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Family dynamics and support network of family caregivers of people with progressive cancer

Dinâmica familiar e rede de apoio de cuidadores familiares de pessoas com câncer progressivo

Dinámica familiar y la red de apoyo de los cuidadores familiares de personas con cáncer progresivo

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ABSTRACT

Objective: To analyze family dynamics, the support network of family caregivers of individuals with progressive cancer, and their needs for comprehensive care.

Method: Qualitative, descriptive study developed based on the Calgary Family Assessment Model framework. It was conducted from September 2022 to April 2023, through participant observation at a public health institution in São Paulo and interviews with six family caregivers. The analysis was performed using Genogram and Ecomap, following the Calgary Model, with the support of software for data organization.

Results: The data were categorized into structural, developmental, and functional family assessments. They revealed the strengthening of family relationships with strong bonds, an increased level of burden on the caregiver as cancer progressed, neglect of self-care, and financial difficulties. Due to the burden, caregivers struggled to outline the composition of their support network, but the employed model enabled the identification of its elements, with faith being mentioned by all.

Conclusion: The diagnosis and progression of cancer led to changes in family structure, development, and functionality which need to be individually assessed to improve care planning. This involves mobilizing elements and services according to the reality of families.

Descriptors: Palliative care. Caregiver. Family relationships. Neoplasms. Nursing.

RESUMO

Objetivo: Analisar a dinâmica familiar, a rede de apoio de cuidadores familiares de pessoas com câncer progressivo e suas necessidades para a integralidade no cuidado.

Método: Estudo qualitativo, descritivo, desenvolvido à luz do Modelo Calgary de Avaliação Familiar. Foi realizado de setembro de 2022 a abril de 2023, por meio de observação participante em instituição pública de saúde de São Paulo e entrevistas com seis cuidadoras familiares. A análise foi realizada a partir do Genograma e do Ecomapa, conforme o Modelo, com auxílio de softwares para organização dos dados.

Resultados: Os dados foram categorizados em avaliação familiar estrutural, desenvolvimental e funcional. Revelaram estreitamento de relações familiares com vínculos fortes, aumento do nível de sobrecarga da cuidadora conforme a progressão do câncer, abandono do autocuidado e dificuldades financeiras. As cuidadoras, devido à sobrecarga, tiveram dificuldade de elencar a rede de apoio, mas o modelo empregado possibilitou a identificação dos elementos que a compõem, sendo a fé citada por todas elas.

Conclusão: O diagnóstico e a progressão do câncer acarretam mudanças na estrutura, desenvolvimento e funcionalidade familiar, as quais necessitam ser avaliadas individualmente para melhorar o planejamento do cuidado, acionando elementos e serviços ao cuidado de acordo com a realidade das famílias.

Descritores: Cuidados paliativos. Cuidador. Relações familiares. Neoplasias. Enfermagem.

RESUMEN

Objetivo: Analizar la dinámica familiar, la red de apoyo de los cuidadores familiares de personas con cáncer progresivo y sus necesidades para la integralidad en el cuidado.

Método: Estudio cualitativo y descriptivo, desarrollado bajo el Modelo Calgary de Evaluación Familiar. Se llevó a cabo de septiembre de 2022 a abril de 2023, mediante observación participante en una institución pública de salud de São Paulo y entrevistas con seis cuidadoras familiares. El análisis se realizó a partir del Genograma y Ecomapa, según el Modelo Calgary, con la ayuda de software para la organización de los datos.

Resultados: Los datos se categorizaron en evaluación familiar estructural, de desarrollo y funcional. Revelaron el fortalecimiento de las relaciones familiares con vínculos fuertes, el aumento del nivel de carga de la cuidadora a medida que avanza el cáncer, abandono del autocuidado y dificultades financieras. Las cuidadoras, debido a la sobrecarga, tuvieron dificultades para identificar la composición de la red de apoyo, pero el modelo empleado permitió la identificación de los elementos que la componen, siendo la fe citada por todas ellas.

Conclusión: El diagnóstico y la progresión del cáncer conllevan cambios en la estructura, desarrollo y funcionalidad familiar que deben ser evaluados individualmente para mejorar la planificación del cuidado, activando elementos y servicios de acuerdo con la realidad de Las familias.

Descriptores: Cuidados paliativos. Cuidador. Relaciones familiares. Neoplasias. Enfermería.

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INTRODUCTION

Concomitantly with the high incidence of cancer worldwide, with the highest mortality rate observed in low- and middle-income countries, such as Brazil, the literature shows that the disease carries a significant social burden[1–2]. Notably, 78% of individuals in need of palliative care (PC) reside in these countries, yet only one in ten receives such care[3].

