



# Impact of anticipatory grief in wives of hematological cancer patients

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## Resumen

Las esposas suelen ser las principales cuidadoras de los pacientes adultos que padecen una enfermedad neoplásica. Debido a los altos niveles de sufrimiento de su pareja, tienen más posibilidades de desarrollar respuestas de duelo anticipado. Este estudio tuvo como objetivo investigar el impacto del duelo anticipado en los cónyuges cuidadores de pacientes con cáncer hematológico en tratamiento en un hospital universitario del interior del Estado de São Paulo, Brasil. Participaron diez esposas, con una edad media de 39 años. Los datos se recogieron mediante entrevistas semiestructuradas y se sometieron a un análisis temático. Se construyeron dos categorías: "Características individuales de los cuidadores que facilitan o dificultan la elaboración de pérdidas y cambios en la vida cotidiana" y "Efectos percibidos en el bienestar subjetivo y la salud mental de las cuidadoras". Como cuidadoras principales, las mujeres son más propensas al impacto del duelo temprano. Los cambios en los roles familiares, sociales y laborales provocados por la enfermedad desencadenaron emociones compatibles con el duelo anticipado. Los recursos personales para afrontar el cambio y la pérdida están influidos por la edad, la educación, la clase social, la ocupación y la religión, que modulan las exigencias de la enfermedad sobre la pareja del paciente. Las mujeres describieron la carga de los cuidados y su efecto en su salud mental y equilibrio emocional. Los resultados muestran que se necesitan más políticas sanitarias para satisfacer las necesidades de las mujeres cuidadoras como grupo vulnerable.

**PALABRAS CLAVE:** Neoplasias Hematológicas, Cónyuges, Cuidadores, Luto Antecipatório, Luto, Oncología, Relacionamientos Conjugais.

## Abstract

Wives are often the primary caregivers of adult patients facing a neoplastic disease. Due to their partner's high levels of suffering, they have a greater chance of developing responses to anticipatory grief. This study aimed to investigate the impact of anticipatory grief on spouse caregivers of patients with hematological cancer under treatment at a university hospital in the interior of São Paulo State, Brazil. Ten wives participated, with an average age of 39 years. The data were collected through semi-structured interviews and submitted to thematic analysis. Two categories were constructed: "Individual characteristics of caregivers that facilitate or hinder the elaboration of losses and changes in daily life" and "Perceived effects on the subjective well-being and mental health of spouse caregivers". As the main responsible for the care, women are more prone to the impact of anticipatory grief. The changes in family, social and occupational roles caused by the illness triggered emotions compatible with anticipatory grief. Personal resources to deal with change and loss are influenced by age, education, social class, occupation status, and religion, which modulate the demands of the illness on the patient's partner. Women described burden of caregiving and its effect on their mental health and emotional balance. The results highlight that more health policies are needed to address the needs of female caregivers as a vulnerable group.

**KEYWORDS:** Hematologic Neoplasms, Spouses, Caregivers, Anticipatory Grief, Bereavement, Oncology, Marital Relationships.

## I. Introduction

Oncological disease, commonly called cancer, is currently one of the most common and feared diseases. Hematologic neoplasms comprise a set of diseases characterized by the multiplication of blood cells, which can affect bone marrow, lymph nodes, and other parts of the body. The most common types are leukemia, lymphoma and myeloma, according to the type of cells affected (Cardoso, Mastropietro, Voltarelli, & Santos, 2009).

By receiving the diagnosis of a reserved prognostic disease, such as hematological cancer, both the patient and his or her relatives may experience dysphoric feelings and catastrophic thoughts (Bergerot, Araujo, & Tróccoli, 2014; Silva, Santos, & Oliveira-Cardoso, 2019). The discovery of the disease and invasive treatment are vital events considered critical for the whole family, as they interrupt the line of continuity of daily life and introduce a interruption in the sense of normality (Ambrosio & Santos, 2011). Facing a life-threatening condition elicits psychological distress, which is exacerbated by the suspension of professional activities, postponement of life projects, abandonment of dreams, plans and perspectives for the future. In addition, there is a disturbance in the feeling of invulnerability, calling into question the belief that potentially fatal diseases only affect others (Cardoso & Santos, 2013).

