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"Spiritual" experience of an older cancer survivor in palliative care: a case report

Experiência "espiritual" de uma idosa sobrevivente de câncer sob cuidados paliativos: um relato de caso

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ABSTRACT: A cancer survivor is a person with a history of cancer, starting from the time of diagnosis until death, not only those who have completed chemotherapy, radiation therapy or surgery and survived it. Life after cancer becomes a disruptive experience that requires resilience to transform an experience that threatens the integrity of life into a source of meaning. This report describes the experience of an older survivor woman facing complications from cancer treatment in inpatient care, where she lived an anomalous experience. The relationship between the patient and her god, as described in the report, was the predominant characteristic of her experience, and her kind and merciful god was a source of support and security. Recent studies reinforce the importance of a positive bond with divinity in this context, demonstrating that these relationships are catalysts for peace, calm and hope in these patients. Evidence of the impact of spirituality on health and instruments for its assessment with the patient have been described and deserve further investigation. This study aimed to present a complex subject that is rarely inserted in academic contexts, discussing the spiritual dimension of the individual as part of their experience, and drawing the attention of the healthcare sector to a comprehensive care of the human being.

Keywords: Health of the elderly. Cancer survivor. Palliative care. Anomalous experience.

RESUMO: É considerado sobrevivente de câncer o paciente com história de convivência com neoplasia, do diagnóstico da mesma até o fim de sua vida, não incluindo somente aqueles que se submeteram à realização de tratamentos oncológicos e sobreviveram. A vida após o câncer se converte numa experiência disruptiva que demanda resiliência do indivíduo, no sentido de transformar a experiência ameaçadora à integridade da vida em uma fonte de sentido. Este relato descreve a vivência de uma idosa sobrevivente enfrentando complicação do tratamento oncológico em internamento hospitalar, no qual apresentou experiência anômala. A relação da paciente descrita no relato com seu deus foi a característica preponderante de sua experiência, sendo este deus bondoso e misericordioso, uma fonte de amparo e segurança. Estudos recentes reforçam a importância da vinculação positiva com a divindade nesse contexto, demonstrando que tais relações são catalisadoras de paz, calma e esperança nesses pacientes. Evidências do impacto da espiritualidade na saúde de forma global e instrumentos para sua avaliação junto ao paciente têm sido descritas e merecem maiores investigações. Este trabalho objetivou apresentar uma temática complexa e de difícil inserção acadêmica, discutindo a dimensão espiritual do indivíduo como constituinte de suas vivências e chamando a atenção do setor saúde, com vistas ao cuidado integral do ser humano.

Descritores: Saúde do idoso. Sobrevivente de câncer. Cuidados paliativos. Experiência anômala.

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INTRODUCTION

A cancer survivor is a person with a history of cancer, starting from the time of diagnosis until death, not only those who have completed chemotherapy, radiation therapy or surgery and survived it[1]. The increase in the number of cancer survivors in the last decades is related to the increase in the 5-year survival rate after the end of cancer treatment, as a result of early detection and treatment[1].

The health needs of cancer survivors can be compared to the health needs of people who have not had cancer and depend on multiple factors, such as the type of cancer, age, stage at detection, previous treatment (whether clinical or surgical) and its adverse effects, and genetic risk factors for tumor recurrence or appearance of new primary tumors[1].

Understanding that, for survivors, the adverse effects of treatment mean they must live with uncomfortable symptoms for years to decades, it is important to assess the related quality of life of these patients in order to develop strategies to improve it[2].

Some studies have pointed out that 20% to 50% of patients treated with radiotherapy for gynecological tumors, for example, continue to experience symptoms associated with bladder, bowel, or genital function, with significant impact on their quality of life[3,4]. The curative options for patients with bladder cancer are radical cystectomy and radical radiotherapy. The first one[5] can affect the patient's physical and psychological well-being and the second[6], despite preserving the bladder, can also affect its function. A study that assessed the prevalence of uncomfortable symptoms in cancer survivors who have had pelvic radiotherapy showed that, in women, higher rates of symptoms are statistically associated with higher rates of depression, reduced overall quality of life, and reduced social functioning[2]. This study also demonstrated that the prevalence of symptoms in the short term (1 to 5 years) is similar to the prevalence in the long term (6 to 11 years), which points to the persistence of these inconveniences[2]. A study[7] that assessed the presence and frequency of bladder, colorectal, and sexual dysfunctions among patients who had radiotherapy for bladder cancer and compared the results with a control group without cancer found that the first group had higher rates of dysuria and bladder catheterization due to urinary obstruction, with statistically significant difference; other symptoms, such as incontinence, pollakiuria and hematuria did not have statistical power in the researched sample.

Although few studies specifically address the experience of women surviving bladder tumors after radical radiotherapy, several studies reflect on the experience of women who survive other cancers[8] and their perceptions of the impact of cancer on general quality of life, physical symptoms, social[9, 10] and sexual issues, and psychological well-being[11,12]. As for the other gender, studies have addressed the experience of men surviving urological cancers, such as bladder cancer and, similarly, have pointed out psychological consequences associated with cancer, including changes in identity and self-esteem and changes in body perception that affect the social relationships of these survivors[2].

