

PARENTAL COOPERATION BETWEEN MOTHERS AND FATHERS OF CHILDREN WITH DOWN SYNDROME

Anna JAZŁOWSKA

University of Silesia, Institute of Psychology, Katowice; anna.jazlowska@us.edu.pl,
jazlowska.anna@gmail.com, ORCID: 0000-0002-6471-2141

Abstract: When a child with intellectual disability (including Down syndrome) is born, the character of relations between the mothers and fathers change. A decrease in the available time becomes a challenge and numerous responsibilities impose parental cooperation. The aim of the present study was to answer the following questions that concern the cooperation between mothers and fathers of children with Down syndrome: (1) in what ways do mothers and fathers share their responsibilities focused around raising a child with Down syndrome, (2) how do mothers and fathers assess their own attitude towards taking care of their child, (3) how do parents perceive their spouses' attitude towards particular parental responsibilities. The study included 126 parents of children with Down syndrome. The results of the analyses conducted show that the parental responsibilities of mothers and fathers of children with Down syndrome are different, they are involved in taking care of their child to a different degree and evaluate their own strain as well as the changes in their lives differently.

Keywords: parental cooperation, parenthood, children, Down syndrome.

1. Introduction

With the birth of a child with a disability or the appearance of a disability in the course of their development, the parents' social contacts undergo quantitative and qualitative changes. The relations between the mother and father of the child are also transforming and adapting to the requirements of childcare as they begin functioning in new, previously unknown roles. In quite difficult everyday life, it is the limited amount of time that spouses or partners can devote to themselves and each other that becomes a challenge. The multitude of responsibilities also requires parents to cooperate closely, and encourages them to seek external sources of support, including the support from parents of other children with intellectual disabilities. The issues of parental cooperation between parents of children with intellectual disabilities (including parents of children with Down syndrome) cannot be considered without a closer look

at the nature of parenthood itself and the features of “special parenthood,” i.e. parenting of a child with a disability (the “Cegiełka” foundation, 2017).

Parenthood is a broad issue that has been studied by researchers from many fields of science. Thus, it can be defined from the biological perspective – as a transfer of life or the primordial bond between mother and child – as well as from the social perspective, which emphasizes the expectations towards the person taking up and performing the role of a parent in society (Bakiera, 2013). Parenting is certainly a dynamic phenomenon in which changes arising from the child and parent's development, and from the course of their relationship, should all be taken into account (Herbert, 2004). Some researchers, however, focus on the specifics of the more difficult “different parenting” (Bakiera, and Stelter, 2010) and deal with the functioning of parents of children with disabilities, including intellectual disabilities. Intellectual disability is associated with deficits in both intellectual and social functioning, as well as in practical skills; it limits independence and the possibility of being held responsible for one's actions (American Psychiatric Association, 2013). At the same time, it should be remembered that intellectual disability is measured in degrees of severity and has various origins (Bobińska, Pietras, and Gałęcki, 2012). One of the causes of intellectual disability is Down syndrome, otherwise known as “trisomy 21” due to its genesis – the lack of separation of the 21st chromosome pair (Cunningham, 1994). In addition to difficulties in intellectual functioning, Down syndrome causes many health problems, such as organ defects, including the heart, digestive system and vision (Komender, 2004; Sadowska, Gruna-Ożarowska, and Mysiek-Prucnal, 2007). Parents raising children with Down syndrome face many challenges, including the need to deal with personal and relationship difficulties, unknown to parents of healthy children (Kornas-Biela, 2009). It is all the more difficult since the process of becoming a parent alone is stressful for many men and women – it causes difficulties in adaptation, including a decrease in the level of satisfaction with the partner/marital relationship, increasing marital difficulties and lowering mood (Kiecolt, Blieszner, and Savla, 2011).

