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Perspectives of being a female informal caregiver of children with disabilities

Perspectivas do ser cuidadora informal de crianças com deficiência
Perspectivas de ser cuidadora informal de niños con discapacidades

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Abstract

Objective: To know the perspective of being a female informal caregiver of children with disabilities. **Methods:** A descriptive, exploratory and qualitative study. The participants were female informal caregivers of children with disabilities. Data collection took place through four virtual focus groups, via the Google Meet platform. The analysis was carried out by means of Thematic Content Analysis. The criterion for categorization was semantic. The categories that emerged were named in the light of the relevant scientific literature. **Results:** Three categories emerged after analyzing the focus groups, namely: Category 1 - Peers as support network; Category 2 - The spirituality experience; and Category 3 - Concerns about social and legal aspects. **Conclusion:** The perspective of being a female informal caregiver of children with disabilities involves a negative and positive aspect. Negative, in the sense that there is dissatisfaction through the judgments imputed by society in relation to them and the legal framework that governs their rights. Positive, through the support network comprised by other mothers of children with disabilities and the spirituality experience in the care context, making the care routine smoother.

Descriptors: Caregivers; Disabled Children; Qualitative Research.

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Whats is already known on this?
There is certain overload of activities in charge of caregivers, which has repercussions on physical, emotional and social aspects. The care of children with disabilities is primarily exercised by the mothers.

What this study adds?
The support network found by the female caregivers goes beyond the family and is also found in the experience with other fellow women. The concerns signal the need for empowerment by this population segment.

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Resumo

Objetivo: *Conhecer a perspectiva do ser cuidadora informal de crianças com deficiência.* ***Métodos:*** *Estudo descritivo, exploratório, de abordagem qualitativa. As participantes foram cuidadoras informais de crianças com deficiência. A coleta de dados se deu por meio de quatro grupos focais virtuais, pela plataforma Google Meet. A análise ocorreu por meio da Análise de Conteúdo Temática. O critério para a categorização foi o semântico. As categorias emergidas foram nomeadas à luz da literatura científica pertinente.* ***Resultados:*** *Após a análise dos grupos focais, emergiram três categorias: categoria 1 - Os pares como rede de apoio; categoria 2 - A vivência da espiritualidade; categoria 3 - Inquietações frente a aspectos sociais e legais.* ***Conclusão:*** *A perspectiva do ser cuidadora informal de crianças com deficiência envolve uma ótica negativa e positiva. Negativa, no sentido de que há uma insatisfação mediante os julgamentos imputados pela sociedade em relação a elas e ao arcabouço legal que rege seus direitos. Positiva, por meio da rede de apoio que demais mães de crianças com deficiência formam e da vivência da espiritualidade no contexto do cuidar, tornando a rotina de cuidados mais suave.*

Descritores: *Cuidadores Informais; Crianças com Deficiência; Pesquisa Qualitativa.*

Resumén

Objetivo: *Conocer la perspectiva de ser cuidadora informal de niños con discapacidades.* ***Métodos:*** *Estudio descriptivo y exploratorio con enfoque cualitativo. Las participantes fueron cuidadoras informales de niños con discapacidades. Los datos se recolectaron por medio de cuatro grupos focales virtuales, a través de la plataforma Google Meet. El análisis se realizó por medio de Análisis Temático de Contenido. El criterio para la categorización fue semántico. Las categorías emergentes se nombraron a la luz de la literatura científica pertinente.* ***Resultados:*** *Surgieron tres categorías después de analizar los grupos focales, a saber: Categoría 1 - Los pares como red de apoyo; Categoría 2 - La experiencia de la espiritualidad; y Categoría 3 - Inquietudes relacionadas con aspectos sociales y legales.* ***Conclusión:*** *La perspectiva de ser cuidadora informal de niños con discapacidades implica un aspecto negativo y otro positivo. Negativo, en el sentido de que se registra cierta insatisfacción debido a los juicios de valor impuestos por la sociedad en relación a ellas y al marco legal que rige sus derechos. Positivo, gracias a la red de apoyo constituida por otras madres de niños con discapacidades y a la experiencia de la espiritualidad en el contexto de la atención, aliviando así la rutina del cuidado.*

Descriptores*: Cuidadores; Niños con Discapacidad; Investigación Cualitativa.*

INTRODUCTION

People with disabilities are defined as those with permanent restrictions of a physical, intellectual, mental or sensory nature. For continuous diagnosis and monitoring, a multiprofessional and interdisciplinary approach is required.(1) According to the United Nations Children's Fund (UNICEF), it is estimated that there are 240 million children with disabilities in the world.(2) In Brazil, the number is 3,905,235, according to the census carried out in 2010 by the Brazilian Institute of Geography and Statistics.(3)