The social burden of the disease affects both the cancer patient and their family members differently, due to the individual resources of each one[4]. This leads to significant impacts on family dynamics and routine, that must adapt to new demands, especially as the disease progresses, that is, the evolution of cancer[5].

The latest definition of the World Health Organization (WHO) states that palliative care is intended for patients with life-threatening diseases, including their families, focusing on improving quality of life and alleviating physical, psychosocial, and spiritual suffering[6]. These care practices are often poorly understood and require guidance from healthcare professionals, particularly during disease progression when care demands increase[7].

Data indicates that Palliative Care is generally limited and predominantly available in the private network, inaccessible to many patients due to financial barriers or the lack of adequate public services[8]. The National Palliative Care Policy aims to expand access to this care through the Unified Health System (*Sistema Único de Saúde* – SUS), integrating it into existing health services and training professionals to care for patients requiring this type of assistance[9].

Informal caregivers (usually family members) or formal caregivers (hired) are potentially exhausted throughout the disease process, leading to symptoms of emotional and physical overload[10–11]. Therefore, the health team must exercise PC throughout the care, aiming at the well-being of both the cancer patient and their family members, because, as the cancer progresses, caregivers may feel powerless, which affects the way they provide care[5].

In the face of the process of illness and palliation, the family structure changes, as well as the need for support to cope with the disease[5]. To provide assistance in this process, it is necessary to understand the subjectivities in caring for each family, allowing for the planning and implementation of appropriate care[12]. There are also different ways of coping with the process of death and dying, as well as the demand for direct nursing intervention to facilitate this process[12].

The WHO definition of PC includes care for the family, but the literature lacks methods to identify and direct this care[6]. Given the projected increase in PC cases[3], the challenges posed by cancer progression, and the need for comprehensive support to improve quality of life, it is essential to understand family dynamics, their interactions with support networks, and their needs to effectively plan and implement recommended palliative care. This highlights the importance of understanding these dynamics to outline health promotion and prevention actions adapted to each context.

The Calgary Family Assessment Model (CFAM) enables understanding of family dynamics, relationships, and support networks, allowing for family-centered care[13–14]. The use of this method has been widely explored, demonstrating a range of thematic areas and can be applied at all three levels of health care[13–14]. Finally, it serves as a tool to strengthen the bond between families and healthcare professionals, improving care delivery and family approaches, especially in nursing[14].

Although used in complex contexts such as psychiatry, pediatrics, high-risk care and violence against the elderly, there are few publications on the application of the CFAM in oncology[14]. In research, the Model is characterized by identifying weaknesses and strengths, enabling personalized care planning, that enhances care quality, nurse-family relationships and the family's ability to care, as well as patient outcomes[14–15].

Considering the importance of nursing's role in the family approach and the increase in the number of cases requiring PC, which is expected to double by 2060[3], this article aimed to answer the following guiding question: "What is it like to care for and live with a family member with progressive cancer?". In this sense, the objective of this study was to analyze, in light of the CFAM, the family dynamics, the support network of family caregivers of individuals with progressive cancer and their needs to effective comprehensive care in a public health service.

METHOD

This is a qualitative and descriptive study that used the Calgary Family Assessment Model as a theoretical and methodological framework. The CFAM is a multidimensional model composed of three categories – structural, developmental and functional –, developed by the construction of the Genogram and the Ecomap, aiming to assess the family and develop a rich contextual basis, as well as a collaborative interviewer-interviewee relationship[13].

Although widely applied in various populations, such as the elderly, children and individuals with chronic diseases, studies focused on the oncology population and PC are still scarce[14–15]. The increasing number of these cases highlights

the importance of paying attention to family caregivers[3]. The application of CFAM in this context adds to the literature a potential tool for healthcare professionals in preventing and promoting family health and engagement.

The study involved six family caregivers. In only one case there was a previous relationship with the interviewer based on participant observation, the others were indicated by healthcare professionals where the cancer patients received care. The main family caregivers of individuals with progressive cancer, over 18 years old were included, with a caregiver being defined as the person who provides daily care to the patient, accompanying them to the necessary healthcare services[9].

The exclusion criterion was not being involved in the patient's care since the diagnosis phase, due to the impossibility of outlining the changes in family dynamics before and after this milestone. It is important to highlight that there were five refusals to participate due to caregiver burden and lack of time and/or the impossibility of engage in conversation amid a situation of significant emotional burden.

CFAM was chosen as the research method due to the variety of its scope and the relationship between the domains of family structure, development and functionality, enabling a detailed understanding of the family context the exploration of health needs, as well as creating a space for listening, support and health education[12,13–14].

