Care of Children With Disabilities in Rural Areas: Meanings and Impact on Everyday life and Health. Study Protocol

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Abstract
The general objective of this study is to describe and analyze the meanings that participants gave to the experience related to maternal caregiving activities of children with disabilities in the rural context and their impact on daily life and health. In order to achieve this general objective, the following specific objectives were established: (1) To describe the meanings given to experiences related to caregiving activities of children with disabilities; (2) To analyze the impact on daily life and health that these mothers attribute to those activities; (3) To describe how they experience the support provided by the social and healthcare system in rural areas. An interpretative paradigm was selected, using a qualitative approach and a phenomenological design. Twelve mothers were included. Data were collected through semi-structured interviews. A discourse analysis of the narrative information was performed using open, axial, and selective coding processes and the constant comparative method.

Keywords
motherhood, care, disability, gender, rural

Contributions to Current Understanding
A study is needed which examines the meaning that mothers of children with disabilities who live in rural areas give to child care experiences and their perception of the impact of those experiences on their everyday lives and health. The information provided in this regard can be very useful in designing and implementing public policies for the care of persons with functional diversity and their families which ensure access to quality care services, thus providing or promoting equitable access with equal opportunities which overcome the barriers present in rural areas.

Our intention is to describe what they experience when they care for their children and what the lived experience is like. We are interested in giving a voice to the protagonists of care, trying to capture both their subjective experience and describe the common elements shared with other caregivers (Creswell, 2013; Hernández et al., 2014). For these reasons, an empirical phenomenological design is the one that best fits the research objectives (Patton, 2015).

From this methodological approach we have selected as the main method for data collection the in-depth interview, method usually used in phenomenological studies. The main source of the data that support this research are the interviews carried out...
with the caregiving mothers, who experience the work of caring for their children on a daily basis.

Unlike other studies, access to the field and recruitment of mothers is also different. We have chosen to use the experience of an NGO—which has specific knowledge of the cases of greatest impact and affection among the mothers caring for children with disabilities to whom they offer their services—and the field resources available to them, in a rural context where access and mobility to this segment of the population was complex. This NGO carried out the initial filtering and selection, and once the informants agreed to participate in our study, the time and space of the rehabilitation of their children in the NGO was used to carry out the interview, seeking to have a minimum impact on their routine and care of their children.

With regard to the analysis of the data, an inductive analysis has been chosen, “which is characterized by a construction of categories emerging from the content, and which could therefore be inferred” (Arbeláez & Onrubia, 2016). In this sense, the predetermined categories with which other studies on mothers of children with disabilities have been carried out, although they have been validated, are still a previous template to which any experience must be adjusted, and which have a lower potential for innovation and exploration of unique realities and experiences.

In addition, in order to ensure the trustworthiness of the results, we have complemented the interviews with other research methods such as reviewing the notes in the field notebook or contrasting them with the professionals of the NGO where the interviews are conducted.

**Background**

Usually, the birth of a child implies important changes in the daily lives of their parents (Buzzanell et al., 2017). The challenge of adapting the family’s occupational routines will be much more significant when the child has some type of disability (Cankurtaran Öntas & Tekindal, 2016; Larson, 2010; McCann et al., 2012), since parents will have to provide support of greater or lesser intensity and temporality in such aspects as activities of daily living (especially food and hygiene), transport, communication, playing, or social participation (Bourke-Taylor et al., 2010; Ranehov & Håkansson, 2018).

In his multivariate model, Resch (2012) claims that the welfare of parents of a child with some type of disability depends on different variables which can be grouped into three general domains: (a) individual characteristics of the child, such as health, age, and sex; (b) the subjective assessment of the parents, such as stress level and the belief in personal growth due to the challenges of raising a child with disability; and (c) environmental/social characteristics, such as economic difficulties, family resources, support, and access to services.

According to the literature available, in all societies for which there are records, it is mostly women who perform care tasks of children with disabilities (Bourke-Taylor et al., 2010; Ranehov & Håkansson, 2018; Tomeny, 2017). In many cases, this leads them to leave their jobs in order to devote more time and energy to caregiving activities (Yagmurlu et al., 2015). Quitting their jobs, together with the reduction in purchasing power and the possible reduction in social participation activities, may have important consequences in their daily lives (Hodgetts et al., 2013) which can significantly increase stress and health problems (Chambers & Chambers, 2015; Gallagher & Whiteley, 2013; Heitink et al., 2017). These health problems are more pronounced in mothers than in fathers of children with disabilities (Allik et al., 2006). On the other hand, some authors have found that the mothers of children with disabilities find enormous satisfaction and an extraordinary sense of vitality in child care (Murphy et al., 2007).