In this perspective, the arrival of a child with a disability in the family represents changes in its dynamics, with postponements of life projects and social life deprivation, in addition to economic and material impacts, as a result of losing the income source due to unemployment and increased expenses. In addition, there are subjective aspects related to this universe, such as feelings of grief, overload, fear, uncertainty and loneliness.(4)

Therefore, due to the multiple limitations imposed by the disability and its chronic character, this clinical situation requires the presence of a caregiver. In the context of children with disabilities, this role is mostly assumed by the mothers since, historically, the female figure has her role linked to caregiving.(5-6) In this sense, mothers assume the role of informal caregiver, which is defined as the main person in charge of providing continuous care. However, they do not receive any remuneration or technical-scientific preparation to perform such function.(6)

In addition to that, the social support that these female caregivers receive is practically restricted to other women belonging to different generations, such as grandmothers, aunts and sisters. Thus, the experience of this role entails a profound self-renunciation, which reverberates in scourges to biopsychosocial health, such as changes in nutritional and sleep patterns, impacts on the stress levels and on mental health, and anxiety and depression diagnoses.(4)

Therefore, considering the arduous and lonely path that informal caregivers have to take, from the arrival of children with disabilities in the family to experiencing the care routine for them, it is necessary to create a speech space for these women so that, from their perspectives, any interventions aimed at improving their life context can be devised. Thus, in view of the above, this study aimed at knowing the perspective of being a female informal caregiver of children with disabilities.

METHODS

Type of study

This is a descriptive and exploratory study with a qualitative approach, in which the Consolidated Criteria for Reporting Qualitative Research criteria were considered.(7)

Setting

The study took place in a virtual environment due to the Coronavirus disease 2019 (COVID-19) pandemic.

Study period

The current study was developed between April and July 2021.

Entry to the field

Inclusion of the researcher in this study was preceded by prior contact via a telephone call, followed by a face-to-face meeting with the coordinator of an Association from the municipality of Petrolina in February 2020. Subsequently, the researcher was added to the Association's WhatsApp group and started interacting remotely with the research participants, due to the physical isolation recommended by the health authorities during the COVID-19 pandemic.

Participants and sampling criteria

The participants were female informal caregivers of children with disabilities linked to an Association. Inclusion criteria: being over 18 years of age and being the main caregiver. Loss criteria: not participating in all focus groups.

Following the recommendation in relation to the number of participants in the focus groups (between 6 and 15 individuals), in order to enable the participants' effective participation and adequate discussion of the topics, this study invited 15 members of the Association through WhatsApp. However, only 12 comprised the final sample, as three discontinued their participation due to personal problems.(8)

Data collection

Data collection took place through 4 virtual focus groups, which made use of the Google Meet platform due to the recommended physical distancing during the COVID-19 pandemic. After due authorization by the participants, collected by registration via chat, the videoconferences were recorded making an audiovisual capture of the focus groups. The focus groups lasted a mean of one hour and were held in the night shift, at the participants' request.

The triggering issues were as follows: Uncertainty in the arrival of a child with a disability; Uncertainty in the face of knowledge related to the rights of a person with a disability; Where do I find strength?; Identifying the caregiver's support network; and The caregiver's social and emotional aspects in the universe of caring for people with disabilities.

It is important to note that only the first issue was previously brought up by the research team; all the others were deliberated collectively at the end of the previous focus groups.

To delimit the number of focus groups, by triggering issues, one to two meetings are recommended. However, this study was able to saturate the data with a focus group for each triggering issue.(8)

Characteristics of the research team

The focus groups consisted of the researcher in charge (who assumed the moderator role), two observers linked to the research team and the participants. The researcher in charge is a professor at a public university and was a PhD student in Nursing at that time. The observers were students attending the Nursing course where the researcher teaches.

The researcher has experience in the development of qualitative research with the theme of “Caregivers of people with disabilities” since 2015, due to the development of her MSc thesis. To align the observers' performance, the researcher in charge trained the students.

Data analysis

The analysis took place through thematic content analysis, comprising the stages of pre-analysis, exploration of the material, treatment of the results, inference and interpretation. The criterion for categorization was semantic, following the guidelines of mutual exclusion, homogeneity, pertinence, objectivity, fidelity and productivity.(9) The categories emerged were named according to the expression of the participants' speech and then interpreted according to the scientific literature.

Ethical aspects

The research was initiated after due approval of the Ethics and Research Committee (*Comitê de Ética e Pesquisa*, CEP) of the Osvaldo Cruz University Hospital Complex (*Complexo Hospitalar Hospital Universitário Osvaldo Cruz*, HUOC) and of the Pernambuco Cardiac Emergency Service (*Pronto Socorro Cardiológico de Pernambuco*, PROCAPE), under opinion No. 4,641,381. It complied with resolution No. 466/12, which approves the guidelines and regulatory standards for research involving human beings in the health area and used a Free and Informed Consent Form (FICF) with its participants.(10) To preserve the participants' anonymity, they were identified as "female caregivers" plus the corresponding ordinal sequence.