The perspective of life throughout the process, which begins with the diagnosis of cancer, goes through treatment, and can reach the state of survival, gives rise to challenges and transformations that are described as a biographical rupture[13] in the life of the individual. Life after cancer becomes a permanently disruptive experience[14] that requires resilience to transform a threat to the integrity of life into a source of learning.

One of the main strategies for promoting resilience is spirituality. In a consensus conference on general quality of life in the United States, experts associated spirituality to religious support and attention to existential issues of life, such as purpose[15,16]. Spirituality is understood as a general aspect of human experience in the relationship with what is considered transcendent, and it is expressed through beliefs, values, and practices[16]. In other words, spirituality represents the path through which an individual seeks meaning in their life. Religion, on the other hand, is understood as a set of beliefs and practices conveniently accepted by a community and usually having instituted rules and a leader or guiding figure[17, 18]. Religiousness, then, would be the individual experience of the various members of the same religion, which can be somewhat individual or collective, intrinsic or extrinsic, organizational or non-organizational[17-19]. Through spirituality, cancer patients and cancer survivors can develop strategies for coping with the condition, whether it is with difficult news, with the treatment proposed, or with the finitude of life, and can find a sense of peace and health in the midst of illness[18].

OBJECTIVE

This case report presents an alleged spiritual experience of an older woman during hospitalization in a ward of the Instituto de Medicina Integral Prof. Fernando Figueira (IMIP) for the entire state of Pernambuco.

MATERIALS AND METHODS

The study patient was hospitalized in IMIP's House of Palliative Care Prof. Saulo Suassuna from January to April 2019. She was alert and oriented in relation to her health situation during the entire hospitalization and was independent and autonomous for her basic activities of daily living. Consultations with members of the multidisciplinary team and consultants from other specialties were carried out and registered in medical records.

Bibliographic research of national and international

literature was carried out, including literature reviews, case reports, case studies and original articles published in the last 10 years (from 2009 to 2019) in English or Portuguese. The bibliographic search was performed in June 2019 and the articles were obtained in the databases Science Direct, Scopus and MEDLINE, using the descriptors "health of the elderly", "palliative care" and "cancer survivors". Additionally, studies published before the period established were included when considered relevant.

ETHICAL ASPECTS

This work was submitted to the Human Research Ethics Committee of the Instituto de Medicina Integral Prof. Fernando Figueira and approved under registration CAAE 30408320.4.0000.5201. The recommendations of Resolution 466/2012 of the National Health Council, regulated by Resolution 580/2018 of the same Council, were followed, aiming to respect the four basic principles of bioethics: autonomy, nonmaleficence, beneficence, and justice. To preserve the identity of the patient, only her initials were used in the description of the data.

As information was obtained only in the patient's medical record, the Ethics Committee authorized the Exemption from the Informed Consent Term (appendix A). The confidentiality of the data exposed was secured.

CASE REPORT

L.M.S, 80 years old, female, born and residing in Recife-PE, admitted to the IMIP Emergency Service in January 2019 due to hematuria associated with severe, abrupt, continuous, and progressive pelvic pain for 1 day. She had a previous history of malignant bladder cancer diagnosed 8 years before admission and treated conservatively with chemotherapy and radiotherapy (last session 2 years before admission), as she refused the first-choice treatment, which would be cystectomy. At the time, she believed that there was no benefit in such an aggressive procedure that could limit her quality of life and functionality, which were, at that time, very important to her. In this context, a diagnosis of hematuria resulting from radiation cystitis due to previous radiotherapy was suggested, and a long treatment process was initiated in the Oncology and Palliative Care inpatient units, with support from the assistant Urology team through interprofessional consultations. Laboratory and imaging tests (kidney and urinary tract ultrasound, retrograde urethrocystography, and cystoscopy) were performed to rule out other infectious causes, local tumor recurrence, or new tumors. Confirming the absence of a new tumor and with the patient still refusing the cystectomy, in addition to the contraindication of new radiotherapy for hemostasis, bladder irrigation with alum was performed to stop the bleeding, without success.

During the approximately 90 days of hospitalization, between tests and interventions, long-term urinary catheterization and bladder irrigation with 0.9% saline solution continued. The patient still presented with macroscopic hematuria, which sometimes got worse with large clots, obstruction of the lower urinary tract and intense associated pain, requiring constant repositioning and change of bladder catheter and urgent administration of analgesics.

