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RESERCH

SOCIOCULTURAL FACTORS CONTRIBUTING TO THE QUALITY OF LIFE OF FAMILY CAREGIVERS OF CHRONIC CARE-DEPENDENT ADULTS: A QUALITATIVE STUDY IN BRAZIL

FATORES SOCIOCULTURAIS QUE CONTRIBUEM PARA A QUALIDADE DE VIDA DE CUIDADORES FAMILIARES DE ADULTOS DEPENDENTES DE CUIDADOS CRÔNICOS: UM ESTUDO QUALITATIVO NO BRASIL

FACTORES SOCIOCULTURALES QUE CONTRIBUYEN A LA CALIDAD DE VIDA DE LOS CUIDADORES FAMILIARES DE ADULTOS DEPENDIENTES DE CUIDADOS CRÓNICOS: UN ESTUDIO CUALITATIVO EN BRASIL

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ABSTRACT

Objective: to explore sociocultural factors contributing to the quality of life of family caregivers of chronic care-dependent adults in Brazil. **Methods:** this qualitative study was conducted from October 2016 to March 2017 in Belo Horizonte, Minas Gerais, Brazil. Twenty-five family caregivers of care-dependent chronic adults were interviewed by two researchers through home visits. A script with seven open questions related to the care process was used. The interviews were recorded in audio, transcribed and then analyzed through conventional content analysis. COREQ was used for adequacy of the manuscript structural quality. **Results:** the study participants described different sociocultural factors contributing to their quality of life. These factors were categorized into three main categories: The impact of sociocultural constructs on the caregiving process; Self-care and its nuances: old challenges for caregivers; and Support from outsides: challenges and possibilities. **Conclusions:** the caregiver's quality of life is influenced by their sociocultural characteristics and conditions, presenting a relation with their way of living and expressing themselves and, therefore, subject to change. The development of social and healthcare policies for caring families is urgent for prevention of family burden and promotion of sustainable families living with chronic non-communicable diseases.

Keywords: Caregivers; Quality of Life; Noncommunicable Diseases; Cost of Illness; Family Health.

RESUMO

Objetivo: *explorar os fatores socioculturais que contribuem para a qualidade de vida de cuidadores familiares de adultos dependentes de cuidados crônicos no Brasil.* ***Método:*** *estudo qualitativo realizado de outubro de 2016 a março de 2017 em Belo Horizonte, Minas Gerais, Brasil. Vinte e cinco cuidadores familiares de adultos dependentes de cuidados crônicos foram entrevistados por dois pesquisadores por meio de visitas domiciliares. Foi utilizado um roteiro com sete questões abertas relacionadas ao processo de cuidar. As entrevistas foram gravadas em áudio, transcritas e, posteriormente, analisadas por meio da análise de conteúdo. O COREQ foi utilizado para adequação da qualidade estrutural do manuscrito.* ***Resultados:*** *os participantes do estudo relataram diferentes fatores socioculturais que contribuem para sua qualidade de vida. Esses fatores foram categorizados em três categorias principais: O impacto dos construtos socioculturais no processo de cuidar; O autocuidado e suas nuances: velhos desafios para os cuidadores; e Estado e cuidadores: desafios e possibilidades.* ***Conclusões:*** *a qualidade de vida do cuidador é influenciada por suas características e condições socioculturais, apresentando relação com seu modo de viver e de se expressar, sendo, portanto, passível de mudanças. O desenvolvimento de políticas sociais e de saúde para famílias cuidadoras é urgente para a prevenção da sobrecarga familiar e para a promoção de famílias sustentáveis que convivem com doenças crônicas não transmissíveis.*

Palavras-chave: *Cuidadores; Qualidade de Vida; Doenças não Transmissíveis; Efeitos Psicossociais da Doença; Saúde da Família.*