On the other hand, researchers point to the existence of many protective factors among parents of children with intellectual disabilities that allow them to cope and gain positive educational experiences. Some parents describe their parenting of a child with Down syndrome as a source of happiness and positive changes (Przybyła-Basista, and Kózka, 2016). Personal and relational resources, which are an important link in the process of the parents' adaptation, can be considered as important protective factors. In the array of personal resources the researchers include, among other things, partners' empathy that allows mutual support and thus better functioning in critical situations (Walsh, 2003). Relational resources, in turn, are primarily good family relationships which include supporting the partner or spouse (Van der Veek, Kraaij, Garnefski, 2009a). Particularly important is the father's attitude, which has a great impact on the functioning of the mother of a child with Down syndrome (Cunningham, 1996). Studies show that mothers of children with Down syndrome receive a large amount of support from their spouses and assess their behaviour as very helpful

(Garcia-Tunon, 1997). The fathers of children with Down syndrome do not differ from the fathers of children with a different disability in terms of daily parental involvement and aspects such as taking over childcare responsibilities, caring for the development of the child's social competences, partaking in making decisions about their upbringing and being available in terms of childcare (Ricci, and Hodapp, 2003). Moreover, the quality of marriage is often assessed similarly by parents of children with Down syndrome and by parents of normally-developing children (Bobkowicz-Lewartowska, 2013). In this context, it is also important that the parents' relationship should not become just a sphere of work, rehabilitation and effort; it should meet the needs of spouses or partners in terms of closeness and the need for belonging. Constant thinking about one's own situation and blaming oneself for the child's disability are associated with depressive symptoms, difficulties in achieving goals and a less satisfying relationship with the partner, while a positive reformulation of one's own situation is associated with positive effects, greater concern on the part of the partner, a sense of being supported by the immediate environment and a greater sense of self-efficiency in coping (Van der Veek, Kraaij, and Garnefski, 2009a). In this way, it is important to know the emotions that parents experience, their ways of coping and the parents' subjective perceptions of reality.

The birth of a child is experienced differently from the perspective of each parent (Kaźmierczak, 2015); hence, mothers and fathers perceive parenthood in different ways. Mothers and fathers are separate observers, and their feelings result from their own observations of children's behaviour and are not identical to the feelings of the other parent (Ricci, and Hodapp, 2003). Researchers dealing with the issues related to parenting point that the perception of one's parenthood is a complex issue related to a whole spectrum of emotions, and the relationship with the partner plays a crucial role in achieving happiness associated with fulfilling the role of a parent (Nelson, Kushlev, and Lyubomirsky, 2014). In this way, mothers and fathers differ both in terms of factors causing their stress and those affecting the process of adaptation to the role of a parent of a child with disability (Neely-Barnes, and Dia, 2008)., Comparing a group of mothers and fathers of children with Down syndrome in terms of uneasiness and anxiety levels, Szpich, Skórczyńska and Sadowska (2002) showed that higher level of anxiety is much more common among mothers (56%) than among fathers (30%). This may be due to the fact that it is usually mothers who spend more time with their children, perform more nursing activities, or give up their job more often than fathers to look after a sick child. In turn, fathers of children with Down syndrome show a higher level of stress than mothers when it comes to emotional bond with the child (Shonkoff et.al., 1992). As to the protective factors, social support is crucial for mothers when it comes to achieving mental well-being, while individual resources (e.g. in the form of ego-resiliency) are particularly important to fathers in the context of well-being (Kózka, and Przybyła-Basista, 2018). However, this does not mean that fathers do not benefit from social support and that it does not constitute an important source of mental strength for them. At the same time, many more studies have been conducted with regard to the functioning of mothers of children with Down syndrome

than on the subject of the experience of fathers. It should be remembered that learning about the emotional experience of fathers seems extremely important due to their relationship with the father's motivation to provide the child with proper care that would be based on sensitivity and commitment (de Falco et al., 2009). One of the aspects of parenthood is working with the other parent on organising daily childcare.

