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Types of support to families of children with disabilities and their influence on family quality of life

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Abstract *Different types of supports to families are among the aspects that contribute to family quality of life. This study aims to identify the types of supports that families of children with disabilities, users of early intervention services, consider relevant and how public administration influences the quality of this support. This is a qualitative study based on a critical social paradigm. Sixteen mothers and four fathers were interviewed and their contributions were analyzed using discourse analysis. The importance of family support and networks of parents of children with disabilities were highlighted. The role of the supports by health professionals is also crucial and, therefore, cuts in public health and social services have exacerbated the inequity in health. In practice this is highlighted in relation to those who can and the ones who cannot afford additional services. Other approaches in the support to families are suggested.*

Key words *Family quality of life, Qualitative research, Family care*

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Introduction

Research focused on conceptualizing family quality of life derived from studies conducted on the impact of having a family member with a disability[1,2]. In addition, interest on family quality of life also emerged as an evolution of research on individual quality of life, and thus shares its basic principles[3]. Therefore, it is understood that both individual quality of life and family quality of life are multidimensional constructs influenced by various objective and subjective factors. They are often composed of the same dimensions for all individuals or groups, although some aspects may be more important than others. Studies in this area are also characterized by the use of multiple research methodologies specifically aimed at understanding this phenomenon and developing practical proposals to improve the lives of people with disabilities and their families[4-6].

It can be highlighted that the pioneers on family quality of life research are the group of the Beach Center on Disability Research at the University of Kansas (USA) and the International Project on Family Quality of Life, which was initially composed of researchers from Canada, Australia and Israel. Both groups have contributed significantly to the development of the conceptual framework and instruments for measuring family quality of life.

The group of the Beach Center on Disability Research at the University of Kansas has published a series of studies on the development of a definition for family quality of life[7,8] and an instrument for its measurement[8,9]. According to the authors, the family consists of all members who are considered part of it, whether by blood, marriage relationships or even without any of them, but who help and care for each other regularly. Therefore, family quality of life includes all family members and refers to what is necessary for everyone to have a satisfying life at the individual level and in the family unit. Thus, family quality of life consists of five dimensions: family interaction, parenting, emotional well-being, physical/material well-being and disability -related supports[8]. This instrument has been adapted and validated in Spanish by the University Institute for Community Integration (INICO)[10,11].

Researchers on the International Project on Family Quality of Life developed a conceptualization for family quality of life based on their experience in the field of individual quality of life[12]. According to this research group, families enjoy a satisfactory quality of life when they get what they strive to achieve; they are satisfied with what they have achieved; and are able to live the life they want to live[13]. From this perspective they have developed a conceptualization of family quality of life that integrates nine dimensions defined as health, financial well-being, family relationships, support from other people, support from services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civic involvement. Studies have been conducted on the validation of the psychometric properties of the Family Quality of Life Survey (FQoLS-2006)[3,14]. Currently there are two versions of the scale: a general version for families without members with disabilities and one version for primary caregivers of people with intellectual disabilities. In addition, the instrument is already translated into different languages, including Spanish[12].

Additionally, researchers from the Itineris Foundation conducted a study in 12 countries in Latin America (Argentina, Mexico, Guatemala, Honduras, Peru, Bolivia, Chile, Puerto Rico, Venezuela, Brazil, Colombia and Uruguay) in order to develop the Latin American Quality of Life Scale (ELCV, from the original *Escala Latinoamericana de Calidad de Vida*)[15,16]. This group based their research on the dimensions of individual quality of life proposed by Schalock et al.[5], although the ELCV has individual and family applicability. Finally, another group to note is the research group on Disability and Quality of Life: Educational Aspects (DISQUAVI) of the Faculty of Psychology, Education and Sport Blanquerna of the Ramon Llull University (Spain)[17].

While there may be differences between the contributions of different groups, supports are generally considered as a key element on family quality of life. These supports can be directed to the disabled person and indirectly can have an impact on the family, or even direct support to the family as a whole.

This study aims to investigate the influence of supports to families of children with disabilities that attend physiotherapy services in early intervention, in order to identify how public policies can influence on the improvement of family quality of life.