RESUMEN

Objetivo: *explorar los factores socioculturales que contribuyen a la calidad de vida de los cuidadores familiares de adultos dependientes de cuidados crónicos en Brasil.* ***Métodos:*** *este estudio cualitativo se llevó a cabo de octubre de 2016 a marzo de 2017 en Belo Horizonte, Minas Gerais, Brasil. Veinticinco cuidadores familiares de adultos crónicos dependientes de cuidados fueron entrevistados por dos investigadores a través de visitas domiciliarias. Se utilizó un guión con siete preguntas abiertas relacionadas con el proceso de cuidado. Las entrevistas fueron grabadas en audio, transcritas y luego analizadas mediante análisis de contenido convencional. Se utilizó el COREQ para la adecuación de la calidad estructural del manuscrito.* ***Resultados:*** *los participantes en el estudio describieron diferentes factores socioculturales que contribuyen a su calidad de vida. Estos factores se clasificaron en tres categorías principales: El impacto de*

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los constructos socioculturales en el proceso de cuidado; El autocuidado y sus matices: antiguos retos para los cuidadores; y El apoyo desde fuera: retos y posibilidades. ***Conclusiones:*** *la calidad de vida del cuidador está influenciada por sus características y condiciones socioculturales, presentando una relación con su forma de vivir y expresarse y, por tanto, sujeta a cambios. El desarrollo de políticas sociales y sanitarias para las familias cuidadoras es urgente para la prevención de la carga familiar y la promoción de familias sostenibles que viven con enfermedades crónicas no transmisibles.*

Palabras clave: *Cuidadores; Calidad de Vida; Enfermedades no Transmisibles; Costo de Enfermedad; Salud de la Familia.*

INTRODUCTION

Chronic Noncommunicable Diseases (CNCDs) are responsible for approximately 71% of deaths worldwide.[1] A similar epidemiological situation is observed in Brazil, where these diseases are responsible for 72% of deaths annually.[2] That is why in 2011, the Brazilian Ministry of Health, in collaboration with academic, scientific and nongovernmental organizations, coordinated the process of developing the "Strategic Action Plan for Combating CNCDs in Brazil between 2011 to 2022". This plan aims to ensure intersectoral collaboration actions in the fight against CNCDs and to reduce inequities and disparities in health.[3,4]

When CNCDs do not result in death, they can contribute to poverty, isolation, and marginalization and can generate permanent conditions and disabling injuries that limit an individual's autonomy, reducing their ability to perform self-care, which makes them dependent on others.[5,6] This situation has more serious repercussions in population groups that exhibit a higher level of social vulnerability, such as a situation of care-dependency that negatively impacts on the person diagnosed with a chronic disease as well as on their family members, often principal carers.[7,8] Furthermore, when caregivers of care-dependent persons suffer chronic diseases themselves, it was found that their quality of life (QoL) decreased more significantly.[9]

When analyzing this phenomenon under the optics of the family systems, we realize that the family is deeply affected by situations in which CNCDs result in a chronic care-dependent adult, because any life events experienced by a family member is capable of affecting the family as a whole, be it positive or negative.[10]

When examining the situation of care-dependent adults, one may perceive that the greater the level of care-dependency of a person's, the lower the QoL of the caregiver and the greater the impacts on family members. However, a cross-sectional study conducted in Brazil explored the relationship between the level of care-dependence and family caregivers´ QoL and identified other factors that were strongly related to the caregiver's QoL and not the degree of care-dependence of the individual. Virtually all of these factors could be modified, such as encouraging the adoption of healthy lifestyle habits, family encouragement to share care, among others.[9] These findings denote the diversity of factors that may contribute to the diverse experiences of families caring for their ill care-dependent member. Beliefs and attitudes can also influence families´ experience and caregivers´ QoL when dealing with complex chronic conditions.[10] Therefore, cultural beliefs and social contexts should be explored when seeking to understand the meanings that family gives to a situation that causes suffering,[11] such as a situation of care-dependency of a loved one. Studies in different contexts are needed to provide a deeper understanding of the factors that influence the QoL of family caregivers of chronic care-dependent adults.