RESULTS

Referring to the results, they were structured based on the participants' socioeconomic characteristics and on the creation of three categories through the analysis of their testimonies. Regarding the participants' socioeconomic characteristics, all of them have a maternal bond with the child and are female. The other variables observed are described in Chart 1 below.

Chart 1. Socioeconomic characteristics of the participants. Pernambuco, Brazil, 2022.

	No. of children	No. of children with disabilities	Profession	Schooling	Family income	Marital status
Caregiver 1	03	02	House chores	Complete High School	From 2 to 3	Divorced
Caregiver 2	05	01	House chores	Incomplete High School	Up to 1	Married
Caregiver 3	04	01	App Driver	Incomplete High School	From 2 to 3	Single
Caregiver 4	01	01	House chores	Complete Higher Education	Up to 1	Stable union
Caregiver 5	02	01	Farmer	Complete High School	Up to 1	Married
Caregiver 6	05	01	Farmer	Incomplete High School	Up to 1	Married
Caregiver 7	03	01	House chores	Incomplete High School	Up to 1	Single
Caregiver 8	01	01	House chores	Complete Higher Education	Up to 1	Stable union
Caregiver 9	01	01	Professor	Graduate Studies	From 2 to 3	Single
Caregiver 10	05	03	Micro-entrepreneur	Incomplete Higher Education	From 2 to 3	Married
Caregiver 11	02	01	Bureaucratic assistant	Complete High School	From 2 to 3	Single
Caregiver 12	04	01	House chores	Incomplete Elementary School	Up to 1	Stable union

Source: The authors, 2022.

Three categories emerged after analyzing the focus groups, namely: Category 1 - Peers as support network; Category 2 - The spirituality experience; and Category 3 - Concerns about social and legal aspects.

Regarding Category 1, “Peers as support network”, the testimonies reveal that the group moments allow identifying people with similar life contexts that enable a unique sharing and welcoming environment where affective bonds can be built that translate into a support network among caregivers, as shown in the interviewees' statements:

> “These meetings have been very interesting. They're moments that we talk about and share situations which, on a daily basis, we wouldn't share with other people, not even with those at home, with our blood family, and here we have this opportunity and it does me a lot of good.” (Caregiver 1)
>
> “You created this space so that we could talk and exchange experiences, because in a way the mothers' stories motivate us.” (Caregiver 2)
>
> “[...] This sharing moment is just ours [...]” (Caregiver 4)
>
> “[...] Transmit to each other this strength to go forward in the face of these barriers and continue coping with this prejudice against women, which is a social issue.” (Caregiver 3)
>
> “[...] It is gratifying to know that we're managing, yes, to take care of those who take care, to have a group that is only for mothers[...]” (Caregiver 12)

Regarding Category 2, “The spirituality experience”, in the testimonies it is observed that they find comfort through the challenges inherent to their routine, through the spirituality experience, as observed in the participants' statements.

> “[...]God, he never gives a cross to a person, to you if he knows you can't carry it. I think that it calms the heart more.” (Caregiver 2)
>
> “As if to get us out of our world and into a world that God has prepared for us.” (Caregiver 5)
>
> “God empowers us every day so that we can win over and overcome every barrier.” (Caregiver 7)

Regarding Category 3, “Concerns about social and legal aspects”, the testimonies signal to which extent there is social judgment about these female caregivers and loss of individuality, to become exclusively caregivers, in addition to them feeling wronged before the legal framework that guides them, as pointed out in the participants' statements.

> “When I went out like this somewhere I felt guilty. I'd come back quickly afraid to leave him at home just because people were going to talk […].” (Caregiver 9)
>
> “I used to say ‘I'm nothing else, I can't do anything else’ because, in addition to the oppression I had inside me, I had people's prejudice.” (Caregiver 10)
>
> “Because of this benefit I have from him, I can't have a training and work, because I have to choose: either he receives the benefit or I work.” (Caregiver 11)
>
> “The fact that many people refer to me as a suffering mother.” (Caregiver 6)
>
> “[...] Thinking about the caregiver because we see public policies aimed at people with disabilities, but we see almost nothing for the caregiver.” (Caregiver 8)

DISCUSSION

The participants' socioeconomic characteristics reveal that all of them have a maternal bond with the children. This fact us corroborated by a study developed in southern Brazil, which aimed at outlining the profile, feelings and quality of life of caregivers of patients with disabilities, treated in a dental outpatient clinic.(11)

Thus, the caregiver role and the idealization of motherhood are linked to the profile outlined in the common imaginary targeted at women. This reality imputes to women an ideation about the experience of their female identity and the motherhood standards, which have repercussions on physical, emotional, social and economic burdens.(12-13)

