Abstract

The family is a space for learning that is in constant renewal and enrichment. However, when one of its members has a disability, the family plays a major role in the daily reconstruction of the intimate and social life of its members. And as ageing is inevitable, parents are constantly worried about who will take care of their children. Children become increasingly more dependent as parents face physical limitations in caring for their children.

A qualitative descriptive exploratory study using a phenomenological approach was carried out to answer the initial question: “Do parents of adult children with disabilities experience specific needs?” Based on this methodology, data were collected through semi-structured interviews with five elderly parents caring for their disabled children and attending the CEFP (Centre for Integrated Vocational Education and Training).

Results indicate that these parents live for their children, which is inherent to a moderate level of care dependence for self-care functions such as personal hygiene, walking, dressing and undressing. They care for the children by themselves, and they feel alone in their role.

Keywords: elderly; caring; children; parents; adults with special needs.

Resumo

A família é considerada um espaço de aprendizagem que está em constante renovação e enriquecimento, no entanto, quando um dos seus elementos é portador de deficiência, a família assume um papel primordial na reconstrução diária da vida íntima e social dos seus membros. Os pais vivem com preocupação constante quem irá cuidar dos seus filhos, porque o envelhecimento é inevitável: logo, estes ficam cada vez mais dependentes, já que os progenitores enfrentam incapacidades físicas para cuidar dos filhos.

Este estudo qualitativo tem características fenomenológicas, sendo igualmente exploratório descritivo, e surgiu da seguinte pergunta de partida: “Será que os pais de filhos portadores de deficiência na idade adulta expressam necessidades específicas?”

Cum base na metodologia utilizada, acolhe de dados foi efetuada através de entrevista semiestruturada a cinco pais idosos que cuidam de seus filhos deficientes e que frequentam o Centro de Educação e Formação Profissional Integrada (CEFPI).

Dos resultados obtidos salientamos que estes pais vivem em função dos filhos e para os filhos; tal facto está inerente à dependência de cuidados em grau moderado, destacando-se o autocuidado higiene, deambular, vestir e despir. O cuidar dos filhos não é partilhado, cuidam sozinhos dos filhos e sentem-se sós no desempenho do seu papel.

Palavras-chave: idosos; cuidar; filhos; pais; adultos com necessidades especiais.

Resumen

La familia es considerada un espacio de aprendizaje que está en constante renovación y enriquecimiento, sin embargo, cuando uno de sus miembros tiene una discapacidad, esta juega un papel importante en la reconstrucción de la vida íntima y social de los miembros. Los padres viven con la constante preocupación de quién se hará cargo de sus hijos, pues envejecer es inevitable y conlleva que los hijos sean cada vez más dependientes y que los padres se enfrenten a discapacidades físicas para cuidarlos.

Este estudio cualitativo con características fenomenológicas, que es a la vez exploratorio descritivo, surgió de la pregunta inicial: «¿Presentan los padres con hijos adultos discapacitados necesidades específicas?». Con base en la metodología utilizada, la recogida de datos se llevó a cabo a través de una entrevista semiestruturada a cinco padres ancianos que cuidan de sus hijos discapacitados y asisten al Center of Education and Integrated Professional Formation (CEFPI).

De los resultados obtenidos se observa que estos padres viven en función de los hijos y para los hijos; un hecho que es inherente a la dependencia a los cuidados en grado moderado, sobre todo a autocuidarse, llevar una higiene, caminar, vestirse y desvestirse. El cuidado de los hijos no se comparte: los padres desempeñan solos este papel y por ello, se sienten solos.

Palabras clave: ancianos; cuidado; hijos; padres; adultos con necesidades especiales.

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**Introduction**

The family can be defined as a group of human beings, a social unit or a whole collective, composed of members connected by consanguinity, emotional affinity or kinship law, including significant people. “The definition of family does not only rely on blood ties, but also and above all on affective relationships” Relvas (as cited in Martins, 2002, p. 113).