In Brazil, where the families have a key role in caring for their care-dependent members, the Strategic Action Plan for Combating CNCDs has already led to advances in surveillance, health promotion and comprehensive care for individuals with CNCDs and their families.[3,4] Nonetheless, there is limited information about the experiences of patients and families facing chronic care-dependency situation. Besides, few studies has explored the sociocultural factors contributing to the QoL of family caregivers of chronic care-dependent adults. Therefore, the present study was conducted to narrow this gap.

Aim

The aim of this study was to explore sociocultural factors contributing to the quality of life of family caregivers of chronic care-dependent adults in Brazil.

METHODS

Study design

As part of a larger study, this qualitative study was conducted in accordance with the guidelines from the Consolidated Criteria for Reporting Qualitative Research (COREQ)[12] and undertaken using a content analysis approach for providing detailed description of phenomena. This approach is appropriate for understanding a particular phenomenon from the perspective of those experiencing it.[13] Therefore, in this present study this approach was used to provide a detailed understanding about the sociocultural factors contributing to the QoL of family caregivers.

Setting and participants

This study was conducted in primary healthcare coverage areas at two Primary Healthcare Facilities (PHF) in the city of Belo Horizonte, Minas Gerais, Brazil. The community health teams are responsible for offering primary healthcare to families in the community. Each team is composed of a family physician, a registered nurse, a nurse technician or Nursing assistant, and community health workers (CHWs). The latter are important links between the families and the healthcare facility.[14]

Caregivers of families registered with their local PHF were selected for this study. CHWs invited family caregivers to participate in this qualitative study. Inclusion criteria were being aged 18 years or older, and being a family member of an adult (older than 18 years old) with some degree of care-dependency. For this study, we used the Barthel Index criteria, an instrument that assesses the degree of care-dependency.[15] Caregivers who were paid to provide care to the care-dependent adult were excluded from this study.

Participants were selected with maximum variation, including a range of ages, different types of family relationships as well as different diseases that cause care-dependency. Sampling was conducted using purposive sampling and was continued up to data saturation. Twenty-five family caregivers participated in this study. None of the participants who were invited declined participation.

Data collection

Data were collected via in-depth semi-structured interviews opened using questions on participants´ sociodemographic characteristics such as age, marital status, family relationship with the care-dependent adult and the health status of caregivers. The interviews were continued using seven open-ended questions to explore the experiences of caregivers in relation to the caregiving process. Probing questions such as “could you please explain further about this? or “what do you mean by this” were used to understand the participants´ narratives.

The interviews were conducted through home visits by two researchers previously trained, both Nursing students with experience in collecting qualitative data (one from undergraduate course and the other from the graduate course). In the attempt to verify if the caregivers participating in the study understood adequately the proposed interview guide and schedule of questions, three pilot interviews were conducted. There was no need to modify the thematic guide because the questions were clear and precise, allowing the participants to describe their experiences. Data were collected from October 2016 to March 2017. The interviews were audio recorded and lasted an average of 30 minutes.

Data analysis

The 25 interviews were independently transcribed by the two interviewers. The transcripts of the interviews were not given back to the participants but the two interviewers compared the transcribed interviews to verify possible divergences in the transcribed speeches, which contributes to greater credibility and reliability of the study. Data analysis was performed through the three-phase content analysis by Bardin.[16] Phase 1 - Pre-analysis: performed through successive readings of all collected subject reporting (corpus) in order to provide an approximation and interaction with the content; phase 2 - Exploration of the caregiver reporting, in which exploration and treatment was performed, followed by coding and initial categorization of the analysis content. Subsequently, the initial categorization of the content of analysis formed a corpus, which was submitted to phase 3 - Treatment of Responses. During this final phase, classification and regrouping of elements that encompassed different variables and similar meanings were performed, and this process resulted in the identification of three different thematic categories that represent the analyzed information.

Then, the findings were reported in the data reporting phase. For a better contextualization of the findings, we presented the participants’ quotes identified by a codification using the letter ‘C’, referring to ‘caregiver’, followed by a number and the type of family relationship of the care-dependent adult (e.i. C1- wife).

