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Caregivers are important in supportive, palliative, and hospice care

I invite you to read Issue 4, Volume 18, 2024 of *Palliative Medicine in Practice*, which contains four original articles, two review manuscripts, two case reports, a biographical note, and an obituary.

This Issue opens the original article entitled "An observational study of socioeconomic status and demographic profile of advanced cancer patients receiving palliative care in tertiary care institution of Bihar, India" authored by Mumtaz Hussain, Puja Kumari, Vinod Kumar Verma, and Nidhi Arun. Access to high-quality healthcare without financial constraints is necessary for inclusive universal health coverage. Low socioeconomic status (SES) individuals have less access to palliative care services. The study was conducted to evaluate the demographics and socioeconomic status of palliative care patients with advanced cancer. The prospective observational study included 118 patients with advanced cancer receiving palliative care. Their clinical, demographic, and socioeconomic data were collected in predesigned social assessment sheets and medical records. The SES was evaluated using the modified Kuppuswamy scale. Out of the total study participants, 54 (45.8%) were illiterate. Most of the participants had social insecurities like financial insecurity (n = 50, 42.4%), followed by insecurities regarding the future of the family members (n = 37, 31.4%). The frequency of lung cancer (n = 30, 25.4%) was the highest among the participants, followed by breast (n = 20, 17%) and gall bladder cancer (n = 15, 12.7%). The mean family income of the patients was Indian Rupees (INR) 10,847.5 ± 8,026.3 ($130.61 ± 96.64). Most of the participants (38, 32.2%) belonged to lower middle SES. Type of cancer, social insecurities, and type of caregiver were significantly associated with gender ($p < 0.05$). Most patients and their families were financially limited, and a significant portion of patients expressed financial insecurities and social stress about the future of their families. Gender was significantly associated with a type of cancer, social insecurities, and type of caregiver.

In a second research article "Coping mechanisms employed by caregivers of cancer patients seeking treatment at a tertiary care center in Northern India" Shipra Saini, Happy Dagar, Ankit Yadav, Khushi Singla, Sakshi Tanwar, Mitasha Singh, and Pooja Goyal presented a study that aimed to determine the coping strategies and their factors using the stress coping behavior scale (SCBS) in caregivers of cancer patients. This was a hospital-based cross-sectional study conducted on 190 caregivers of cancer patients. Data was collected in the oncology wing of the hospital. A pre-designed interviewer questionnaire was administered along with a Stress Coping Behavior Scale (SCBS). Linear regression was done to see the effect of different factors on the coping mechanisms of caregivers. The mean age of the caregiver was 38.48 ± 13.89 years. Most of the caregivers were males (52.1%) and living in a nuclear family (42.1%). The number of caregivers ranged from 2 to 18 in cancer patients' families. The mean

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score in avoidant coping was 1.64 ± 0.37, problem-based coping was 2.52 ± 0.52 and emotional-focused coping was 2.18 ± 0.37. Linear regression shows that avoidant coping was not significant with any factors, Problem-based coping was significant with marital status, education level of caregiver, type of family, and type of treatment received by patients, and emotional coping was significant with gender, marital status of caregiver, duration since time of cancer and number of caregivers of cancer patients. Caregivers of cancer patients are mostly their blood relatives or close family members. A positive or negative coping strategy is influenced by gender, marital and educational status, type of family and number of caregivers, duration of cancer, and treatment modality. Utilizing positive coping strategies by caregivers will not only enhance their quality of life but will even improve the caregiving of their diseased relatives.

A third original manuscript entitled "The mental health of family caregivers: do the complementary roles of personality trait, social support, and resilience matter?" was written by Obinna Osita Ike, Ifeoma Juliet Nwufo, and Peace Chisaokwu Adubi. This present study investigated the roles of personality, social support, and resilience in the mental health of family caregivers. The study based on self-report measures of the Big Five Personality Inventory, Social Support Scale, Resilience Scale, and General Health Questionnaire adopted a descriptive cross-sectional design. The participants in the study were 250 caregivers. Hierarchical multiple regression was used for data analysis. Results showed that the dimensions of the big five personality traits neuroticism ($\beta = -0.15$, $p < 0.05$), extraversion ($\beta = 0.16$, $p < 0.05$), openness to experience ($\beta = 0.17$, $p < 0.05$), conscientiousness ($\beta = 0.15$, $p < 0.05$) and agreeableness ($\beta = 0.13$, $p < 0.05$) significantly associated with family caregivers' mental health. In addition, social support ($\beta = 0.13$, $p < 0.05$) and resilience ($\beta = 0.13$, $p < 0.05$) were positively associated with the mental health of caregivers. Families, providers of health care, hospital management, and policymakers in the health care sector should take cognizance of these endogenous and exogenous factors (*e.g.*, social support, personality traits, and resilience) in the development of intervention and support services for both existing and potential health caregivers. This is pertinent since their mental health is dependent on the positive correlation among these variables of interest.