Data collection was carried out by two methods – participant observation (PO) and semi-structured interview (SSI) – guided by the question: "How does family dynamics occur for the care of [name of cancer patient]?", both conducted by the main researcher, an undergraduate nursing student from a public university with experience in data collection in qualitative studies, supervised by a PhD in Health Sciences. The researcher's introduction, study objectives and other questions were clarified at the beginning of the interview.

PO in the participant-as-observer consists of in-depth participation and joint experience of the routine relevant to the objective for a determined period[16]. It was conducted by the immersion of the main researcher, from September 2022 to April 2023, for approximately 56 hours, in the oncology outpatient clinic and in the PC inpatient unit of a public institution in São Paulo (SP), where some participants remained during this period.

In the outpatient clinic, medical, nursing, and multidisciplinary consultations were observed, along with case discussions and routine family. In the hospital setting, the routine of care of the inpatient unit and the interaction of professionals with the family were observed. The PO allowed for an understanding of the service dynamics to better understand the reality of family caregivers at the time of the interview, and records were made in a field diary.

The SSI lasted an average of 60 minutes, with two possible locations, depending on the participant's preference and availability: online, via video call on the Google Meet® platform or in person (hospital or outpatient clinic), in a space reserved for data collection. Two of the interviews were conducted online and four in person.

The interviews, conducted from October 2022 to April 2023, were divided into three stages. The first consisted of a sociodemographic questionnaire, with questions asked verbally and completion of the characterization form. Next, after explanation of the graphic representation, the second stage involved the development of the Genogram and the third, the Ecomap. In the online interviews, the graphic representation was made with Canva®; in the in person interviews, it was initially drawn on paper and then transferred to Canva®.

In the construction of the Genogram, the family structure was identified and illustrated, followed by an understanding of the levels of relationship among members. For the Ecomap, the concept of support network was explained and then, the participants identified the elements that comprise it and the level of connection between the family core and each mentioned element.

The interviews were fully transcribed and analyzed based on the CFAM categories. To ensure anonymity, the participants and their families used the letters "P" and "F", respectively, followed by an Arabic numeral, according to their order of inclusion in the study. Data analysis was performed with the QSR Nvivo 12® software. There was no return of materials to the participants or feedback on the results. However, the researcher verbally verified the accuracy of the graphic representations after they were created with the participants.

Finally, the theoretical and empirical relationship helps to interpret and explain the phenomena observed in the research, with the way in which family communication and the nonverbal language of the participants are described indicating the points that can be explored for later addressing health needs.

For the writing of this study, the "Consolidated Criteria for Reporting Qualitative Research" was used as a guide[17]. The research was approved by the Research Ethics Committee involving human beings of the affiliated institution (Opinion No. 0621/2022) and all participants signed the informed consent form.

RESULTS

The results will be presented based on the multi-structural assessment of the CFAM. The first category refers to the Structural Assessment, which investigates family composition, bonds and relationships; the second, the Developmental Assessment, which aims to understand the reorganization of the family in the face of a cancer diagnosis; and, finally, there is the Functional Assessment, which highlights how individuals behave in relation to others. Participants P1 and P5 were interviewed online, the others interviewed in person, in a hospital setting.

The three assessments influence each other, considering the plurality of relationships that constitute the lives of human beings, as well as those of their families. The conceptual map in Chart 1 presents a summary of the research results, which will be described below.

Structural Assessment

In the Structural Assessment, the composition of families, relationships, bonds and support network were investigated, which allowed us to understand the context and family experience, as well as aspects such as the ages of caregivers and individuals with cancer, family income and employment.

From the six families studied, four (F1, F2, F4 and F5) consisted of a couple with biological children, a structure called a "nuclear family"; one was characterized as a "reconstituted family" (F3), that is, in which a new marital bond was established and there was a child from another relationship; and one, as a "single-parent family" (F6), composed of a single person assuming parenthood and their child.

As presented in Table 1, all caregivers were women; in the PO it was also noted that the majority of accompanying individuals were female in the healthcare service. It was observed that the dependence on care increased with the age of the patient and the stage of cancer progression, with difficulties in mobility both in the healthcare service and in the transportation to the hospital being evident in the PO. In one case, the family wanted the patient to stay at home but faced difficulties in finding a public PC service in their city.

Individuals with the disease in families F1, F2 and F4 required monitoring in healthcare services, care with nutrition, medication and management of adverse effects. In families F3, F5 and F6, patients had a high degree of dependence, requiring additional assistance with walking, changing diapers and bathing.

