Sexual function and fertility in CNS cancer patients: a neglected impact of radiotherapy on quality of life

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Abstract:

Central nervous system (CNS) cancer presents a significant challenge for patients and their families, especially when treated with radiotherapy. Sexual problems in cancer patients during oncological therapies are an important issue that is often overlooked, but they have a significant impact on their quality of life. This study aims to explore the experiences of this target group, with a special focus on the impacts on sexual function and fertility. Using a multidimensional and qualitative approach to identify the effects of radiotherapy treatment on sexual function and fertility, data were collected through surveys and in-depth interviews with patients, RTTs, radiooncologists and medical staff. Patients undergoing radiotherapy in Albania are often reluctant to discuss sexual problems related to cancer and oncological treatments. However, the data show that many CNS cancer patients experience significant impairments in sexual function, such as decreased sexual desire, difficulties achieving an erection, painful sensations during sexual intercourse, and concerns about their fertility, which affect their personal lives and decisions about starting a family in the future. This situation is exacerbated by the lack of information and psychological support regarding these issues. This study highlights the need for planned interventions and psychosocial support for patients dealing with these issues. Education and information for patients and healthcare professionals are essential to address the consequences of radiotherapy and improve the quality of life for these individuals. Raising awareness about these issues is an important step toward creating a more supportive environment for CNS cancer patients. Patients may be more open to discussing these issues in a trusted and supportive setting, especially if healthcare professionals create a safe atmosphere and encourage conversations about sexual health.

Keyword: CNS Cancer, sexual problems, fertility, radiotherapy

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Introduction:

Central nervous system (CNS) cancer poses an extraordinary challenge for patients and their families, profoundly impacting quality of life, the ability to function normally, and emotional well-being. These impacts become particularly complex when patients are treated with radiotherapy. Globally, the challenges associated with treating CNS cancer include managing a wide range of pathologies, such as medulloblastoma, ependymoma, spinal meningioma, glioblastoma, etc. Moreover, the treatment of head and CNS cancers through advanced radiotherapy techniques, such as 3D conformal radiation therapy (3DCRT), IMRT, and VMAT, aims to maximize therapeutic effects while preserving as much healthy tissue as possible. Despite the numerous benefits these techniques bring, in the treatment of CNS tumors, a harsh reality remains: the side effects of radiation in sensitive areas, such as the hypothalamic-pituitary region, reproductive organs, and peripheral nerve function, can have significant consequences on patients' sexual function. Radiotherapy applied to the CNS regions and their proximities can lead to decreased sexual desire (libido), erectile dysfunction, loss of sensitivity, pain during sexual contact, and hormonal changes that affect fertility. Additionally, other bodily changes, such as

hair loss, fatigue, and skin dryness, have implications for self-confidence, mental health, and body image, influencing intimacy and satisfaction.

Objective:

This study aims to explore the experiences of CNS cancer patients regarding the effects of radiotherapy on sexual function and fertility, with a particular focus on the Albanian context and the support provided by the healthcare system.

Materials and Methods:

A multidisciplinary and qualitative approach was utilized to identify the impacts of radiotherapy. Data collection involved surveys and in-depth interviews with patients, radiotherapy technologists (RTTs), radio-oncologists, and other medical personnel. The study included 55 patients aged 10 to 70 years who underwent treatment between July and October 2024. These patients received radiotherapy doses ranging from 54 to 60 Gy, administered over 5-6 weeks in fractionated sessions. Among them, 53 were receiving radiotherapy for the first time as part of their treatment, while two had undergone re-irradiation. The focus was on identifying ichallenges associated with radiation doses in the treated regions and their effects on sexual function. Particular attention was given to documenting personal experiences, difficulties, and patient perceptions concerning sexual function and fertility during and after treatment. Furthermore, the research aimed to explore the long-term impact of radiotherapy on patients' ability to plan and expand their families, making this aspect a central focus of the investigation.

Results:

We observed that most patients refused to talk about these issues. Eighty percent of patients in the written survey, which was given to them during the first three weeks of radiotherapy in order to complete it themselves, avoided the questions or reported no impact on their sexual concerns. In the second interview, conducted orally during the fourth week, patients addressed the issue, which they found uncomfortable, in two ways: either by stating that they felt too sick to discuss it, focusing on the diagnosis and health condition rather than secondary issues and side effects, or by considering the topic too private and taboo.

In a third interview with radiotherapy technicians and medical staff during the last week of treatment, it was noted that patients felt more comfortable being asked about their sexuality and admitted to having sexual problems. This shift was attributed to a change in the research approach, including sexual changes as part of a broader questionnaire on side effects, asking more concise, rephrased questions about possible changes due to treatment, not limited only to sexuality, and providing explanations for each question regarding expected or possible side effects while offering assistance and information. This shift was also credited to the rapport built with the treatment staff and the passage of time (a few weeks into therapy when side effects became more apparent).

Out of 55 patients, only six were willing to openly discuss these challenges from the beginning and address them directly. Three of the 55 patients reported having no partners. Thirteen patients aged 10–40 expressed concerns regarding oncofertility but admitted that at the time of diagnosis, they had not focused on this or had avoided the subject. However, all 13 acknowledged that not only the diagnosis but also these concerns hindered them from planning a normal family life in the future.

Six out of 11 patients aged 20–40 admitted to being in a relationship but had not openly addressed concerns about having children, as they did not feel their relationships were stable enough. They avoided discussing the diagnosis and directly addressing side effects with their partners. One of the 11 patients in this age group had a young child, for whom breastfeeding was discontinued due to radiation. This patient reported difficulties in communicating with her spouse. Four other patients reported relationship problems at the onset of diagnosis and treatment due to poor communication or misunderstandings with their partners. They avoided addressing current or future concerns directly but noted that communication had improved in recent weeks.