Rigour

Transferability was ensured through maximum variation sampling. Besides, the fact that the interviewers had good communication skills helped the participants feel comfortable talking about their experiences of caring for a dependent family member at home, thus collecting reach data. Credibility was ensured through meticulous transcriptions and analysis of the data, and through rich verbatim descriptions of participants' narratives to support findings. Furthermore, appraisal of emerging codes and final categories by two senior researchers in qualitative methods promoted dependability.

Ethical considerations

The research was approved by the Research Ethics Committee [Blinded]. The caregivers voluntarily signed an Informed Consent Form (ICF) after being informed about the study proposal across all phases. Privacy and confidentiality of information were guaranteed to all participants.

RESULTS

Overall, 25 family caregivers participated in this study. Twenty-two participants (88%) were female and eighteen (72%) were between 18 and 59 years old. Sixteen participants (64%) were a child of a care-dependent, more than half were married (56%), possessed no training for care (92%), belonged to a religious affiliation (92%), practiced leisure activities (72%), did not divide the time spent caring for a care-dependent (84%), and 48% responded that they had some CNCD. Table 1 shows participants´ sociodemographic characteristics.

The data analysis resulted in three main categories that provided a further understanding of the sociocultural factors related to the caregivers' QoL. These categories were: 1 - The impact of sociocultural constructs on the caregiving process; 2 - Self-care and its nuances: old challenges for caregivers and; 3 – Support from outside: challenges and possibilities.

1 - The impact of sociocultural constructs on the caregiving process

This main category describes how social constructs, whether they be customs, beliefs or attitudes, influence the caregiving process. Caregiving and the execution of domestic chores, done by female caregivers were highlighted in the participants 'narratives.

> *Also, I am his only daughter. He has three sons. So, sometimes you have to give him a bath, because men don't perform the same care like women do ...* (C22 - daughter)

> *Nothing has changed, because all my life I have had to be a housewife. Nothing has changed.* (C19 - daughter)

Some participants referred to family help for care as a factor contributing to the caregiving process. For instance, a 27-year-old daughter indicated the importance of having her husband´s and brother´s help, especially when caring tasks required greater strength such as lifting or moving the dependent adult:

> *... I can't go up the ramp with her in the wheelchair. I call for my husband and brother to help together. You have to call for help. (C22 - daughter)*

A 57-year-old daughter also found her husband's involvement in caring for his elderly dependent father very helpful:

> *My husband also helps me a lot. He gives my father a bath for me when I am tired ...* (C8 - daughter).

In contrast, when care was not shared between family members, caregivers expressed frustration and difficulties:

> *…I don´t manage because there's no help from another person and it's very difficult.* (C1 - wife)

> *If I don't have someone here to help me, I do everything by myself, and it's much more difficult.* (C22 - daughter)

In addition to sharing care activities, religious affiliation was perceived as an influential socio-cultural factor in the experience of caring. For most of the participants religion was viewed as a mitigating factor that helped caregivers to face psychological overload. Religious beliefs seemed to improve stress control by offering better coping mechanisms:

> *I was getting very stressed in the early years. I was asking God for wisdom each day. The situation was getting worse around here. I would lie in bed and ask God for wisdom and He was giving me it... (C16 - daughter)*

Therefore, religion was a powerful source of strength to deal with physical and mental challenges when caring for a relative.

Table 1 - Sociodemographic characterization of family caregivers of care-dependent adults, *Belo Horizonte, Minas Gerais*, Brazil, 2017 (N=25)