Onco-hematologic diseases currently have advanced treatment protocols, which include Hematopoietic Stem Cell Transplantation - HSCT (Beattie & Lebel, 2011). For both patient and family members, HSCT represents a promising prospect for healing after the diagnosis of some types of hematologic cancers, but it also involves considerable risks, including the possibility of the patient's death due to the aggressiveness of the procedure.

The risk of death means that the process of deciding on HSCT as a therapeutic option is experienced as another critical event, which adds to the stress experienced with the diagnosis of the potentially fatal disease, potentializing tensions and distress (Cardoso et al., 2009). It is expected that the patient and his or her family members will experience anticipatory mourning reactions during this period (Matias, Cardoso, Mastropietro, Voltarelli, & Santos, 2011).

The effect of anticipatory grief on bereavement outcome has been much debated (Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). Grief is a process that results in the break-up of a bond. It is a private as well as a public experience. This process is composed of grief, which are the recurring thoughts about loss that are expressed to people close to and experienced in a unique way.

The simple threat of separation or death can, in itself, trigger mourning reactions. According to literature review, in a family in which one of its members is diagnosed with a chronic or terminal illness, there are several experiences of mourning processes: the personal mourning of each individual, the mourning for changes in family dynamics, social mourning, religious mourning, and finally, mourning for the consummate death (Fonseca, 2012). The patient's family and their social bonds suffer with the news and the pain of imminent loss. However, taking into account the process that occurs while the person is alive, this phenomenon is called anticipatory grief (Hottensen, 2010).

The anticipation of loss is essential for family members to prepare for the death of their loved one and can facilitate adaptation to death when the loss actually occurs (Nielsen et al., 2016). However, excessive concentration on anticipating

loss (severe anticipatory grief) can be emotionally crippling if resources are not activated to harness this experience in order to preserve or even improve the quality of life (Fonseca, 2012). When the experience of anticipatory grief is maladjusted, i.e. has high or premature levels of suffering, it can lead to complicated mourning after the death of the sick person. High levels of pre-loss grief and low levels of preparedness during caregiving were associated with poor bereavement outcome such as complicated grief (Nielsen et al., 2016).

There is evidence that spouses suffer more than other family members because they feel closer to the patient (Johansson, Sundh, Wijk, & Grimby, 2012), in addition to being more likely to develop negative responses to anticipatory grief due to greater awareness of death. Spouses live with high levels of suffering of the partner and multiple losses related to the tasks of caregiver, such as restriction of freedom, changes in the relationship with the partner and in the performance of roles, losses in social involvement and the renunciation of personal projects and ambitions (Areia, Fonseca, Major, & Relvas, 2019).

Considering that clinical practice proves the emotional impact of partner illness and the resulting changes in various spheres of family life, generating overload of functions for women (Beattie & Lebel, 2011), it becomes imperative to know the reality of caregiving wives. This research is based on the assumption that due to close contact with high levels of physical and psychological distress of the partner, wives are more susceptible to high levels of anticipatory grief.

This study aimed at investigating anticipatory grief in women of hematologic cancer patients undergoing conventional treatments or hematopoietic stem cell transplantation.

## II. Method

It is a qualitative, transversal, descriptive-exploratory study.

### Participants

The following inclusion criteria were adopted for the sample composition: age over 18 years old, wife of patients diagnosed with onco-hematologic disease, hospitalized for conventional treatments or HSCT in a hematology ward at a university hospital in the interior of São Paulo State, Brazil. The participants should be accompanied throughout the period of hospitalization to perform the treatment. Exclusion criteria: women who had not systematically accompanied the patient during the course of treatment. The sample consisted of the wives of all patients admitted consecutively to the hospital unit.

### Hipóteses e variáveis do estudo

The hypothesis was formulated: personal resources to deal with anticipatory grief can be influenced by the phase of the life cycle in which the person finds himself (age), education, social class, profession / occupational status and religion.