Regarding healthcare services, the caregivers reported that their families exclusively used the Unified Health System (*Sistema* Único *de Saúde* – SUS). At the time of data collection, the patients were treated between outpatient clinics and the hospital, located in the same neighborhood in São Paulo, and did not receive home visits from the Family Health Strategy (FHS) team. The caregivers reported not seeking healthcare services for themselves, and all admitted to abandoning at least one self-care activity in their routine.

This abandonment can be explained by the need for continuous care and accompanying patients to healthcare services. In the observed outpatient clinic, patients were scheduled by period (morning or afternoon) and seen at any time within that period, causing exhaustion and stress due to the wait times. Additionally, many families lived in another city, relying on transportation provided by the government, with common schedules for all passengers.

Despite the unique circumstances of each family, most caregivers had to take time off from professional work, resulting in financial difficulties in some cases. A common aspect among the families was the strong bond between the members living together, mentioned in the support network with the other strong bonds within the family.

The Genogram and Ecomap of F4 were chosen to present these results, as an example of the data preparation, as shown in Figure 1 and Figure 2.

Regarding the support network, all participants were initially unable to cite elements, but when they recalled memories and situations, they were able to identify several components. By observing the graphic representation of the network, they realized that they were not alone and that they could share responsibilities and seek help.

The Ecomap of F4 revealed a vast support network, where faith and visits from people from the caregiver's church were cited as important allies in coping with the disease. However, the caregiver abandoned the course she was attending, and self-care activities due to caregiving demands.

The hospital and outpatient healthcare teams were described as fundamental, mainly for their care, guidance and concern for the family's well-being. More than half of the caregivers expressed gratitude at the end of the interview, mentioning the support and care provided by the listening space of the research.

It was observed that cases of progressive cancer were managed by oncology teams, without a dedicated team specifically for PC. In this sense, measures to control chronic pain and improve quality of life were not addressed with the primacy of a specialist in the area.

In the other families, faith was also cited as the primary support network and considered essential for the process of coping with the disease, as mentioned in the following statements:

Chart 1 – Conceptual map of family dynamics and the support network of family caregivers of individuals with progressive cancer, based on the Calgary Family Assessment Model developed by the researchers through QSR Nvivo 12®. São Paulo (SP), 2024.

Structural assessment
Characterization of: • Family regarding type, family income, age of the person with cancer and number of residents in the household; • Caregiver, addressing age, employment and degree of kinship with the person with cancer.
The **Genogram** graphically demonstrated: • Family structure; • Kinship relationships; • Bonds.
The **Ecomap** highlighted: • Elements of the support network of the family core: faith, healthcare team, children, neighbors, friends, and other relatives; • Type of relationship among the network elements; • Strength of the bond.
Developmental assessment
Change to a new role: • The participant became the main caregiver; • Family members needed to organize themselves to assist with care.
Impact on work: • The caregiver's need to take time off or retire; • Need to reduce working hours.
Impact on self-care occurred due to: • Interruption in visits to religious temples and medication use; • Interruption or reduction in the frequency of physical activities and beauty care; • Reduction in rest periods; • Absences from medical appointments; • Dropping out of training courses.
Functional assessment
The main caregiver describes her relationship with the family member with cancer as that of a "mother".
Tightening relationships in which the bond was previously characterized as strong.
Greater affection in daily life among family members living together.

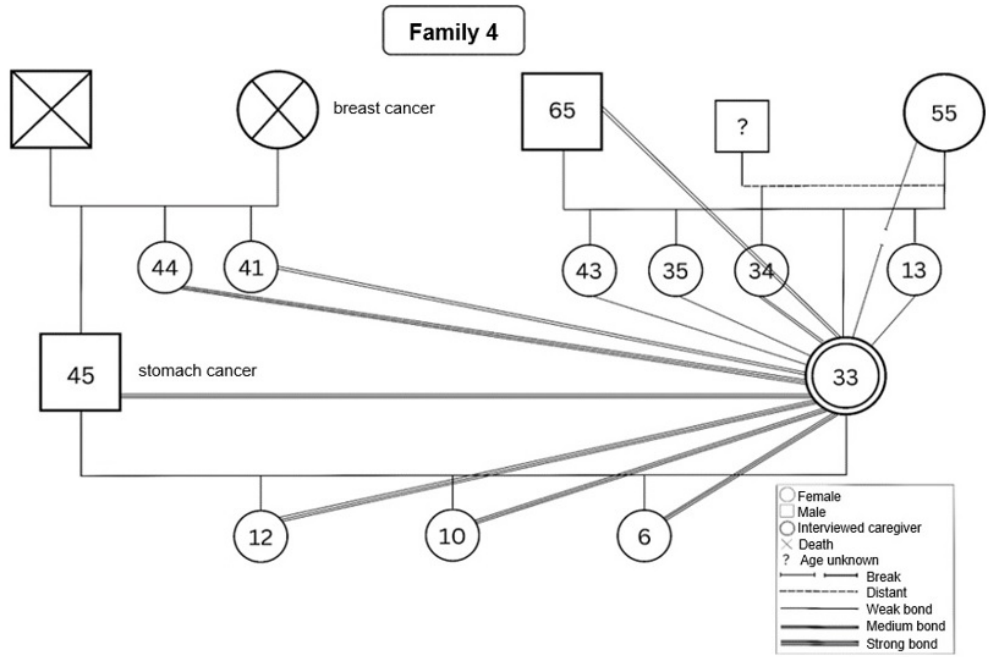
Source: Developed based on research data (2024).

