Helsinki.

The criterion for inclusion in the study was parents with a disabled child or children. The criterion for exclusion from the study concerned persons who were not parents of a disabled child.

Completed survey questionnaires were carefully checked of the authors to minimize bias and increase the quality of online survey research. Fully completed questionnaires were received from 103 participants and informed consent was obtained from all of the study participants. No personal data of respondents was collected (including IP addresses of computers, e-mail addresses and user account data of portals through which the link and request to participate in the survey were shared). The authors' computer system used to process data received from the study had appropriate security software and a password known only to the study authors. Authors followed the principles of good practice in conducting scientific research.

Only fully completed surveys were included in the statistical analysis. 103 respondents answered all questions, which is approximately 1428 users of the target portals (7.21%). Moreover, due to the number of children with diagnosed disabilities in Poland, the conducted study should be considered a preliminary trial study.

Statistical analysis

For the answers in the questionnaire authored by the author, the numbers and their percentage share in subgroups were calculated. The relationship between the features was estimated based on Pearson's χ^2 test, and the effect size was presented using Cramer's V (V_C) test. Spearman's rank correlation coefficients and their significance were calculated.

Analyzing the respondents' answers based on the Generalized Self-Efficacy Scale, the sum of points for each respondent was calculated. Pearson's correlation coefficients (rxy) and their significance were estimated. Cronbach's alpha coefficient (α_C) was also calculated. Due to the lack of a normal distribution of all variables (Shapiro-Wilk test), the statistics were supplemented with medians (Me) and interquartile ranges (IQR) and values of the Spearman rank correlation coefficient (rS).

The analyses were carried out using the STATISTICA 13 statistical package (TIBCO Software Inc.; 2017). In the study, the significance level was $\alpha = 0.05$.

Results

Data from 103 respondents were included in the analysis of the studies. Table 1 characterizes the group of parents of children with disabilities in terms of sociodemographic data.

Category		**N**	**%**
Sex			
Women		86	83.5
Men		17	16.5
Age range in years			
18–25		13	12.6
26–35		37	35.9
36–45		35	34
46–60		10	9.7
over 60		8	7.8
Reside			
City		70	68
Village		33	32
Education			
Master's Degree		7	6.8
Higher Bachelor's Degree		19	18.4
Average	General	20	19.4
	Professional	20	19.4
Vocational		9	8.7
Basic		28	27.2
Professional activity			
Full-time		25	24.3
Part-time		46	44.7
Farmer		10	9.7
Pensioner		7	6.8
Parental leave		7	6.8
Doesn't work		8	7.8
Status of the surveyed persons			
Married		65	63.2
In a civil partnership		35	33.9
Lonely		3	2.9
Number of children in the family			
One		13	12.6
Two		58	56.3
Three		25	24.3
Four		6	5.8
Five		1	1
Number of children with disabilities in the family			
One		95	92.2
Two		8	7.8
Age of a disabled child in years			
0–2		20	19.4
3–5		37	35.9
6–10		35	34
11–14		8	7.8
15–18		3	2.9
Financial situation of the disabled child's family			
Very good		7	6.8
Endorsement		35	34
Average		48	46.6
Evil		13	12.6
Involvement of parents in paid work			
Both parents		24	23.3
One of the parents		65	63.1
They are not gainfully employed		14	13.6

Table 1. Characteristics of respondents. N, number; %, percentage.

The vast majority of parents (87%) spend between 10 and 20% of their family income on the treatment and rehabilitation of children with disabilities. Respondents with poor financial situation stated that they lack money to meet the most basic needs of life.

The relationship between the assessment of the financial situation and the proportion of income devoted to rehabilitation was significant (r_S 0.35 $t_{(N-2)}$) 3.41; $p=0.0010$) in the group of women completing the survey. In addition, there was a significant relationship between the assessment of the economic situation of the respondents and the place of residence ($\chi^2P = 27.32$; $p < 0.0001$; Vc 0.51). Parents of children with disabilities who live in rural areas and have less education are less well off financially.