A fourth research manuscript entitled "Attitudes towards death among the nursing staff in oncology departments and hospices" is authored by Kinga Jaglak and Ewa Kobos. This study aimed to analyze attitudes towards death among the nursing staff in hospices and oncology departments. Overall, 159 members of the nursing staff in stationary hospices and oncology departments participated in the study. The Death Attitude Profile-Revised (DAP-R) was used to collect research material. The median (Me) results for the particular dimensions were as follows: approach acceptance: Me = 42, fear of death: Me = 27, neutral acceptance: Me = 29, death avoidance: Me = 17, and escape acceptance: Me = 21. Concerning neutral acceptance, the median values for the oncology hospital and hospice staff members were Me = 29 and Me = 26, respectively. Oncology nurses show a higher tendency towards neutral acceptance compared to the hospice staff. The respondents with a secondary level education demonstrated a higher tendency towards escape acceptance and death avoidance. Nurses with previous experience in oncology, hospice, or palliative care in addition to their current job demonstrate a higher tendency towards fear of death.

In the first review article Gautam Sarma, Hrishikesh Kashyap, Partha Pratim Medhi, Rupam Kalita, and Dhanjit Lahkar "Unravelling the landscape of image-guided radiotherapy: a comprehensive overview" presented an overview of image-guided radiation therapy (IGRT), which is essential to modern radiation therapy. It ensures precise radiation delivery to tumor targets, sparing healthy cells and tissues. IGRT techniques upgraded themselves to a level where the technology allows for tracking the real-time image of the tumor during treatment and significantly improves the accuracy and precision of radiation therapy. By integrating advanced imaging modalities such as cone beam computed tomography, magnetic resonance imaging, and positron emission tomography, clinicians can visualize the tumor and surrounding tissues in three dimensions. It also can account for intrafraction variations, such as organ motion and changes in tumor size or shape, which can occur throughout treatment. Using IGRT techniques, clinicians can adapt the treatment plan in real time to ensure optimal radiation delivery to the tumor while sparing healthy tissues. Moreover, IGRT is crucial in managing systematic and random errors during radiation therapy. These errors could lead to underdosing of the tumor or overdosing of healthy tissues, compromising treatment efficacy and patient safety. To mitigate these errors, imaging and frequent verification of the treatment are necessary throughout the treatment. A comprehensive summary of IGRT, its diverse modalities, clinical integration, quality assurance tests performed, and the role of artificial intelligence in IGRT is presented in this article.

A second review article "Facebook counseling in the field of complementary and alternative medicine among Polish breast cancer patients: a narrative review" is authored by Aneta Brygida Jędrzejewska, Barbara Janina Ślusarska, and Grzegorz Józef Nowicki. Breast cancer patients often use complementary and integrative therapies as supportive care as suggested by online sources during cancer treatment and when coping with the side effects of treatment. However, the evidence for the effectiveness of such therapies is limited. This review aimed to critically analyze Facebook's advice to women with breast cancer regarding the use of CAM and assess their safety and effectiveness through a narrative review. The search yielded 1,300 pieces of advice provided by the community of Facebook groups. These were analyzed, and their safety and effectiveness were assessed. Many different CAM therapies were identified, which were grouped into five categories. Currently, searching for information on CAM on Polish-language Facebook groups by breast cancer patients poses a risk of obtaining advice of unproven effectiveness. Patients are exposed to suggestions that they should take products that may interact with conventional treatment or that they may be persuaded to give up conventional treatment. Cancer care providers should consider the complexity and implications of the unmet need for information and support for breast cancer patients that result in seeking CAM advice on Facebook groups. Measures should be taken to ensure that breast cancer patients can find reliable evidence on CAM online and on social media.