Table 1 – Summary of the Structural Family Assessment. São Paulo (SP), 2024.

Family	Age (years)		Caregiver's Degree of Kinship	Employment	Type of family	Family income	
	Caregiver	Person with cancer				Income (minimum wage)	Number of residents
1	61	73	Ex-wife	Retired	N	Between 2 and 3	2
2	30	54	Daughter	Nurse	N	More than 3	3
3	21	48	Daughter	Self-employed	R	More than 3	3
4	33	45	Wife	Housekeeper	N	Only 1	5
5	47	72	Daughter	Adm. Assist.	N	More than 3	3
6	69	49	Mother	Retired	M	More than 3	5

Source: Developed based on research data (2024).
N: nuclear; R: reconstituted; M: single-parent.

Figure 1 – Genogram of Family 4. São Paulo (SP), 2024.



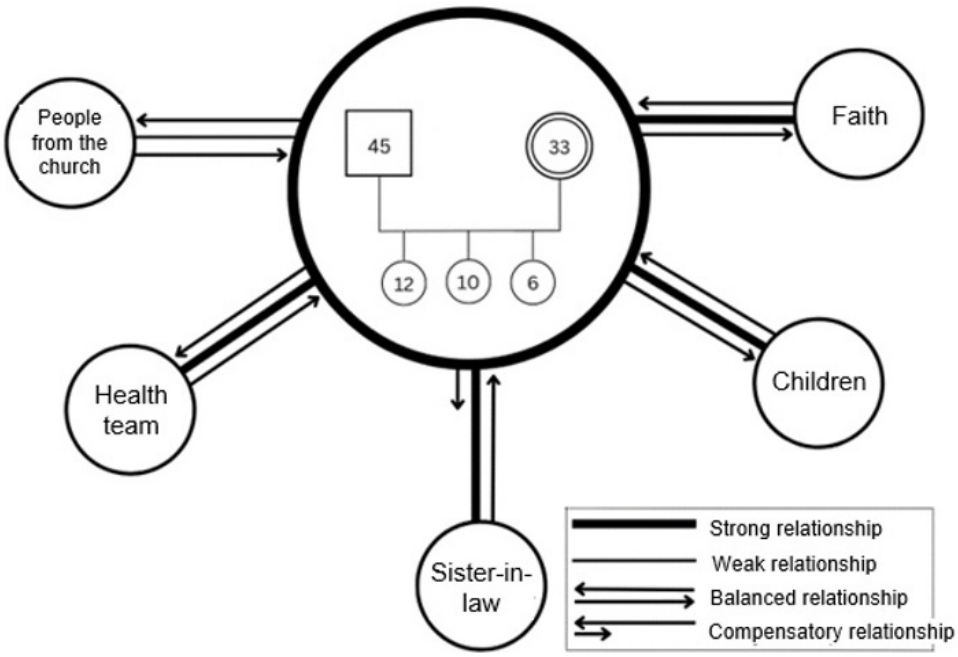
Source: Developed based on research data (2024).

It helped a lot, because I had my faith, but it wasn't as strong as it is now. (P3)

I always had [faith], but I think it increased a little more after cancer, faith strengthens. (P4)

I only became stronger when I entered the religion that taught me this, explained a lot to me, and I gained greater resilience than they [family] [...], *and my family suffers more than I do, I feel it, I notice, because I have to talk a lot, guide and calm them* [...]. (P5)

Figure 2 – Ecomap of Family 4. São Paulo (SP), 2024.



Source: Developed based on research data (2024).

Most caregivers declared not practicing religion (F1, F2, F3, and F4), and those who did practice reported not attending their religious institutions due to the intensified caregiving activities. After the family member's diagnosis, five of the six caregivers included the outpatient and hospital healthcare team in their support network. The people most frequently mentioned as support network were children (P1, P4, and P6), siblings (P4, P5, and P6), followed by neighbors (P1 and P6), other family members (P1 and P4), and friends (P3 and P5).