In the studied group of parents, the amount of earnings did not determine the amount of money spent on the child's rehabilitation and it was usually similar in most families. However, in families where the financial situation was poor or average, a large part of the other needs of family members were not fully met.

Analysis of own research based on the author's questionnaire (part A)

Table 2 presents the respondents' answers to selected aspects of caring for a disabled child at home.

More than half of the respondents spend 3 to 6 h a day (n = 53; 51.5%) on activities such as bathing, feeding, rehabilitation, playing, and learning, and slightly fewer people spend 1 to 3 h (n = 50; 48.5). The majority of respondents spend 6 to 10 h a day on daily indirect care (n = 68; 66%) on daily indirect care through the presence of a disabled child and observation. Women significantly more often ($\chi^2P = 9.66$; $p = 0.0217$; Vc 0.31) also mentioned other people who devote a lot of time to caring for a disabled child, such as grandparents and husbands. On the other hand, men strongly indicated the mother as the main caregiver of the disabled child and in 1/4 of the cases the joint care provided by both parents in comparable amounts.

Parents did not indicate involving healthy siblings in caring for their disabled brother or sister. Perhaps it was at a younger age or out of concern for feeling exploited. However, parents indicated that healthy siblings had a positive influence on the disabled child, which was probably the result of spending time together and being active through play.

Analysis of own research based on the GSES scale (part B of the questionnaire)

Table 3 presents the results of the respondents according to the Generalized Self-Efficacy Scale (GSES) consisting of 10 statements to which the respondents could answer in the range from 1 to 4 categories (1 corresponds to the statement – no, 2 – rather not, 3 – rather yes, 4 – yes).

The above analysis supports the conclusion that the self-efficacy of family members of disabled children is 1 sten lower than the average, which translates into their lower confidence in their abilities, reduced motivational potential, and, consequently, worse coping with problems and difficulties in everyday life. At the same time, no significant differences due to gender were noted.

Discussion

Every challenges caring for a disabled child is a special moment in the life of the family. All family members experience new situations and problems that they have to deal with and learn to live with[5,6,8,9].

Research conducted in Poland and around the world proves that the most important needs of parents of children with disabilities are still: obtaining reliable information about disabilities and specialist services, shortening the waiting time for advice, material support, increasing cooperation of all institutions dealing with a child with a disability and his or her family, and comprehensive psychological assistance for the entire family, not just the person with a disability[20–23].

Our research shows that in most families the mother devotes the most time to caring for a disabled child (61.2%). The participation of grandparents also turned out to be important (nearly 1/4 of the respondents). Similarly, in the Tomczyszyn[9] study on families with intellectually disabled children, nearly 72% of respondents indicated the mother as the primary caregiver of the disabled child, although the aforementioned studies did not take into account the participation of people other than the parents. Also, Smith and Blamires[24], based on qualitative evidence from a systematic review of the literature on the functioning of mothers and their challenges in caring for children with cerebral palsy (CP), concluded that mothers are the primary caregivers for children with disabilities. Both his research and Tomczyszyn's research show that the father is not very independent in caring for and bringing up a disabled child. If fathers were involved in caring activities and rehabilitation exercises, it was usually with the mother's participation[6,8,9]. Buchnat[18] also examined 303 parents, including 234 women and 69 men. The predominance of women (biological mothers) was typical of the research conducted; moreover, the profile of families of children with disabilities showed a predominance of single-parent families in which the care of children was provided exclusively by women. This is a very heavy physical and mental burden for mothers. Undoubtedly, efforts should be made to motivate fathers and other family members to provide greater assistance in caring and educational activities for a disabled child in the family, to prevent the social exclusion of mothers and their excessive emotional burden[10,11].

