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MATERNITY, CARE, AND ONCOLOGY: AN EXPERIENCE REPORT

MATERNIDADE, CUIDADO E ONCOLOGIA: UM RELATO DE EXPERIÊNCIA

MATERNIDAD, CUIDADO Y ONCOLOGÍA: UN RELATO DE EXPERIENCIA

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ABSTRACT

The diagnosis of childhood cancer imposes significant disruptions on family life, with mothers frequently assuming an intense and often invisible caregiving burden. This experience report aims to describe and analyze this maternal experience, seeking to broaden the discussion on gender, work, and mental health within this context. The qualitative methodology employed participant observation and focus groups with mothers at a philanthropic support home. The results highlighted exclusive dedication, strong identification with the caregiver role, and the invisible labor dimension. The discussion delves into gender asymmetry in care, the internalization of the "maternal instinct," financial dependence, and the suffering from unrecognized symbolic grief. Furthermore, a scarcity of self-care practices was observed. It is concluded that this form of motherhood is a solitary and exhaustive function, demanding renunciations and calling for social recognition and supportive public policies.

Keywords: *Psychology; Motherhood; Focus Group..*

RESUMO

O diagnóstico de câncer infantil impõe rupturas significativas na vida familiar, e as mães frequentemente assumem um intenso e invisibilizado trabalho de cuidado. Este relato de experiência visa descrever e analisar essa vivência materna, buscando ampliar a discussão sobre gênero, trabalho e saúde mental nesse contexto. A metodologia qualitativa empregou observação participante e grupos focais com mães em uma casa de apoio filantrópica. Os resultados destacaram a dedicação exclusiva, a forte identificação com o papel de cuidadora e a dimensão do trabalho invisível. A discussão aprofunda sobre a assimetria de gênero no cuidado, a internalização do "instinto materno", a dependência financeira e o sofrimento por lutos simbólicos não reconhecidos. Observou-se, ainda, a escassez de práticas de autocuidado. Conclui-se que essa maternidade é uma função solitária e exaustiva, exigindo renúncias e clamando por reconhecimento social e políticas públicas de apoio.

Descritores: *Psicologia; Maternidade; Grupo Focal.*

RESUMEN

El diagnóstico de cáncer infantil impone rupturas significativas en la vida familiar, y las madres frecuentemente asumen un intenso e invisibilizado trabajo de cuidado. Este relato de experiencia busca describir y analizar esta vivencia materna, con el objetivo de ampliar la discusión sobre género, trabajo y salud mental en este contexto. La metodología cualitativa empleó observación participante y grupos focales con madres en una casa de apoyo filantrópica. Los resultados destacaron la dedicación exclusiva, la fuerte identificación con el rol de cuidadora y la dimensión del trabajo invisible. La discusión profundiza sobre la asimetría de género en el cuidado, la internalización del "instinto materno", la dependencia financiera y el sufrimiento por duelos simbólicos no reconocidos. Se observó, además, la escasez de prácticas de autocuidado. Se concluye que esta maternidad es una función solitaria y exhaustiva, que exige renuncias y clama por reconocimiento social y políticas públicas de apoyo.

Descriptores: *Psicología; Maternidad; Grupo Focal.*

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INTRODUCTION

Cancer is characterized as the disordered growth of cells that invade tissues and organs and can spread to different parts of the body. In children, the most common types include leukemias, lymphomas, and tumors of the central nervous system. The childhood oncological diagnosis represents an abrupt break in daily life, mobilizing not only the child, but the entire family around the treatment, which is usually prolonged, invasive and emotionally demanding[1].

For the mothers, who mostly assume the role of caregivers, this condition entails a significant practical and subjective displacement, which can lead to the discontinuity of their routines and the exclusive dedication to the monitoring of the child. This care work, fundamental for life, remains paradoxically invisible, lacking social recognition and effective support from public policies[1].

Therefore, the present manuscript aims to present an experience report of a field project, developed within the scope of a university discipline of the psychology course. Through a focus group with women, we sought to describe the intense exercise of care that, although informal and often not recognized, configures a type of work. It is intended, with this, to contribute to the expansion of discussions on the intersections between work, gender and mental health.

METHODS

This is a qualitative study, configured as an experience report, which seeks to deepen the understanding of a phenomenon, through critical reflection on direct experiences and practical contexts[2,3]. Specifically, the present work describes the interaction of psychology students with mothers, the main caregivers of children with cancer, in a philanthropic support house. Headquartered in Fortaleza, in the state of Ceará, this organization is dedicated to welcoming children and adolescents undergoing cancer treatment or other health conditions, along with their caregivers. The entity offers a support house that enables the stay of families from the interior of the state or from other states, allowing the monitoring of treatment in local hospitals.

Data collection was carried out through institutional visits conducted between February and May 2025. In the first visits, participant observation[2] was chosen as a methodological tool, allowing the researchers to immerse themselves in the studied context in a non-intrusive way. In addition, informal conversations were held, aiming at establishing a bond and the initial exploration of the participants' narratives. Finally, two focus groups were conducted[2,3], a technique that fostered broad discussion and thematic deepening, allowing participants to express their experiences and generate questions relevant to their context.