Although researchers do not agree on an unambiguous definition of parental cooperation, referred to in the literature as coparenting, many of them attempt to extract components that comprise the notion. Feinberg (2003) proposes an interesting approach, defining coparenting as a parental agreement on how to bring up children, as mutual parental support and appreciation of each other's actions, division of responsibilities and joint determination of family relations. Cowan and Cowan (1988) also focus on parental cooperation, family integrity and satisfaction in sharing responsibilities towards the child. Weissman and Cohen (1985), in turn, describe parental cooperation as parenting alliance and detail the components of this construct, which include: putting effort into raising a child, appreciating the involvement of the other parent in childcare, respecting the opinion of the other parent and being ready to communicate with the other parent. Therefore, parental cooperation, like parenthood itself, is a multidimensional issue, and the variety of situations in which mothers and fathers find themselves is compounded by this complexity. It would seem that in the situation of raising a child with Down syndrome, cooperation between parents is necessary not only for the good of the child but also for the parents themselves and for other children growing up in the family.

Parental cooperation may occur not only between partners or spouses but also between parents of different children. In this way, cooperation takes the form of social support. In turn, social support is indicated as one of the most important factors in the process of adaptation to the role of a parent of a child with Down syndrome. Social support is a mediator of the relationship between everyday stress and parental satisfaction, and positive parental behaviour (Crnic, and Greenberg, 1990), as well as of the relationship between stress and mental well-being (Kózka, and Przybyła-Basista, 2016). Parents who declare a greater level of social support experience fewer decreases in mood than parents who receive inadequate or no support (Bost et al., 2002). Among many types of help, parents of children with Down syndrome most appreciate financial support, as well as help from specialists and other parents raising children with disabilities (Pisula, 2007). Creating jobs for adults with disabilities is also a very important issue, which, unfortunately, is still not an easy task, also due to the existing prejudices (Grzyb, Morgała, and Madejska, 2018). In the situation of increased needs related to raising a child with Down syndrome, natural support networks, such as family, friends or neighbours, are often activated (Nomaguchi, and Milkie, 2003). Durmaz et al. (2011) indicate that the birth and upbringing of a child with Down syndrome do not have to result in a sharp change in the parents' social contacts, although some of the parents declare a reduction in the frequency of meetings with friends and acquaintances. In turn, cooperation with professionals significantly reinforces parental sense of control and strength (Dunst, and Dempsey, 2007). What is more, parents

working with people from their surroundings set up non-governmental organizations to provide various types of support to people with disabilities and their families (Wolny, 2018). External support is important already at the stage of waiting for the birth of a child with Down syndrome. Future parents can take advantage of support groups, find early intervention centres, good doctors, and talk to more experienced parents about their fears and doubts. At the same time, it should be noted that mothers are more likely than fathers to consider organizations as helpful (Skotko, Levine, and Goldstein, 2011).

Diversity in the context of parental cooperation and its many meanings encourages closer, even empirical, attention to the issue and leads to learning about the experiences of mothers and fathers, especially those facing “special parenthood,” i.e. having a child with Down syndrome.

2. Methods

The main aim of the study was to learn about the perceptions of mothers and fathers with regard to the responsibilities of taking care of a child with intellectual disability. The second goal was a qualitative analysis of mothers' and fathers' statements regarding contacts with parents of other children with intellectual disabilities. Due to the presented objectives, the following three research questions were posed in the paper: (1) how do mothers and fathers share responsibilities related to raising a child with intellectual disability, (2) how do mothers and fathers assess their attitudes towards taking care for their child, (3) how do parents perceive the spouse's behaviour in terms of fulfilling specific parental obligations. Researching the issues related to parenting in the face of the child's intellectual disability seems very important due to the numerous research results presenting the strain on these parents as much stronger than that on the parents of healthy children and as strongly affecting the parents' mutual relations as well. Based on the data found in the literature, it was assumed that parental cooperation – especially in the spouse-spouse or partner-partner dyad – plays an important role in parental struggles.