The presence of healthy siblings has a significant impact on the functioning of a family with a disabled child. Healthy children often show a higher level of empathy, tolerance, and willingness to help others than in families with no disabled children[14,15]. Our research found that almost 3/4 of the respondents positively assess family relations resulting from the presence of healthy siblings. At the same time, it should be emphasized that this is a way of assessing the family situation by parents and may not always translate into a similar opinion in children. The research carried out by Marks et al.[25] shows that people with disabled siblings are more likely to choose professions related to helping others.

Based on a systematic literature review by Hartling et al.[26] showed that disability in the family may have a harmful impact on the psychosocial health of healthy siblings and pointed out the benefits of care aimed at

Category	N	%
Degree of disability		
Significant	60	58.3
Moderate	42	40.8
Light	1	1
Type of disability		
Coupled (motor, visual and/or auditory, intellectual, autism spectrum disorder)	82	79.6
Vision and/or hearing	13	12.6
Movement	8	7.8
The level of difficulty in caring for a disabled child in relation to the difficulty in caring for a healthy child		
Definitely higher	78	75.7
A little taller	22	21.4
It's hard to say	3	2.9
The person in the family who devotes the most time to caring for a disabled child		
Mother	63	61.2
Grandparents	24	23.3
Both parents	11	10.7
Father	5	4.9
Time spent caring for a disabled child in relation to caring for a healthy child		
I definitely spend more time taking care of a disabled child	90	87.4
I have only one child who has a disability and I give him my full attention	13	12.6
Time spent each day providing direct care for a disabled child		
3–6 h	53	51.5
1–3 h	50	48.5
Time spent every day on indirect care of a disabled child		
6–10 h	68	66
3–6 h	21	20.4
1–2 h	14	13.6
The impact of a child with a disability on family relationships and ties		
Initially, family ties were loosened, but now they have been strengthened	57	55.3
Family ties have become very loose and the family is going through various relationship crises	31	30.1
Family ties have completely disintegrated	15	14.6
The impact of healthy siblings on the functioning Family's relationship with a disabled child		
Definitely positives	70	68
Rather positives	17	16.5
A child with a disability does not have a healthy sibling	13	12,6
It's hard to say	3	2.9
Getting help from a psychologist		
She doesn't use it, but she would take advantage if there was such a possibility	81	78.6
All family members are under the care of a psychologist	6	5.8
Only a disabled child is under the care of a psychologist	7	6.8
He doesn't use it because he doesn't feel the need to	9	8.7
The greatest difficulties in caring for a disabled child in the home environment are caused by parents		
Emotional contact	44	42.7
Changes in family and social relationships	21	20.4
Feeling a lack of support from family or care institutions	17	16.5
Financial Issues	12	11.7
Limitations in time capacity	9	8.7

Table 2. Respondents' answers to the questions of the author's questionnaire. N, number; %, percentage.

reducing anxiety, improving mood and adapting behavior in healthy siblings. This type of care allows for optimal potential for emotional and behavioral outcomes in healthy siblings. Undoubtedly, providing healthy siblings with psychological and emotional support is an important element of their proper development and building family bonds in the presence of a disabled child in the family[5,16,18].

Our research has shown that the vast majority of parents of disabled children (78.6%) feel the need to use the help of a psychologist, but they do not have such a possibility. Only 12.6% of families receive psychological care (the child alone or the child and the family). Some families of disabled children live in rural areas, which means

Categories	M	SD	r_{xy}	Me	IQR	r_S
I'm always able to solve difficult problems if I try hard enough.	2,47	0,591	0,81***	3,00	1,00	0,83***
If someone opposes me, I have ways to get what I want.	2,43	0,587	0,80***	2,00	1,00	0,81***
It's easy for me to stick to my goals.	2,03	0,810	0,30***	2,00	2,00	0,33***
I am convinced that I would be able to cope effectively with unexpected events.	2,46	0,725	0,83***	2,00	1,00	0,86***
Thanks to my ingenuity, I am able to cope with unexpected situations.	2,47	0,725	0,85***	3,00	1,00	0,87***
I can solve most problems if I put in the effort.	2,54	0,711	0,87***	3,00	1,00	0,87***
I can remain calm in the face of difficulties because I can rely on my coping skills.	2,47	0,669	0,83***	3,00	1,00	0,82***
When I'm struggling with a problem, I usually find several solutions.	2,53	0,669	0,75***	3,00	1,00	0,76***
When I'm in a predicament, I usually know what to do	2,61	0,645	0,84***	3,00	1,00	0,83***
No matter what happens to me, I can deal with it.	2,54	0,638	0,86***	3,00	1,00	0,85***
Total SUWS [points]	24,54	5,171	$\alpha_{cr}=0.92$	27,00	10,00	-

