



(RESEARCH ARTICLE)



The impact of leukemia on quality of life and mental health: Insights from a case study examining physical, social, and cultural implications

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International Journal of Science and Research Archive, 2024, 11(01), 1469–1477

Publication history: Received on 25 December 2023; revised on 30 January 2024; accepted on 02 February 2024

Article DOI: <https://doi.org/10.30574/ijrsra.2024.11.1.0202>

Abstract

Introduction: Leukemia presents a significant health challenge globally, affecting patients physically and mentally. The symptoms and adverse effects of treatments impact the health-related quality of life (QOL) of leukemia patients. Family caregivers, often family members, play a crucial role in care provision, especially in regions with limited professional nursing.

Aim: This research aimed to explore the QOL of a leukemia patient, the effects on the individual and family, factors contributing to well-being, social support networks, and healthcare resources. Insights gained could enhance the QOL for patients and families confronting this challenging disease.

Method: A qualitative case study approach was employed. The researchers focused on a single instance, utilizing semi-structured interviews. This technique allowed for an in-depth exploration of the experiences from anthropological perspectives. Data collection involved non-structured interviews with a 42-year-old woman diagnosed with acute leukemia, who had previously recovered from breast cancer.

Results: Leukemia patients and family caregivers face substantial psychological distress due to caregiving roles. Anxiety, stress, and depression in caregivers can be mitigated through tailored programs addressing their psychological needs. Such interventions are likely to positively impact the overall quality of life for families. Future research should explore specific factors contributing to psychological distress and evaluate the effectiveness of needs-based programs.

Conclusions: To enhance the well-being of both adult leukemia patients and their family caregivers, healthcare professionals should consider family-level intervention programs. The resilience demonstrated by individuals like Ms. Maria, who navigate challenges with determination, serves as inspiration for others facing acute leukemia. Further studies should delve into patient and caregiver factors affecting psychological distress, offering a comprehensive understanding of the holistic care needed for leukemia patients and their families.

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Keywords: Leukemia; Quality Of Life; Family Caregivers; Psychological Distress; Needs-Based Program; Holistic Care

1. Introduction

The American Cancer Society's estimates for leukemia in the United States for 2023 referred to 59,610 new cases of leukemia (all types) and 23,710 deaths from leukemia (all types). Approximately 20,380 new cases were attributed to acute myeloid leukemia (AML) in adults¹.

In Europe, statistics from 2018 on cancer indicate that leukemia is projected to account for 437,033 new cases and 309,006 deaths across 185 countries, with a mortality rate of 3.2% (Bray et al., 2018). This presents a significant and escalating health challenge. Meanwhile, a range of symptoms including fatigue, pain, loss of appetite, and insomnia affect 24-83% of acute leukemia patients, substantially diminishing their health-related quality of life (QOL)².

Furthermore, the primary treatment for acute leukemia is chemotherapy, which can lead to various adverse effects such as nausea, vomiting, anorexia, alopecia, and myelosuppression, further impacting the overall quality of life³. Existing evidence underscores that nearly all cancer patients, including those with hematologic malignancies, encounter a multifaceted spectrum of challenges that jeopardize their physical, psychological, and spiritual well-being^{4,5}.

Assessing quality of life offers a comprehensive evaluation of how a disease disrupts a person's adaptive functioning, considering their values, perspectives, satisfaction, living conditions, accomplishments, cultural context, and spirituality. Families emerge as pivotal agents in the healing process and recovery. Cancer is not solely an individual's ordeal but rather a family affair. In regions influenced by Confucianism and where professional nursing is scarce, family caregivers – often the patient's spouse, children, or close relatives – play an essential role in care provision. This frequently entails altering their daily routines or even leaving their employment^{6,7}.

Family members typically serve as the primary sources of social and emotional support for leukemia patients⁸. Understandably, family caregivers bear a particular responsibility and burden in looking after their loved ones and monitoring their experiences during treatment. Negative encounters endured by family caregivers not only undermine their own quality of life but may also compromise their capacity to deliver care⁹.

Furthermore, the literature underscores that family caregivers tending to cancer patients often grapple with significant physical and psychological challenges, encompassing anxiety, depression, weakness, hopelessness, fatigue, fear, guilt, and sleep disturbances, which further compromise their quality of life¹⁰⁻¹².

Leukemia patients, in particular, necessitate substantial support and care due to the intricacies of the disease itself and the side effects linked to chemotherapy¹³. Data indicates that around one-fourth to one-fifth of mothers of acute leukemia patients endure persistent posttraumatic stress disorder for up to 2 years. The caregiving burden significantly impacts the quality of life (QOL) of leukemia family caregivers¹⁴. A link has been established between reduced psychological distress, enhanced family relationships, the maintenance of family integration, an optimistic outlook on the situation, increased employment of adaptive coping and information-seeking, and decreased reliance on maladaptive coping¹⁵.