### Instruments

Semi-structured interview script: the interview script contained questions that investigated aspects related to anticipatory grief, namely: emotional reactions to the husband's diagnosis, perception of changes in personal and family life after the illness, perception of losses (labor, financial, affective, in social interaction), facilities and difficulties encountered when exercising the role of caregiver during treatment, impacts of the husband's illness situation on the health and psychological well-be-

ing of the interviewee, expectations regarding treatment and vision of the future.

Economic Classification Criterion - Brazil Criterion: this standardized instrument aims to characterize the position of families in the social structure. The social strata vary from class A (high purchasing power) to class D-E (low purchasing power) (Associação Brasileira de Empresas de Pesquisas [ABEP] (2019).

### Procedure

Hospital admissions monitoring was performed to identify consecutive cases of hospitalized men diagnosed with onco-hematologic disease during the data collection period (n = 10). The primary caregivers of these patients were invited and accepted to participate in the study. The interviews were applied face to face, individually, in a single meeting held in a reserved room of the hospital institution. The interviews were recorded and lasted an average of one hour and a half.

### Data Analysis

The corpus of analysis consisted of the full transcripts of the interviews. The spouse caregivers' reports were submitted to reflective thematic analysis. It is a method that identifies, analyzes and reports patterns (themes) in the reports obtained. The Thematic Analysis is operated by the development of six phases, being: 1) Familiarization with the data, 2) Construction of initial codes, 3) Search by themes, 4) Analysis of the themes 5) Definition and assignment of names to the themes and 6) Production of the report (Braun & Clarke, 2019).

### Ethical considerations

The study was approved by the Research Ethics

Committee (CAEE nº 93706818.1.0000.5407) and followed the ethical procedures recommended by Resolution nº 466/12 on research involving human beings.

## III. Results

Table 1 presents the demographic characteristics of participants, identified with fictitious names in order to ensure confidentiality of data.

Table 1.

Demographic characteristics of participants and clinical data of husbands (N = 10).

Name	Age	Education	Profession / Occupational status	Children	Economic classification*	Spouse's diagnosis	Diagnostic time
Lara	25	High school	Housekeeper	3	D-E	Multiple myeloma	4 months
Vitória	26	High school	Housewife	3	C1	High grade B-cell lymphoma	18 days
Bruna	31	High school	Housewife	2	D-E	Aplastic anemia	3 years
Lucia	31	High school	Cook	2	C1	High grade B-cell lymphoma	4 months
Lilian	36	High school	Community health worker	1	C1	High grade B-cell lymphoma	18 days
Rosa	36	Elementary school	Worker trader [unemployed]	1	D-E	Burkitt's lymphoma	3 months
Roberta	36	Higher education	Physiotherapist	1	B2	Acute lymphoid leukemia	40 days
Júlia	49	Higher education	Civil servant	2	B2	Acute promyelocytic leukemia	6 days
Maria	57	Elementary school	Housewife	3	C2	Acute myeloid leukemia	14 months
Marta	63	Elementary school	Housewife	3	C2	Multiple myeloma	6 months

\* Class A: equivalent to 2.5% of the Brazilian population; Class B: 20.9%; Class C: 48.3%; Classe D-E: 28.3%.

The sample was composed of women mostly young (25 to 36 years old). The predominant level of schooling was equivalent to complete high school (11 years of study), which is considered a favorable element for learning the tasks that the family caregiver must perform during the spouse's treatment. Most of the participants had a profession. All of them had at least one child. Most were from low-income backgrounds. They all declared themselves religious, with Christian religions predominating. The majority of the participants came from other municipalities in the State of São Paulo. Leukemia and lymphoma were the prevalent diagnoses. The husbands of Lucia, Lilian, Vitória, and Rosa had no indication for HSCT because they were still undergoing conventional treatments and, depending on how they responded, could or could not be candidates for transplant. Bruna, Marta and Maria's husbands were the only

ones who had recently undergone HSCT, and in the case of the first two, at the time of the interview, the bone marrow grip was still awaited. Only Maria's husband had a longer time of diagnosis (14 months), the others varied from six days to six months, which suggests that the wives could still be processing the shock of the recent discovery of the disease.

