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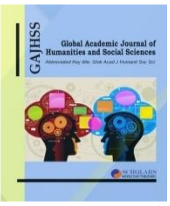

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Original Research Article

Exploring The Needs of Parents Raise Children with Physical Disabilities and the Importance of Families' and Children's Social Support

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Abstract: The present study investigated the emotions, the daily life of the parents of children with physical disabilities, the effects that exist in the relationship of the couple as well as the importance of social support from professionals and from the wider family and friendly environment. The results of the research indicated that the need to provide social support to the families of children with disabilities is vital and is strongly highlighted by the qualitative research conducted in 36 families of children with physical disabilities. The need for social support of families with children with disabilities is more intense in the initial phase, when the child with disabilities is born, but also throughout of family life as well as in the particularity of upbringing, education, socialization of their child. Adequate family social support has positive effects on both family members (father, mother, siblings) and the child with a disability. Also, social support improves the ability of parents with children with special needs, develops their social skills and is related to the better functioning and well-being of the family. Aggravating factors that affect the emotions and daily life of the parents are the socio-economic life of the parents, the long-term care of the child and the quality of the marital relationship.

Keywords: Disability, marital relationships, parental feelings, parents of children with physical disabilities, physical disabilities, social support.

1. INTRODUCTION

According to Meirsschaut, Roeyers & Warreyn, (2010), raising a child with a disability is a demanding and arduous process for the family, which is called upon to not only function smoothly, but also to face the challenges that arise from this experience. It is observed that the family environment of a child with disability goes through various stages with emotions that alternate from the phase of diagnosis, daily upbringing to the phase of active or passive acceptance of child's disability. Woodgate, Ateah & Secco, (2008), argued that the existence of a child with disability in a family affects both daily life and relationships between members of the family, and also affects family's relationships with the wider social environment, as a result often leading to the occurrence of phenomena isolation and stigma. In addition, because of disability, the need of families of children with disabilities is to overcome the disorganization that usually exists and adapt to a new form of functioning, leads them to search for forms of social support (Banach, Iudice, Conway & Couse, 2010).

According to researches by Benjak, Mavrinac & Šimetin, (2009), Benson, (2006), Benson & Karlof, (2009), Davies & Hall, (2005), Koydemir-denzden & Tosun, (2010), Lin, Tsai & Chang, (2008), Neander & Engström, (2009), Tehee *et al.,* (2009),

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Twoy *et al*., (2007), reported that parents, at the initial stage of diagnosing of their child's disability, experienced feelings of anxiety, depression, anger, shock, denial, fear, guilt, sadness, grief, despair, confusion, hostility or emotional collapse. Subsequently, of the child and family life, negative emotions turn into positive feelings of love, joy, acceptance and satisfaction, but at the same time they experienced feelings of anger, sadness, frustration, guilt and pain, especially when they compare their children with others. In many cases, families of children with disabilities experienced and perceived that their children are stigmatized by society because of their disability (Brewin et al., 2008; Papageorgiou & Kalyva, 2010; Phetrasuwan & Miles, 2009).

Algood, Harris, & Hong (2013), referred that caring a child with special needs is a demanding and time-consuming process that requires knowledge and information from the family in relation to the child with disability. Raising a child with disabilities causes intense stress to parents, increased fatigue due to long-term care responsibilities, social isolation, disruption of professional careers and reduced family income (De Rigne & Porterfield, 2015; Polfuss *et al*., 2016). Parents are also concerned about their children's victimization by other children and society and the risk of bullying to their child (Eisenhower *et al.,* 2005; Hastings *et al*., 2005; Oelofsen & Richardson 2006; Pisula 2007).

Brehaut *et al*., (2009), and Di Giulio, Philipov & Jaschinski, (2014), stated that long-term care of a disabled child causes tension, conflict between spouses, decreases marital satisfaction and quality, and increases the chances of leading to divorce. According to Bangasser & Valentino, (2014), mothers of children with disabilities experienced higher levels of anxiety, which contributes to emotional disorders.