Among the diverse array of burdens, financial strain has been identified as a notable obstacle to accessing treatment, with the remission phase deemed the emotionally most challenging period¹⁶. Information regarding the burden faced by caregivers of acute leukemia patients remains scant. Research concerning the quality of life of adult patients with acute leukemia and their family caregivers in Cyprus is limited, underscoring the necessity for the design and execution of related studies.

2. Materials and Methods

Aim

The aim of this research was to study the quality of life of a patient with leukemia and the physical and mental effects on the person and his family. Additionally, the study aimed to explore the various factors that contribute to the overall well-being of individuals with leukemia, such as their social support networks and access to healthcare resources. Understanding these aspects can provide valuable insights for improving the overall quality of life for both patients and their families facing this challenging disease.

2.1. Method

This study took a qualitative case study approach since it was thought to be the most suited for the topic at hand. According to Noor¹⁷, utilizing this methodological technique allows researchers to focus on one instance and highlight the experience of one case from a variety of perspectives. Given the foregoing, the researchers decided to employ this technique because their primary goal was anthropological. The word 'case study' can apply to either a single case or a small group of participants, occurrences, or facets of a topic or problem. It is classified as qualitative research methods since it does not seek to involve a large number of participants, collect data from broad or representative groups, or generalize its conclusions. The process is quite similar to ethnographic research. Because they are time consuming, their primary value is the volume of data gained, which can only be achieved through long and painful observation and recording, followed by subsequent analysis. While it does not normally begin with a hypothesis, one or two hypotheses may emerge after examining the data that will necessitate additional inquiry using other research approaches¹⁸.

2.2. Data collection

The data collection tool that was used in the current study was a non structured interview, which was sufficient for the study of this case as confirmed by Robson¹⁸, who states that interview can be used as the sole or dominant tool in a case study. In the case of this study, semi-structured interview was used, with predefined questions that could provide flexibility to the interviewers.

2.3. Sample

The sample of this study was a 42-year-old woman and a mother of three children, aged 10, 17, and 18. She has achieved a tertiary level of education and resides in Larnaca city with her husband and family. Ms. Maria was initially diagnosed with breast cancer at the age of 40, for which she underwent appropriate treatments and achieved a successful recovery. Unfortunately, subsequent to her breast cancer treatment involving cytostatic drugs and radiation, she was diagnosed with acute leukemia.

This new health challenge has not only affected Ms. Maria but has also had implications for her entire family. Hospitalization has been necessary due to recurring febrile episodes resulting from the immunosuppressive effects of her ongoing medication. Despite her own health struggles, Ms. Maria is making efforts to fulfill her family responsibilities while being confined to the hospital. In addition to her fight for survival, she is also contending with the demands of her three teenage children. While her husband provides constant support, the entire family faces numerous challenges arising from increased needs and responsibilities. Remarkably, Ms. Maria effectively manages and guides both her husband and children through these difficulties, and no significant financial hardships were mentioned.

The personal interview with Ms. Maria shed light on how she and her family members are coping with this new and complex situation. The responses obtained from the interview provide valuable insights into their strategies and experiences.

2.4. Research procedure

The research process followed the instructions of the Greek Ministry of Education and Religions in 2008 on how to make an interview more effective. So, for the introduction of the interview, the researchers, as recommended, explained the purpose of the interview, assured conservation of personal data and requested that the conversation was going to be recorded. Afterwards, a warm-up was held, where questions were asked to make the interviewee feel comfortable. Then, the main part of the questions was followed. Throughout the process, calmness was maintained, with the aim of eliminating any tension created during the interview, and in the end, the researchers thanked the interviewee for all the information he gave and the time he spent. The duration of the interview was one hour and was carried out with physical presence. During the process, the researchers kept notes and at the same time recorded the interview after obtaining consent from the participant.

2.5. Data collection

Five one-hour meetings were held at the patient's home in an appropriate and intimate setting, with no interruptions for the discussion. Semi-structured interviews began with an open-ended discussion with the study subject and a close family about the person's feelings, experiences, and concerns about the disease. Interviews were audio-recorded to verify verbal response accuracy while capturing the emotional impact of patient responses. Demographic data and a genealogy tree were also gathered.