The analysis of the research corpus allowed two thematic categories to be constructed.

**Category 1: Individual characteristics of caregivers that facilitate or hinder the elaboration of losses and changes in daily life.**

**Age:** most participants were aged between 25 and 36 (seven). This may imply differences in individual grief resolution conditions. Our hypothesis is that younger women have greater tolerance to stress, a higher level of vital energy to invest in the care of their husband, and flexibility to adjust to routine changes. During transplantation, primary caregivers must accompany their husbands in the infirmary all the time and are responsible for providing basic care. This is consistent with the literature: family caregivers of cancer patients reported high levels of distress, low levels of social support and low levels of coping abilities. Increased age was found to accentuate these processes (Goldzweig et al., 2013).

Our results showed that the fact that younger wives have children of school age (therefore highly dependent on parental supervision) is a complicating factor in the adjustment in families. They find it difficult to assume the responsibilities required by the spouse's treatment, which implies frequent and prolonged hospitalizations. "The children for me and my husband were our main concern. Now the priority is him. If I need to stay two, three days in the hospital, the little one needs to

stay with his aunt" (Rosa, 36). "My sister helps me, it's hard because the children need care, they have to go to school" (Rosa, 36). (Vitória, 26). Only one participant said that she did not ask for help from people she knew because she thought that only she should be responsible for her husband's care. "When we started coming to the hospital, I wanted to learn not to depend on anyone. I who bring him, I who seek him. Because I like this independence too, although I have many people supporting, I do not like it. I don't like to be bothering other people, because it's my problem and his" (Lucia, 31). Some younger participants experienced very limited social and family support: "I talked only with God himself, because those who are not going through this do not feel the same thing you do. They don't understand what you are feeling" (Bruna, 31).

On the other hand, the older caregivers (Julia, Maria and Marta) had adult and independent children and therefore were more willing to remain with their spouses. They also showed maturity and patience in dealing with problems and adjusting to crises, accepting the uncertainties of the disease and the changes in family dynamics. Therefore, our findings do not corroborate the evidence in the literature that older caregivers to older patients might not be able to use social support as much as caregivers to younger cancer patients (Goldzweig et al., 2013; Green, Wells, & Laakso, 2011).

**Education:** Six participants had completed 11 years of studies. The others had up to eight years of study. The level of formal education is related to the individual's ability to abstract information from the environment, understand general aspects of the disease and treatment, and thus better exercise the role of family caregiver of the patient. They may also have better conditions to maintain self-care behaviors. The results corroborate that

medium and high levels of formal education favor the understanding of the tasks related to treatment.

**Social class:** Eight participants belonged to the lowest positions in the social pyramid (C and D-E), which correspond to 76.6% of the Brazilian population; two participants belonged to class B, which corresponds to 28.3% of the population. The socioeconomic condition and the social class to which women and their families belong are directly related to the health-disease process, since they influence the exposure or not to several risk factors, the access to health resources and the flexibility and diversity of therapeutic options to which they have access, also impacting the particular way of living mourning losses (Santos, 2020). According to literature, people living in poverty can have worse health outcomes (both mental and physical), which can be attributed to limited employment opportunities, lower earning potential and fewer accumulated savings, resulting in fewer economic and social support opportunities. In addition, poverty is a primary risk factor for food insecurity.

The results of our study show that most participants have more restricted levels of access to material resources and medical services, which could hamper health care. However, the limitations arising from the lower socioeconomic position of families are partially mitigated thanks to universal access to the Brazilian public health system, which allows patients access to comprehensive onco-hematologic treatment, totally free and of high quality. The Brazilian Unified Health System (SUS) is internationally recognized as one of the most inclusive and successful public health policies in the world.

"Then we talk to the doctor: 'how are we going to do this treatment that is so expensive?', because we don't have that money? She said: 'I will give

you the contact of a doctor, he will take you in and you will enter through SUS' (Bruna, 31). "When we entered here, they said that we were in one of the best hospitals to treat the disease he has. The team is very good, the doctors are very good. There are doctors who are references in treatments" (Roberta, 36).