Methodology

This study was carried out in Mallorca, Balearic Islands (Spain). It is a qualitative research based on the critical social paradigm[18]. The purposive

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sample consisted of parents of children less than 6 years old who have a disability or developmental disorder and attend physiotherapy. Participants were recruited through early intervention services of Mallorca in which health professionals facilitated access to potential informants. A socio-demographic questionnaire was utilized to identify characteristics of the families. The selection of participants was based on the inclusion criteria regarding the child's disability, family members, time that attend early intervention services, socioeconomic profile of the family and housing location. Participants were 4 fathers and 16 mothers of children with a disability or developmental disorder.

The information was gathered through face-to-face individual or dyads (father and mother) semi-structured in-depth interviews in order to reach saturation. Interviews were recorded in two tape recorders and transcribed Verbatim. Discourse analysis was utilized for data analysis. Only texts that constitute discourses, as defined by Antaki et al.[19] and Peräkylä and Ruusuvuori[20], were selected and analyzed. Discourses regarding family supports and the involvement of public policies in the transformation of services aimed at improving family quality of life were selected for analysis. This study is part of a broader research that also involved pediatrics early intervention physiotherapists. Triangulation of information through different sources and methods was utilized as a means of methodological rigor. The Ethics Committee of the University of the Balearic Islands approved this work.

Results

Initially, all contributions arising from the interviews agree on the importance of supports to family quality of life. Thus, the support received by the extended family (parents, siblings, close friends, etc.), other parents in similar situation and health professionals represent an aspect that undoubtedly contributes to family quality of life.

Participants described the collaboration of the extended family on childcare in certain circumstances and as an occasional economic support. Parents pointed that the possibility of leaving children in the care of a member of the extended family is an element that contributes to their family quality of life. However, it also became apparent that not all families have their extended family nearby to offer this support. On the other hand, there are families who cannot count on this kind of informal care because of difficulties arising from the child's condition. The quote below illustrates this situation.

We can't leave the child with her grandmother as any other child. If the girl is sick, so we have to take her to work with one of us. Or we can't go to work. (P_01d)

Occasional financial support is another form of support received from the extended family. It happens at peak times and for some participants it is perceived as a crucial aspect. Additionally, the consideration that public aid is insufficient emerged on the accounts. Thus, the possibility of counting with a financial support is a reassuring aspect for families.

The State really doesn't help. [...] *Or you have family to help, or... Thank God we have it, but of course, it is a problem*. (M_06d)

Another support for families is determined by the role of professionals of early intervention services. They appreciate the continued advice and the possibility to share their questions and their concerns with professionals. The words of this mother below illustrate this:

The fact of going to treatment two days a week and talk about certain things, I feel like life is rolling very normal. And here we get a continued advice, ok? It is always a welcome. A permanent support and it covers... I think it answers all my doubts, my fears. [...] *I feel like I have a constant support here*. (M_07)

Specifically, families highlight that the support received by physiotherapists is related to both the psychomotor improvement of children, as well as to provide information on child development and words of reassurance. The latter represents a kind of emotional support.

I think that if it were not for them (physiotherapists)*, my son wouldn't be as he is now, gaining autonomy. For me it would take more time thinking: what happened? Why is he like this? I mean, feeling a little guilty, even if I'm not but I'd feel guilty. Their support allowed me to be happier in a way that… well, I have their support. I know that they're helping me to get things for my son*. (M_02)

In the opinion of the participants in this study, home services can be a key support for families who have children with disabilities. They consider that home care supply for public and subsidized services could be beneficial for improving family quality of life, mainly because it would minimize displacements to services. However, in the context of this study, families' accounts regarding home care shows a utopian perception, and not as an available service. It can be observed in the words of this mother.

It would be great for quality of life that children who needed could receive physiotherapy at home. That would be great, you know? Like the elderly who get home care physiotherapy. That would result in better quality of life for everyone. (M_14d)

Another type of professional support comes from schools where physiotherapists attend children with disabilities. Interviewees consider that physiotherapy in schools is an important support while children attend public early intervention services or other private services. However, it is insufficient once the child has been discharged of early intervention services. Specifically, participants refer to little time spent on each session and the infrequency of physiotherapy sessions a week, demonstrating insufficient human resources.