The life of a family who has a member with a disability is almost always an “adventure”, a life commitment and a commitment for life, either in the construction of daily life routines or in moments of leisure. Having a child with disability contributes to triggering feelings of anxiety, apprehension, and frustration, not only regarding the present but mainly the future. These feelings are motivated by the awareness of the lack of resources and support institutions in society.

Child care has been studied by several researchers in the different areas of knowledge, leading to a reflection on the consequences for parents of having a disabled child. When deciding to study this theme, and although our sociocultural/professional context makes us even more aware that this is sometimes a very difficult problem for parents, we realise that this is a reality with which professionals have to deal to be able to meet the needs expressed/felt by the parents.

After a search on the topic, several authors such as Sousa (2003) and Xavier (2008) were critical in our decision to choose a qualitative paradigm. More than understanding the phenomenon in its statistical representation, we are concerned with deepening our understanding of these parents experiences in order to identify types of care which may contribute to improving the lives of families with disabled adult children.

For this study, we have outlined the following objectives: to analyse the need for care felt by elderly caregivers with disabled children; to understand the difficulties and fears felt by parents of disabled children; to identify nursing contributions to care provision; to describe the social and health support identified as useful resources for the families of disabled people; to identify health care needs of elderly parents with disabled children.

**Background**

The United Nations (UN), in its General Assembly on 6th December 2006, and in the presence of 192 countries, established not only the rights of disabled people but also defined the concept of disability. The UN defined that “the person with disability is a person who suffers from a physical, mental, or sensory impairment that limits their ability to perform daily activities, caused or aggravated by social or environmental conditions.” (UN, 2006) Article 1.

In families who care for dependent disabled adults, social isolation is frequent and the caregiver’s loneliness may be a consequence inherent to the functions performed within the family. Souza and Boemer (2003) that family and mental disability issues should be addressed by giving special emphasis to the family’s psychological well-being, particularly of the parents. These families need to be analysed with the purpose of understanding the dynamics between their members within their own social environment.

Bedia, Cilleros, Primo, and Fernández (2009) advocate that the families with disabled children are always present and have to find solutions and resources, while adapting to situations with the available resources and seeking support from the institutions and society when they are confronted with everyday challenges throughout the life cycle.

Barbosa, Chaud, and Gomes (2007), in his study “Experiences of mothers of disabled children”, aimed to so as to understand the meaning behind this experience. This qualitative study with a phenomenological approach was based on Heidegger, and the sample was composed of five mothers with disabled children. The researchers concluded that the mothers expressed feelings of sadness and appeared not to be prepared to deal with having a disabled child. This study confirmed that there are changes in how the family functions, not only in couple dynamics, but also in the relationship with the other family members. Another important aspect is the fact that the mothers do not find the help they need from nurses.

The study by Sousa and Boemer (2003) on “The being-with a mental handicapped child - uncovered facets” began with the research question “How has it been to care of your child?” and used a phenomenological theoretical-methodological approach. The sample was composed of 11 couples and two mothers with mentally disabled children. The researchers...
concluded that fathers share a strong emotional bond with their child; however, they demonstrated difficulties in conceiving the being-with-deficiency. Fathers showed that they participate in caring for their children, but the idea still prevails that the child’s care is a responsibility of the mother.

The literature review showed that the ongoing studies in this area do not include the families of elderly parents with adult disabled children, focusing only on families with young children. However, these studies served as a starting point for the consolidation of our research and for questioning whether families with adult children face the same feelings/concerns and difficulties.

Methodology

This is a descriptive qualitative exploratory study, whose aim was to understand in depth the problems of elderly parents with disabled children. A purposive sample was used in this study.

In view of the methodology used, the interview was considered as the best data collection tool. Interviews were conducted in the medical sector of the CEFPI (Centre for Integrated Vocational Education and Training). At the moment of the interview, and after consent for recording was obtained, only the interviewee and the researcher were present, so as to ensure privacy and confidentiality. The interviews lasted on average 30 minutes, and data collection occurred between November and December 2009.

In this study, a structured interview based on a script and field notes was used by one of the researchers. Due to prior knowledge of the field under study and the fact that the scope of this study lies within the participants’ area of intimacy, the interview was divided into two parts: one for sample characterisation and the other for the theme.