These results are consistent with the evidence in the literature, especially in the context of low-income families. Social support was found to be crucial in successful adaptation among cancer patients and their partners (Green et al., 2011).

**Profession / Occupational status:** Six participants had professional activity, two of them health professionals. The provision of care implies accompanying the husband in exams, medical appointments and hospitalizations, which brought ruptures and discontinuity of professional activities. "I'm stopping working because of him, because I'm no longer able to reconcile school, work and domestic duties" (Lucia, 31). "There's no way I'll go to work and come every three hours to pass his diets through the probe, so he'll need a lot of care now" (Lilian, 36).

For the two wives who were health provider, having familiarity with the hospital routine and medications made adaptation easier, but having mastery of knowledge in this area made the process of accepting the husband's diagnosis more difficult. "It's horrible for you to know about this issue. It is preferable for you to be a layman, who then the doctor speaks and you leave without knowing the seriousness of the disease. But when you are a health professional, you know exactly what the doctor is talking about" (Roberta, 36). "This has to be questioned in the area of health, because sometimes we are not cool and how you have to administer medication? How will you do if you have to intubate a person, if you are not well? We are not superheroes" (Lilian, 36). "I take a technical

course in nursing, I studied these diseases before I knew he was sick" (Lucia, 31). "I want to get out of health care, I want to do another degree, accounting sciences" (Lilian, 36).

**Religion:** all the participants declared themselves to be adherents of a religion, predominantly Christian (Catholic, Evangelical). Spirituality was highlighted as the main resource to face the dilemmas. Having faith, believing in the benevolence of a Higher Power provided relief and comfort, strengthening the hope of overcoming difficult days. "I think if it hadn't been for my faith, I wouldn't have made it this far" (Vitoria, 26). "I feel that God is saying that everything is going to change, that my husband is going to be okay, that it's just a storm that's going to pass. So that's what gives us strength, right" (Lara, 25). "We have this hope, this peace that comes from God, so this gives strength daily to us," (Lara, 25). (Roberta, 36). "You have to trust in God, have faith and believe that He exists" (Marta, 63). (Marta, 63) "I don't focus much on religion, but on God. For me it is Him. I have to talk to Him, ask Him, thank Him" (Rosa, 36).

The religious practices (praying daily, participating in services) were intensified after the illness, mainly through prayers. Praying made the caregivers feel closer to the sacred, strengthening spiritual support. "I am praying more, more than usual, especially when it comes to crisis" (Lilian, 36). "I've been praying a lot, a lot more [...] we start asking more when something bad happens, because while everything is fine you leave, don't worry so much, forget God more" (Rosa, 36),

Although considered an important source of support, some participants stated that having faith sometimes was not enough to mitigate the suffering that the husband's illness triggered. They said there were times when they rebelled against God,

but that faith was soon restored, functioning as a calming balm for their rebellion. "There is a day when I don't really believe in God, when I talk like this: 'it won't help me to keep praying and praying, he won't make it'" (Rosa, 36). "I still joke with God: 'if this doesn't happen, I'll be very angry,' because other times I needed God, I wasn't helpless" (Lilian, 36). "The end can be what we want: that he be healed. Or not. Because, suddenly, God can take him. But we don't worry about the end, about what will happen, because we know that if this is within God's purpose, it will be so. If God decides to take it, it is for the glory of God" (Roberta, 36).

Even exposed to trials and ambiguous feelings regarding the consistency of their faith, the participants found in their spirituality a sense for illness. Finding purpose in life provides relief and comfort for suffering. "If we are going through this, it is because God loves us. And God knows all things. And surely we all have a foundation in our lives" (Lara, 25). "I never stopped believing because of that, on the contrary, I always thanked Him. I thank God because it is He who gives me strength" (Vitoria, 26).

### **Category 2: Perceived effects on the subjective well-being and mental health of spouse caregivers**

This thematic category explored the perceived effects of anticipatory grief on the health and well-being of caregivers whose spouses were being treated for onco-hematological disease.