The first case report entitled "Subcutaneous drainage of chronic refractory edema in cancer patients: case presentation" authored by John Cardenas, Luisa Trujillo, and Xiomara Carmona reports the case of a patient with progressive retroperitoneal sarcoma who develops severe lower limb lymphedema of multifactorial etiology, refractory to treatment. Edema is a frequent manifestation in patients with advanced diseases. The symptomatic impact it generates, the functional limitation, and the decreased quality of life are often underestimated in those affected patients. Many strategies for their management are employed, but the therapeutic response and tolerance are limited in patients with advanced diseases. The following study presents a patient in whom subcutaneous lymphatic drainage was performed with clinical improvement and impact on quality of life. In this article, there is a discussion of the topic and a review of the available literature on the presence of lymphedema in patients with cancer and the different available therapeutic options.

A second case report entitled "Concurrent pleural and pericardial effusions in advanced lung adenocarcinoma" is authored by Yusuf Haz Condeng, Harun Iskandar, Andi Makbul Aman, Haerani Rasyid, and Syakib Bakri. Lung adenocarcinoma is a common malignancy that often spreads to different organs, such as the pleura and pericardium. The concurrent presence of pleural and pericardial effusions often signifies an advanced stage of the disease. The authors presented a case of a 71-year-old male diagnosed with advanced lung adenocarcinoma complicated by concurrent pleural and pericardial effusions. Diagnostic imaging and cytological analysis confirmed the diagnosis, guiding subsequent treatment. Pericardiocentesis and thoracentesis were initiated to alleviate symptoms and improve quality of life. The case underscores the complexities involved in managing advanced lung adenocarcinoma accompanied by pleural and pericardial involvement.

We have recently received bad news that on 20th October 2024, Professor Robert Twycross passed away surrounded by His loving Family. We are immensely grateful for His great impact on modern palliative care but broadly looking on a whole medicine and health care in the UK and in other countries that should be provided with a holistic approach, including dignity and partnership with patients and attention to details [1–14] and also for His voice on difficult ethical issues [15–20]. For many years among many countries, Professor Robert Twycross visited Poland and together with Professor Jacek Łuczak organized numerous courses for Polish and Eastern European physicians and nurses who developed palliative care in their countries. Two manuscripts are devoted to a friend and distinguished authority for those involved in palliative care all over the world: "Robert G. Twycross (1941–2024) — pioneer of palliative care" by Doctor med. Halina Bogusz and Assistant Professor Aleksandra Kotlińska-Lemieszek and "To the memory of Robert Geoffrey Twycross 1941–2024" by Professor Zbigniew Żylicz and Professor Małgorzata Krajnik. We send our cordial condolences to the Family. Honor His Memory!

We invite you all to participate in the 17th International Conference of our journal planned on 5th–6th June 2025 in Gdańsk (https://paliatywna2025.konferencje.viamedica.pl/) after the 19th World Congress of the EAPC in Helsinki on 29th–31st May 2025. We will be celebrating the 30th Anniversary of establishing the Department of Palliative Medicine at the Medical University of Gdańsk founded and chaired by Professor Krystyna de Walden Gałuszko and continued by Professor Monika Lichodziejewska-Niemierko with the whole team. Professor Sebastiano Mercadante and Friends invite to Palermo for the Conference "Women in palliative care" planned on 10–12 April 2025.

I encourage you to read articles published in this and archived Issues and share your knowledge and experience by sending your manuscripts (for Authors from Poland also in Polish) regarding broadly understood palliative, supportive, and hospice care. Detailed information can be found at: https://journals.viamedica.pl/palliative_medicine_in_practice.

On behalf of an Editorial Board and all Editors of *Palliative Medicine in Practice* and Directors of Via Medica I wish all Readers and Authors of our journal a happy and prosperous New Year.

With cordial greetings,
Wojciech Leppert

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An observational study of socioeconomic status and demographic profile of advanced cancer patients receiving palliative care in tertiary care institution of Bihar, India

Abstract

Introduction: Access to high-quality healthcare without financial constraints is necessary for inclusive universal health coverage. Low socioeconomic status (SES) individuals have less access to palliative care services. The study was conducted to evaluate the demographics and socioeconomic status of palliative care patients with advanced cancer.

Patients and methods: The prospective observational study included 118 patients with advanced cancer receiving palliative treatment. Their clinical, demographic, and socioeconomic data were collected in predesigned social assessment sheets and medical records. The socioeconomic status was evaluated using the modified Kuppuswamy scale. Descriptive statistics were performed. Student's t-test and Chi-square tests were performed to compare continuous and categorical variables respectively.