Social support is a multidimensional social phenomenon that includes physical and psycho-emotional help and support for parents in order to deal effectively the difficulties and stress they experienced. Social support is an important potential resource and source of information and inspiration for parents with children with special needs (Cuzzocrea *et al*., 2014; Taylor, 2007).

2. RESEARCH PURPOSE

This study aimed at identifying the needs of parents caring for a child with physical disabilities and explore the role of social support through professionals and extended family environment. Specifically, the objectives of this study aim to define the needs of parents of children with physical disabilities, and to find out what extent the needs of these parents are being met, and to determine the best ways to meet the needs from the caring parents' perspective. Therefore, this study implemented surveying techniques that include close- and open-ended questions to answer the following questions:

1. What is the level of needs of parents caring for children with physical disabilities?
2. What are the most and least important needs identified by parents caring for children with physical disabilities?
3. Are parents of children with physical disabilities receive social support from professionals?
4. Are parents of children with physical disabilities receive social support from their extended family environment

3. RESEARCH METHODOLOGY

According to Isari & Pourkos (2015), the semi-structured in-depth interview consists of a set of predefined questions and is used as a guide to the topics to be covered in the interview. This type of interview is flexible: a) in terms of modifying the content of the questions according to the participant, b) in terms of deepening some issues with participants that are considered appropriate, c) in terms of the order in which the questions are asked and d) in terms of adding or removing questions or topics for discussion.

3.1. Data analysis

Interview analysis is based on interpretive phenomenological analysis which attempts to capture the ways in which individuals or groups give meaning to their social world and build their lived experience on the phenomenon (Smith, Flowers, & Larkin, 2009).

3.2. Participants

The present study participated 36 parents who raise a child with special needs, aged 6 to 12 years. The 75% of parents were women (27) and the 25% of parents were men (7). 90% of the parents were married 27 and 10% were divorced. Most of parents had 2 children (78%) and 22% had one child. 50% of parents had full time employment, 25% are housewives and 25% had part time job. The fathers of the sample worked as full-time employees. The parents had an average age (35 + 6), lived in urban areas of Limassol district, the majority of parents (70%) had a higher education, as well as the majority of participants (85%) had family income from 1500 to 3000 euros monthly. All families received money from the Minimum Guaranteed Income to satisfy their children's needs. There was a medical diagnosis that the children had physical disabilities and they needed specialized care from the day that they were born until today.

4. FINDINGS

Topics: Needs Categorization	***Findings***
Children's disability	Due to children's disability, families' daily life is affected and changed. Children have limited ability in various daily functions at the individual level Children are unable to self-care, as children at the same age Children with disabilities are deprived of basic rights and services Low quality of life of children with disabilities and their families
Parents' feelings and thoughts	First phase, the birth of a "different" child is a source of intense negative emotions for parents Initial feelings of deep shock, sadness, anger, rejection of the child, fear, anxiety and distress The denial and concealment of the problem from the wider environment. Next phase, the adaptation and orientation phase. Parents search for information Parents seek help generally Constant effort to help and care for their children Parents search for collaboration with professionals Emotional phase of overprotection and organization of family life around the child with disabilities.
Families' daily life problems	Intense emotional manifestations such as emotional frustration and anger Chronic fatigue and sadness in a relationship with changes and restrictions in their lifestyle. In Cypriot society it is taken for granted that the family has an obligation to provide support / care to children with disabilities. Increased difficulties in providing comprehensive support and care. Parents have no free time for any occupation other than child care.
Support / Care for children with disabilities	Long-term effects are identified during support / care. Care is often extremely prolonged and without the reward of the child's gradual independence Leads to chronic fatigue and exhaustion affecting the relationships of family members. Aggravating factors in education are the difficult living conditions of families, and the type of children's disability
Children's special education	Complete and harmonious development of each children's personality Improvement and maximum utilization of its potential Equal social development of the children. Smooth transition from school to society. Support and assistance in their education.
Parent's Health	Parents have neglected themselves Parents' priority is the health and needs of their children. They feel helpless
Couple's Relationships	The majority of parents describe their marriage as happy and state that they are loved The couple usually do not sleep together because they often sleep with their children due to the fact that their children need supervision and constant care. They emphasize that several times the couple can clash over issues concerning the family, children, finances and believe that this is mainly due to the fatigue and exhaustion they feel. Their mission as parents is to love and care their children
Families' Living conditions	Their house needed alterations and changes according to children's special needs Special equipment is needed to serve children's special needs
Families's financial situation	The state covers to a small extent the financial needs of children with disabilities Parents do not have the financial possibility to provide the desired solutions, such as ergonomic arrangement of children's house, assistive technology, employment of personal assistant. The daily provision of support / care acts restrictively in terms of meeting the other obligations such as work, family, personal obligations that parents had.