Nevertheless, the stigma of being misunderstood by their partner or the oncotherapy staff was observed in 95% of patients. Among the six patients who initially addressed their issues directly, there was a noticeable lack of preparedness among nurses and technical staff to provide accurate responses and alternative solutions. This highlighted the need for further attention to this issue.



In 50 patients aged 20–70 who were sexually active before diagnosis and their first RT, a loss of sexual desire was observed during RT. Regardless of radiation fields or the preservation of normal organs, all aspects of cancer and treatment had an impact on patients' sexual experiences. Despite this, patients complained about various aspects of sexual disturbance. This was true not only for patients with different diagnoses but also for those with the same diagnosis, even if they received the same treatment dose.

Sixty percent of patients admitted that by the third week of radiotherapy, they began to feel overwhelmed with daily tasks and preferred to avoid their partner due to reduced sexual desire. Thirty percent reported a lack of support from their partner, linking this to bodily changes, scarring, hair loss, difficulties achieving sexual satisfaction, and rapid fatigue, which also affected their partner.

Among the 50 patients aged 20–70, sexually active before diagnosis and RT, a loss of sexual desire during RT hindered them from maintaining a normal sexual life. In our group, there were five patients (four females and one male) who received treatment with lumbosacral fields. These patients were informed by radiation oncologists about the potential for sexual disturbance, infertility or sterility. One female patient with a medulloblastoma diagnosis reported amenorrhea caused by radiation.

Patients treated for tumors such as medulloblastoma and ependymoma were noted to be at higher risk for developing hypogonadism due to damage to the hypothalamic-pituitary axis, leading to decreased hormone production that directly affects sexual and reproductive functions. Lumbosacral radiation fields increased the risk of sexual dysfunction.



Another important aspect was observed in a patient with meningioma. Although radiotherapy is often precisely targeted to limit damage to other tissues, involvement of peripheral nerve segments can result in symptoms affecting sexual sensitivity and intimate satisfaction. Meanwhile, treatment of head cancers was observed to carry an increased risk of hormonal disorders, which affect sexual dysfunction through disruptions in hormone synthesis related to sexual and reproductive functions.

It was noted that radiation treatment fields influence uncertainty regarding future childbearing possibilities, a problem causing significant distress among young patients or their parents. This group included six patients. The potential for alternative solutions (egg and sperm freezing) faced two serious issues: first, patients

needed timely information about these techniques before starting radiotherapy, but they initially refused to consider other therapies besides cancer therapies, focusing solely on survival. Second, the costs of these options exceeded their financial capabilities, given the uncertainty of whether these alternative options would ever be used.

Discussion:

The diagnosis and treatment of CNS cancer are highly complex, and patients experience numerous changes in sexual function, such as erectile problems, vaginal dryness, muscle weakness, and impotence. They undergo bodily changes such as hair loss, neurological deficits, weight changes, and alterations in sexual function, including reduced sexual desire, difficulty achieving erections, pain during sexual intercourse, and concerns about their fertility. These issues negatively impact personal relationships and decisions about starting or expanding a family. Difficulty or loss of sexual desire is further exacerbated by changes in partner dynamics, where couples begin to treat each other as patients rather than partners, leading to problems in communication and expression of desires.

However, Albanian patients undergoing radiotherapy for CNS cancer often feel ashamed or afraid to discuss their sexual problems. Nevertheless, collected data shows that many of them experience significant barriers in addressing this issue, as the focus, both within families and healthcare, is directed towards survival regardless of the consequences on quality of life, rather than on their sexual rights and future implications. The situation is further worsened by the lack of information and education for patients on this issue.

Dealing with sexual and fertility issues caused by cancer treatment is a complex reality for Albanian patients. The lack of support, as well as the taboo surrounding these issues in local culture, exacerbates the difficulties patients feel. In particular, communication between patients and healthcare professionals remains poor, with many patients not feeling safe or motivated to discuss these topics. The taboo around discussing sexual health and the lack of a multidisciplinary approach to addressing these issues leave patients feeling isolated and unprepared to cope with their physical and emotional changes. The impact of sexual problems related to radiotherapy often remains underestimated by healthcare staff due to the complexity of sexual health and inadequate training. This situation is further worsened by patients' reluctance to talk about these issues.

Interventions aimed at improving the quality of life for patients should include education for both staff and patients to address and minimize the effects of radiation on sexual function and fertility, by timely informing patients about options for preserving eggs or sperm. In addition, psychological support and personalized therapeutic interventions are essential to help patients feel heard, understood, and prepared to cope with the changes in their sexual lives after treatment. This comprehensive approach will create a more supportive environment for Albanian patients, giving them the opportunity to regain control over their quality of life and face the unique challenges of CNS cancer and its treatment.

Conclusion:

The diagnosis and treatment of CNS cancer are complicated and significantly affect sexual function and fertility. Issues such as decreased sexual desire, difficulties in intimate relationships, and uncertainties about the possibility of having children are critical concerns that need to be addressed. The stigmatization of these problems and the lack of support worsen the situation. A comprehensive approach that includes education, clear information, and support is essential to improve the quality of life of patients and assist them in facing the unique challenges of CNS cancer treatment. It is crucial to raise awareness and enhance education for both patients and medical staff, creating a safe and supportive atmosphere for open conversations about sexual health. Only through a comprehensive approach can the quality of life for these patients be improved and the complex impacts of cancer treatment be better addressed.

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