Table 3. The generalized self-efficacy scale (SUWS; N = 103). N, number; Me, median; IQR, interquartile ranges; rS, the Spearman rank correlation coefficient; M, mean; SD, standard deviation; r_{xy}, Pearson's correlation coefficients; SUWS, the generalized self-efficacy scale. ***Statistical significance $p < 0.001$.

that they have to travel to a specialist, and due to the lack of time resulting from numerous responsibilities, many families cannot afford it. The financial aspect of psychological assistance is also important. For these reasons, the mental health of family members of children with disabilities is often neglected. It should also be taken into account that for almost half of the respondents (42.7%) the psychological aspect, i.e. emotional contact with a disabled child, turned out to be the greatest care challenge. Similarly, in a study conducted by Otrębski et al.[27] Among families with children with multiple disabilities, it was also found that in 96% of families, no one is covered by psychological assistance. On the other hand, Gur and Reich[28], based on a systematic review, concluded that interventions of medical professionals based on strengthening acceptance and commitment were effective in increasing the psychological flexibility of parents of children with disabilities. They suggested the need for a multidisciplinary approach to family care, with particular attention to assistance in critical periods such as diagnosis and developmental changes.

Treatment and rehabilitation of disabled children are almost always associated with a heavy burden on the household budget[29,30]. Our research has shown that the financial situation of the majority of families (n = 48; 46.6%) is at an average level, and 87% of parents allocate between 10 and 20% of their family income for the treatment and rehabilitation of disabled children. The women indicated that the better the financial situation of the family, the higher the percentage of income allocated to the treatment and rehabilitation of a disabled child. In a study conducted by Otrębski et al.[27]. It has been found that families spend about 1/4 of their household budget on therapy and rehabilitation of disabled children and can cover only part of these costs. On the other hand, slightly more than 10% of respondents stated that their income is sufficient to meet al.l the needs of life, including the treatment and rehabilitation of a disabled child, which is a result similar to that obtained in their research[31,32].

The results obtained in Buchnat's research[18] revealed that most parents with a disabled child (n = 144) received support in the field of rehabilitation, then financial help (n = 122) and psychological help (n = 102), and the least in terms of organizing free time for baby disabled (n = 39) and legal assistance (n = 36). However, in none of these areas did the level of support exceed half of the respondents, and the surveyed parents declared in the survey that they had access to various areas of support. This proves the ineffective functioning of information and support and large disproportions in the effectiveness of its operation. It is important for parents to have an integrated support system enabling them to obtain comprehensive help and information in one place[33].

The financial situation of families of disabled children may vary depending on demographic conditions[34–36]. Our research has shown that rural residents are more likely to assess their financial situation as bad than urban dwellers. To a large extent, this is related to the various opportunities for gainful employment. It is much easier to find a suitable job in cities than in the countryside. In such a situation, many families of disabled children are forced to base their household budget primarily on social benefits from the state, which are not always sufficient to cover all the needs of the family. In a study conducted by Otrębski et al.[27] It has been shown that in families of disabled children in which one or both parents work, the income is higher than in families living on sources other than work, with an average of 7 out of 10 families receiving at least one of the sources of income from various types of social assistance.