Developmental Assessment

In this sphere, the aim is to understand how the diagnosis of progressive cancer alters family organization, considering the physiological decline of patients and the impact on care needs. The Developmental Assessment highlighted changes in the role of the person who became the primary caregiver, the change of residence of the person with cancer, and the effects of the responsibilities on work, self-care activities, financial difficulties, and family reorganization.

The reports showed the need for assistance with daily activities, medication and diet management, monitoring well-being, and accompanying the patient to healthcare services for consultations, treatments, and hospitalizations. All this care was intensified with the disease progression.

> [...] *before, he [the person with cancer] was more independent* [...]. *But now the care is more intensive with him at home to get up, to eat, for everything, right?* (P5)
>
> *It is very, very tough, very painful to take care of him [person with cancer], there are times when things run out, it's hard.* [...] *I leave in the morning, and I don't have time to return at night [when accompanying with the person with cancer during hospitalization].* (P6)

The caregivers prioritized the care of the family member with cancer, resulting in changes in the routine and a reduced workload in four of the six analyzed cases, as observed in families F3, F4 and F5. In family F1, the ex-husband's cancer diagnosis led to the retirement of the primary caregiver, who postponed the process for years. Caregiver P2 works in the same healthcare institution as the patient, facilitating access to treatment, while P6 was already retired.

> [...] *it was at time to retire, but I didn't accept stopping, but then, when I saw that he started to weaken, I said: "I will stop and take care of him".* (P1)
>
> *Now I work less, I have to prepare meals on time, give him medicine on time, and those things. And, when it's time to come to the hospital, I have to stop everything to come with her [person with cancer].* (P3)

There was a decrease in activities that represented self-care and quality of life in the caregivers' daily routine – such as physical activity, rest, beauty care – and the interruption of attending medical appointments, church and academic training.

> *I take medication to sleep, but now I can't take it every day, because sometimes he [person with cancer] feels sick all night, and I can't sleep.* (P1)
>
> [...] *the gym and the course; after finding out about the cancer, I stopped doing them.* (P4)
>
> *For now, I haven't been to church anymore, no* [...]. *Because I'm with him [person with cancer].* [...] *now I've been here [at the hospital] with him all the time, I can't even go to the doctor.* (P6)

Additionally, due to the need for specific care and increased monitoring, four of the six people with cancer changed residence, in half of the cases to the caregiver's house:

> [...] *she [person with cancer] lived with my sister, and when she found out about the diagnosis, she went to live with my grandfather [the father of the person with cancer]. Because she lived far away, and if something happened, there would be no one to come get her.* (P2)
>
> *Now he [person with cancer] will have to live with me.* [...] *before, he was more independent. Now I will have to take care of him more intensively.* (P5)

In two cases of greater socioeconomic vulnerability, financial difficulties were reported due to expenses with medications, transportation, food, and personal hygiene. In one case, the caregiver suspended her own medication to prioritize the patient with cancer, and in another, financial difficulties impacted the acquisition of resources for crafting, which contributed to the family's income.

> [...] *even for his [person with cancer] medication, I couldn't buy my materials to work* [...] *Expenses are higher, the medication is very expensive.* (P1)
>
> *The medication the doctor prescribed for me, I didn't take this month because I couldn't afford it* [...], *I prioritized his [person with cancer].* (P6)

In cases of dependence in daily activities, it was necessary to involve other family members or the support network to assist with care, allowing the caregiver to perform tasks outside the home. Even when there was no dependency, family reorganization was necessary for activities – such as transportation to healthcare services (F3) and care in the absence of the main caregiver, affecting family routines, such as work (F4) –, impacting daily routine:

> [...] *I couldn't go out anymore, even to go to the market I had to call one of my children to stay here with him [person with cancer] or call the neighbor.* (P1)
>
> [...] *I tell her [the oldest daughter, 12 years old] to keep an eye on her father [person with cancer] and send me messages.* [...] *she helps with the dishes, sometimes he's not well, she sweeps the house, makes coffee, feeds him, goes to the bakery to buy bread.* (P4)

Thus, the progression of cancer increased dependence on daily activities, significantly impacting routine due to greater care demands. This scenario highlighted the need for space t for listening, time for self-care and personal activities, financial resources, timely health care and mobilization of the support network to share responsibilities.

Functional Assessment

This assessment shows how individuals behave with each other. Stand out: relationships that were reconfigured after the diagnosis; increased affection in daily life; and tightening of previously strong bonds.