The second part of the interview focuses on a set of more or less direct questions aiming at making parents talk about their experiences with their child. This type of question was chosen because it covers several areas of family life and does not restrict participants’ answers. For example, the questions: “Can you describe your day-to-day life? (a “normal” day); “What needs/difficulties have you experienced while taking care of your child?”, allowed participants to describe their everyday lives, convey their needs and express their feelings.

The following inclusion criteria were defined: parents of a disabled adult of the CEFPI, who live with the disabled person; able to communicate and older than 65 years. After data collection, data were organized. Thus, after the interviews were recorded, they were transcribed to computer files, and each parent was assigned a code preceded by a number (from 1 to 5).

Bardin’s content analysis technique was used in this study. Data were organized and then hand coded, using different colours according to the registration and context units. Then, tables were created to include the encoded units with the same code of the five conducted interviews. During the second reading, discourses with the same meaning were identified which could be assembled around a single concept. Therefore, categories emerged. In a third reading on the categories, more specific ideas expressed by participants were identified, and subcategories emerged.

Results and discussion

Development of disability

Sousa and Boemer (2003) in their study “The being-with a mental handicapped child - uncovered facets”, citing Buscaglia (1997), mentioned that it is society which defines disability as an inability, something unwanted and with limitations for the person who has it.

Based on the parents’ discourse, we can determine what type of disability reported by parents is “Disability resulting from birth” (EM1); “Consequence of childbirth, the child was born via Caesarean section, it seems that the cord has affected a portion of the brain” (EP5); “Down Syndrome” (EP3).

Ishikawa and Raine (2010) argued that obstetric complications affect brain development; genetic causes entail cognitive changes.

According to Baldor and Brien (2009), most individuals with intellectual disability may not present specific characteristics during childhood. However, limitations only become visible upon entry to school: “I never thought my little boy would be like this” (EM1); “At three years old, he was a normal and quite intelligent child, and be still is today” (EM4).

Learning Difficulties

A child with special educational needs often presents learning difficulties. This situation is usually identified
at school age (with a greater impact on the 1st and 2nd cycles of Basic Education) since during an activity the teacher can observe any abnormal behaviours or inabilities for the child’s age or level of education (Malveira, 2007). However, educational interventions may be implemented at any age through individualized educational plans and programs which can help these students acquire writing and/or reading skills and even deepen other skills "In a short period of time be learned bow to read and write" (EM3); “He learned bow to be very methodical when doing arts and crafts” (EM4).

One of the pedagogical support measures that teachers can use is individualized teaching, not only for students with disabilities (and in this situation, it lies under the responsibility of the school cluster’s educational support team) but also for students with learning difficulties. The number of students per class, the number of students who require support and the school subject itself often put the development of the skills desired by the teachers at risk. After analysing the interviews, we found that parents sought specific support "A private special education teacher” (EM3); He didn't attend a public primary school, he went to a private school” (EM4). In the education institution, parents’ involvement is essential throughout their children’s educational path. “I was the one who taught him and if I taught him more, he would learn more” (EM4). According to Correia (2003), the school should involve the family, but this responsibility should not fall exclusively within the school institution but also in the family.

Self-care
As Santos and Saratt (2008) advocate, self-care is inherent to life and is closely related to the survival of the human being, who performs activities for its own benefit with the aim of maintaining health and well-being. “He shaves himself” (EM1), “Perfectly autonomous” (EP5); “At the end of the day, when he gets home, the first thing he does is take a bath. He is very methodical, be takes a bath on Mondays, Wednesdays and Fridays” (EP5); “If it’s shaving day, be shaves” (EM1).

Self-care is essential to life; however, in most cases, in a situation of illness, severe psychological changes or disability, whether permanent or temporary, there is a high dependence in self-care. Thus, family intervention is essential for the survival of the human being with quality of life. "He depends on me for everything” (EM2); (EP3); "His father shaves him” (EM4); "I wash him, be only washes his face because he can still do it” (EM2); “I help her wash down there because she can still wash the front but she can’t reach the back” (EP3).