When addressing the territorial contexts where children live, it should be considered that families living in rural areas have to face a number of needs and barriers resulting from rurality, such as isolation and difficulties linked to geography (Murphy et al., 2012; Sodi & Kgopa, 2016), the lack or shortage of means of transport to access the different professional rehabilitation services from rural areas, or the remarkable lack of support services which ensure adequate care of children with disabilities and their families (Bristow et al., 2018).

In order to meet the needs arising from the care of dependent persons, the Spanish Government passed in 2006 the Act on the Promotion of Personal Autonomy and Care of dependent persons (Dependency Act, from hereon), a range of legislative measures which extended and tried to organized long-term care policies (Camacho et al., 2008). The Dependency Act recognizes “equality in exercising the subjective citizen right to promotion of personal autonomy and care of dependent persons.”

However, its implementation has not been without criticism: on the one hand, due to its conceptualization of dependency and autonomy (Guzmán et al., 2010), to the lack of resources and services offered, the waiting time for assessment as dependent person and for access to the benefits derived from the recognition of this right (Martínez, 2014), or even the fact that this law perpetuated the burden of care on families and particularly on women (Serrano et al., 2013).

On the other hand, the economic crisis and the implementation of public expenditure control policies by the main European governments. Among these was the Royal Decree-Law 16/2012, which caused important changes in the original measures included in the Act and which originated a “comprehensive reform” or “refounding” of the Dependency Act (Montserrat, 2015) since it significantly restricted the rights of beneficiaries and reduced the supply of benefits and services.

Even though the Dependency Act was more oriented toward care for the elderly, it finally had to adjust also to care for children with disabilities and their families. According to data from the Sistema para la Autonomía y Atención a la Dependencia as of December 31, 2019, 66,612 children under the age of 18 were considered as beneficiaries of the dependency care system. This figure represents 5.97% of the total number of beneficiaries.
There is no study in the literature which uses a qualitative approach to explore the experience of care of children with disabilities who are beneficiaries of the dependency care system in Spain. The few studies which are available in this field either have a quantitative approach or focus on other populations such as older persons or adults with disabilities.

Objectives

The general objective of this study is to describe and analyze the meanings that participants gave to the experience related to maternal caregiving activities of children with disabilities in the rural context and its impact on daily life and health.

In order to achieve this general objective, the following specific objectives were established:

1. To describe the meanings given to experiences related to caregiving activities of children with disabilities.
2. To analyze the impact on daily life and health that these mothers attribute to those activities.
3. To describe how they experience the support provided in rural areas by the social and healthcare system.

Explanation and Justification of Method

This study has been carried out following a qualitative methodology, as well as a phenomenological research approach (Denzin & Lincoln, 2012) based on the analysis of the contents of the participants’ speech (Creswell, 2013). This methodological approach allows describing the common meaning that participants give to their experiences of a phenomenon. Therefore, it is coherent with the principal goal of our study, inasmuch as we sought to know the meaning of lived experiences of mothers taking care of their children with disability (Moustakas, 1994). Thereby, we were able to explore, describe, and understand the meaning that participants gave to their reality and lived experiences. Thus, we have chosen to use a thematic content analysis that allows us to find the meaning that these contents have within their specific social context. In contrast to the analysis of thematic content from predetermined categories, we have selected an inductive content analysis, which allows us to construct emerging categories from the content of these interviews (Arbeláez & Oruñia, 2016).

Materials and Methods

- **Study period**: The study was carried out between September 2018 and September 2019. The fieldwork was conducted between March 4, 2019 and June 28, 2019.
- **End of the study**: The study concluded on September 20, 2019.
- **Scope of the study**: The study starts from the discipline of Occupational Therapy and was conducted among the mothers of children with disabilities who attended a Non-Governmental Organization located in Plasencia, a small town in northern Extremadura, western region in Spain, which serves children with cerebral palsy and other developmental disorders who come from rural areas in this region. Table 1 includes the study schedule.
- **Measurements and intervention**: Two techniques were used to collect data from the field study: (1) an in-depth interview (Brinkmann & Kvale, 2015; Denzin & Lincoln, 2012) guided by a series of semi-structured questions, although with the possibility of exploring and going into other topics which were not considered initially but arose during the interview (Carpenter & Suto, 2008). (2) A fieldwork diary (Hernández et al., 2014), which provides information about the context of the study and other elements to build a perspective of the participants’ lives. This can be useful when other investigators who did not attend the interview work with the information, and facilitates future analysis (Phillippi & Lauderdale, 2018).

A script was designed to structure the interviews based on the objective of the study, following other related papers carried out in other settings or in other similar contexts (Online Appendix A). Some questions of the interview were subsequently modified to adapt them to the contents emerging from the participants’ accounts and new questions were included. These interviews were conducted by the same investigator (PACG), who has experience in qualitative research and in the use of in-depth interviews.