In addition, another aspect that has emerged in parents' accounts is the effect of discontinuity of professionals raised by temporary employment contracts. This results in a loss in quality bearing contact between the therapist and the family. In these circumstances, communication may not be as continuous as in early intervention services.

The problem is that they change, because as they are hired by the Govern (Balearic regional government) *and they don't want to offer permanent contracts, so there is a different physio every 3 months, 4 months and it's like 2 or 3 each year*.

In any case, one of the most valued elements is that there is coordination between physiotherapists at schools and at early intervention services. Participants consider that support to child and family is more productive if there is collaboration between professionals.

They also contact with the center. I see they try to work in the same direction. (P_16d)

Nevertheless, families prioritize sufficiently endowed public services to meet the needs of their children, which according to interviewees it does not occur in the context of this study. So, families must seek alternatives for longer or more often therapeutic care. This quote illustrates this general consideration:

There should be more places and more physios to work with children. We shouldn't have to pay for private services. At school too. There should be more physios and the kids should spend more time on therapy. Because there are many parents who can't pay for a private physio and can't offer their child the chance to have therapy more often and work harder just for an economical issue. (M_09)

This aspect was certainly one of the key elements that underpin the different contributions of the participants, showing a situation of inequity in health care for economic reasons and how it affects the family in general.

Then, of course, those who can pay can offer something else to the child and the ones who can't, what happens? The child hasn't the right to get a walker or can't have a life like my son? So, that's what happens, everything is for economical reasons! So, in my opinion, it isn't fair that many children don't have the same chances because of daddies and mummies economy. (M_09)

Another circumstance of inequality that emerged from participants' accounts is related to technical aids for their children. Due to their high prices, families cannot afford to purchase them. Besides, public funding is usually not enough. This leads to an anxiety that affects the family in overall. Considering that interventions in childhood are decisive for possible adult development, the following quote shows how this inequality is perceived in the context studied.

This girl I saw the other day walking and her mother said: "yes, it is the walker of another child." Well, why can't she have a walker for her own and use it at home too? [...] *I think these issues need more social consciousness, isn't it? Social and political! I mean, priorities. I think it should be a priority*. (M_02)

The condition of injustice was present in reference to the need of advocacy expressed by families. That is, the need of constantly demanding with the government to receive what is rightfully theirs, plus all the complexity comprising having a child with disabilities.

I still have to ask the government to take responsibility and, even doing so, we don't really get what my daughter needs... I feel like there are first-class and second-class citizens. I mean, for example, a person breaks a leg and goes to the hospital and this person gets the physio he or she needs to rehabilitate that leg, but when this rehabilitation takes a long time, then of course you don't get the treatment you need, plus the budget constraint that says such a child can only get this. [...] *And then they* (the government) *tell you that the laws are not to be accomplished; they are a framework where to go*. (M_01d)

Thus, it became clear in speeches that bureaucratic activities and efforts to provide continuing care for children are actions that require even more time and overload the family routine, in addition to the emotional stress they generate.

The lack of priority from government on child healthcare is generally perceived with in-

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dignation. Participants' accounts highlight that efforts made during childhood can be decisive for the future of these children, as seen in the words of this mother when she emphasizes the word "fundamental".

I think that these things should have more social consciousness. Social and political. [...] *I think this is kind of an investment for the future because if you invest on a child's development, then after a few years this child will be autonomous, and if not, this child will be always dependent on someone else* [...] *then they'll go to social welfare, or later to the government. Why not doing it when they're young and it's a FUN-DA-MEN-TAL age for development?* (M_02)

Regarding non-professional support, parents' speeches show the support received by the peer group, in this case by other parents of children with disabilities. According to them, participation in associations is an element that contributes to family quality of life because it gives them the opportunity to share their experiences and information sources.

