

The quality of life of caregivers of cancer patients

HAJRI AMAL, MOUNTASSIR MAROUANE, EL WASSI ANAS, ERGUIBI DRISS, BOUFETTAL RACHID, EL JAI RIFKI SAAD, CHEHAB FARID

Department of general surgery, IBN ROCHD University hospital of Casablanca, Casablanca, Morocco

*Correspondence: Marouane Mountassir

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Abstract

In the Moroccan context, where gastrointestinal malignancies are frequently detected at an advanced stage, the essay discusses the effect of these diseases on the quality of life of caretakers. The shift of care responsibilities from medical professionals to family members is emphasized. A questionnaire translated into Moroccan Arabic will be used in the study's assessment of this quality of life. About fifty caregivers participated in a cross-sectional study, which found that women—who are frequently illiterate—play a critical role. The findings indicate that while spiritual well-being is largely maintained, caregivers' psychological and social wellbeing is significantly impacted. The most affected caregivers are those who share a roof with the ill or are low-income. The article's conclusion emphasizes the necessity of giving caregivers proper financial and psychological assistance as well as legal recognition of their significance.

Keywords: quality of life, gastrointestinal cancer, caregivers.

Introduction :

Because providing care for cancer patients has a substantial impact on their physical, psychological, social, and economical well-being, caregivers' quality of life—especially that of those with gastrointestinal cancers—is an important consideration. Studying this topic is therefore important. Due to their high incidence and severity, stomach cancers are a significant global public health concern.

These malignancies are frequently detected at an advanced stage, or even at the stage of complications, in the Moroccan environment. Due to the chronic nature of diseases and advances in oncology, family members, who are often the primary caregivers, are now responsible for providing care instead of medical experts. As a result, the standard of living for those providing care becomes crucial and urgent. Therefore, it's important to recognize, comprehend, and provide support for family

caregivers and the patients they look after.

Results and discussion :

Using a transcultural translation of the "Quality of Life Family Version" questionnaire in Moroccan Arabic, this study aims to assess the quality of life of caregivers of Moroccan patients with gastrointestinal cancer. Over the course of 11 months, from December 2021 to November 2022, we carried out a descriptive cross-sectional study at the Ibn Rochd Hospital in Casablanca's Radiotherapy-Oncology Department (Mohammed VI Center) and the Digestive Cancer and Liver Transplantation Surgery Department (Wing III). For this study, we enlisted about fifty hospitalized caregivers of patients with gastrointestinal malignancies. The process of gathering data was carried out during open hours. The participating caregivers were asked to fill out the questionnaire after giving their approval.

Our sample had an average age of 46.08 years, 72% of participants were female, and 72% of them were married. These findings suggest that women are essential in providing care for cancer patients.

Of the caretakers, 82% had a low monthly income, 26% were actively employed, and 44% were illiterate. These results are in line with the study by Elcaid Salma, which found that no caregiver was illiterate, however in the study by Kilic and Oz, over a quarter (23%) of caregivers lacked literacy. This illustrates Morocco's persistently high illiteracy rate, which was projected to be 32.2% in 2014.

In our study, patients' spouses made up more than a third of the caregivers (38%) and consisted of 24% wives. While parents made up just 6% of the caregivers, children made up one-third of the sample (24% of whom were daughters), which is in con-

trast to the findings of the Kilic study but in line with those of Judkins Jonathan and Elcaid Salma. According to this study, children in Morocco, as opposed to Turkey, are crucial to the treatment of people with gastrointestinal malignancies, particularly the elderly. Spouses continue to play a vital role in the treatment of cancer patients, nevertheless. The fact that women are overrepresented in both situations attests to their crucial role in the treatment of cancer patients.