The study group consisted of 126 people, including 59.52% of mothers ($n = 75$) and 40.48% of fathers ($n = 51$). All (100%) parents remained in marriage during the study. The average age in the group of examined mothers was 45.33 years (min. 25, max. 69, SD 10.08), and 48.31 years in the group of examined fathers (min. 26, max. 69, SD 10.36). The average age of a child with Down syndrome in the group of mothers was 13.11 years (min. 1, max. 39, SD 8.98), and 13.47 years in the group of fathers (min. 1, max. 36, SD 8.87).

The surveyed parents were mainly residents of the Śląskie, as well as Dolnośląskie, Opolskie, Łódzkie, Mazowieckie and Zachodniopomorskie voivodeships. The research was conducted individually and through the authorities of schools, rehabilitation centres, early intervention centres, psychological and pedagogical counselling centres, occupational therapy

workshops, associations of parents and friends of people with Down syndrome, and associations of parents of children with other types of disabilities.

The research was conducted using the author's original surveys (Survey for Mum and Survey for Dad) which included questions about the scope of parents' cooperation.

3. Results

The first part of the research concerned the specifics of taking care of a child with intellectual disability resulting from the occurrence of trisomy 21, i.e. Down syndrome, in the child. The study was aimed at finding answers to questions about: (1) the way in which mothers and fathers share responsibilities related to raising a child with intellectual disability, (2) the assessment of their attitude towards childcare, (3) their assessment of the behaviour of their spouse.

Most mothers (72.00%) and fathers (66.67%) indicated that mothers are the persons who mainly look after the child. A quarter of the parents (22.67% of mothers and 25.49% of fathers, respectively) look after their child together. As to the activities performed by mothers and fathers, almost all mothers (94.67%) and half of the fathers (43.14%) are involved in childcare activities. A greater proportion of mothers perform duties related to children's education and trips or rehabilitation activities compared to fathers. Many mothers and fathers (about 70%) devote time spent with their children to play. As for the parents' assessment of the division of responsibilities, over two-thirds of mothers (64.00%) and three-quarters of fathers (74.51%) consider the division of responsibilities to be fair, and almost one-fifth of mothers (18.67%) and a quarter of fathers (23.53%) consider the division to be unfair. The above results are presented in Tables 1, 2 and 3.

Table 1.

Taking care of the child – division of duties

Who mainly?	According to mothers (n = 75)	According to fathers (n = 51)
I myself	54 (72.00%)	4 (7.84%)
The spouse	4 (5.33%)	34 (66.67%)
Together	17 (22.67%)	13 (25.49%)

Table 2.

Taking care of the child – categories of activities

Activity	Mothers (n = 75)	Fathers (n = 51)
Nursing/care	71 (94.67%)	22 (43.14%)
Play	55 (73.33%)	36 (70.59%)
Education	61 (81.33%)	19 (37.25%)
Rehabilitation trips	43 (57.33%)	16 (31.37%)
Taking to classes/to the doctor's	51 (68.00%)	29 (56.86%)
Rehabilitation activities	48 (64.00%)	14 (27.45%)

Table 3.*Involvement in care – is the division of responsibilities fair?*

Assessment of the division of responsibilities	According to mothers (<i>n</i> = 75)	According to fathers (<i>n</i> = 51)
Fair	48 (64.00%)	38 (74.51%)
It is hard to say	13 (17.33%)	1 (1.96%)
Unfair	14 (18.67%)	12 (23.53%)

Mothers and fathers also assessed involvement in childcare – both their own as well as of the spouse. Thus, mothers assessed their involvement as very large (58.67%) or large (37.33%), while fathers mostly either as large (43.14%) or moderate (39.22%). The assessment by mothers and fathers of their spouses was also taken into account. Almost all fathers assessed the involvement of the mothers of their children, i.e. their spouses, as very large or large (98.02% in total). As for the mothers, almost half of them assessed the involvement of their spouses, i.e. the fathers of their children, as large (49.33%), one-fifth as very large (21.33%) and the rest as moderate (18.67%). About 10% of mothers indicated low involvement of their spouse in taking care for the child with Down syndrome. The above results are presented in Tables 4 and 5.