ID	Age	Sex	Relationship	Marital status§	Training	CNCDβ	Religion affiliation	Leisure time	Share caregiving
C1	77	Female	Spouse	Widow	No	Yes	Yes	Yes	No
C2	19	Male	Grandson	Single	No	No	Yes	Yes	Yes
C3	70	Female	Daughter	Widow	No	No	Yes	Yes	No
C4	41	Female	Spouse	Married	No	Yes	No	Yes	No
C5	35	Male	Son	Single	No	No	Yes	Yes	Yes
C6	61	Female	Daughter	Married	No	No	Yes	Yes	No
C7	72	Female	Spouse	Married	No	Yes	Yes	Yes	No
C8	57	Female	Daughter	Married	No	Yes	Yes	Yes	No
C9	53	Female	Daughter	Married	Sim	No	Yes	Yes	No
C10	41	Female	Sister	Divorced	No	No	Yes	No	No
C11	42	Female	Daughter	Married	No	No	Yes	Yes	No
C12	48	Female	Daughter	Married	No	Yes	Yes	Yes	No
C13	48	Female	Daughter	Married	No	Yes	Yes	Yes	No
C14	49	Male	Son	Single	No	Yes	Yes	Yes	No
C15	52	Female	Daughter	Married	No	No	Yes	Yes	No
C16	47	Female	Daughter	Single	No	Yes	No	Yes	No
C17	37	Female	Daughter	Married	No	No	Yes	No	No
C18	62	Female	Spouse	Married	No	Yes	Yes	No	No
C19	51	Female	Daughter	Divorced	No	No	Yes	Yes	No
C20	52	Female	Sister	Single	No	Yes	Yes	Yes	No
C21	53	Female	Daughter	Married	No	No	Yes	Yes	No
C22	27	Female	Daughter	Married	No	No	Yes	Yes	No
C23	59	Female	Daughter	Widow	No	Yes	Yes	No	Yes
C24	65	Female	Sister	Widow	Yes	No	Yes	No	No
C25	59	Female	Sister	Married	No	Yes	Yes	No	Yes

§Marital status; βChronic Non-communicable disease; *Quality of life

2 - Self-care and its nuances: old challenges for caregivers

This category relates to issues involving the caregivers' willingness to perform self-care. For some caregivers, who considered their health as poor because they suffered themselves from a chronic disease, it was difficult to reconcile the care of their dependent family member with their own illness. This was illustrated in the narrative of a 57-year-old daughter who had to quit her work due to health problems and who cared for her mother in need of care.

> *Ah, I used to work outside. Right now, I don't. I had to quit. I quit also because of my illness, because I worked on the road, in sales, and I take controlled medication, and one of the side effects is that I have to urinate a lot. Then I stopped taking the medication and ended up in the hospital. And finally, I thought it best to quit my job for her sake, because I used to come home and find her doing something wrong. So, it all culminated in one thing.* (C8 - daughter)

Leisure activities, considered a strong predictor of QoL, were also given up by caregivers, either because of the activities were inherent to the caregiving process or, still, as in the following narrative, giving in to the wishes of the care-dependent adult himself.

> *... I had to give up some things, a job, even my social life a little bit... Leisure, for example, I can't go out and leave her alone. There are so many things that got worse, you know. For example, she is jealous of me. She doesn't like it when many people come here, especially those who come more often…* (C5 - son)

Another factor perceived during the interviews and that is related to self-care were the caregiver's sleeping habits, which, when altered and inadequate, can affect normal routine and family dynamics. This can be identified in the following quote from a 52-year-old daughter caring for his old father:

> *All night, he doesn't seem to be normal. All night he walks around inside the house. Sometimes the other residents and*

> *me don't sleep. The next day, when we have to go to work with little sleep the previous night, is when he goes to sleep, and we have to go to work. The situation is not easy.* (C15 - daughter)

3 - Support from outside: challenges and possibilities

This last category addresses aspects in which the support from the public sector, through formulation of policies and programs, could favor the care process and, consequently, contribute towards caregivers' QoL.

All the participants regardless of their care situation saw the importance of support from healthcare professionals and health agencies. Many caregivers reported having to learn care procedures as a daily routine, without training or guidance,

> *... we learn on a daily basis, because there is no practice or educational courses available. So, you stumble, fall, get up, and learn from your experience.* (C20 - sister).

However, some caregivers expressed their satisfaction and the importance of receiving guidance and support from healthcare professionals:

> *I was a little bit disoriented because I didn't know how to deal with it (medication). So, this posed a problem and her (the neurologist) orientation was fundamental to me, because it solved the problem.* (C11 - daughter)

Economy within the family was also important and influence the experience of caring for a care-dependent adult. On the one hand, the fact that some caregivers had to abandon their jobs to care for their sick relative had a significant impact on the family. On the other hand, some participants indicated that all income of the care-dependent adult was being used to purchase personal care items, like diapers and hygiene products.