Use of services
Primary health care is still the best strategy to respond to people’s health needs, giving them the universal access to health care that they need.

The code of ethics for nurses (104/98. DR No. 93 1st Series) disseminates the idea that nurses should be aware of the needs of the community in which they are inserted, as well as promote health. Our analysis shows that there is a certain distancing of nurses from the population regarding health care provision. “I hardly know the nurses” (EP3); “Yes, before it was easier, now we have to make an appointment to speak with the nurse” (EM1).

Based on the assumption that the nursing practice in primary health care aims at the promotion of health and prevention of disease, with a special emphasis on health education activities, management and assessment of care provided to the individuals, families and groups, and coordination/maintenance of a given community, a distancing of nurses both from the family and the community was observed. “I would like nurses to be more active regarding the health of disabled people such as my son, so they could help us take care of them” (EP5); “Nurses only put dressings, nothing else” (EP3). We found that the type of support provided by health professionals is practically non-existent.

It should be noted that even after the recent reform of primary health care, through our participants’ discourse we can confirm that these parents and their children are not provided with care by the nurses.

Everyday experiences of parents
After the analysis of the narratives, we observed that elderly parents are associated with tasks which, according to Stanhope and Lencaster (1999), are performed by most families, although the types of functions vary depending on families’ characteristics. In these families there is an overload of tasks as a result of the children’s characteristics. These tasks may be related to providing food: “I usually do the shopping after leaving my son at the centre” (EM1);
“I usually go shopping during the day” (EP3); “We usually go to the supermarket” (EM4).

Still according to the same author, a family environment that promotes health is essential, and we can conclude that the participants in this study are concerned with house cleaning and laundry: “I take care of the clothes, clean up the house, I like to keep everything neat and tidy” (EM1); “Clean the house” (EP3); “Or organizing things at home” (EM4); “I stay at home to take care of things” (EP5); “I have to iron, clean the house” (EM2).

In addition to the abovementioned tasks, it should be noted that one of the mothers in this study contributes to the home economy in so far as she takes care of the backyard and tends to the animals. “I get home and I feed and tend to the chickens” (EM1); “In the afternoon I still go to the backyard to weed or plant my things” (EM1).

**Participation in domestic tasks**

The narratives show participation in household chores. Despite being a common and normal situation within a family, in families with disabled children this reality ends up having another dimension, because if, on the one hand, it is a way for disabled people to contribute to the performance of domestic tasks (even if they are the most basic), on the other hand, a single family member is not overloaded with tasks, although the tasks developed by children are very basic, particularly kitchen chores: “Keeps the cutlery shining” (EM1); “Knows how to lay the table” (EM1); “Helps me lay the table” (EP3); “Empties the dishwasher, lays the table” (EM4); “I tell him to go to the pantry to get potatoes and he does” (EM4); “Empties the dishwasher” (EP5); “He rinses the dishes to put in the dishwasher” (EP5); “She sometimes dries and stores the dishes from lunch, and when I get home she is still doing this. She is very slow” (EP3).

These tasks are essential for children to know how to behave and what to do.

In addition to the abovementioned activities, the children also participate in cleaning and tidying the house “He is very neat” (EM1); “He likes everything in its place” (EM1); “He sometimes uses a small cloth to dust” (EP3); “When he’s in the mood he helps Ana” (EP5); “His drawers are all neat and tidy” (EM1); “Makes the beds” (EM1); “He puts his clothes in the drawers” (EM4); “He makes the beds” (EP3).

It should be noted that one of the mothers mentioned that her son does not perform any tasks; “Nothing, he does nothing, I’m the one who does everything” (EM2), but this fact is associated with a high level of dependence.

These families need intensive, effective and continuous support, hence the importance to better understand their social life.