Table 4.*Involvement in care – own perception*

Assessment of one's own involvement	Mothers (<i>n</i> = 75)	Fathers (<i>n</i> = 51)
Very large	44 (58.67%)	7 (13.73%)
Large	28 (37.33%)	22 (43.14%)
Moderate	3 (4.00%)	20 (39.22%)
Small	0 (0.00%)	2 (3.92%)

Table 5.*Involvement in care – perception of the spouse*

Assessment of the spouse's involvement	According to mothers (<i>n</i> = 75)	According to fathers (<i>n</i> = 51)
Very large	16 (21.33%)	42 (82.35%)
Large	37 (49.33%)	8 (15.67%)
Moderate	14 (18.67%)	1 (1.92%)
Small	7 (9.33%)	0 (0.00%)
Very small	1 (1.33%)	0 (0.00%)

Another question concerned changes in the lives of mothers and fathers – those related to the child's disability. Two types of answers can be distinguished in both the group of mothers and the group of fathers. Almost half of the mothers (48.00%) replied that it was their life that their child's disability changed more compared to the changes in their spouse's life, while the other half assessed the impact of the child's disability as the same for them and their spouse (49.33%). Similarly, half of the fathers (49.02%) answered that it was the life of their spouse – the life of the child's mother – that was changed more, while the other half of the fathers

(45.10%) assessed the impact of their child's disability as equal in the case of themselves and their wives. The above results are presented in Table 6.

Table 6.

Child's disability – whose life changed more?

Greater change	According to mothers (<i>n</i> = 75)	According to fathers (<i>n</i> = 51)
In my life	36 (48.00%)	3 (5.88%)
In my spouse's life	2 (2.66%)	25 (49.02%)
Equal change in both our lives	37 (49.33%)	23 (45.10%)

4. Discussion

The analyses carried out allow for conclusions and comparison with previous research reports in this area. First of all, it can be seen that both mothers and fathers of children with Down syndrome declare active participation in childcare. Hardly any father describes his level of involvement in childcare as small. Most activities connected with childcare are indicated by both mothers and fathers of the children. However, mothers are, for the most part, the main carers of the children – both mothers and fathers agree on this point. Mothers are more often involved in the care and rehabilitation of children than fathers. It can be concluded that, despite the growing tendency among fathers to engage in childcare in recent years, mothers are still the ones most burdened with childcare, also in the case when one of the children is born with a disability or acquires it during development. At the same time, it should be remembered that father's commitment is very important and is associated with the child's well-being, cognitive development and increase in social competence (Cabrera et al., 1999), hence, on the one hand, the data obtained are optimistic, but on the other hand, they make one think about how to support mothers and fathers in their mental and physical coping with everyday challenges. This is also important in the context of the other research results obtained, according to which both mothers and fathers struggle with changes in everyday functioning due to the child's disability. The birth of a child with a disability is an event destabilizing the balance of both parents and the whole family system, forcing family reconstruction and putting parents on the path of adaptation (Stelter, 2013). Almost half of the parents, however, indicate that the changes are much greater in the case of mothers, for it is the mothers that are more likely to take greater responsibility for childcare than fathers (Carpenter, 2000); fathers, in turn, focus more on work, and thus provide the resources needed not only to support the family, but also to provide the child with disabilities with proper forms of therapy and rehabilitation. It is also indicated that fathers' involvement increases when they have the right motivation to care for their children, adequate parenting skills, when they receive social support in their fatherhood and do not experience work-related limitations (Ricci, and Hodapp, 2003).