2.6. Data analysis

Thematic analysis was performed to find and evaluate patterns in the data, which is commonly employed in qualitative research and when there is limited knowledge about the issue. This method allows for the formation of knowledge to be guided by the data of the participants rather than any predefined constructions¹⁹. In the current study, data analysis served as the foundation for nursing assessment and the identification of the patient's nursing needs after the nursing process. A nursing care plan (NCP) is the process of identifying existing requirements as well as anticipated needs or risks. Nurses, their patients, and other healthcare providers communicate through care plans to accomplish health care outcomes^{20,21}. From holistic and customized care plans to standardized care plans for patients with EB, the nurse care planning process ensures the quality and consistency of patient care.

2.7. Validity and reliability

To ensure the research's validity and reliability, we determined whether our approach was appropriate for the concerns we wanted to investigate. We also exchanged ideas with other academics about our approach. At the same time, if the same person was interviewed again, the results may be the same. Furthermore, questions that are relevant to their purpose and are based on data from worldwide literature have been developed. The researchers considered credibility, transferability, dependability, and conformability in order to conduct a valid and reliable study. The degree to which the study approach and findings are consistent with each other is referred to as credibility in qualitative research. Natural laws and phenomena, standards, and observations that are widely acknowledged. This criterion was used to collect data for this investigation. This instance also had the ability to generalize, in terms of how far the research findings could be applied to other contexts or situations, therefore it could be classified as transferable. The researchers kept the dependability element in mind, knowing that modifications that occur over the course of study will have no effect on the research outcomes. Finally, in order to assure conformability, the researchers used methods such as recording the procedures for rechecking data and uncovering negative cases that contradict earlier observations.

2.8. Ethics

Ethical considerations were rigorously adhered to throughout the study. Prior to participating in the interview, participants provided fully informed written and verbal consent, ensuring their voluntary and conscious involvement. During the interview, the researcher meticulously documented the proceedings, employing notes and photographs while also recording the conversation with explicit permission from the participant. It was consistently emphasized that participants retained the autonomy to withdraw from the study at any point without consequence. Furthermore, participants were comprehensively informed about the preservation of their anonymity and the safeguarding of their personal information, ensuring their confidentiality throughout the research process.

3. Results

The case study centers around Ms. Maria, a 42-year-old woman. She is a mother of three children aged 10, 17, and 18, respectively. Ms. Maria holds a tertiary education degree and resides with her husband and family in the city of Larnaca. Her medical history includes a breast cancer diagnosis at the age of 40, which she successfully treated and recovered from using appropriate therapies. Unfortunately, she has now been diagnosed with acute leukemia, likely stemming from the cytostatic drugs and radiation employed during her breast cancer treatment.

Presently, Ms. Maria and her family are confronted with the challenge of dealing with this unexpected development. She has undergone hospitalization due to recurring febrile episodes attributed to the immunosuppressive effects of her medication. From her hospital bed, she strives to manage the day-to-day responsibilities of her family. This situation places her under significant stress, compounded by the fact that, aside from contending with her own health battles, she must also care for her three teenage children.

Despite these adversities, Ms. Maria's husband remains a steadfast source of support, both emotionally and in caring for their children. The family encounters numerous challenges due to heightened demands and responsibilities. Nevertheless, Ms. Maria effectively orchestrates and guides her husband and children through these difficult times. Financially, there have been no reports of serious issues.

Outlined below are the summarized responses obtained from the patient:

"At first, upon hearing the diagnosis, I remained composed, influenced by my previous encounter with breast cancer about two years ago. Despite this prior familiarity, being diagnosed with acute leukemia introduced me to a new realm of emotional, social, and physical challenges. I find myself grappling with feelings of sadness, anxiety, anger, and a

struggle to manage my emotions. Blood cancer has posed obstacles to my social interactions, impacting both my physical and mental well-being significantly. Persistent fatigue is a constant companion, often lingering days after treatment. Nights turn into restless hours as I grapple with insomnia.

Fatigue, depression, and anxiety have emerged as the dominant and distressing symptoms for individuals like me dealing with acute leukemia, as they encroach upon our daily routines and social roles. A noticeable change in complexion, weight loss, and excessive evening perspiration further affect my social life. The toll extends beyond me; it engulfs my entire family. Their unwavering support is my pillar, and I recognize that my journey would be insurmountable without them. But, the weight of my illness has repercussions on their mental well-being too, casting them into the realm of anxiety and burdened with daily tasks that now present challenges.

Even the simplest of chores, like housework, have become arduous tasks for me. As previously mentioned, I was hospitalized due to recurring febrile episodes, a consequence of the medication's immunosuppressive effects. The return home after a month-long hospital stay was a heartwarming reunion, resonating with caregivers who welcomed me back.