Results: Out of the total 118 patients, 71 (60.2%) were females and 47 (39.8%) were males. The mean age of the patients was 49.9 ± 13.9 years. Out of the total study participants, 54 (45.8%) were illiterate. Most of the participants had social insecurities like financial insecurity (n = 50, 42.4%), followed by insecurities regarding the future of the family members (n = 37, 31.4%). The frequency of lung cancer (n = = 30, 25.4%) was the highest among the participants, followed by breast (n = 20, 17%) and gall bladder cancer (n = 15, 12.7%). The mean family income of the patients was Indian Rupees (INR) 10,847.50 ± ± 8,026.30 ($130.61 ± 96.64). Most of the participants (38, 32.2%) belonged to lower middle SES. Type of cancer, social insecurities, and type of caregiver were significantly associated with gender ($p < 0.05$).

Conclusions: The majority of patients and their families were financially limited, and a significant portion of patients expressed financial insecurities and social stress about the future of their families. Gender was significantly associated with a type of cancer, social insecurities, and type of caregiver.

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Keywords: socioeconomic status, demographic profile, advanced cancer, palliative care

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Introduction

Worldwide, 18 million new cases of cancer were reported in 2018 and 9.5 million cancer patients lost their lives [1]. According to the recent World Health Organization estimates, cancer is the leading cause of death worldwide, accounting for nearly 10 million deaths in 2020. Over 35 million new cancer cases are predicted in 2050, a 77% increase from the estimated 20 million cases in 2022 [2]. In 2016, cancer claimed 813,000 lives in India, making up more than over 8% of all fatalities [3]. In 2020, there were 19.3 million incident cancer cases globally, according to projections from the Global Cancer Observatory (GLOBOCAN). GLOBOCAN projected that 2.08 million cancer cases will be diagnosed in India in 2040, representing a 57.5 percent increase from 2020. Low understanding of symptoms and risk factors, a significant stigma associated with cancer in the community, limited access to healthcare, and high out-of-pocket expenses are all factors that contribute to India's high cancer death rate. A cancer diagnosis has significant effects on households in low- and middle-income nations. In a recent study involving nearly 9,000 cancer patients in Southeast Asia, it was found that 75% of patients had either passed away or faced financial ruin 12 months after diagnosis [1].

With a focus on the patient's physical, psychological, social, and spiritual well-being, palliative care for people with advanced cancer strives to help patients and their families. The continuum of treatment that is required to address the significant burden of serious health-related suffering endured by individuals with chronic noncommunicable illnesses includes palliative care. Palliative care has been highlighted as a crucial aspect of universal health coverage in recent Lancet Commission reports and World Health Assembly resolutions [4]. Equal access to palliative care treatments at the end of life (EOL) for all patients with advanced cancer, regardless of their socioeconomic status (SES), is a key component of universal health coverage. Though many patients with advanced cancer in low- and middle-income countries, particularly those from low SES, suffer poor outcomes at the EOL and believe that their care is of low quality, this is not always the case [5].

Due to the disease and its associated side effects, patients with advanced cancer frequently have low health-related quality of life. It is well established that socioeconomic disadvantage affects cancer diagnosis, treatment, and access to resources, but less is known about how it affects the severity of symptoms in individuals with advanced disease [6]. Socioeconomically disadvantaged cancer patients are more likely to be diagnosed later in the course of the illness, to experience poorer health outcomes, and to succumb to the disease at a higher rate than those who are socioeconomically well off [7]. In the past, research on palliative care inequalities has placed a higher priority on demographics and access to treatment than symptom burden related to socioeconomic variables. When it comes to cost reductions at the home level, which are crucial for patients and families, current methodologies have mostly failed to collect pertinent data from low- and middle-income nations. This study sought to determine the SES, demographics, and frequency of social difficulties that patients with advanced cancer who were getting palliative care experience.

Patients and methods

This prospective observational quantitative research was conducted in the Department of Anesthesiology and Critical Care Medicine, Indira Gandhi Institute of Medical Sciences (IGIMS), Sheikhpura, Patna, Bihar, India.

Ethical approval

The study was initiated after approval from the Institutional Ethical Committee of IGIMS, Patna (672/IEC/IGIMS/2018). The study was conducted by the Declaration of Helsinki. All the participants provided signed informed consent before participating in the study. The informed consent form was explained both in English and in the local language (Hindi) to the participants before taking their signature on them.

Inclusion and exclusion criteria

Advanced cancer patients in palliative care who gave their agreement to take part in the study were included. All cancer types and age groups were included in the study. Patients who did not provide signed informed consent were excluded from the study.

