

FAMILISM TRENDS IN THE BRAZILIAN PUBLIC HEALTH SYSTEM: THE PERCEPTION OF SOCIAL SERVICES ABOUT EXCESSIVE WORK RESULTING FROM CARING FOR PEOPLE WITH CANCER IN PALLIATIVE CARE

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Abstract: With the adoption of neoliberalism, there has been a decrease in state involvement in responding to the needs of the working class and an increase in the responsibility of families to provide care for their members, reproducing familism. In the Unified Health System (SUS), especially in oncology care, this perspective has been expanding, based on different government actions that add to the deepening of the defunding of high complexity health care, the privatization of the sector that directly interferes with the inclusion and permanence of people sick with cancer in the proposed treatment and the precariousness of both the working conditions of those who work in public health services and the conditions of health care for the user population. Thus, this study systematizes, in light of the literature review in the area and the documentary analysis, elements present in the professional work with families carried out by Social Services, especially those with cancer, based on the understanding of social workers - participants in the research from the Palliative Care Center of Pedro Ernesto University Hospital, linked to *Universidade Estadual do Rio de Janeiro*, located in the city of Rio de Janeiro - Brazil. The results demonstrated the demands presented by families to Social Services as well as the overload resulting from the need for care and entry into the unprotected job market that causes the worsening of suffering in various dimensions of social life. Finally, it demonstrated the need for strategies to prevent the reproduction of familism, but without disregarding that this is a trend incorporated into health policies.

Keywords: Familism. Health policy. People with cancer. Palliative care. Social work.

INTRODUCTION

The insertion of Social Service in the health area demands that the professional category expand its knowledge and practices to competently work on the issues raised by the population, as well as respond to the demands of the health system itself (NOGUEIRA, 2011).

To mitigate the consequences of the expressions of the social issue - here conceived as the set of expressions of inequalities in mature capitalist society, whose foundation is inscribed in social production that is increasingly collective and in work that is largely social, although its fruits are appropriated and monopolized by only a part of society (IAMAMOTO, 1998) - Social Work has historically taken social policies as institutional responses. However, these policies are full of contradictions, because, at the same time that they guarantee the reproduction of the workforce, they also increase the productivity of capital and, thus, contribute to the maintenance of the status quo. In view of this, according to Alves and Mito (2015), the State has historically used the family as a fundamental piece in social protection.

This article addresses this issue from the perspective of problematizing this trend, demonstrating the understanding of social workers from a Palliative Care service aimed at people with cancer regarding the excessive workload of their families with the care that these individuals require. The aim of the study was to verify to what extent the intervention of social workers can or cannot contribute to the transfer and overload of care required of families by health services, especially palliative care.

This is a qualitative study, whose final sample consisted of six social workers who worked/worked at the Palliative Care Center (NCP) of Pedro Ernesto University Hospital

(HUPE), between 2010 and 2022. Semi-structured interviews were used as the primary source, conducted remotely to facilitate the participation of social workers, especially those who no longer work at the Hospital. In addition to the fieldwork, the ratification of the legacy of health in assigning families the duty of care was also a theme studied in the bibliographic and documentary research, based on secondary sources.

This research complied with all ethical assumptions determined by the National Research Ethics Committee (CONEP) of the National Health Council (CNS). Therefore, the research project was registered on the Brazil Platform, evaluated by one of the Research Ethics Committees (C.E.P.) linked to ``Universidade Estadual do Rio de Janeiro`` (UERJ), receiving the Certificate of Presentation of Ethical Appreciation (CAAE) Number 64396922.1.0000.5282 and the favorable opinion for its implementation Number 5,759,042.

This article is organized into two sections. The first presents some reflections on the relationship between Social Services and families and the confrontation of familism. The second section addresses the data from the research carried out based on the analysis of the work of social workers with the families of people served by Palliative Care services. Finally, the final considerations point to the process of prioritizing the familistic model by the Brazilian State as one of the strategies for spreading counter-reforms in health that, associated with the lack of a comprehensive care policy, demands that social workers working in the Unified Health System (SUS) develop more qualified and politicized strategies for intervening in the expressions of the social issue.

FAMILISM IN BRAZILIAN HEALTH POLICIES

Social protection systems arise from the needs of society to prevent or reduce the impact of social risks on individuals who are considered vulnerable, such as children and the elderly, the sick, the disabled, among others.