This is because there is certain romanticization around women's role linked to motherhood, which does not dialog with reality, especially in the context of people with disabilities. Problematizing on this point involves nuances of a social, political, scientific and biological nature. Consequently, it is important to recognize that this female role is the result of a patriarchal society that has historically objectified, marginalized and hindered women's rights.(14)

Referring to Category 1, "Peers as support network", it is understood as a support network of people and relationships that are significant for the individual, allowing for the construction of relationship links.(15) This reality weaves a social support capable of alleviating the distress inherent to the care routine, favoring emotional support, exchange of information by peers and well-being.(16-18)

In this perspective, the findings of this study dialog with a research developed in northeastern Brazil, where the participants signaled the need for a social support network and spirituality, to be able to face the palliative care routine.(19) It is through this social situation that they identify their peers, share their desires and find resilience and strength to continue.

Regarding Category 2, "The spirituality experience", it is observed that spirituality becomes a resilience means in the face of destiny. Historically, spirituality has participated in the health-disease process, where health conditions were associated with beliefs and the supernatural field. However, with the rise of the biomedical model, care for an individual was mostly related to biochemical readings and to the microscopic and specialized view.(20)

Thus, in the context of caring for children with disabilities, who have a chronic clinical condition, the female caregivers indicate that they find in spirituality a way to promote well-being, as they feel strengthened by the subjective support contributed by spirituality. Some studies corroborate this topic, such as the one developed in Indonesia, which points out that spirituality fosters lower incidence of fear on the part of the participants.(21) In turn, another research study developed in Brazil identified that belonging to a religion can favor the promotion of quality of life and coping through challenging contexts.(22)

Therefore, in view of this reality, the need for Nursing assistance for this population segment becomes eminent, in the light of a holistic perspective, as recommended by the transcultural theory of American nurse Madeleine Leininger, who considers what she calls "religious factors" as an influence within cultural care, which nurses should offer to individuals, families and communities.(23)

Referring to Category 3, "Concerns about social and legal aspects", it is noted that it is necessary to expand this perspective of the caregivers in order to empower them by confronting the social stigmas that are continually being flogged. Thus, for effective health promotion, it is necessary to adopt "empowerment" in the context of these people's lives.(24)

"Empowerment" aims at raising individual and/or social awareness through a critical and reflective look at the reality experienced, glimpsing at the transformative potential of both people and communities. In this perspective, "empowerment" corroborates the implementation of the strategic axes recommended by the Ottawa Charter, namely the formulation of healthy public policies, reorientation of health services, development of personal skills, favorable environments for health and reinforcement of community action.(25-26)

Thus, only through this critical awareness raising process, which values equal access to the rights, self-care and health promotion of this population segment, will caregivers be able to face the multiple challenges inherent to their care routine. In this sense, this study contributes a peculiar perspective in relation to the target audience in question, as it reveals that, in addition to the family, peers constitute an important support network. In addition to that, spirituality favors confronting the challenges inherent to the daily routine and the concerns related to social and legal aspects, which thus call for the need to empower this population group.

Finally, with regard to the limitations found in this study, they are associated with the research virtual format during the COVID-19 pandemic, where the difficulty connecting to good quality Internet and technological inputs, such as smartphones, tablets and notebooks, hindered access for some participants.

CONCLUSION

After conducting this research, it was identified that the perspectives of being a female informal caregiver of children with disabilities involve a negative and positive aspect. Negative, in the sense that, for them, there is dissatisfaction through the judgments imputed by society in relation to them and the legal framework that governs their rights and those of their children. In addition to that, they report loss of their individuality for becoming exclusively their children's caregivers.

Referring to the positive perspective, they associate sharing spaces with other mothers of children with disabilities through groups as a way to weave affective bonds and, thus, create a powerful support network. In addition, the spirituality experience in the care context became a space of refuge and encouragement for the participants, thus softening the experiences inherent to the care routine.

Given the above, this research contributes to the visibility of this commonly marginalized population segment. In addition, it assists in guiding actions, public policies and/or intervention studies that contemplate the target audience in question, contributing to their development in an assertive manner and considering the singularities of the context. Therefore, the suggestion is to develop participatory research studies that contemplate the multiple demands of caregivers of children with disabilities.

CONTRIBUITIONS

Contributed to the conception or design of the study/research: Carvalho IJSA, Coura AS. Contributed to data collection: Carvalho IJSA. Contributed to the analysis and/or interpretation of data: Carvalho IJSA. Contributed to article writing or critical review: Carvalho IJSA, Coura AS, França ISX, Sousa FS, Linhares FMP, Lira ALBC. Final approval of the version to be published: Coura AS, França ISX, Sousa FS, Linhares FMP, Lira ALBC.

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