"A shock [...] I was afraid of losing, because we are very afraid of losing the person [...] because I already had the suspicion, until the doctor confirmed: 'yes, that's what you were suspecting' (Lucia, 31). "I was shaken [...] I said: 'my husband with blood cancer?' I thought it was the end of the

world" (Lara, 25). "When there was the possibility that it was this disease, I thought at the time: 'wow, if he dies, what will happen? [...] So the first thing that comes to mind is death" (Roberta, 36).

The participants reported distress when receiving the confirmation of the diagnosis. Such suffering was enhanced by the ruthless manner in which the doctor communicated the bad news. "No, the doctor who spoke to us was not very delicate. I don't think we were lucky that day here" (Vitória, 26). "For me it didn't shock so much, I already had a notion of what it was, but I think if it was a person who didn't know, the doctor could have spoken differently" (Bruna, 31).

In addition to the lack of empathy and compassion of professionals, participants expressed concern that their husbands might not tolerate the toxicity of treatment. "It all came to my mind. I said, 'My God, will he make it through?', 'will he make it through?" (Lara, 25). "I was sad, not for the lymphoma, but for the fact that I know that he is a person who doesn't have a good head to deal with an illness situation" (Lilian, 36).

For some participants, the physical fatigue generated by the burden of care was a major challenge to be managed. Without receiving sufficient support, they had to reconcile domestic chores and children's education with the demands of their work and care for their husband's health needs. "Tiredness, thus, more physical. Because the baby demands a lot and has the house too. I don't have a housekeeper" (Bruna, 31). The changes in family dynamics have also affected the children, especially the youngest. Other family members (mother, brothers, wife's uncles) have been asked to give some support in caring for their children.

On the other hand, the participants consid-

ered that they had to be strong and could not show weakness in the face of adverse situations. This is why they strive to "keep up appearances" of strength in front of their partner and children. They prioritized meeting their spouse's needs and neglected their own care needs: "My role is to be strong. I see myself as a warrior on his side" (Lara, 25). "Close to him I try to stay firm, understand? If he sees that I'm fine, he'll be fine too" (Lúcia, 49). "I have to stay strong because I have the girls, I have to give them strength and transmit security" (Júlia, 49).

Some participants showed an optimistic posture and recognized that they were learning from adversity, which increases well-being: "I think we need to learn to take care of ourselves more, maybe with all this we will see little things that we didn't pay attention to before" (Maria, 57). "I think it's good for us to value even more the small things. And we value people even more, because here at the hospital you find a lot more people suffering" (Roberta, 36). "Everything will get better, as it gets better and better. It will be better for him, for me, for everything. It will come back to the life we had when we started dating" (Lara, 25). "Everything happens in life. It will be normal again. Let's be strong now, that victory comes later" (Maria, 57).

The participants noticed personal transformations with the experience of their spouse's illness. "A learning of patience that I needed to go through. Because my life changed, not only his life, but mine too" (Lilian, 36). "It changed a lot, my personality changed a lot, my way of thinking changed a lot. Then you see that you are nothing" (Marta, 63). Two participants said they didn't notice changes in themselves: "For now nothing, because I've closed myself, I need to go back to my routine to see what changes, because until now I haven't

stopped yet" (Lilian, 36). "They talk like this: 'ah, you feel stronger? No! I was already tough before. I haven't seen change in me yet" (Lúcia, 31).

Some participants reported that after the illness they feel they have become emotionally closer to their husband, which is perceived as desirable, as well as being in charge of care. "He became much more attached after the illness, me in him and him in me" (Maria, 57). "You know, I think it helped strengthen our relationship, to have more respect for each other, to have more love for our neighbor" (Lara, 25). "It has come closer because every day, most of my day, I am with him" (Roberta, 36). "It seems to have brought us closer together. I think we are even more united" (Vitória, 26).