**The social life of the family**

In these parents’ age range, isolation is common, as they no longer have a professional activity and can experience limitations due to physical or mental problems. However, in these cases, isolation is more strongly felt due to the limitations of their dependent children. Parents’ time is divided between daily chores and the care provided to their children, “I always have a very busy day at home. There is no time for conversations. I spend days without even talking to my sisters” (EM1); “I have a very busy day. There’s no time for talks” (EM2). It should be noted that parents’ isolation is more evident in the mothers, because the functions inherent to being a mother and a housewife are time-consuming. The same does not apply to the fathers, which is confirmed by the data collected: “I go to the café to read the newspaper and chat with friends” (EP5); “I go to the shopping centre to talk with some friends” (EP3); “I go up to Miramar to meet some couple friends and chat” (EP3).

Leisure activities for disabled people require an additional effort from parents, since society still does not recognize leisure as an essential right of disabled citizens. Marcellino (1995), cited by Loss (2008), argues that leisure can be seen as a cultural action since educators can transform it into a factor of social and human change. While analysing our participants’ discourse, we noted that these parents provide their children with a very poor range of leisure activities “If I am able to go out with him at the weekend, he comes with me. If not, he stays home” (EM1); “We usually go out at the weekend” (EM1); “He spends the weekend at home, lying down or sitting in bed” (EM2); “At the weekend we always go out to lunch with some couple friends” (EP3); “Really likes going to parties and fairs” (EM4); “At Christmas he always goes to the circus, at Saint John’s Feast he likes to go downtown and party with a plastic hammer” (EM4); “He comes to all the parties here at the centre” (EM4).

These activities are in a way inherent to both the parents’ age group and cultural level.
The parents consider physical activity to be important, but they do not offer their children opportunities to exercise: “I’d like him to swim” (EM1); “I’d like that he went out more, even if it was just for a walk around the neighbourhood” (EM2); “It would be important for her to do some exercise, but only if it was here at the centre” (EP3); “I’d really like that there was a gym here at the centre” (EP5).

Leisure activities may be filled with joy, development, pleasure, and companionship. Messa et al. (2007) argues that leisure is a moment for the exercise of citizenship and contributes to social inclusion. However, by analysing the narratives, we realized that the activities developed contribute in some way to social isolation “Watching TV” (EM2); “Listening to music, watching TV” (EM1); “Listens to music, watches TV” (EP5). Holiday time is filled with activities other than those previously mentioned: “In the holidays we go to the beach for a whole month, Lavadores, Salgueiros, Espinho, whichever I feel like, but always from bus to bus, always the two of us” (EM1); “On holidays we always go to the Algarve” (EP3); “On holidays we go to the Algarve” (EM4); “On holidays we always go to the beach (...) (Benidorm/Algarve) and to a medical Spa” (EP5).

Daily life is filled with a great diversity of activities, and a triggering of emotions often results from accomplishing these activities. These emotions are not only related to the performance of the task itself but also to personal characteristics and the surrounding environment.

**Emotions expressed by the parents**

When caring for someone, several feelings may arise. Glajchen (2004), cited by Botelho (2008), mentioned that caregivers may experience psychological changes (anxiety, stress and depression) “But this is painful. My daughter is a constant concern, she is always in my head” (EP3); “This is my cross to bear” (EP3); and physical changes “I am tired, very tired. To dress him, I have to be on my knees and I have a lumbar hernia, I’m really not well. At the end of the day I am always tired and I don’t go to bed early” (EM2).

When one of the family members is ill or dies, the balance of the family unit is broken, leading to a significant change in the family structure, as the disease of a family member shakes up the whole system. A clear idea in the participants’ discourse is the concern with their health “My only fear is that I become ill. I have no one to help me” (EP5). We can see that these parents care for their children on their own and experience caregiver’s loneliness. Caring for a dependent person in a family environment is no easy task and the demands of being an informal caregiver may even lead to problematic situations, considering the negative impact that they bring upon the family structure and functioning.