Ms. Maria's husband provides a candid insight, stating, 'The responsibility is immense, especially as Ms. Maria's condition demands stringent precautions due to her leukopenia. Daily chores like washing and cleaning are now off-limits. The bedroom has undergone a complete transformation, with sheets changed every other day. Amidst all this, I often find myself mentally adrift. The pressure is overwhelming, and I admit, I'm no superhero; I too have my limits.'

Our daily routine has undergone a significant shift. Once, I maintained a regular 9-to-5 job, yet now, I've had to embrace a more adaptable role to accommodate my wife's medical appointments and caregiving needs. Mornings now revolve around adhering to medication schedules, ensuring she starts her day with a nourishing breakfast, and preparing for upcoming doctor visits. This marks a complete departure from our routine before her diagnosis.

Throughout our relationship, we've always functioned as a partnership, but now, I find myself shouldering medical responsibilities I never envisioned. I've become proficient in administering medications, managing her dietary requirements, and assisting her with mobility during times of weakness. My role in offering emotional support has also taken on a new dimension – I'm there to lend an empathetic ear, provide reassurance, and offer encouragement, and it has become an integral aspect of my role.

Regrettably, our social life has suffered. Once avid socializers, we frequented outings with friends and family. Presently, our social circle has contracted, and our interactions are limited due to my wife's compromised immune system. The adjustment has been taxing on both of us, particularly the absence of gatherings and events that once brought us happiness.

From a financial perspective, the strain has been considerable. Substantial medical bills and treatment costs have compounded our existing financial obligations. We've had to make sacrifices, trimming certain expenses, to ensure we can afford the vital care. It's a stressor we hadn't anticipated.

I endeavor to seize fleeting moments whenever possible – a brief stroll, a tranquil cup of tea – to replenish my own energy. However, I recognize the need to refine the balance between tending to my own well-being and fulfilling my caregiving responsibilities.

Our immediate family has been our steadfast foundation. They've shown exceptional understanding and extend help whenever feasible. The presence of online support groups has also proven invaluable. Connecting with fellow caregivers navigating parallel experiences offers a sense of camaraderie and shared empathy.

We navigate life one day at a time. The future remains uncertain, and that can be disconcerting. Nevertheless, we hold onto hope and concentrate on the strides she's making. I firmly believe in her resilience and strength, and united, we'll confront any challenges that lie ahead.

4. Discussion

One of the most pivotal issues highlighted by both participants during the research process is the patient's stay at home. Opting for home care instead of hospitalization allowed the family caregiver and the patient to share moments in a familiar setting, a finding congruent with the observations of Fridthjof et al.²². Moreover, research has demonstrated that the quality of life for family caregivers tends to diminish notably during hospital stays, while home care contributes to an improved sense of well-being for patients^{23,24}. The concept of home encompasses various dimensions such as

privacy, identity, safety, and intimacy — elements that our participants identified as crucial for their well-being despite their challenging circumstances. The ability to channel their energies toward paramount factors, such as fostering family togetherness within a commonplace environment, is also depicted as a means of exercising autonomy to allocate time, resources, and emotional reserves meaningfully, thereby nurturing a sense of empowerment in maintaining individual identities at home²⁵.

Occasionally, Ms. Maria receives her treatment within the confines of her home. This at-home treatment approach was also underscored as advantageous by participants in various studies, as it eliminated the need for the family caregiver to expend time on hospital visits, especially significant for families with children, and contributed to alleviating their burden^{25,26}.

Through a series of studies, it is evident that caregivers face the challenge of monitoring symptoms, communicating with medical staff, and particularly addressing practical issues stemming from leukopenia^{26,27,28}. The extent of responsibilities and their impact on daily life was greater and more burdensome than what family caregivers had anticipated, even though they felt well-informed before hospital discharge²⁶.

Apart from the fear of the patient's mortality, the primary challenge and burden of home treatment were the practices and restrictions that imposed additional tasks and responsibilities on caregivers for which they felt unprepared. This issue is also addressed by Jepsen et al.²⁶, who describe it as a significant undertaking involving precautions such as thorough cleaning, removal of potted plants, medication administration, and addressing instances when the patient did not adhere to health professionals' instructions. Consequently, caregivers found themselves with minimal leisure time, constantly on call, and often unable to maintain employment. This perspective aligns with other research indicating that family caregiver burden was closely linked to disruptions in family activities, recreational pursuits, and social engagements due to leukopenia precautions^{26,29}.