	The financial cost for a child with a disability is huge and translates not only into increased costs (transportation, necessary space arrangement, appliances, suitable living conditions, treatments, etc.), but also reduced family income. Some parents are unable to work due to 24-hour care for their child due to limited support from the extended family, welfare services and the community The standard of living of the whole family is degraded and there is a serious problem of their survival.
Society / Stigma	Οι γονείς δεν έχουν καθόλου ελεύθερο χρόνο για οποιαδήποτε άλλη ενασχόληση πέραν από τη φροντίδα του παιδιού. Social isolation of children and their families. Fear of comments and negative attitude towards their child and to the family. Parents as well as the child can not enjoy basic daily activities and services
Social support for families by professionals / Support services and treatments for children with disabilities	Children with disabilities need to receive various services and treatments such as psychological support, speech therapy, occupational therapy, etc. but state services are rigid and do not offer the necessary services to children. Parents due to increased financial difficulties cannot turn to the private sector for services due to increased treatment costs They emphasize the need to work with experts to help both the child and the family
Social support for families by extended family and friendly environment	Parents and children are supported by the wider environment, mainly from grandparents The wider family environment is more supportive than the friendly one The wider family environment offers relief and time to parents to relax

5. DISCUSSION

5.1. Families' needs

Parents reported that their children, due to their disability, have limited ability in various daily functions on an individual level and inability to perform a series of actions and activities that are considered normal for a child of their age. In everyday life, children find it difficult to participate and enjoy basic activities and services and this limitation is due to children's disability and has a serious impact on the quality of life of both children and the family. The high dependence of a child with special needs on his parents causes fatigue from increased responsibilities (Polfuss *et al*., 2016).

The long-term effects are identified during support / care. Care is often extremely prolonged and without the reward of the child's gradual independence, it inevitably leads to chronic fatigue affecting the relationships of Family Members. The severity of the disability, ie people with severe disabilities and multiple dependency needs, implies the need to provide ongoing physical care, which can be exhausting for the members of the family (parents) who have taken it on. Caring for a child with special needs requires more time, knowledge and greater quality and duration of care compared to a non-disabled child (Algood, Harris, & Hong, 2013).

Families in their daily lives had to face a number of problems, crucial for their smooth operation as a family. Family members and the child with disability experienced a series of intense emotional manifestations such as emotional frustration and anger, resulting in chronic fatigue and sadness in a relationship with changes and limitations in their lifestyle. However, there are increased difficulties in terms of the knowledge, ability and power of families with children with disabilities in providing comprehensive support / care. Similar results showed researches by De Rigne & Porterfield (2015) Polfuss *et al*., (2016), Powers, (2001), Seltzer *et al*., (2001), that the effects on the family of a child with disabilities are the fatigue from increased responsibilities, the reduced time for daily routine, the social isolation, the disruption of the professional career, the reduction of the family income.

The birth of a healthy child is undoubtedly an important milestone in parent's life because child completes their marriage and their family, both emotionally and socially. The birth of a child is usually a moment of joy and celebration for the parents but also for their close family and friendly environment. Parents experience satisfaction and self-realization after creating a new person of their own. However, the birth of a "different" child from what the parents expected, is a source of intense negative emotions. It is a deep shock, the beginning of an internal conflict between what they expected and dreamed and the reality that they have to accept this situation, but also to face it. Dominant emotions experienced by parents are sadness, anger, rejection of the child, fear, anxiety and distress, while the first reactions of parents are the denial and concealment of the problem from the wider environment. In the first stage of having a child with disability, parents have significant needs. They need to know what is wrong with their child, what the future holds, why the problem arose, and in what ways they will address their child's different needs, namely treatment, care and education. According to Kandel and Merrick (2007), those parents who manage to accept the fact of their child's disability, they are more able to process of knowing the special characteristics of their child in order to be able to cope with their responsibilities (Bangasser & Valentino, 2014)