All the interviews were conducted between May and June 2019, in rooms of the children’s rehabilitation centers, while these had their rehabilitation sessions. These rooms met the appropriate conditions of privacy and comfort to have a dialogue where the mothers could express themselves sincerely.

The data collection was carried out using audio recordings of the in-depth interviews with the mothers and the interviewer’s field notes. The field notes were collected during the different interviews and included data on the place of the interview, as well as additional information provided by participants before, during and after the interview. The duration of the in-depth interviews was between 90 and 120 minutes. The researchers agreed to finish the data collection once all the information was compiled and data saturation was reached.

To ensure anonymity, all the participants’ personal characteristics which could facilitate their identification were removed from this article. Once the interviews had been transcribed, the original audios were destroyed.

Table 1. Schedule of Research.

| Date                  | Task                                      |
|-----------------------|-------------------------------------------|
| September 2018        | Bibliographic search and reading           |
| October 2018          | Preparation of the research project       |
| December 2018         | Submission of the proposal to the ethics committee |
| March–May 2019        | Collection of information through fieldwork with the use of interviews with participants |
| May–July 2019         | Analysis and interpretation of the results |
| September 2019        | Preparation of the discussion and final conclusions |
Sampling/Recruitment

○ Participants: The selection of participants was carried out between March 2019 and May 2019, following a theoretical purposive sampling. Inclusion criteria: (1) mothers of children with disabilities living in rural areas of northern Extremadura (Spain)—that is, towns with less than 5,000 residents—and who had not lived in cities during the child’s lifetime; (2) beneficiaries of some type of benefit and/or service from the Sistema para la Autonomía y Atención a la Dependencia (System for the Autonomy and Care of Dependent Persons), the set of public and private services, as well as of economic benefits provided for by the Spanish Dependency Act for the promotion of personal autonomy and care and protection of dependent persons and their families; and (3) those who voluntarily accepted to participate in the study by signing the informed consent form. Exclusion criteria: families whose children were 18 or older and/or receiving services not linked to the Dependency Act.

○ Recruitment strategy: The recruitment strategy involved contacting different professionals from an NGO of disabled persons in northern Extremadura—one of the regions with the largest number of rural towns—for a first selection of mothers whose children were users of the early care and rehabilitation program and who met the inclusion criteria previously established. Subsequently, the mothers selected by the organization were contacted by telephone; if they agreed to participate, an appointment was arranged at the most convenient time for them.

When the meeting took place, the reason for the interview was explained again and all the information regarding the study was provided in writing, as well as the informed consent form, which was signed by all women participating in the study. This form states that participation is voluntary, that it would not have any direct implication for their children’s rehabilitation process but that it might be useful to improve care practices and professional interventions. It was reiterated that all information would be handled confidentially.

○ Justification of the sample size: The strategy for determining the number of participants in the study has been based on data saturation, that is, until no additional new concepts can be found (Schreier, 2018).

Data Handling/Analysis

The content analysis was performed by a thematic analysis of the data (Giorgi, 1997) with the help of the computer program ATLAS.ti 8.0 (Scientific Software Development GmbH, Berlin, Germany). Firstly, two researchers (JAFM and PMM) went through the transcriptions independently and generated the analysis units by free-flowing data (Hernández et al., 2014). Secondly, the open coding process was initiated, following a constant comparison procedure and a recursive analysis strategy (Schensul & LeCompte, 2013). This analysis was inductive, without pre-established analysis criteria or hypotheses. Thus, different coders were established, grouped later in subcategories. Thirdly, by means of an axial coding process (Hernández et al., 2014) those subcategories were integrated into wider categories of greater conceptual amplitude, based on a set of semantic linkers. Finally, following a selective coding process (Gallicano, 2013), the categories were grouped into themes, corresponding to the study’s objectives, in which the participants’ experiences and meaning are accurately grasped.

The notes of the field diary were used during the process of coding and analysis of the accounts. The researchers carried out the analysis by comparing the notes and interpretations of the individual analyses, while trying to reach a consensus. The differences between the researchers were resolved through discussion.

In order to complete the process, an external audit was conducted for the review of the data analysis by an investigator who is an expert in the field and in qualitative analysis.

Ethical and Legal Aspects

This study was approved by the Clinical Research Ethics Committee of the Integrated Health Management Area of Talavera de la Reina (Code 8/18). These research procedures were performed according to bioethical principles established in the Belmont Report, along with the Declaration of Helsinki and the Convention on Human Rights and Biomedicine of the European Council. All participants gave informed consent. Confidentiality was maintained throughout the study and only the research team has had access to the data obtained.