The diagnosis caused significant changes in the life of the person with cancer and the caregiver, changing the family dynamics. In half of the cases, the person with cancer was divorced and, due to the illness, reestablished the bond. In two cases, this resulted in cohabitation, and in one case, the ex-wife took on the role of primary caregiver.

> *We're divorced, but I take care of him [person with cancer]. At the time, he went to live with my daughters, and, after he got sick, I brought him [to the caregiver's residence]* [...]. (P1)
>
> *Now with the problem, they [the caregiver's divorced parents] are in the same house, but each in their own room, but she [caregiver's mother] doesn't take care of him, I do.* (P5)

After the diagnosis, there was a strengthening of the already close bonds and, in only one family, there was an approach between previously distant members. Previously strong relationships intensified, especially between the caregiver and the person with cancer, and coexistence between members of the same household became more affectionate and attentive.

I think our family has gotten closer, and friends only ask [...]. (P3)

[...] *I think it had been about 30 years without talking [person with cancer and his sister]. Then, I found out he got sick, got in touch, yesterday, she was talking to me* [...]. *They [siblings of the person with cancer] never contacted me* [...]. *And, after he got sick, they started talking to me* [...]. (P1)

After the diagnosis, the most significant change was the reconfiguration of family roles. The main caregivers started to see the person being cared for as a maternal figure, assuming all responsibilities and feeling co-responsible for the disease process. Other family members also adjusted their roles, both in care and in the relationship.

[...] *my relationship with my father [person with cancer] is primarily that of a child. He is a son, a father, a brother* [...]. *Now he is going to live with me, and I am going to be his mother, to really take care of him. He already sees me as a mother* [...]. (P5)

The relationship between the three of us became more affectionate, between me, my husband and her [person with cancer]. In the past, everyone was in their own home. [...] *after my mother got sick, he [caregiver's husband] kind of took her as his mother, you know? He feels like her son, so he worries, feels more affection, those kinds of things.* (P3)

With other members, there was a strengthening of already close relationships, as well as greater affection among people within the same family unit.

In addition to the change in the role of daughter to main caregiver, one participant, despite being an oncology nurse, did not recognize her mother's situation as PC, highlighting the stigma of this end-of-life care rather than care for life-threatening illnesses. This highlights the need for ongoing training for healthcare professionals and health education for family members.

DISCUSSION

The study contributes to understanding the family dynamics of people with progressive cancer and their support network, highlighting the strengthening of relationships only among family members with strong bonds, the burden on female caregivers, the increase in burden as the disease progresses, financial difficulties and the neglect of self-care. The centralization of care hindered the perception of the support network as resource, evidenced by the use of the CFAM. This reinforces the need for care planning by healthcare professionals, adapted to specific family realities.

The research demonstrated the effectiveness of the CFAM as a tool applicable at different levels of health care – secondary and tertiary. It enables professionals to improve support for patients with progressive diseases and their families, regardless of social and financial conditions, promoting a more inclusive, welcoming, humane and efficient healthcare system, as recommended by the National Palliative Care Policy[9].

The participating caregivers were female, with an average age of 43 years, corroborating national and international studies on caregivers of individuals in PC[7,14,18–20]. The degree of kinship of the caregivers, mostly daughters of the person with cancer, is similar to that found in a Chinese sample, 45.6%[21]. A qualitative study was also identified in which the majority of caregivers had the same degree of family association[18].

Considering that data collection occurred in a public health institution, all individuals with cancer were receiving care through SUS, reflecting that only 26% of the Brazilian population has health insurance[21]. All expressed satisfaction with the service and the healthcare team, highlighted by five of the six families as an important part of the support network.

However, none of the families received home visits from the Family Health Team (FHS), which is due to the lower coverage in the state of São Paulo (38.8%) compared to the national average (63.6%)[20–22]. This reality makes it difficult to identify and resolve demands beyond cancer and access to consultations, as caregivers prioritize the treatment of the person with cancer over their own health. In this context, the FHS could play a crucial role in understanding family dynamics and promoting health care, including the use of the CFAM tool.

While one study indicated little change in family bonds[18], analysis with the CFAM revealed that the disease intensified the closeness among members with strong bonds, while medium and weak bonds remained unchanged. The sensitivity of the CFAM to family changes reveals the strengthening of these bonds, which is seen as a potential to enhance relationships, involving more members in caregiving, and reducing the caregiver's burden.

European data show that individuals with cancer living alone have worse depression and vitality ratings[23]. In most cases, caregivers had to live with the person with cancer to facilitate the organization and provision of care, given the situation of disease and its implications for daily routine[18,24]. This change allows for constant monitoring of the patient's well-being, but implies a continuous state of alert, hindering caregivers' rest.