The parents went through a series of emotional stages until the diagnosis of the child's disability. The parents' feelings at first, with the birth of the child, were based on biological reactions concerning the protection of the defenceless infant and doubts about their ability to raise the child. In the next stage, the parents went through a stage of mourning, feelings of sadness, grief, despair, anger, and were in a very difficult position, especially when they had to explain to others the situation of their child and when they were in public with the child. They felt guilty because they had negative feelings about their child, such as rejection, anger or resentment, because they felt responsible for the child's difficulties and because they felt helpless to deal with the situation. They also felt feelings of fear caused by uncertainty about the future. They feared that they might lose the child because they could not survive, or because they could not take care of their child and would have to entrust their care to others. With the transfer of the children home, the adjustment and orientation phase began. The processes for a realistic assessment of the situation began and the parents wanted to know what they can do. They needed accurate information about their child's health status, they to find out ways to deal with it and prepare for the child's best possible development. They began to seek help and information and to plan for the future. Parents are in a constant effort to help and care for the child, receiving information from doctors and other specialized staff. Parents are in the emotional phase of overprotection and the organization of family life around the disabled child. (Benjak, Mavrinac & Šimetin, 2009; Benson, 2006; Benson & Karlof, 2009; Davies & Hall, 2005; Koydemir-denzden & Tosun, 2010; Lin, Tsai & Chang, 2008; Neander & Engström, 2009; Tehee et al., 2009; Twoy *et al*., 2007).

The majority of parents described their marriage as happy and reported that they are loved until day. After the birth of a child with a disability, parents reported that the couple usually does not sleep together because they often sleep with their children due to the fact that their children need supervision and constant care. They emphasize that several times the couple can clash over issues concerning the family, children, finances and believe that this is mainly due to the fatigue and exhaustion they feel. They emphasize that they love and care for their children, trying not to miss them anything. According to Carpenter *et al*., (2016), when the support from the spouse is low, there is a greater chance that the child caregiver will have difficulty adjusting psychologically, to show more intense feelings of anxiety and depression. Similar results are reported by Cavonius-Rintahaka *et al*., (2019), family functionality determines from the level of support, specifically, in families where responsibilities and child care are evenly distributed and all nuclear individual's family participate according to their abilities, then the results of support are positive. When the spouse does not enjoy support from the family environment, the parent who has taken care of the child with special needs experienced high levels of anxiety and depression. Family support is associated with a sense of optimism, which positively contributes to the emotionally of the parent-caregiver, facilitates and improves the parent-child emotional relationship and improves parental effectiveness (Ekas *et al*., 2010; Boyd, 2002). Mavrogianni (2009) expresses the view that the paternal role in the upbringing and care of the child with special needs is also related to the quality of the relationship between the two parents.

A common feature mentioned by parents is that their home needed modifications and changes to be able to meet their child's needs. As they also report, in many cases special equipment is needed to serve the special needs of their child. Half of the parents would like to renovated their house but they can't because of financial difficulties. The financial costs of the daily support / care of the child with a disability are covered to a minimum by the state. Few parents have the financial ability to provide the desired solutions, such as ergonomic arrangement of their children's space, assistive technology, employment of personal assistant. The daily provision of support and care towards disabled children acts restrictively in terms of satisfied the other responsibilities, job, family, personal that parents have. The financial cost for a child with a disability is huge, into increased costs (travelling, special furniture, appliances, adequate living conditions, treatments, etc.), but also reduced income. In many cases, it is difficult for parents (especially mothers) to work because the child needs 24-hour care as well as there is limited support from the wider family and society. The standard of living of the whole family is degraded and there is a serious problem of survival of the family. In addition to the internal conflicts, social prejudices and frustrations that parents are trying to resolve and deal with, they must give up their professional careers resulting in low self-esteem of the parents, but also the poor financial level of the family. Research showed that job provides mental balance and health to mothers who have not quit their jobs and are better able to experience the negative social effects of caring for and raising a child with special needs (Seltzer *et al.*, 2001). A key factor that affects the family with a child with special needs is the negative changes in the work of the parents. Balancing the upbringing of a child with a disability with the professional work of the parents is a difficult struggle. In some cases, the burden of responsibility can be overwhelming, leading parents to reduce the number of hours at work or leave the workforce as unemployed. These changes at work lead to additional financial difficulties, as the family is already burdened with expenses for their child's health care and medical care. Financial stability is disrupted, incomes are declining and due to the high cost of paid childcare, mothers often decide not to work and raise their disabled child themselves (Baydar *et al.,* 2007).