More specifically, throughout the process, both the mothers participating in the study and some of the NGO’s workers were afraid to participate in the interviews because they believed that by showing their critical comments on the benefits granted by the Dependency Act—even if it was meager and insufficient—this could be known by the administration that manages this aid and could result in a penalty. Therefore, it was made explicit at all times that the investigator had no connection whatsoever with the Dependency Act, that the anonymity of the entire content of the interviews would be preserved, that the recordings would be destroyed once they were transcribed and that any data that could identify them would be deleted. Similarly, the chief interviewer spent time in the waiting room of the NGO in order to make his presence more familiar to the families of the children with disabilities.

On the other hand, we were concerned with collecting their experiences in as neutral and balanced a way as possible, asking and recording not only the negative aspects that affected their lives, but also the positive aspects of the experience of being the main protagonists of this unique care for their children. Therefore, the initial interview questions were modified to allow a more global approach to the unique experience of care and not to exceed the focus on the negative aspects.

○ Confidentiality of the information: This study was carried out paying special attention to confidentiality of the
study’s participants. All the information generated and collected during this study is in compliance with the Spanish Organic Law 3/2018 of 5 December on Personal Data Protection. The document with the transcription of the participants’ accounts was coded with a letter and number. All documents containing personal information were kept under lock and key in an archive of the Faculty of Health Sciences (Universidad de Castilla – La Mancha) to which only the investigators had access. Once the research team had transcribed the interviews, the audio recordings were destroyed.

- **Informed consent:** Obtaining the participants’ informed consent was of fundamental importance. Firstly, as already noted, a manager from the NGO contacted by telephone with the participants, and informed them verbally of the study and the implications of their participation. They were also informed that their refusal to be interviewed would not have any consequences on their children’s treatment. Likewise, it was stressed that they could stop participating in the interview at any time.

Subsequently, the investigator who was going to conduct the interview met the participant and provided them with a document with information about the study and an informed consent form, as well as a participation withdrawal document.

**Rigor**

The strategies used to ensure the trustworthiness of our study were:

- **Credibility:** In order to increase the credibility of data, a prolonged engagement in the field and the triangulation of data sources, methods, and investigators were established (Creswell, 2013; Denzin & Lincoln, 2012; Strauss & Corbin, 1998). The triangulation of methods was carried out using in-depth interviews and a field diary to obtain data from the study participants. The triangulation of investigators was carried out during the analysis of the data. Additionally, an external audit was conducted for the review of the data analysis. The triangulation of data sources was carried out by means of meetings with professionals and family members after the interviews with the mothers in order to cross-check the data emerging from this study with the information provided by professionals and other mothers and/or fathers.

- **Dependability:** Given that qualitative research tries to understand the experiences of human beings, remaining faithful to the way individuals interpret their own experiences, data dependability—understood as the extent to which “the data obtained in research are true to the persons studied and to other persons who have experienced or have been in contact with the phenomenon under study” (Mertens, 2018)—is a criterion of vital importance. In order to increase the data dependability, we opted for a detailed analysis of the records collected in field notes when conducting and analyzing the in-depth interviews, verbatim transcriptions of the interviews, and member checking, once the initial interpretation of the data obtained was completed, by asking the participants whether the data interpretations represented accurately and appropriately their experience and the meaning they gave to their child care activities.

**Transferability:** In order to increase the transferability of findings, a rich, thick description was the strategy carried out (Erlandson et al., 1993; Stake, 2010), describing in detail the participants and characteristics of our study. In this way, other researchers could be able to transfer the study to other settings and to determine whether the findings can be transferred due to shared characteristics.

The consolidated criteria for reporting qualitative research (COREQ) guidelines (Tong et al., 2007) have been followed to ensure the quality of the study.

**Limitations of the Study**

Among the limitations found for this study, it should be noted that all participants come from the same geographical area. Thus, it would be useful to have participants coming from other areas within the region where there are numerous rural towns. Likewise, it would be relevant to compare the perspectives and meanings about care of children with disabilities of mothers from rural areas to those of mothers from urban areas.

On the other hand, this study has focused on primary caregivers, although it has been found that care tasks are closely connected with the care provided by other women, such as grandmothers and sisters. The information that these women could provide would be of great value to conceptualize the experiences and meanings of care in rural contexts. Similarly, it would be very relevant to know the perspectives and meanings that fathers give to both the care tasks that they perform and those performed by their partners.

**Implications for Research and Dissemination**

This study has a pioneering and original character that may allow us to explore the needs and aspects of support presented by women who care for children with disabilities in rural contexts who also receive aid from the Dependency Act, one of the most relevant social policy measures implemented in recent years to care for people with disabilities and their families. This knowledge can be useful in decision-making for managers of organizations working with disabled persons and their families, and for those responsible for the design, implementation and evaluation of public policies. On the other hand, this research can be replicated in rural contexts both in Spain and in other countries.
This paper can be presented in meetings of families of persons with functional diversity, in scientific congresses, and its findings can be published in scientific journals.

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Supplemental Material

The supplemental material for this article is available online.

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