**Needs felt/expressed by the parents**

Araújo, Paul, and Martins (2009) in his study “Home care of the dependent elderly: a few heart-felt considerations from someone involved” observed that the participants, based on their experiences, mentioned more difficulties in providing support for universal self-care because these require greater physical effort both in the provision of hygiene care and in mobilization, thus contributing to fatigue, wear and revolt. During the act of caring, caregivers may be overwhelmed by feelings of stress which are often motivated by the overload of care, the type of care dependence and factors internal and external to the caregiver. “I find it very difficult, but I have to face the fact, I won’t send her anywhere else” (EM2). After analysing the interviews, the type of self-care that is referred to more often and appears to be the most difficult for parents is personal hygiene “I have many difficulties, but the worst thing really is the bath” (EP3); “It was really hard for me but now I am used t. That’s the way it is, it’s my cross to bear” (EP3); “To take a bath” (EM2); “To take a bath and shave” (EM4). It should be noted that these parents have a strong connection with their children.

The parents in this study emphasize the little dependence of their children in relation to their chronological age, since they need constant supervision in their activities. “Only needs guidance in terms of space” (EP5); “To go out, be never walks alone on the street, nor is be alone alone” (EM4); “Walks on the street, we’ve never accustomed her to doing many things” (EP3). It should be noted that there is dependence in terms of mobility; one of the participants in the study mentions his son’s difficulty in using public transportation and the need/desire to have his own means of transport. “I would love to have a van that would take him to the centre, it is hard” (EM1).
Family support resource centres

One of the factors which may or may not generate caregiver’s stress is social support. Sierra, cited by Figueiredo (2007), mentions that social support can contribute to generating less stress in the caregivers, “If it weren’t for you, I would be in an even more painful situation” (EP3); “The centre is the only help I have to take care of my daughter” (EP3). However, when support to the family is absent or inadequate, or poorly oriented, it can generate stress. “I have to find someone to help me take care of the house, iron, cook. I can’t take it anymore” (EP3). Figueiredo (2007) highlights that one of the ways to reduce/alleviate stress may be an effective social support to meet caregivers’ needs, “The only support I have is from the City Hall of Gaia that takes my son to the Centre” (EM2); “The centre is the only help I have to take care of my daughter” (EP3). However, most of the times, the caregiver gets social support to take care of his/her relative, making the job “lighter”, and helping caregivers free themselves from certain situations which are potential stress generators.

Conclusion

Ageing is a natural phenomenon of the life cycle which is intimately connected to the human being. Thus, all sectors of society are held accountable and intervene in a constructive and positive way in taking care of their elderly. Elderly parents take on the care of their children by themselves. This fact is embedded in the reality of our society, which is not “ready” to establish partnerships to care for disabled people. In addition, the support available for parents is scarce or non-existent in most cases. We analysed parents’ needs (elderly caregivers with disabled children), and we concluded that they need help to deal with self-care, guidance and transportation. Thus, the identification of these aspects suggests that health institutions need to rethink the responses they provide to this population.

After the identification of caregivers’ needs, it was important to understand the difficulties and fears experienced by parents of adult children with disabilities. Thus, we observed that parents face social isolation because of their physical condition, scarce or non-existent social relationships and a very limited range of leisure activities. Parents show feelings of loneliness and weariness, which is a consequence of their age and/or disease, and a great fear of not being able to take care of their children due to these situations of illness.

In order to identify the contribution of Nursing to cope with these situations, we concluded that the difficulties and fears experienced by parents with disabled children are related to the lack of support, particularly regarding the future, since support from Nursing teams is practically non-existent.

Finally, social and health support which is useful to families in this situation is provided by local structures (City Hall, Health Care Centre), specialized centres, namely the Centre for Integrated Vocational Education and Training, and also individual professionals, such as Physiotherapists and housecleaners.

We believe that in the near future this issue will raise more interest among researchers by the simple fact of being understudied. However, we acknowledge the need to address it so as to understand the needs of elderly parents who care for disabled children.

The results of this study lead us to believe that there is still a long and arduous way to go regarding elderly parents who care for their children. Nurses are expected to take responsibility for the provision of care to these people who are so different, but so special. We hope that this simple study may be a starting point for future studies, as well as for the design/implementation of care plans which meet the identified needs.

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