Social isolation is one of the biggest problems facing the children with disabilities and their families. The distance of the family from the rest of the world was manifested at every stage of the child's development. The experiences of parents, who realize the magnitude of the problem, reported fear of comments and a negative attitude towards their child at school who is deprived of socializing with children of their age. All of the above push for greater isolation of the child and the family, in order to protect themselves from comments, stigma, curiosity of the people and from the feeling of bitterness and inferiority. Thus, both parents and the children cannot enjoy the basic daily activities. According to Karasavvidis (2017), the family that raise a child with disability perceives this fact as a "threat due to the fear of social stigma". The concern of parents is that stigma is often accompanied by a negative evaluation of the children with disability, devaluation and underestimation of all their possibilities and abilities of the children with special needs (Jahoda & Markova, 2004; Todd *et al.*, 2000).

5.2. Social support of families by professionals / Support Services and therapies for children

The integration of children with disabilities is a long-term process that requires the contribution of various services, professionals, actions, based on the individual needs of the children with disabilities and their families, in order to ensure their equal participation in society. In order to formulate an individualized plan for addressing the needs of the child, the cooperation of a doctor, psychologist, social worker, special educator, speech therapist, occupational therapist, physiotherapist is required, whose contribution requires coordination so that the evaluation and strategy are effective. The cooperation of all therapists and specialists involved in the care of the children with a disability and the support of their families has as its main purpose the improvement of the children's and their families' functionality. According to Hoch and Ferguson (2005), all parents of children with disabilities are consulted and informed by specialists, such as doctors, social workers, psychologists, physiotherapists, occupational therapists, speech therapists, special educators. Also, parents seek additional information, develop new contacts, share experiences, and seek help and emotional support from their own family, relatives and friends (Mankoff *et al.,* 2011; Skeels *et al.*, 2010).

The education of disabled children aims mainly at the complete and harmonious development of children's personality and their abilities. The purpose of education is to provide basic vocational education to children based on their abilities, in order to move smoothly from school life to society. According to the data collected regarding the education of children with disabilities, children need support and assistance in their education. Negative causes associated with learning disabilities are medical conditions, sensory disturbances, chronic problems, causes related to psychosocial conditions, such as adequate living conditions of families and which lead to reduced educational opportunities (Bethell et al., 2012; Vessey, 2011; Engelke *et al.*, 2014).

It is important for children with a disability and their family to enjoy supportive services that contribute to the empowerment of both the individuals and their family. The social support that the parents or family receives from government agencies (hospitals, health centers, schools) and from professionals (doctors, psychologists, social workers, speech therapists, occupational therapists, physiotherapists) is called formal support. Services such as counselling, information and education, provide and develop parents' skills according to their children' needs (Dunst, 2002; Perry, 2004).

Children with disabilities have multiple needs, which arise from the nature of disability and if they do not receive the necessary help and support they suffered then from emotional and behavioral disorders. The involvement of many specialties from different scientific fields is required, and they offered effective treatment to children, they minimized the risks of additional handicaps and to improve the quality of life of the family and the child with a disability. Douma, Dekker and Koot (2006) argue that the majority of parents sought social support for information and to reduce discomfort and stress. They also sought information about the child's needs and problems. In addition, it turned out that parents do not know where to turn for help and support for the problems they face with their child. In a study by Higgins, Baile and Pearce (2005), it was found that social support has a significant effect on family functioning, increases the level of family satisfaction, contributes to better personal and family adjustment. Social support protects parents from mental health issues (White & Hastings, 2004) and is a key prerequisite for dealing with stress, especially for mothers of children with disabilities (Pozo & Sarriá, 2014) and the ability to enjoy parents' life and overcome difficulties with optimism (Al-Kandari *et al.*, 2017).