The truth is that many parents have helped us, in the association, so we got not only professional help but also support from all the people who have lived or are living the same situation. And they have more experience, their children are older, so they have helped us a lot: search here, search there, check this website, or take this that I don't use anymore. We got a lot of help, from parent to parent. [...] *I think it is a very beneficial partnership*. (M_01d)

It seems to be especially important in families of children with minority syndromes, as seen in the words of the mother below.

The only information we got about Rett syndrome was through the Catalan association. [...] *Rett syndrome is a minority syndrome. Many professionals here don't even know how to spell it*. (M_14d)

However, their speeches also revealed that not all parents choose to get into associations or parent groups and they try to lead a normal life with no link to any peer groups.

Finally, the results of this study show that it is necessary to seek the maximum normality on family routine in order to enjoy a good family quality of life. Therefore it is essential to count on some supports to carry out the family daily routine, highlighting the support received by the extended family and economic resources.

We have to try to make our life as normal as possible, ok? In our case many people help. Her mother (referring to his wife's mother) spends a lot of hours here. So we try to make a normal life. [...] *We practice sports. We try to go out occasionally with friends or only the two of us as a couple or with the girls...* (P_14d)

Discussion

The importance of supports for quality of life in families of children with disabilities is unquestionable. According to the literature, these can happen from various sources and ways, which will be detailed below. In this study, respondents agree on the influence of supports by the extended family (grandparents and uncles of the child, etc.) and professionals attending the child and the family. Fathers and mothers interviewed also added the support received from other parents in a similar situation.

Commonly, fathers and mothers may count on the support of grandparents especially in regard to care tasks not only of the child with impaired development but also of other children. The support of the extended family can also happen as an economic support at times. On the other hand, support by professionals means both active listening of doubts and concerns, as well as advice regarding aspects of everyday life. Particularly with regard to the intervention of physiotherapists, its influence on motor development of children is seen as a support for both the autonomy of the child with an impact on daily routines, and for the psycho-emotional well-being of the entire family. Finally, the support of other parents primarily on partnerships is an element that allows them to share their anxieties and learn from other experiences, while it is important to note that there may be families who do not want to relate to people in a similar situation.

Other studies have reflected similar findings. The work of Davis and Gavidia-Payne[21] states that professional support is one of the strongest predictors of family quality of life. Regarding other sources of support, extended family seems to positively intervene in family interactions and parental satisfaction with their roles as parents. Moreover, in their study they include the support of friends although their influence is limited to improving emotional well-being and not as part of informal care.

However, the high importance given to supports and the low level of satisfaction with them is a recurring finding in the literature. Studies by Brown et al.[22] and Werner et al.[23] coincide low scores for the domain "support from others" of

the FQoLS in almost all dimensions. It shows the lack of practical support from family, friends and neighbors perceived by families. Similarly, participants in the study by Neikrug et al.[24] showed dissatisfaction in this domain but mainly in relation to the "support from services".

In this way, Cagran et al.[25] verified that despite all Slovenian families get the support of school services (special education, day programs, pediatric aid), more than half of the families in their study indicate that they do not receive the help they need. The most common obstacles that families find are related to transportation, waiting lists, difficulties on the access to services, discourteous treatment by professionals and lack of information about where to find local support programs.

On the other hand, the majority of parents on the study conducted by Steel et al.[26] indicated that they were satisfied or very satisfied with the support from services related to the child's health, but not on the attention to the family. Parents generally reported a lack of practical help and support during weekends, holidays or busier moments in family life. They also indicated that the search for a nanny for their child with a disability is more difficult than for other children or very expensive. According to these authors, the availability of services does not necessarily mean that they are achievable, accessible and affordable, even when there is a need for support.

The results of our study show the key importance of family support in the context analyzed. Thus, the presence of grandparents who live nearby and have a good health condition and/or good economic status may emerge as one of the most important supports, especially given the insufficient coverage of professional services for formal care, as well as the need of resources for child care or technical aids. It is relevant, therefore, to take into account the impact that may be for grandparents their role as the main support[27]. This should guide further studies and policies that take into account possible adverse effects on aged people as a consequence of continued informal care to children with special needs.