#### IV. Discussion

The results show that the changes in family, social, and occupational roles caused by the illness of the spouses triggered emotions compatible with the anticipatory grief women. This is consistent with the literature, which points out that grief puts into action a cognitive, emotional and behavioral process, which is experienced by both the patient and their relatives (Fonseca, 2012). The totality of participants in this study experienced reactions to the perceived losses when living with their husbands' serious illness. Personal resources to deal with the changes are influenced by age, education, social class, occupation status and religion, which modulate the demands of the illness on the patient's partner. The changes were perceived in the family dynamics already in the pre-diagnostic stage, at the beginning of the symptoms, and permeated the whole process of illness. Spouse caregivers alternate moments of psychic disorganization and reorganization. According to the literature, it is expected that the changes persist after the end of

treatment, whether the cure or death of the patient (Hottensen, 2010).

Women reported that they had to join forces to reorganize their daily lives and establish new domestic arrangements to conduct their lives from the diagnosis. In this complex scenario, moving forward is not a simple task. Psychosocial adjustment requires caregivers' willingness to learn the numerous skills required by their spouse's treatment follow-up, assimilate basic medical knowledge, and learn to live with limitations, which is consistent with the literature (Cardoso, Santos, Mastropietro, & Voltarelli, 2010).

The diagnosis of hematological cancer triggers devastating emotions both in the patient and family members. The emotional reactions to adverse events go through various stages, which develop in nonlinear progression. These stages involve an initial moment of shock and denial, which can be followed by anger, resentment, guilt, depression and acceptance (Ambrosio & Santos, 2011; Blanc, Silveira, & Pinto, 2016). Depressive symptoms are commonly identified and can be differentiated, in a first phase, because they refer to pain and loss from what the sick person had in the past (mainly the loss of health and social, occupational roles, which have financial impacts), while the second phase refers to future losses, which tend to be cumulative with the progression of the disease. In this second phase, feelings of sadness, regret and loneliness predominate, which anticipate the affective disconnection (Cardoso & Santos, 2015).

This study has shown that one of the greatest challenges for wives is to learn to overcome the impact of negative emotions that permeate the entire treatment. It was noted that emotional reactions tend to be unstable and oscillating. Wives express hope and faith in their partners' recovery;

on the other hand, sometimes they openly conjecture the possibility of death, although they do not talk about it with them. This finding reinforces the recommendation that health professionals welcome the female spouse caregivers' ambivalent feelings, supporting them so that hope can overcome the moments of skepticism and discouragement that accompany the treatment.

Family caregivers of cancer patients are considered a vulnerable group for the development of psychological morbidity and health impairment (Nielsen et al., 2016). Depressive and anxiety symptoms can be aggravated by pessimistic thoughts. The narratives highlighted catastrophic thoughts, such as fear of a future without their husbands' physical presence. They face a scenario of uncertainty and the risk of imminent loss. Some anticipated and tried to imagine what life would be like if the worst outcome happened. Nine of the participants had children and the husband was the main provider of family income in most homes. The physical and psychological exhaustion was accentuated by the rupture of the routine, constant displacements to fulfill the treatment, facing sleepless nights in hospital and living with financial limitations (Cardoso et al., 2010). Women described burden of caregiving and its effect on their mental health and emotional balance. These results highlight the need to carefully screen the economic and mental and physical health needs of cancer patients families in order to provide an appropriate intervention in this context.

It was observed that participants avoided externalizing their feelings for fear of exposing their "weaknesses", which is consistent with the literature (Sutherland, 2009). The healthy spouse's movement to hide their feelings and needs is supported by a belief that to support their husbands they must be unwavering. They assume that this would

increase their partner's security and reduce their emotional and physical suffering. They strived to maintain a strong appearance when they were with their partners, strengthening their fighting spirit for life and nurturing optimistic expectations as to the outcome of the treatment, even when they themselves were not so convinced that he would survive. They prioritized satisfying their partner's needs and cared about their children's well-being, often to the detriment of their own needs. Stoicism is a defense mechanism based on the denial of one's own fragility. This posture can increase the vulnerability and suffering of caregivers (Sutherland, 2009). This eventually makes them neglect their self-care, which is consistent with the literature on family members of cancer patients (Areia et al., 2019).