It is very important for the family to receive support, so that: to rely on its own strengths, to aim at the improvement and development of their child with disabilities, to act as a claimant of the rights of the child with disabilities and to aim at the maximum degree of autonomy of their child with disability. In case the family does not receive support, it is very likely that negative family and social behaviors will occur which are caused by the unbearable burden of child care and often extreme situations are observed, such as family breakup, psycho-neurotic conditions, parental depression, etc. Carter and colleagues (2004) reported that parents use a combination of different types of support in an effort to maximize the benefits of each type of support, receiving support from the nuclear family, the extended family, the friendly environment, the education system, from health and prevention services.

Regarding the social support of parents and family from the wider family environment, the results of the research showed that there is enough support and help from the wider environment, mainly from the grandparents of children with disabilities and the wider family environment offers relief and personal time to parents. Similar results are reported by the research of Benson & Karlof, (2009), and Lindsey & Barry (2018), referred that social support plays a key role in the well-being of parents who receive it, the negative effects of long-term care of a child with special needs are reduced, helps reduce psychological distress, negative mood and depressive symptoms. Manning *et al.*, (2011), Sharabi & Marom-Golan, (2018), and Smith et al., (2012), underlined that social support from the wider family and friendly environment reduce stress, anxiety and encourage parents - caregivers of children with disabilities. The present study found that the wider family environment is more supportive than the friendly. Similar results showed the previous research by Luther, Canham, and Cureton (2005) that social support was higher for extended family members than for neighbours.

6. CONCLUSIONS

In the initial stage of diagnosing a child's disability, parents went through various emotional stages until they accepted their child's disability and sought help either from professionals or from the wider family and friendly environment. Parents have distanced themselves socially to protect their child, for fear that their child may be stigmatized at school or in society. Over the years, they appear to have recovered and reorganized their lives, but as it is established and as they point out, they still experience increased stress that is often accompanied by anger and rage that results in marital conflicts. They referred that an important factor is the communication and cooperation between the parents and the family. Parents have realized the issue of child disability and the consequences of disability and they have been mobilized to overcome difficulties, seek information, acquire new skills, they have confidence in family strengths, and they have adapted effectively to child's health status and the new conditions of their lives.

Social support is vital, both the family and the disabled child. Parents can receive various services to strengthen, support the family from the long-term care of the child, the psychological support of the parents to be able to manage their emotions but mainly to be able to effectively manage the difficulties and obstacles they face in their daily lives. For children with disabilities, treatments are of the utmost importance throughout their lives because they will make a very positive contribution to their health and quality of life in order to improve their abilities and skills as much as possible; and remain functional over time (adulthood).

Supportive services will improve the child's abilities and skills to the maximum possible level of functionality (physically, mentally, emotionally), facilitate the treatment of grief and ongoing support of parents and siblings of the disabled child, help the family and the child to participate socially, will lead the family and the child to autonomy, will help the family and the child to communicate creatively and effectively with others (extended family, school, society), will help the family and the child to develop their social skills and relationships based on cooperation, initiative and mutual trust, develop support networks (informal, formal), improve living conditions, strengthen the family from the lifelong burden of responsibility, promote the person with a disability in training programs and vocational training, according to age and existing needs, face daily difficulties, problems and obstacles, facilitate the provision of social care and family care needs, support the family and the individual in matters of future housing, employment and security, offer counselling and treatment for the child and the family, evaluate the special educational needs of the child at each developmental stage according to the age and needs of the child, develop educational programs according to the possibilities and needs of the child, offer special support to both the child and the family to address difficulties at school and in society. The state plays a key role in developing appropriate services to support, and empower both children with disabilities and their parents.

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