From this perspective, the responsibilities of families, in the private sphere, are similar to the functions of public policies, in the public sphere (TEIXEIRA, 2012).

According to Teixeira (2012), in a poorly developed protection system, the family outlines its subsistence and care strategies to ensure some protection in the face of State omission. The author problematizes this context as follows:

The private sector (profit, philanthropic and non-governmental) and the informal sectors (family and community) return as sources of social protection, seen as more efficient, effective and with lower costs. However, as the market increasingly focuses on satisfying profitable needs (and therefore on those with purchasing power), a huge burden will fall on the family, which functions as a buffer against the crisis, a shock absorber, an instrument for reducing the feeling of social exclusion and promoting the well-being of its members (TEIXEIRA, 2012, p. 84, emphasis added).

In Latin America, the centrality of the family's role in social protection "is a trend [... contained in] welfare regimes [...] and in the orientation of new social policies." (TEIXEIRA, 2012, p. 85). From this perspective, the responsibility of the family reinforces the dependence of members on family resources and support. The Brazilian reality has changed little over the years, since the country did not have a solid welfare state, which determined the implementation of social protection based on targeted actions aimed at the most impoverished people. Furthermore,

references in disputes, as Souza, Alcântara and Acquaviva (2021) point out, are marked by the decentralization or centralization of the participation of the family unit.

In contrast to the familistic reference, the protective proposal - or defamilization, as stated by Esping-Andersen (1991) - is consolidated in social protection through the promotion of universal social rights. This reference requires the participation of the State in the elaboration of social policies. In this scenario, the participation of the family is less in the face of social needs, and it is up to the State to “[...] ‘socialize in advance the costs faced by the family, without waiting for its capacity to be exhausted’” (MIOTO, 2010, p. 171, author’s emphasis).

Although Brazil did not experience the Welfare State, in the 1980s, the country was at the forefront of the popular struggle for democracy after the military regime, an effort that resulted in the promulgation of the Federal Constitution of 1988. Among the main advances established by this document, the creation of the social security system stands out. However, these advances were not sufficient for the structural changes proposed by the neoliberal approach implemented in Brazil from the 1990s onwards, which compromised the desired direction.

Alves and Miotto (2015) consider that, from the 1990s onwards, the debate on familism, that is, on the responsibility of family obligations in social policies, gained space in the face of the State’s absence in participating in social needs, given the neoliberal attacks.

For the authors, the scenario of dismantling social policies elevates the family unit to the level of an essential and fundamental element of the State, in relation to the responsibility of care, in preserving the health of individuals and in curing people whose illness has worsened. The family becomes a true *partner* of the State in terms of care practices, given

the lack of funding, resources and a qualified workforce.

Souza, Alcântara and Acquaviva (2021) point out as an example of this the reinforcement of the family’s role in care, throughout the trajectory of the SUS, through programs, guidelines and projects, such as the Family Health Program; the Practical Guide for Caregivers; the Better at Home Program; the National Humanization Policy; the booklet entitled “Open Visit and the Right to a Companion”.

The Family Health Program is a strategy that places burdens on families regarding primary care. According to Soares (2020), the program highlights the contradictions between the public and private sectors in the SUS (Unified Health System), including adherence to targeted actions to the detriment of universalization, as well as adherence to the familiarization of care, which contradicts the logic of defamiliarization.

The “Caregiver’s Practical Guide” presents the family as a founding element of care administration and naturalizes this process, disregarding the objective and subjective aspects of such attribution. In this publication, the caregiver is presented as “[...] a human being with special qualities, expressed by the strong trait of love for humanity, solidarity and dedication.” (MINISTRY OF HEALTH, 2008, p. 8).

Aimed at people with rehabilitation needs, the elderly and people with chronic or post-surgical illnesses, the Melhor em Casa Program has a multidisciplinary team that trains the caregiver - who may or may not be a family member - in the homes, officially explaining “the incorporation of families in the management of health care, which is characterized as a founding attribution of health services.” (SOUZA; ALCÂNTARA; ACQUAVIVA, 2021, p. 281).

Like the Practical Guide for Caregivers, the National Humanization Policy increasingly enables the inclusion of families in the management of care. In these actions, we can clearly see the naturalization of family responsibility and its use as the core of solidarity and care, from the moral perspective of love for others and humanity.