Data collection

In outpatient clinics, a palliative care consultant evaluated the patients and recruited the patients willing to participate for evaluation and analysis. Only the patients who were taking palliative care were included in the study. Demographic and clinical data were collected from the medical records. Participants were evaluated using a self-designed social assessment sheet and a modified Kuppuswamy scale to determine SES. The participants were asked to fill in the assessment sheets. For the patients who did not read or write, the questions were explained in their local language and the responses were filled in the sheets by the first author. The modified Kuppuswamy scale was used to estimate the SES of the participants. The patients were graded into five distinct socioeconomic classes based on their separate scores using the modified Kuppuswamy scale, which uses education, occupation, and monthly family income to determine the socioeconomic scale [8]. The modified Kuppuswamy scale used in the present study applies to both urban and semi-urban populations. The patients were classified into different socioeconomic classes according to their scores on the modified Kuppuswamy scale: 26–29 (upper class), 16–25 (upper middle class), 11–15 (middle class), 5–10 (lower middle class), and < 5 (lower class).

Statistical analysis

Statistical analysis was carried out using STATA (Stata Corp., College Station, TX, USA, Version 17 for Windows). A descriptive analysis was performed. Mean and standard deviations were calculated for continuous variables, while frequencies were used for categorical data. Results were expressed as mean ± SD and percentages as required. Student's t-test was used to compare continuous variables and for categorical variables, Pearson's chi-square test was used. A p-value of < 0.05 was considered statistically significant.

Results

Of the 118 patients included, most of the subjects were females (n = 71, 60.2%). The mean age of the patients was 49.9 ± 13.9 years. Out of 118 participants, 42 (35.6%) were in the 51–60 age group, followed by 25 (21.2%) in the 61–70 group, and 24 (20.3%) in the 41–50 group. Fifty-four (45.8%) patients were illiterate and only 7 (5.9%) subjects were graduates. In most cases, the caregivers were either children (n = 64, 54.2%) or their spouses (n = 46, 39%). The patients enrolled in the study had social insecurities like financial insecurity (n = 50, 42.4%), insecurities regarding family members future (n = 37, 31.4%), progression of disease (n = 23,19.5%), and fear of death (n = 8, 6.8%) (Table 1). Thirty (25.4%) patients had lung cancer, followed by breast cancer (n = 20, 17%) and gall bladder cancers (n = 15, 12.7%) (Table 2).

The mean and median monthly family income of the patients was INR 10,847.50 ± 8,026.30 ($130.61 ± 96.64) and INR 8,000 (range 2,000–30,000), $96.33 (range $24.08–361.23) respectively. Following the administration of the modified Kuppuswamy scale, it was found that 38 (32.2%) of individuals had scores between 11 and 15, indicating that they were from the lower middle SES, 33 (27.9%) were from the upper middle class, and 21 (17.8%) were from the upper class. Twenty-six (22.1%) participants were from a lower class and had scores below 15 (Table 3).

Table 1. Demographic characteristics of the patients (n = 118)

Patient characteristics	Frequency	Percent [%]
Age category		
10–20	7	5.9
21–30	5	4.2
31–40	14	11.9
41–50	24	20.3
51–60	42	35.6
61–70	25	21.2
71–80	1	0.8
Gender		
Male	47	39.8
Female	71	60.2
Qualification		
Illiterate	54	45.8
High school	36	30.5
Intermediate	21	17.8
Graduate	7	5.9
Caregivers of the patients		
Spouse	46	39.0
Children	64	54.2
Parents	8	6.8
Social insecurities of the patients		
Insecurities regarding family members' future	37	31.4
Financial insecurity	50	42.4
Progression of disease	23	19.5
Fear of death	8	6.8

Data were presented as N, %

Association of different demographic and clinical parameters and SES with gender

All the studied parameters were evaluated for their association with gender. Gender is significantly associated with type of caregiver (p = 0.005) (Table 4). Gender is associated significantly with type of cancer (p < 0.001) (Table 5). There was a significant association between gender and social insecurities (p = 0.04) (Table 6). No other studied demographic or clinical parameters were significantly associated

Table 2. Diagnosis of the patients (type of cancer)

Type of cancer	Frequency	Percent [%]
Gall bladder	15	12.7
Breast	20	17
Pancreas	4	3.4
Liver	10	8.5
Ewing	7	5.9
Tongue	10	8.5
Ovary	3	2.5
Lungs	30	25.4
Genitourinary	10	8.5
GIST	4	3.4
Multiple myeloma	2	1.7
Chondrosarcoma	1	0.8
Parotid	2	1.7