Despite the advantages of living together, this arrangement increases the burden of care, revealing the need for support. This increase is linked to higher levels of overload, anxiety and depression, reducing the time and willingness of caregivers for self-care and personal activities, which results in greater psychological symptomatology[11,18–19,25]. In this study, this was manifested as a reduction in the well-being of caregivers and abandonment of self-care activities.

Asian studies show that most caregivers are negatively affected after assuming this role[19,21]. Among the repercussions is the need to reduce the workload to accompany patients to healthcare services and assist them with daily activities. A Turkish study showed that 48.1% of the sample (N=378) reported professional impact[19].

These factors highlight the need for attention from the healthcare team, since women face greater burden and lower quality of life compared to men, both in national and international studies[19,25]. This aspect is attributed to multiple responsibilities – such as profession, children, household tasks– and societal expectation that women perform these activities without help[19,25]. The role of healthcare professionals is essential, considering that most caregivers are women.

A Brazilian study revealed that 40% (N=20) of caregivers of cancer patients in palliative care had severe burden, which was associated with a decrease in the quality of life of the cancer patient[25]. The main reason for refusing to participate in the study was emotional overload and the difficulty in balancing the study with caregiving responsibilities, highlighting the need for healthcare professionals to pay closer attention to these issues.

The need for help in caregiving[18], mentioned by the research participants, highlights the importance of a more active support network to alleviate the burden on main caregivers, especially on individual needs such as attending religious meetings and medical appointments. This aligns with international evidence where social support is positively associated with quality of life[21], contributing to the prevention of illness and health promotion.

Social support helped many caregivers feel better about this new role[21,26]. In line with this, faith was mentioned in this study as the main source of support, giving caregivers strength to cope with the new scenario, as well as serving as a means of overcoming obstacles, giving meaning to the moment experienced and feeling hope[26–27].

The healthcare team also plays a crucial role in supporting caregivers. Conversations with professionals helped prepare family members for the changes[26–27], and caregivers highlighted the importance of bonds, understanding, and affection. Considering the challenges and vulnerability of informal caregivers, it is essential that the healthcare team offers support in managing emotions, redefining experiences, recognizing demands, and maintaining self-care and well-being[17].

An international study using the Calgary Model shows that creating environments with people with similar experiences helps to share experiences and provide support[28]. In the context of this study, it is crucial to implement effective interventions due to frequent contact with patients and their families at secondary and tertiary care levels, as well as to train the healthcare team.

In the PO, there was a shortage of professionals knowledgeable in PC and specialists in the area, contrasting with the integrative review that highlights the importance of palliative care knowledge among nurse[29]. These professionals are essential for the transition of care, adjustment of roles after diagnosis and providing information that helps in decision-making[29].

The CFAM provides a multidimensional view of family characteristics, allowing professionals to understand the individual needs and the family needs as a whole. It also reveals the potential of professionals and areas in which they can improve the physical, psychosocial and spiritual quality of life, making them effective agents in family health.

Although this is a qualitative study, its limitations include the small number of participants, associated with the burden of caregivers and the lack of time for activities beyond caring for patients with progressive cancer, as well as the lack of feedback on the materials to the participants.

This burden highlights the urgency of recognizing and including informal caregivers in care. More research focused on informal caregivers is needed so that healthcare professionals can adequately address the real needs of caregivers and promote comprehensive care, as recommended by the National Palliative Care Policy.

CONCLUSION

The results of the study show that the diagnosis and progression of cancer cause significant changes in family structure, development and functionality. A tightening of previously strong family relationships and a strengthening of bonds within the family core were observed, fostering greater unity and support since the diagnosis.

Stands out the prominence of women in family caregiving, along with the increased burden on caregivers, who face abandonment of self-care, financial difficulties and the need to give up commitments and hobbies due to new responsibilities.

The burden faced by caregivers made it difficult to identify the elements of their support network. The CFAM helped them map this network, highlighting the possibilities for external support and sharing of responsibilities. This finding underscores the importance of graphic representation in identifying available resources.

Integrating information from the Genogram with data from the Ecomap allows professionals to have a holistic view of the influences on the individual's life, enabling more effective planning of interventions that consider family and social factors, as well as behaviors and habits.

The Calgary Family Assessment Model proved to be an effective tool for bonding with caregivers and can be applied at different levels of health care. It highlights the importance of quality relationships in caring for caregivers of individuals in PC, in compliance with the National Palliative Care Policy. Despite limitations, caregivers felt welcomed by the listening space offered by the research.

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