The booklet “Open Visit and Right to a Companion” - published by the Ministry of Health in 2004 - justifies the role of the family in care services, defending its participation in the responsibility of caring for its members, reinforcing the call for solidarity (MIOTO; DAL PRÁ, 2015).

Social policies, while recognizing the important role of families in the social protection of their members, also tend to overload them with responsibilities, with a strong appeal to the predominance of women as family references, subject to the implications and social demands on their protective function, without the necessary state support for its performance.

This way, it becomes clear how the neoliberal approach presents in social policies, particularly in health, manifests itself in the attack on acquired rights. This occurs when the State withdraws its responsibility to intervene in the manifestations of social issues and, instead, transfers the burden of providing care to families. This transfer of responsibility is legitimized by the actions, services and programs instituted and implemented by the State itself.

Social Services have the ability to gather crucial information about the experiences of the working class, enabling the transformation of the conditions of the groups they serve. Thus, the importance of social workers in understanding both the opportunities and challenges that affect their work is highlighted, in order to develop approaches that can reduce the contradictions inherent in this societal

context in the direction of the interests of the population.

In this sense, it is important to understand how the intervention of the profession contributes to overcoming the obstacles encountered by sick people and their families in the process of accessing and remaining in the treatment process, which includes the need for health care.

In the oncology area, the reality of family accountability has been deepened by the defunding of highly complex healthcare and the privatization of the sector, which directly interfere with the inclusion and permanence of people with cancer in the proposed treatment. Understanding these transformations that have occurred in the area of the right to health points to the subjugation of the population's needs to capitalist interests. At least, this is the perspective of analysis that we sought to undertake in the next section of this article.

THE OVERBURDEN OF CARE FOR FAMILIES OF PEOPLE WITH ADVANCED CANCER FROM THE PERSPECTIVE OF SOCIAL SERVICES

The reflections presented in this section are derived from the results of the investigation that had as its research field the HUPE, more precisely the services offered by the University Center for Cancer Control (CUCC) which also involves the Palliative Care Center. The final sample involved six social workers, whose insertion in the NCP/HUPE occurred between 2010 and 2023, the year in which the study was conducted.

The research demonstrated that the care of people with cancer treated by CUCC and/or NCP was carried out by families, but that they did not always reveal the issue of burden experienced in their experiences, which may indicate the culture of family responsibility. Among the participants, five of them stated

that the issue of burden is not made explicit.

This overload is not always explicitly stated in the first consultation. Many caregivers and family members have difficulty verbalizing and talking about the overload, but rather, it presents itself as issues raised by caregivers and family members at some point during care in the outpatient clinic (PARTICIPANT 5).

Social care is the moment when the professional, through attentive listening, captures both the verbal and body language of the user population, being able to obtain elements to understand and identify gaps that need to be addressed. Thus, the social worker needs to have the ability to listen, question and observe what is not explicitly said, but which reveals itself as expressions of the social issue experienced by the subject for whom the social worker's work is directed.

In this sense, it is essential to highlight that it is up to the social worker, during the consultations, to identify the implicit demands that the population does not recognize or does not perceive as primary needs, but that manifest themselves in some way in their living, working and health conditions.

This reality can be identified in the testimony of Participant 2 as follows: "Look, it's interesting, because I didn't hear these family members talk about overload. It was noticeable. [...] so, I noticed the overload and we talked about it [...] for me, it didn't appear as a demand". Therefore, agreeing with the author, it is important that the social worker, especially in palliative care, be aware of the demands that are not always expressed through speech, but that can be revealed through the body.

The research also identified that the burden on families, caregivers and companions of people with cancer in palliative care materializes/materialized in daily life through the illness and exhaustion of those who provide care. The statement of participant 3

makes this condition clear: "A phrase that I hear a lot from companions is – I am sick along with him. Because it ends up somatizing. The companion ends up getting sick together in the psychological sense. He feels sick just as much as he does."

The current neoliberal policy that justifies minimal state intervention in relation to social needs presents a peculiar perspective of reality. As the state plays a limited role in supporting families, without being completely absent, it ends up transferring to the family the responsibility of caring for and protecting its members, considered essential for the proper functioning of society.