GIST — gastrointestinal stromal tumour; data were presented as N, %

Table 3. Socio-economic status of the patients

Kuppuswamy score	SES	Frequency	Percent [%]
26–29	Upper class	21	17.8
16–25	Upper middle	33	27.9
11–15	Lower middle	38	32.2
5–10	Upper lower	12	10.2
< 5	Lower	14	11.9

SES — socioeconomic status; data were presented as N, %

Table 4. Association of gender with type of caregiver

Gender	Caregiver	Frequency	Percent [%]	p-value
Males	Spouse	25	53.2	0.005
	Children	17	36.2	
	Parents	5	10.6	
	Total	47	100.0	
Females	Spouse	21	29.6	
	Children	47	66.2	
	Parents	3	4.2	
	Total	71	100.0	

Data were presented as N, %; Chi-square test was performed to evaluate the association of gender with type of caregiver; p-values less than 0.05 were considered significant

with gender. There was no significant (p = 0.46) difference in the mean monthly income of males (INR 10,170.21 ± 6,907.21) ($122.46 ± 83.17) and females (INR 11,295.77 ± 8,706.98) ($136.01 ± 104.84).

Table 5. Association of gender with type of cancer

Gender	Type of cancer	Frequency	Percent [%]	p-value
Males	Gall bladder	2	4.3	< 0.001
	Breast	1	2.1	
	Pancreas	3	6.4	
	Liver	4	8.5	
	Ewing	5	10.6	
	Tongue	6	12.8	
	Lungs	13	27.7	
	Genitourinary	8	17.0	
	GIST	4	8.5	
	Chondrosarcoma	1	2.1	
	Total	47	100.0	
Females	Gall bladder	13	18.3	
	Breast	19	26.8	
	Pancreas	1	1.4	
	Liver	6	8.5	
	Ewing	2	2.8	
	Tongue	4	5.6	
	Ovary	3	4.2	
	Lungs	17	23.9	
	Genitourinary	2	2.8	
	Multiple myeloma	2	2.8	
	Parotid	2	2.8	
	Total	71	100.0	

GIST — gastrointestinal stromal tumor; data were presented as N, %; Chi-square test was performed to evaluate the association of gender with type of cancer; p-values less than 0.05 were considered to be significant

Discussion

The current study evaluated the SES and demographic profiles of advanced cancer patients receiving palliative care. A considerable number of patients showed social insecurities for their families' future, and most patients and their families were poor socioeconomically. According to the *Global Atlas of Palliative Care*, just 12% of the 57 million people and children who require palliative care are now receiving it [1]. In comparison to their more affluent neighbors, persons who experience socioeconomic hardship spend a greater proportion of their shorter lives

Table 6. Association of gender with social insecurities*

Gender	Social insecurities	Frequency	Percent [%]	p-value
Males	Insecurities regarding family members' future	21	44.7	0.04
	Financial insecurity	16	34.0	
	Progression of disease	9	19.1	
	Fear of death	1	2.1	
	Total	47	100.0	
Females	Insecurities regarding family members' future	16	22.5	
	Financial insecurity	34	47.9	
	Progression of disease	14	19.7	
	Fear of death	7	9.9	
	Total	71	100.0	

*Data were presented as N, %; a Chi-square test was performed to evaluate the association between gender and social insecurities; p-values less than 0.05 were considered to be significant

in poor health and carry a heavier load of chronic diseases, multi-morbidity, and symptom burden. Socioeconomic disadvantage is a risk factor on its own for greater mortality in populations with and without cancer and is linked to higher healthcare utilization and expenditures in the last year of life [9].

Cancer presentation and diagnostic delays can be influenced by socioeconomic circumstances, and patients in more socioeconomically deprived locations are less likely to be referred to hospice care services [10]. It has been discovered in the past that low-SES individuals experience greater delays in upper gastrointestinal tumor symptom recognition and primary care visitation. According to a study by Bus et al. [11], low-SES individuals had more comorbid conditions and were diagnosed at older ages and with more advanced tumor stages. Even with comorbidities, tumor stage, and age adjustments, high-SES individuals still had a greater chance of receiving curative therapy. After age, tumor stage, histology, and location were taken into consideration, high SES also had a favorable impact on life expectancy in the palliative group [11]. According to a comprehensive analysis, cancer patients in lower socioeconomic categories had a much lower likelihood of passing away at home and faced greater obstacles to receiving palliative care [12, 13]. According to some data, using specialized palliative care may change how socioeconomic status affects the site of dying [14]. Low SES is a risk factor for hospital deaths in high-income nations, according to another systematic study, as well as other signs of possibly subpar end-of-life care [6].