The research results also show that one-fifth of the surveyed parents consider the division of childcare responsibilities unfair. In general, parents of children with Down syndrome are satisfied with their marital or partner relationship, and among the main problems related to their child's disability, they mention primarily financial difficulties; nevertheless, there are arguments between parents related to the child's difficult behaviour and the appropriate response to it, resulting in stress within family relationships (Carpenter, 2000). Therefore, it would be important in this context to ask parents about the division of responsibilities and why it is unfair according to them, about whether this state of affairs is a source of stress for them, about which group (mothers or fathers) is particularly affected by this inequality and what actions should be taken to ensure that they are satisfied with the division of responsibilities. In turn, the compatibility between the parents' perception of themselves and of their spouse can be emphasised. It can be concluded that the involvement of both parents in the process of raising a child with Down syndrome results in both mothers' and fathers' involvement in various processes going on in the family and their knowledge of the events within it. It should be noted that good quality of the parents' relationship and the partner's effectiveness in providing support are very important for the individual functioning of mothers and fathers, as well as of their children and of the entire family system (Van der Veek, Kraaij, and Garnefski, 2009b; Hsiao, 2014). These protective factors play a very important role in the context of the strain on parents' marital or partner relationships. Moreover, men expressing satisfaction with their marital relationship are more involved in their child's developmental activities, and thus they are more satisfied with themselves as parents (Plopa, 2008; McBride, and Rane, 1998; Floyd, Gilliom, and Costigan, 1998); in the case of mothers, having support in close relationships with their husbands or partners is one of the psychological factors that prevent burnout (Pisula, 2007).

The data obtained certainly expand the area of factors that protect parents and contribute to the successful course of adaptation to the role of a parent of a disabled child. However, the limitations of the conducted research, including the relatively small size of the study group, should also be remembered. Moreover, in the future, the examined group of parents should be less diverse in terms of children's age (studies should include parents of children in the age group distinguished on the basis of development indicators, e.g. parents of preschool children). It would allow drawing more detailed conclusions about a specific group of parents and then creating specific guidelines for practitioners (including psychologists, educators or family therapists). Including a control group consisting of parents of children with disabilities and developmental disorders is also worth considering. It would be interesting both from the research and practical points of view to compare the scope of parental cooperation, also in the context of social support provided, between parents of children with Down syndrome and parents of children with other types of disabilities (e.g. with autism). Further research in the field of parental cooperation among parents of children with Down syndrome or in groups of other parents should be conducted using standardised psychological tools adapted to the Polish conditions.

This paper does not exhaust the topic of parental cooperation but it may be an inspiration and encouragement to continue work on the subject. Research on the issues presented should focus on the importance of positive familial, social and institutional relationships in the process of raising a child with Down syndrome. In the case of a child's health difficulties, it is important not only to use personal resources but also to maintain positive relationships with other people in the immediate environment. This knowledge can further serve as the basis for creating support programmes for mothers and fathers, as well as an indication for therapeutic work with couples struggling with specific difficulties of taking care of an intellectually disabled child. Parents of children with disabilities are in fact their own lawyers in the fight for the best developmental conditions for the child they are raising (Skotko, Levine, and Goldstein, 2011). Engaged parenthood, in turn, is another difficult task to perform, involving – as emphasised by Professor Lucyna Bakiera (2014) – activities focused on supporting child's development and being present in their life, and the parents' acceptance of their parental roles.

5. Summary

- Mothers and fathers of children with Down syndrome are involved in parental responsibilities towards their intellectually disabled children.
- Mothers are more involved in taking care for children than fathers, especially in nursing activities.
- Almost one fifth of the examined mothers and almost a quarter of the examined fathers consider the division of duties in the family to be unfair.
- Almost half of the mothers and fathers believe that mothers have experienced greater changes in their lives as a result of having a child with Down syndrome.
- Parental cooperation between mothers and fathers of children with Down syndrome is important both from the point of view of the carers, i.e. parents (also functioning in the roles of spouses), the whole family and the child.

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