Adult patients with acute leukemia typically undergo treatments such as chemotherapy, radiation, and bone marrow transplants³⁰. Chemotherapy is an effective treatment that can enhance the overall survival rates of acute leukemia patients. Nonetheless, it also affects patients' levels of physical activity³¹. The treatment process may induce clinical symptoms as well as psychological distress. In the case of acute leukemia patients, the primary concerns are mainly disease-related symptoms, treatment toxicity, and negative emotions³². These side effects may further impact the patients' quality of life (QoL). Psychological symptoms are prevalent among acute leukemia patients, particularly anxiety and depression². A study highlighted that cancer-related anxiety and depression were the most pronounced symptoms influencing patients' health-related quality of life³³. Furthermore, the extended treatment course and the risk of discontinuation not only foster dependence among acute leukemia patients but also impose a caregiving burden on family caregivers³⁴.

The incidence and mortality of acute leukemia can induce psychological symptoms in patients², and even amplify the burden on family caregivers³⁵.

Caregivers of cancer patients are often considered the "hidden sufferers" within the broader cancer experience. Family caregivers face greater vulnerability as they must manage not only the patient's emotional responses but also their own³⁵. While certain studies have evaluated caregiver burden among caregivers of acute leukemia patients, very few have explored caregiver burden specifically in the context of acute leukemia. Moreover, these studies have primarily focused on single or dual correlates such as social support, coping strategies, and psychological distress, with none comprehensively assessing these variables concurrently. Therefore, it can be inferred that a dearth of research exists that holistically evaluates the entire caregiving experience for those tending to patients with acute leukemia^{29,36,37}.

Elsewhere, it has been demonstrated that insufficient social support correlates with significantly higher burden across all domains except "disruption of family leisure time" and objective burden. Additionally, inadequate family support is linked to greater burden within domains of distress. These findings are consistent with existing literature, suggesting an inverse relationship between social support and burden experienced by family caregivers of cancer patients^{29,36}.

Consequently, it can be posited that any initiatives aimed at enhancing the social support for family caregivers of acute leukemia patients may alleviate their burden. In terms of coping, a greater reliance on avoidance, escape, and distancing as coping mechanisms is associated with markedly higher objective burden, while an increased employment of acceptance-responsibility and positive appraisal as coping mechanisms is tied to reduced objective burden¹.

Existing literature also indicates that the utilization of adaptive coping mechanisms, such as positive appraisal, significantly predicts positive adjustment outcomes among cancer caregivers³⁸. Therefore, it can be asserted that

healthcare professionals dealing with family caregivers of acute leukemia patients should assess the coping strategies employed by caregivers. Encouraging the adoption of adaptive coping strategies and discouraging maladaptive coping mechanisms can potentially ameliorate the overall caregiving experience²⁹.

Higher financial burden, disruption of daily family activities, disturbance of family interaction, and total objective burden are associated with markedly greater psychological morbidity. Previous studies involving family caregivers of patients with diverse cancers also demonstrate a positive correlation between burden and psychological morbidity, manifesting as parental anxiety symptoms, depression, and PTSD¹³. Hence, it can be inferred that mitigating family caregiver burden could potentially lead to a reduction in psychological morbidity among those tending to patients with acute leukemia²⁹.

5. Conclusion

Individuals and family caregivers of patients diagnosed with leukemia experience a high level of psychological distress as a result of their specific caregiving role. The present study indicates that anxiety, stress, and depression among family caregivers of leukemia patients can be mitigated through a regularly tailored needs-based program designed according to the perceived psychological requirements of the caregivers. Adopting such an approach to address the primary needs that arise to support the family is anticipated to have a positive impact on its overall quality of life. Nonetheless, future research should delve into patient-specific and family caregiver-related factors that may contribute to the psychological distress observed in family caregivers of leukemia patients. Based on the study's findings, the researchers propose a research project aimed at assessing the effectiveness of a needs-based program in alleviating the psychological distress experienced by family caregivers of leukemia patients. This project would also explore the program's potential correlation with stress, leukemia-related anxiety, and depression. In the future, healthcare professionals could greatly benefit from considering family caregivers and implementing family-level intervention programs to enhance the mental well-being and quality of life of both adult patients with acute leukemia and their family caregivers.

In conclusion, it is worth noting the remarkable resilience demonstrated by Ms. Mary. Her vitality and determination to live, as evident from her previous experience with breast cancer, provide her with the strength to navigate daily challenges. An individual like Ms. Maria, who stands by her family and supports them through their hospital journey, could serve as an inspiration for other acute leukemia patients.

Compliance with ethical standards

Disclosure of conflict of interest

No conflict of interest to be disclosed.

Statement of ethical approval

Ethical approval was obtained by the Research Committee of Frederick University at 10/05/2023 with the no E5238.

Statement of informed consent

Informed consent was obtained from all individual participants included in the study.

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