Socioeconomic status significantly affects the treatment rates and survival in cancer patients [11]. Studies by Dreyer et al. [15] and Guadamuz et al. [16] have highlighted that cancer patients belonging to low SES were less likely to receive treatments and showed reduced survival. Low SES individuals with pancreatic cancer were shown to be less likely to receive surgical therapy. Esophagectomy was observed to be performed more frequently on high-SES patients with esophageal cancer than on low-SES individuals. In contrast to cancer patients from higher SES groups, low SES cancer patients are more likely to experience higher mortality, depression, and other comorbidities, as well as a greater burden of symptoms [5]. Low SES cancer patients are also less likely to obtain palliative care and die at home [17]. According to a meta-analysis, patients with advanced cancer had the largest unmet requirements in the areas of information, patient care and support, and physical, psychological, and daily living activities [6]. In general, cancer patients with low SES are more likely than their better-off peers to report unmet requirements. Socioeconomic factors can affect how a patient is treated. According to a Canadian study of 34,022 patients with advanced gastrointestinal cancer, those who lived in the most disadvantaged areas were significantly less likely to receive radiotherapy and/or chemotherapy after receiving a diagnosis [10]. In contrast to two studies that indicated low SES cancer patients were more likely to use home-based hospice care services, another research revealed that low SES cancer patients were less likely to obtain hospice care during EOL therapy [12, 13, 18]. According to Kumar et al. [17], the majority of patients and their families had financial resource limitations, and a sizable portion of patients experienced social uneasiness over the welfare of future generations.

Financial insecurity (42%), family member future insecurity (31%), sickness progression (19.5%), and dread of death (7%) were the main social issues in the research scenario [19]. Most of the worries raised by Wright et al.'s [20] investigation were supported by these observations. Palliative treatment was more frequently preferred by women than by males. In the following analysis, female representation was greater than male representation, which is consistent with the reports of Wright et al. [20] and Saeed et al. [21]. Saeed et al [21] found that elderly persons had a lower tendency than younger adults to favor palliative care. In the following study, most participants were in the older age groups, with more than 50% being over 50, while adolescents and young children were scarcely represented.

Patients with higher financial hardship ratings had worse functional well-being, lower emotional well-being, higher anxiety, and higher depression scores, according to Jacob and colleagues [3]. Socioeconomic status was shown by few studies as an independent risk factor for death in cancer patients [22]. According to research by Hapuarachchi et al. [5], patients with low SES reported lower physical, emotional, spiritual, and social EOL outcomes than those with high SES [5]. Following a diagnosis of advanced cancer, poor households in low-income countries are exposed to catastrophic health-related expenses, according to a prospective cohort research by Bates et al. [1]. According to a systematic review conducted by Parajuli et al. [23], cancer patients with low SES are less likely to use palliative services.

It is widely recognized that the characteristics and experiences of individuals accessing palliative care services can vary significantly due to diverse factors, including geographic location, SES, and the organization of healthcare systems. Notably, patients receiving palliative care in developed countries may manifest distinct demographic profiles, disease trajectories, and care needs compared to those in less developed regions [24, 25]. In developed nations, where there tends to be better SES and more structured healthcare infrastructure, patients seeking palliative care may present with unique features. These differences may stem from factors such as enhanced healthcare accessibility, increased awareness and acceptance of palliative care services, and elevated overall standards of living. Acknowledging these potential disparities is crucial when interpreting research findings or devising interventions aimed at enhancing palliative care provision. Tailoring approaches to accommodate the specific requirements and contexts of patients within varying socioeconomic and healthcare settings is essential for promoting equitable access to and quality of care.

Since the study was focused only on the patients of Bihar which is an Eastern Indian state, the findings cannot be generalized to the whole country. Therefore, large multi-centric studies including patients from all the geographical regions of India should be conducted to understand the overall scenario of the country. Another limitation of the study is the small sample size. Further studies with larger sample sizes should be conducted to substantiate the findings of the present study.

Conclusions

Most patients and their families had financial difficulties, and many patients were socially insecure about what would happen to their loved ones following their death. In addition, it was observed that type of cancer, social insecurities, and type of caregiver were significantly associated with gender. The authors advocate for equal access to palliative care treatments for all advanced cancer patients, regardless of their SES.