The sessions had the continuous guidance and support of a teacher in charge, who accompanied the entire process. In addition, it is important to highlight that all ethical precautions were strictly followed. The institutional authorization, confidentiality and anonymity of the participants were guaranteed.

RESULTS

The study began with an exploratory phase, which included institutional visits, observations, and informal interactions with the mothers, aiming at immersion in the context and adaptation of strategies. After this familiarization, two open-label focus groups were conducted, lasting approximately 2 hours, and participating 10 to 12 women per session, allowing variation in the presence of mothers.

The facilitation of the groups was conducted by two psychology interns, who had the weekly supervision of an undergraduate advisor. The meetings were held in a room that, although intended for handicraft activities, was chosen because it offers less circulation of people and, consequently, a more conducive environment for the concentration of the participants. However, it is important to note that, despite the careful selection, there were sporadic interruptions by the institution's employees, which, at times, impacted the full participation of the mothers.

The focus groups began with the presentation of the interns and the clear elucidation of the objectives, with reaffirmation of ethical principles and confidentiality. This alignment was essential to establish a safe and reliable space. In addition, each meeting began with an "icebreaker" activity to promote integration and a welcoming environment.

In the first focus group, the central dynamic was an activity that we named "Drawing my journey", in which the participants were invited to represent their trajectories through drawings or writing. Then, those who felt comfortable shared their creations and reflections. From the sharing, relevant issues emerged, such as family disconnection due to treatment, the pressure arising from the absence of mothers for other children, and the difficulty in allowing oneself to be vulnerable.

In the second focus group, mothers were invited to introduce themselves with a name and a characteristic not related to motherhood. The objective was to stimulate reflection on identity beyond the maternal role, often the only focus of their lives. Despite the education, most automatically mentioned the title "mother", showing a strong identification with the function and little perception of other significant personal characteristics. Also, on that day, the main dynamic was "What my hand does, and no one sees". At this point, the facilitators invited the participants to outline their hands on the paper and fill them with daily activities that were little recognized. The proposal was to give visibility to maternal work and continuous effort that is rarely recognized. Initially, one mother claimed full recognition of her family, generating hesitation in the entire group. However, the mediation of the interns allowed the activity to be reconfigured, thus emerging issues such as gender disparity, double shifts, grief, autonomy, and financial dependence, demonstrating the potential of the dynamic to raise deep reflections.

In short, the focus groups revealed the complexity of the experiences of the participating mothers, evidencing the nuances of their identity, the emotional and social challenges faced and the often-invisible dimension of their responsibilities.

DISCUSSION

The focus group observations revealed complex details about gender roles and the division of care work in the family context. Traditionally, within a heteronormative family structure, the couple is conceived as the pillar of support. In this context, the participants' narratives evidenced a persistent gender asymmetry, in which most of the care burden falls on the woman. This perception is in line with the historically constructed social expectation that women are the main - or exclusive - responsible for the integral care of the family and children[1,4,5].

The sociocultural construction of prescriptive gender roles, which intrinsically associates motherhood with unrestricted and primordial care, not only explains the female predominance in support spaces, but also fosters the deep internalization of the ideology of the "maternal instinct" by the mothers themselves. This internalization, far from being an intrinsic biological manifestation, is, as Elizabeth Badinter[6] elucidates, a social and historical construction that has shaped expectations about women and their relationship with the family. Paradoxically, this perception of care as an innate and exclusive capacity of women is manifested in the frequent contestation of the greater physical participation of parents in the care of their children, even when such resistance proves to be counterintuitive. By creating internal barriers that make it difficult to effectively delegate or share the care journey with their partners, mothers end up perpetuating the cycle of overload[1,4,5], reinforcing the idea that care is an inalienable female responsibility[6].

Overcoming the position of women as the sole caregiver and sharing this function does not depend only on an individual identity redefinition. This is largely due to the structural idealization of motherhood, which imposes the concept of "good mother" as one who sacrifices herself and is always available. So, sacrificial motherhood is a social imperative that demands unconditional devotion from women. Breaking with this idealization requires efforts that transcend the individual sphere, requiring broad social transformations. While these changes do not materialize, mothers continue to face this reality in isolation, perpetuating the overload and insufficient recognition of their work[1,4,5].

In this sense, the care work performed by these mothers, far from being romanticized, constitutes an experience permeated by complex decisions and significant renunciations. The need to prioritize the child in treatment often implies moving away from other children, the spouse, and the routine of the family environment. This situation generates an intense internal conflict, marked by the tension between the desire to keep the family together and the imperative need to direct attention to the child with the greatest demand for care. In addition, the social expectation that women emotionally support the entire family imposes a considerable affective overload. Although mothers sometimes try to mask this burden, it resurfaces in the form of feelings of guilt for absence, fear of losing the bond with distant children, and a deep longing, intertwined in a complex of emotions that demonstrate the non-linearity and suffering inherent to this experience[1,5].