Professional services are another pillar of support for families, but overall dissatisfaction was expressed in terms of availability and frequency. Given the importance of professional services, in this case physiotherapy, a greater contribution from public administration seems necessary to improve these services and avoid inequities both for the well-being of the child and the family. Additionally, given the importance of emotional support, continuous communication and advice on everyday issues should be considered to rethink these services and guide them towards a model that considers the family as a whole[28].

According to Rosenbaum[29] increasingly recognition is being given to two elements that can widen the scope of health professionals on the attention to children with disabilities or developmental disorders and justify their actions. According to this author, this new orientation of services in the studied context should focus on the attention to families and on the International Classification of Functioning, Disability and Health: version for Children and Adolescents[30]. This classification includes an assessment of aspects related to activities and participation (self-care, life at home, etc.) and environmental factors such as natural environments and supports. It is probably the most comprehensive tool in accordance with the concept of ecological child development, although not the only one that includes participation and functionality assessments.

Taking into consideration the importance given by respondents regarding support at home, it seems relevant to look at this natural environment as a contextualized and meaningful key space to families. As noted by Chiarello et al.[31], it is important that parents and children have opportunities to share their priorities with health professionals, as well as to demand the support and resources needed to carry out these activities. They also suggest that physiotherapists should explore more often the interests of children and families regarding participation at home, school and community life.

Communication is a key aspect to carrying out the reorganization of services in order to provide more efficient support to families. There is agreement in the literature regarding the importance of communication as a tool for transformation in services[29,32-34]. In this respect, Trede[35,36] proposes the practice of physiotherapy from a socio critical perspective in which professionals must be able to involve patients and caregivers in a transformative dialogue. The author notes that physiotherapists often have to deal with the tensions between scientific reasoning and the "world of life" of the patient for the provision of a meaningful and relevant service. However, Giné et al.[37] point that even after more than 30 years of early intervention services in Spain, professional intervention remains focused on the child with a primarily rehabilitative purpose. In addition, the model of "expert"

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continuously dominates the relationship with parents. Sometimes, they are also considered as "co-therapists" in which the role of parents in the therapeutic process of their child is limited to compliance with the guidelines transmitted by the physiotherapist. However, they acknowledge that the change to a family-centered intervention takes time. It depends not only on new proposals to adapt training and professional tradition, but should also consider the social, economic, political and cultural reality of the country.

The routines intervention model developed by McWilliam et al.[40] is a good model for rethinking the intervention in physiotherapy services in early intervention, even though it is possible to find different family-centered approaches and methodologies[38,39] on the literature. The routines model is based on the routine of the child and the family and seeks to identify "problem" activities or, in other words, the events in their routine with which they are not satisfied. Based on this, the approach to intervention to support families is decided to provide maximum stimulation to the child so that it is favorable and agreed with them without generating an overload on parents[40,41].

In addition, this model proposes the creation of an ecomap from which professionals can visualize family ecology and identify available resources, such as social support networks[40,41]. The routines intervention has a fundamental feature in regard to family empowerment. It gives them the opportunity to identify what works well and what they want to change. In turn, physiotherapist may obtain information about family quality of life that will permit them to identify which types of support may be necessary and effective for each family.

Conclusion

Families of children with disabilities require support from various formal and informal sources in order to have a better quality of life. In the context of this study it seems necessary to have a deeper understanding on family quality of life in order to implement measures designed to strengthen informal support networks, which could be provided primarily by the extended family. Such understanding could also be useful to mitigate the negative consequences that the provision of continued support may entail for close relatives.

Families also value the support offered by health professionals in early intervention services or schools for children with disabilities. Therefore, actions aimed at generating an equitable system in public services such as improving its availability, coordination and continuity of use will have an undeniable impact on family quality of life. It is also possible to explore the possibilities of home care, especially from family-centered approaches and routines.

This study shows that there is a need for improvement in the availability of family supports in general aspects, but also in some specific issues like the ability of social and healthcare systems to listen to families' needs, ease on administrative procedures, support for the acquisition of technical aids, strengthening of peer networks, availability of formal caregivers or supports for family routine.

Collaborations

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