Another result to be highlighted is that work overload may accentuate the tendency to neglect self-care. The female figure in families is recognized as the main source of care for dependent members. Extreme dedication can cost the woman who cares for her members affective and financial losses, such as exclusion, social isolation, depressive symptoms (Beattie & Lebel, 2011; Blanc et al., 2016; Sá, 2002). These negative consequences can intensify emotional reactions to the impending loss that characterizes anticipatory grief.

According to the literature review, the ability to anticipate loss is considered essential to protect the mental health of family caregivers of patients with onco-hematologic disease. Wives need to prepare for the possibility of loss of their loved one, which can facilitate adaptation to death when it actually occurs. High preparedness was associated with improved caregiver outcome (Nielsen et al., 2016). However, in the course of the treatment it is fundamental that the positive confrontation of

the caregivers is stimulated, strengthening strategies of positive reframing of adverse experiences. The results show that spirituality can be an important ally in the elaboration of loss. As self-reported benefits, wives identify the experience of illness as an opportunity to resignify life and reconnect with their spiritual self.

Thus, the results highlighted the relevance of spirituality as a resource to support and strengthen caregivers, which is congruent with literature (Ambrosio & Santos, 2011; Benites, Nemes, & Santos, 2017), but restrictions were also found. There were times when faith was put to the test, especially when the husband's health conditions worsened and the caregivers faced fear and distress so intense that their faith succumbed. At those moments they questioned whether God's strength would be enough to save them from the tearing pain of death (Reis, Faria, & Quintana, 2017). For this reason, additional support should be given to caregivers with high levels of pre-loss grief and low preparedness (Nielsen et al., 2016).

The results show that oncologic disease enhances compassion. The treatment made possible a greater affective closeness of the couple, which is related to the fact that wives spend more time with their husbands, involved in care tasks. They all claimed that they had a good relationship with their partners before the illness. The quality of the marital relationship previously established has an influence on the satisfactory adjustment of the couple to the disease, which can be maintained or not after the illness (Picheti, Castro, & Falcke, 2014). The participants of this study emphasized the need to strengthen the conjugal union and join forces to face the disease, which is positive, but favors strategies to avoid, minimize or avoid marital conflicts.

The participants mentioned having acquired new skills and valued the learning opportunities they found in the situations in which they perform their role as their husbands' companions during hospitalization. According to the literature review, by assuming the role of caregiver the individual can reconstruct himself and his relationships through his actions and the new roles he assumes. This makes it possible to create a new image both for oneself and for the other. It is a dialectic process that results in its transformation and the construction of a new self (Sá, 2002).

#### IV. Limitations and recommendation

We acknowledge limitations in our study. Our sample size of cancer caregivers was relatively small. Future studies can explore the use of a robust sample and a large, population-based dataset. The knowledge produced by this study favors health managers and public policy makers to plan effective strategies for psychosocial intervention with a focus on stress reduction, increased resilience and perceived social support.

The results may contribute to the implementation of assistance programs focused on the needs of family caregivers, facilitating the work of grief before loss by delivering educational counseling and skill-based programs to enhance their self-care and skills to interpersonally support their husband with hematologic cancer. According to the literature, psychological preparation prior to imminent loss can improve the outcome of post-mortem mourning by helping to adapt to the psychosocial transition and encouraging emotional repositioning that allows surviving spouses to find new directions for life.

#### V. Conclusion

This study explored key issues related to anticipatory grief and its potential effects on the well-being of caregivers whose spouses were being treated for onco-hematological disease. The assumptions that close contact with high levels of physical and psychological suffering of the partner make wives more susceptible to high levels of anticipatory grief were confirmed. Spouse caregivers experienced feelings and emotional reactions consistent with the process of grief. They suffered the impact of changes in the family and social environment, in social/occupational roles and their financial impacts after the partner's illness. Exposure to prolonged psychological suffering may negatively affect physical and mental health and may be associated with participation in health risk behaviors. The negative emotions and physical fatigue generated by burden of caregiving were the biggest challenges that the spouse caregivers had to manage. Despite some adverse outcomes, women attributed gains from the adverse experiences. In this study the spouse's illness was experienced as an opportunity to resignify life.

## VI. References

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