The prevalence of financial dependence among the participants emerged as a complementary theme to the previous discussions. Full dedication to the care of children undergoing treatment often culminates in the interruption of work activities and, consequently, in the loss of financial autonomy. This situation places them in a state of socioeconomic vulnerability, exacerbated by the insufficiency of formal support networks - whether family or governmental (such as the ineffectiveness of financial aid programs). Therefore, the absence of a fixed income of their own not only significantly limits the decision-making power of these women, but also intensifies a cycle of subordination, deepening their dependence and fragility in the face of adversity[1,4,5].

Also, in the context of the experiences reported in the focus groups, the deep anguish and intrinsic suffering that permeate the exercise of care became evident. In addition to the conditions of material vulnerability and the practical difficulties faced, the experience is constantly crossed by complex emotional processes, often associated with different manifestations of grief. According to Franco[7], grief is understood as a process of rupture in the face of a significant loss, capable of impacting the development and life trajectory of an individual. However, this conceptualization extends beyond physical death, encompassing all forms of symbolic losses and existential ruptures that accompany critical moments, such as the processes of serious illness of a child. In these cases, grief can manifest itself due to the loss of the previous routine, future expectations, personal autonomy and well-being, configuring a series of psychic challenges that require elaboration.

In this scenario, mothers deal not only with anticipatory grief8 regarding the potential loss of a sick child, but also with a series of symbolic losses imposed by the child's health condition and the consequences of this care. For example, mothers describe the pain of having to "leave" or "abandon" another child at home, who, although not physically ill, is equally impacted by the sibling's situation. Essentially, the lack of social recognition for these symbolic and anticipatory losses significantly aggravates the grieving process, making it a more complicated and lonely experience. The invisibility of these pains prevents mothers from finding space for the elaboration and necessary support, transforming the absence of recognition into an aggravating factor for their suffering.

Initially, the perception of self-care was predominantly restricted to the spiritual/religious dimension[1], which proved to be an essential regulatory factor in a context of severe illness such as cancer, intrinsically associated with fear of death, pain and suffering. In this scenario, spirituality and/or religiosity operate as a central mechanism for the resignification of experience, offering moments of peace, consolation and renewal. In addition, they act as a fundamental coping strategy, providing strength, courage, a sense of the child's illness and strengthening hope for a cure.

In addition to the spiritual dimension, the mothers emphasize the lack of investment in other self-care practices. Corroborating this idea, the study by Guimarães, Dellazzana-Zanon and Enumo[9] emphasizes that these mothers, typically the main caregivers, bear significant physical, emotional, and social overload, leading them to sacrifice their personal and professional lives, which results in exhaustion and scarcity of time. This selflessness and full dedication, combined with the difficulty in delegating and the responsibility of the maternal role, can culminate in helplessness and the development of symptoms such as anxiety, depression and post-traumatic stress. Although the research highlights that mothers employ adaptive strategies, the results point to the urgent need for health care for these caregivers, who need welcoming listening, space to express feelings and strategies that allow for less painful coping, reiterating the fundamental importance of promoting their well-being and self-care.

In addition, considering the profile of the participants, mostly black mothers and from unfavorable socioeconomic conditions, it is essential to reflect on how social markers of difference, such as gender, class, and race, can accentuate the burden and fragility of these mothers. An intersectional lens demonstrates; therefore, how social inequities potentiate situations of vulnerability, being fundamental for an in-depth analysis and for proposing interventions that are more adapted to different realities[10].

In summary, the analyses reveal that the experience of motherhood in the face of a child's serious illness is permeated by a complex web of asymmetries and invisible sufferings that need a sensitive look and attentive and humanized care.

CONCLUSION

This space confronted us with complex realities, permeated by gender inequalities and often silenced pain. It revealed a care work loaded with affection, but undeniably on the edge of exhaustion. With this, the centrality of care work in the lives of these women became evident, demystifying any romanticization and exposing it as a structural requirement of society that, even today, insists on naturalizing maternal suffering as an inherent part of the condition of being a mother. From the various shared narratives, we realize that, in this context, motherhood transcends experience and takes the form of a function to be fulfilled in a solitary, incessant and undivided way. Providing this moment of listening and voice for these mothers, even in the face of difficulties, seemed to open fissures for a more complex and deeper self-perception.

Working with this group of mothers required us to deal with the deep sensitivity of their accounts and the intense emotions they shared. It was essential to sustain, with extreme care and empathy, intrinsically delicate issues, aware that these women experience a reality marked by pain, overload and renunciations. Conducting this space demanded an attentive and welcoming look, so that they felt safe to expose their experiences. The main challenge was to find ways to connect and manage the speeches without being invasive, always respecting the uniqueness of each one's reality. Given the highly particular context surrounding them, there was no predefined model; We built the path based on constant sensitivity and active listening.

Despite the complexity inherent in working with these mothers, we believe that there is still much to be explored. It is therefore essential to deepen the understanding of the emotional and subjective impacts that cross them in the performance of the role of caregivers. With this work, we hope to contribute to greater visibility and support for this reality.

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