By transferring the role of caring to families and removing their role as intervenors in the expressions of social issues, the State legitimizes this transfer with actions, services and programs planned and instituted by the State itself to "instruct" the family how to care, disregarding the need that it has to be cared for.

The population served there was a population that did not have high financial means. They were people who needed to work, their families could not give up work, in order to provide full care at home. So there were people who had to work and work at home, caring for that sick person. So, this was a very common reality, the overload of people who had families. It was very common for this to appear there (PARTICIPANT 4).

According to interviewee 1, the demand for hospitalization is due to the lack of objective conditions to provide care: "They had a demand for hospitalization [...] because they were unable to provide care at home".

In this sense, the study led us to ask: What are the challenges and difficulties encountered in caring for a person with advanced-stage cancer? What are the influences of the managerial perspective of health combined with the absence of a comprehensive care policy for the population living with a life-

threatening disease? Do families resort to hospitalization in an attempt to obtain basic care, due to the precariousness of Primary Health Care, especially in territories further away from large urban centers?

The logic historically present in health services that considers care as a family responsibility, reinforcing the familistic conception present in public policies, does not take into consideration, the needs of the working class in the face of fragmented and sectoral policies.

The contradiction of the work of the social worker can be identified when, even recognizing familism, the precariousness of public policies causes its reinforcement, as observed in the testimony of Participant 6:

[..]. The person is saying that they are unable to provide care. That's why we contacted the family to try to talk and show them that they need to organize themselves, that care is not the responsibility of just one person. If you can't provide care, at least you can help by hiring someone to provide care. Because sometimes everyone works – oh, I work. But only those who don't work? They can't work because they are providing care, they can't study because they are providing care. That person also needs to get out of that care, go to the mall, get their hair done, which is good for them, go to the beach.

It is important to consider the complexity and challenges involved in caring for a person with cancer, especially in palliative care. The proposal to share care with other family members or hire caregivers is a common solution in the health area to reduce the burden, but it is necessary to consider the reality of the working class, which is already overburdened and unable to afford the costs of these measures, given the process of lack of protection from the State. In addition, a more comprehensive approach is relevant, involving social policies and comprehensive care, in the articulation of needs with policies

that offer adequate support to the working class, considering the subjective and objective dimensions involved in care.

Workers who work in social policies with families must adopt a critical approach that goes beyond the logic of holding families accountable. These families must not be treated as *irregular, negligent or dysfunctional* based on a normative, moralizing and individualizing perspective. Reflections must be made that go beyond these stereotypes and seek to understand the social and structural dynamics that influence the lives of these families. This way, it will be possible to develop more appropriate and effective strategies, promoting a more equitable approach.

This is because the strategy used by the participating social workers to face the demands of overload presented by the families and caregivers of the sick people together with the other NCP workers was to raise awareness among the family and map the possibilities of the support network present in the territory.

[...] And even in the territory we have many difficulties in providing this, due to the scrapping of services. [...] What we do, perhaps, is try to raise awareness and involve other family members through meetings with other family members, so that there is awareness, so that there is no centralization of this care in a single person (PARTICIPANT 5).

Raising awareness among families and identifying the family support network are strategies that must be addressed, as the family can be a place of affection and care, as well as a space of lack of protection and violence, or of absence and rupture of bonds.

This analysis reinforces the need to understand the complexity of family dynamics and the importance of social policies that recognize the role of families, but also ensure the support and resources necessary for them to fulfill their responsibilities adequately, without overburdening individuals and

guaranteeing dignified living conditions for all their members.

In the Brazilian context, the valorization of the family has been highlighted as part of welfare pluralism, which seeks to decentralize the role of the State and strengthen the family as the main institution responsible for social protection. This approach highlights the importance of understanding families as fundamental subjects in the promotion of social well-being, considering their internal dynamics and the broader context in which they are inserted.

I think the best way for us to work is to make the other person think, problematize, question, and think together with the other person, and not for us to create a strategic plan for the other person, but [rather...] to put this discussion on the agenda for the other person. It is a way for us to discuss this organization and this overload of the other person's organization, how the other person organizes themselves. We poke, we problematize so that the other person can organize themselves (PARTICIPANT 4).