The aspects of "psychological well-being" and "social well-being," with average ratings of 3.14 (standard deviation = 0.92) and 3.76 (standard deviation = 0.91), respectively, were the main areas in which caregivers' quality of life was reduced. The "spiritual well-being" dimension, on the other hand, showed a very stable average score of 6.43 (standard deviation = 1.29). Regarding "physical well-being," 4.50 (standard deviation = 1.38) was the average score. Our sample generally showed the lowest average scores in the dimensions of "physical well-being," "psychological well-being," and "social well-being," with the exception of Judkins J et al.'s study at the Mary Potter Palliative Care Clinic in Korçë, Albania, where the average for the "physical well-being" dimension was lower than in our study (4.38 vs. 4.50). This is in comparison to the results published in the literature, particularly studies by Fujinami R et al. (2014), Sun V et al. (2015), Ju Ka et al. (2018), and Elcaid S (2018).

With an average score of 3.92 (standard deviation = 0.91), children were most negatively impacted, followed by parents (average = 4.00, standard deviation = 2.00) and spouses (average = 4.31, standard deviation = 1.24; $p = 0.014$). The caregivers' place of residence also had an impact on this well-being, with lower scores for those who shared a roof with

the patients.

The caregivers' familial relationship with the patient had a substantial impact on their "psychological well-being". Psychological suffering was highest among parents, children, and spouses ($p = 0.001$). Cohabitation with the patient had an impact on this dimension as well. The health and psychological well-being of the caregiver are negatively impacted by the patient's continuous presence. The caregiver struggles to set apart time for themselves and has persistent worry and anxiety that never goes away. Additionally, individuals who had a decrease in autonomy ($p = 0.030$) or difficulties associated to cancer ($p = 0.027$) had a greater detrimental effect on the physical and mental health of those who cared for them. Caretakers saw their loved ones physically deteriorate day by day, going from lively and active people to weaker and weaker people, which made them feel even more distressed mentally.

Parents had the greatest impact on "social well-being," followed by spouses and kids ($p = 0.001$). The lowest ratings were for caregivers who always accompanied patients to the hospital ($p = 0.032$) or who lived under the same roof ($p = 0.001$). Low-income family caregivers ($p = 0.037$) and those without a job were more likely to be impacted ($p = 0.030$). Living with the patient, going to every hospital visit with them, and not doing any professional work cut down on the caregiver's social and familial interactions. A poor salary or a lack of professional activity makes it difficult to provide for the patient financially.

Observing their loved ones with a stoma pouch was extremely challenging for caregivers of patients with digestive stomas in our sample. Seventy-five

percent received a score lower than 2.50. The median score was 3.00, indicating a significant financial impact. The presence of the pouch impacted the caregivers' interpersonal relationships; when the caregiver was the patient's spouse, this had a greater influence on sexual interactions (median = 1.00 and Q3 = 1.00).

One of the side effects of chemotherapy for patients was hair loss. With a median score of 1.00, caregivers of these patients reported significant challenges in observing their loved ones without hair, and a median score of 1.50 indicated that the impact of hair loss was mostly felt in sexual relationships. Self-image and bodily integrity are impacted by hair loss. Similar to stomas, the most difficult side effects or difficulties to deal with for the patient and caregiver are obvious ones. In addition to managing the effects of these changes on the patient's mental health as well as their own, the caregiver must become accustomed to and adjust to their loved one's new appearance. The combination of these elements lowers the caregiver's quality of life by making them feel overburdened by the circumstances.

Morocco needs to formally acknowledge the significance of caregivers in order to establish their position, uphold their rights, define their responsibilities, and provide sufficient resources and means in light of the significant decline in caregivers' quality of life. For this essential aspect of cancer patient care, financial assistance as well as psychological and educational support, the appropriate steps must be made.

Conclusion :

Our research and the literature's findings unequivocally show that caregivers' social, psychological,

and physical well-being are severely compromised, with just their spiritual well-being holding true. The burden of all these duties and obligations has a significant impact on family caregivers' quality of life.

An essential component of cancer patients' care is their caregivers. As such, it is imperative to ascertain their status precisely, protect their rights, and tend to their medical needs. It is true that a caregiver whose life quality is affected cannot give the patient high-quality care.