In the last month of hospitalization, the assistant Urology team suggested the possibility of intravesical formalin instillation for hemostasis, which was attempted without success, due to the detection of a new bladder mass. The mass was biopsied, and the material was sent for histopathological study. The result of the anatomic pathological study showed only ulcerative cystitis, with no evidence of tumor recurrence or a new tumor. It should be noted that hematuria persisted throughout the entire period, despite continuous bladder irrigation. On the day she received this result, the patient went for a walk in the hospital corridors, accompanied by one of her daughters, while keeping silent prayer. At the end of her walk, she concentrated and asked: "Jesus, place your vesture on my bladder and heal the bleeding, for your honor and your glory, in the name of your Father, our Father, who is in heaven". At that moment, she reports that she was taken by strong emotion, with a sensation described as paresthesia, starting in the lower limbs and going upwards, accompanied by a perception of "lightness of body and soul" and "immense well-being". At that time, she reports that she was certain that she had been "touched by the Lord" and her bladder was "healed in Christ".

After this episode, which was immediately reported to her daughter and companion, she described what had happened to several professional assistants in the Palliative Care ward. From that day on, and throughout the following week, she no longer presented any evidence of hematuria, and was then discharged with good clinical conditions, preserved functionality, and no pain or other uncomfortable symptoms. She was also referred for outpatient follow-up in palliative care. The medical record of a subsequent outpatient consultation about 30 days after discharge report maintenance of stable condition, with no new hemorrhagic episodes.

During hospitalization, the patient was calm, lucid, had no changes in consciousness or signs of confusional state, nor did she show changes such as hyper or hypoactivity or positive symptoms. Clinical and laboratory tests did not suggest psychopathological or organic causes that could justify the experience reported, reinforcing its understanding as an anomalous experience.

DISCUSSION

Spirituality can influence coping (that is, the way the individual uses their beliefs, values, and meanings of

life to deal with stressors[21]) with the adversities of life, but it can also be a contributing factor for suffering, causing guilt, shame, lack of purpose, feeling of abandonment and anger directed at the transcendent, among others[22]. Threats to the integrity of individual beliefs and values can even modulate other dimensions of individual suffering, such as physical pain and emotional issues[22]. It is suggested that certain dimensions of religion and spirituality can both promote well-being and worsen the suffering of individuals experiencing crisis or trauma[23]. Nevertheless, the experience of spiritual suffering can go beyond general issues such as guilt or shame, leading to crisis and emergency situations, such as social isolation, severe depression, a desire to interrupt life, and existential crisis[24].

In the follow-up of a cancer patient, the approach to spirituality with a focus on the identification of protective factors and resources for resilience and the early diagnosis of spiritual suffering are related to better quality of life when living with a disease[25]. A correct incorporation of the approach to spirituality in the treatment path of cancer patients and survivors requires a comprehensive care approach, based on a biopsychosocial and spiritual model, developed by a multidisciplinary team[26]. This reflection is of paramount importance, as healthcare teams may neglect patients' religious or spiritual aspects, considering only the general principle of not causing any harm and prioritizing physical problems that could be consequences or initial stages of moral issues or existential suffering[27].

Similar experiences have been reported in psychiatry literature and, in most cases, have been interpreted as mental disorders, with the religious element being seen as an indicator of psychological fragility. In the late 1990s, a study broadened the discussion on the existence of non-pathological spiritual experiences and the necessary distinction between those and psychotic symptoms or pathological conditions[28]. The first would be characterized by adjustment within the context of the person and their religious community, absence of disorganization of the individual, and reference to the well-being generated by the experience, while the latter would present classic negative psychopathological changes.

An international publication suggested that spiritual experiences should be described within a broad category and named neutrally as anomalous experiences[29]. This term refers to unusual experiences or experiences perceived as different from everyday life or from explanations commonly accepted as reality[29]. The spiritual experiences of patients in palliative care could be better understood by distinguishing changes in consciousness, deathbed visions, near-death experiences, and experiences involving an alleged divinity[30]. This study presents characteristics of this last type of experience. Considering that throughout the experience the patient had preserved insight, was calm, conscious, and oriented, and absorbed only positive elements, this event tends to be described as a spiritual experience.

The importance of considering and valuing anomalous experiences in the context of comprehensive care, especially for cancer patients, has been demonstrated[31]. The relationship between the patient and her god, as described in the report, was the predominant characteristic of her experience, and her kind and merciful god was a source of support and security. The literature reinforces the importance of this positive relationship with divinity in this context, demonstrating that these relationships are catalysts for peace, calm, and hope in these patients[33-35].

The present report focuses on the experience of a cancer patient who had an anomalous experience in a health service, provoking reflections in this area on a topic that is little studied, despite its importance for a comprehensive understanding of the human being and their particularities. This care can offer to the professional an experience of meaningful development and a transformative feeling of personal reward[36].

CONCLUSION

The understanding of spiritual experiences and, more broadly, the spiritual dimension of patients, family members and health workers themselves, in all professional categories, has grown in importance in the literature. This new reality demands deeper theoretical and practical studies from professionals in training. Evidence of the impact of spirituality on health and instruments for its assessment with the patient have been described and deserve further investigation. The development of new strategies for incorporating the approach to spirituality in clinical practice in the different health care scenarios within the treatment path of patients and families represents a broad topic to be developed by further investigations.

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