The implementation of the ethical-political project of Social Service demands the increasingly necessary presence of social workers with critical training and focused on overcoming class, gender and race exploitation. To this end, it is essential to delve deeper into the pertinent issues in order to establish an open dialogue, reaffirm defenses and ensure the improvement of professional performance within the scope of social policies and in relation to their users, that is, families.

Actions aimed at families aim to promote citizenship and the defense of their rights, recognizing that the difficulties and problems they manifest are reflections of the conflicts present in family dynamics. However, it is important to highlight that these dynamics are influenced by a history and a family structure that are shaped by the contradictions existing

in society in a given historical context.

The lack of state action resulting from the managerial management of social policies reveals a gap in public policies, especially in health, by leaving families overwhelmed in the face of the challenges faced.

Maintaining the family system benefits the State by exempting it from care obligations, transferring this responsibility to families, who take on this task free of charge. The policies created within this model only aim to reconcile work/family, without effectively redistributing responsibility for care. Instead, these policies only create conditions for families to enter a precarious labor market, while simultaneously keeping them responsible for this care activity. This perpetuates structural inequality and prevents a fair redistribution of care responsibilities in society (ASTELARRA, 2018).

In this sense, it is important to note the progress made with the creation of the Interministerial Working Group (GTI) with the objective of preparing the proposal for the National Care Policy and the proposal for the National Care Plan for Brazil, under the terms of Decree Number 11,460, of March 30, 2023, an initiative of the third Lula government that consists of an important step towards building a more inclusive and equitable care system in the country. This GTI designed a proposal for a National Care Policy, sent to the National Congress by the Federal Government in the form of the Project (PL) Number 2,762/2024, which identifies care as a right and as a priority public for the elderly, people with disabilities, children and adolescents, and those who spend their workforce on care, whether paid or not, such as the families of those who need care. However, the aforementioned PL does not cover people with chronic diseases, such as those living with cancer, and in adulthood, one of the gaps observed. Even so, far from a messianic perspective in relation to this

Policy, it is expected that the contradictions contained therein may serve the interests of the working class more than those of capital.

Finally, we start from the understanding that the centrality of families is a historical process that acquires new meanings in the current phase of structural crisis of capitalism. In Brazil, it is clear that, both in legal devices and in the operation of social programs, the dependence on the recognition of individual rights conditioned on the family situation reinforces the principle of the State as subsidiary in relation to families (MIOTO; CAMPOS; LIMA, 2006).

In this sense, we agree with the authors when they highlight that Brazilian families, far from having been stripped of their functions, have always been overburdened. This means that, despite the pressure and demands placed on families, they continue to be considered the main support for the provision of care and the well-being of their members.

FINAL CONSIDERATIONS

The illness of a family member has an impact on its entire structure, especially when it is a life-threatening illness. This reality becomes even more serious in an unequal society that places responsibility on the family, due to the State's failure to fulfill its constitutionally established responsibilities.

In this sense, knowing the work of the social worker with the families of people with cancer, especially in advanced stages, made it possible to approach theoretical-critical problematizations in relation to the expressions of the social issue, reinforcing the commitment to the ethical-political project of the category and to the guarantee and expansion of social rights of the working

class, in addition to enabling analyses of the scarce rights provided by the social protection network.

The study found that, despite the challenges, HUPE social workers are committed to providing the best possible care to the population of users suffering from cancer. However, precarious employment contracts and the hospital's disrepair make it difficult to achieve this goal. The characteristics of daily life also interfere with the work of social workers. Repetition, fragmentation, immediacy and pragmatism are elements that shape relationships with other professionals and users, as well as the work routine.

Due to these elements, even though the social workers at CUCC and NCP seek to prevent the reproduction of familism, this is a trend currently incorporated into social policies and services, as well as into the conception of family of other health workers.

When addressing Palliative Care and the burden of care, it is important to consider all sick individuals, inserted in the production model of capitalist society, whose objective repercussions on their living conditions and those of their families are markedly unequal.

This critical analysis, however, can only be carried out if we take as a starting point the social determination of the health-disease process, as it addresses fundamental elements for revealing the class character of the population's illness, including the reality of advanced-stage cancer, in order to problematize the prevailing conception in society of health as the absence of disease or the result of it, or even as determined by biopsychosocial factors that mask the processes of oppression and exploitation to which the working class and their families have historically been subordinated.

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