> *His money is being used to buy his diapers.* (C25 - sister)

For some participants, the lack of financial resources forced them to continue caring despite the fact that for some their wish was to be able to put their family member in a Nursing home.

> *I've already tried to put her in a Nursing home, in a place where she can stay, that they will care for her, feed her and give her hygiene. It has to be something like that, but I can't retire her and there's no money to pay for it, because it's too expensive.* (C17 - daughter)

In contrast, when families were financially healthy and could afford to hire specialized support it turned out to be a more positive experience for caregivers, contributing to their QoL. In addition, all caregivers reported how important it was to be able to count on external support, although sometimes they were late

> *... everything I needed I get, of course not the way we would like: immediately. It takes a little longer.* (C20 - sister)

However, ineffective support from public health services and inadequate care from healthcare professionals significantly contributed to poor experience of caring.

> *... there is no structure at the health center for this.* (C1 – wife)

DISCUSSION

The present research brings new qualitative data about the sociocultural factors contributing to experiences of caring for a care-dependent adult in Brazil, and how these experiences impact the QoL of caregivers. Findings showed that there are numerous factors that influence the caregiving process of Brazilian family members caring for their care-dependent. The main factors were the dominance of women for care because "care is a woman duty"; the dependence of the caregivers themselves to care for their family member that causes them to abandon their own lives and habits; and the need of formal support received by health services. The findings of this qualitative study are similar to those that the literature shows and that indicates that characteristics such being male, being separated or divorced, leisure activities, sleep patterns, religious affiliation, possessing some training in care, sharing the caregiving responsibilities, and the care-dependent adult's advanced age were positively related to the caregiver's QoL. While having a diagnosed CNCD, using medication, and being dependent on universal, public healthcare services, resulted in a negative relationship regarding their QoL.[9]

Sociocultural considerations in the care of care-dependent adults

The care process is permeated by social and cultural constructions, one of which is the predominant involvement of women as caregivers.[17] However, in recent decades, new conceptions about female identity have been discussed. The stereotype that attributes women to domestic chores, motherhood, and dependence on men has been deconstructed, which has resulted in a "female emancipation", that of empowering women with new possibilities for greater independence and autonomy over their lives.[18] The participants´ narratives in this study highlight the social and cultural constructions about how women's identity is linked to domestic chores, in addition to raising discussions about the (in)capacity of men to care, resulting in an urgent need to deconstruct these concepts. This study showed that caregiving was delegated to women, without being shared with other family members. The burden represented by informal care, when shared among caregivers, minimizes its negative effects, besides being considered one of the main supports reported by caregivers.[19,20]

Findings also showed that religion was a contributing factor to better manage a situation of long-term caring. This is in accordance with other studies that have found that religious affiliation or even spirituality are able to give meaning to caregivers' lives, adding resilience and improving their way of coping in light of the burden caused by the caregiving process.[21,22] In addition, divorced and single caregivers may present lower QoL than married caregivers.[9,23] Given the results of this study, we can assume that spousal support may be able to reduce the impacts of care burden. Such support might not be found among divorced and single caregivers.

Furthermore, findings indicated that self-care is often neglected by caregivers due to several factors, leading to illness and in "sick people caring for other sick people." These problems can, besides limiting their personal activities, influence the care process. For families in this situation, nurses should assist more closely because they are professionals capable of recognizing weaknesses and potentialities, implementing tailor-made family interventions and design plans for health promotion, disease prevention, and early detection in CNCDs.[10,24,25] In Brazil, nurses play an important role in the implementation of public health policies, whether related to CNCDs, and more recently, they are working in dealing with the long-term consequences of COVID-19.[26] In other words, nurses must be trained to perform assessments and interventions with families, as well as to promote positive family functioning and alleviate the suffering.[10]