The study also measured the self-efficacy of parents of disabled children. A person's stronger belief in their effectiveness translates into perseverance in the pursuit of success and a strong commitment to intentional behavior even in the face of many difficulties. In our research, a result of 24.54 was obtained with a standard deviation of 5.171. Juczyński[19] obtained a score of 27.32 for the average citizen in Poland (SD = 5.31). On the other hand, Schwarzer and Jerusalem[37] on a sample of 1660 adults in Germany, obtained a score of 29.28 (SD = 4.6). Our research showed a reduced self-efficacy index of the respondents compared to the results of Juczyński, Schwarzer, and Jerusalem[19,37]. It follows that the parents we surveyed perceive themselves as less effective in the face of difficulties. This is associated with lowered self-esteem and less perseverance, as well as poorer coping with problematic situations.

The data provided as part of our study may be helpful to decision-makers of healthcare systems in implementing appropriate strategies to help families with a disabled child, especially regarding psychological care. Further research on a larger sample and in-depth analyses using qualitative data are needed, which will allow for a more complete recognition of the situation of families with a disabled child and for targeting supportive actions.

Limitations of the study

This study has several limitations. Because the study was cross-sectional, it was not possible to establish a cause-and-effect relationship between the variables. The greatest difficulties in caring for a disabled child were assessed using one question.

Our study also has some limitations resulting from the method of data collection. On the one hand, the online survey could be administered remotely using mobile devices and provided the opportunity to reach a large group of respondents. By automating the process of collecting and processing data, time could be saved and errors resulting from the human factor could be avoided. Moreover, by completing the questionnaire on their own, respondents had a sense of anonymity and did not feel pressured, which made them feel comfortable when answering the questions. Therefore, they could be more inclined to be honest.

However, on the other hand, the questions included in the online survey questionnaire limited the possibility of delving deeper into the research problem. They could also pose a risk of misunderstanding the questions for some respondents. Some people could be excluded from the research project due to lack of access to the Internet or problems resulting from IT competences. There is also a risk that respondents may not feel encouraged to provide accurate, honest answers and may have a tendency to behave differently online than in the real world.

The form of research conducted via the Internet allowed us to learn about the challenges related to care in families with a disabled child, but qualitative analysis tools are also necessary, including group interviews, which would allow for an in-depth analysis of the difficulties in caring for a disabled child and would increase the generalizability of the study results.

Conclusion

The biggest care call for parents turned out to be emotional contact with a disabled child. At the same time, the level of psychological care provided to children with disabilities and their families was disproportionate to their actual needs. The mother devotes most of her time in the family to caring for a disabled child, and the presence of healthy siblings has a positive effect on family relationships. Families of children with disabilities living in rural areas are less well off financially. The self-efficacy index of parents of children with disabilities is lower than the average values obtained in other surveys. This translates into worse coping of problems with respondents, and lower levels of perseverance and ambition.

Our study showed that the family plays an important role in caring for a disabled child, and raising a child has an impact on the mental state of all family members, especially the mother. Children with disabilities often require complex care throughout their lives, and are more exposed to behavioral and emotional challenges compared to their typically developing peers. Therefore, emotional contact with the child and understanding their needs turned out to be a primary challenge for the parents participating in our study. Our respondents had difficulties in combining care and economic activity, and also showed lower self-confidence and lower self-esteem. The positive influence of healthy siblings on the disabled child in our study can bring many significant benefits, which should be treated as a family potential that requires support. However, parents of disabled children who are only children do not have a point of reference in terms of child care, which is why the difficulties and problems they experience in care and upbringing can often seem beyond their capabilities. These parents especially need support from their environment and professionals.

Taking into account the burdens experienced by parents of disabled children, their support should be the focus of state social policy. What is important is well-organized care, defined from the family's perspective, by a multidisciplinary team of professionals, focused on the needs of the entire family.

Data availability

The datasets analysed during the current study are available from the corresponding author on reasonable request.

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Author contributions

A.B. conceptualisation, methods, statistical analysis, writing and editing the main manuscript text, M.L. writing the main manuscript text IB.C. writing the main manuscript text. All authors reviewed the manuscript.

Declarations

Competing interests

The authors declare no competing interests.

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