Promoting healthy family caregivers

Study findings indicated that the practices of leisure activities was inexistence because caring for their dependent family member was the priority. However, evidence suggests that participation in leisure activities leads to emotional well-being and has been found to be beneficial for reducing the occurrence and impact of CNCDs, thus resulting in higher levels of caregivers´ QoL.[27] This highlights an important gap to be addressed by nurses, who could better understand the barriers that prevent a caregiver from practicing leisure activities. Such a strategy could contribute to the direction of actions, as way to intervene, together with the family, against barriers that prevent the caregiver from engaging such activities, in addition to the need to redefine leisure for the caregiver.[27] One caregiver reported that he was deprived of such practices due to the feelings of jealousy, expressed by the care-dependent adult, which draws attention to the need to develop actions, not only limited to the caregiver, but that can also be used to better understand the caregiver-care-dependent family member involved in the care process. Hence the importance of recognizing the family as a dynamic relational system, influenced by external and internal factors.[10]

An important factor contributing to the caregivers´ QoL was their health status and feelings of depression, anxiety and fatigue, symptoms that are associated with sleep disorders.[28] Most participants referred to the poor quality of sleep as a result of continuous care to the care-dependent relative, which requires a state of prolonged alertness, in addition to repeated sleep awakenings, generating physical and emotional exhaustion. The search for strategies that increase the quality of sleep of caregivers could contribute to minimizing these impacts.[29]

The need of government policies and regulations to support families

Given the intersectoral repercussions caused by caregiving burden, it is imperative for managers and policymakers to examine improvements in supporting caregivers and their families.[30] Programs that target training for caregiving activities would be important, as caregivers in this study who had received some type of training expressed satisfaction and a feeling of competence in caring for their care-dependent family member. This finding coincidences with other study that have found that training and guidance resulted in higher optimism and problem-solving competence among caregivers.[31] Therefore, providing training to caregivers and other family members is important to minimize caregiving burden, especially in when transition from hospital to home care.[32]

Furthermore, most participants referred to the impact of long-term caring on family finances- There is the need for government actions to reduce this problem, since some families lack the financial resources to buy basic supplies.[33] In Brazil, retirees who qualify for permanent disability and who require the assistance of a caregiver, receive an additional 25% on their monthly retirement benefits.[34] However, this additional benefit does not extend to other retirees who require caregivers, nor to people who became dependent and who have not reached retirement age. A similar approach is used in Canada through a non-refundable tax credit created by the federal government to help Canadians who care for family members with physical or mental disabilities, the credit amount varying according to the family caregiver situation and the level of care-dependency of the relative.[35,36]

Poor access or delays to access to the public health service was also related to dissatisfaction experience of caregivers, also found in other study.[37] In Brazil, although there is a lack of specific policies to assist families in this situation, initiatives do exist in some municipalities. In Belo Horizonte, Minas Gerais, the 'Greater Care Program' was developed 2011, through a partnership between the social services and healthcare sectors. In this program, families with care-dependent elderly are selected to receive the assistance of a formally trained caregiver on specific dates and times.[38] Similar initiatives have been found internationally that support family caregivers. For instance, Eurocarers, which is a European network of caregiver organizations from 26 countries, aims to promote initiatives to allocate subsidies for the creation of intersectoral policies and programs supporting informal.[39] Therefore, it seems important to have well-structured public health service facilities together with social policies that seek to improve the health and welfare conditions of families living with complex chronic conditions and in care-dependent situations.

The findings of the present study provide a new perspective of the diversity of sociocultural factors that influence the QoL of Brazilian family caregivers. Most of these factors are related to the attitudes, beliefs and the way of living of caregivers, being factors that can be modified. Healthcare professionals can be supportive through acknowledging the valuable and essential work of family caregivers, especially during the challenging times, and educating them to have healthy habits, such as practicing exercise and leisure activities, eating well, promoting adequate sleeping and sharing caregiving tasks within the family. In addition, strategies capable of offering social, financial and psychological support to caregivers and families can have a positive impact on a nation's health agendas.

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