Article information and declarations

Data availability statement

None.

Acknowledgments

None.

Ethics statement

The study was initiated after approval from the Institutional Ethical Committee of IGIMS, Patna (672/IEC/IGIMS/2018). The study was conducted by the Declaration of Helsinki. All the participants provided signed informed consent before participating in the study. The informed consent form was explained both in English and in the local language (Hindi) to the participants before taking their signature on them.

Author contributions

Patient recruitment, conceptualization, data collection, and analysis — MH; data analysis and drafting of the manuscript — PK, VKV, NA.

Conflict of interest

The authors declare no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

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Supplementary material

None.

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Original article

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Coping mechanisms employed by caregivers of cancer patients seeking treatment at a tertiary care center in Northern India

Abstract

Background: India enjoys a cultural setting wherein informal caregivers predominantly take care of their chronic or terminally ill cancer relatives. Caregivers are needed even for minuscule activities all through the cancer journey. However, with the rapid switch of societal westernization, the health system must focus its services on the burnt-out caregiver too. The study aimed to determine the coping strategies and their factors using the stress coping behavior scale (SCBS) in caregivers of cancer patients.

Participants and methods: This study was a hospital-based cross-sectional study conducted on 190 caregivers of cancer patients. Data was collected in the oncology wing of the hospital. A pre-designed interviewer questionnaire was administered along with a Stress Coping Behavior Scale (SCBS). Linear regression was done to see the effect of different factors on the coping mechanisms of caregivers.

Results: The mean age of the caregiver was 38.48 ± 13.89 years. The majority of the caregivers were males (52.1%) and living in a nuclear family (42.1%). The number of caregivers ranged from 2 to 18 in cancer patients' families. The mean score in avoidant coping was 1.64 ± 0.37, problem-based coping was 2.52 ± 0.52 and emotional-focused coping was 2.18 ± 0.37. Linear regression shows that avoidant coping was not significant with any factors, Problem-based coping was significant with marital status, education level of caregiver, type of family, and type of treatment received by patients and emotional coping was statistically significant with gender, marital status of caregiver, duration since time of cancer and number of caregiver of cancer patients.

Conclusions: Caregivers of cancer patients are mostly their blood relatives or close family members. A positive or negative coping strategy is influenced by gender, marital and educational status, type of family and number of caregivers, duration of cancer, and treatment modality. Utilizing positive coping strategies by caregivers will not only enhance their quality of life but will even improve the caregiving of their diseased relatives.

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Keywords: relatives, attendants, cancer survivors, avoidant coping, problem-focused coping, emotional coping

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Introduction

Cancer is an unregulated growth of cells in any organ system. It can occur in humans of any age group, sex, nationality, ethnicity, economic status, educational strata, and geological and geographic distributions. The disease has the potential to restrain a person from achieving his full physical, physiological, psychological, and economic potential. It is a major concern for the patient, his/her family, the clinician, the healthcare provider, and the taxpayer [1]. The burden of disease is increasing day by day, it has been projected that the number of cancer patients in India will be 15,069,793 by the year 2025 [2].

Caregiver is defined here as the person who looks after the cancer patient and is often not paid to do so. Spouses, parents, adult-child, or partner are mainly the caregivers. Neighbors, co-workers, or close friends can also fill for this. A reliable and good caregiver plays an important role in a cancer patient's well-being [3].

Disclosure of cancer diagnosis is a dramatic turmoil both for the patient and their family members. Family and caregivers face challenges at all fronts — physical, emotional, social, and financial, which has been confirmed by the available evidence. The state of mind of the caregiver will not only affect their behavior, health, and mental status but also indirectly affect the patient's health as well [4]. Consequently, this leads to a necessity to adopt coping mechanisms to cushion the effect of the burden experienced during caregiving. Coping is defined as the thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful, it has been a focus of research in the social sciences for more than three decades [5].

Coping style is an individual's ability to deal with the upcoming stressors. These are sets of traits that become evident in response to individual stress. Some coping mechanisms are beneficial while some are not. Negative coping styles like maladaptive coping can have harmful effects on an individual's mental health [6]. In Indian culture where caregivers of patients with advanced diseases are mostly close family members or extended joint family members, it is important to assess the psychosocial burden and its associated factors among the caregiver to improve the quality of life of cancer patients and their caregiver. To the best of the authors' knowledge limited studies have been done on this cohort in the Indian setting. With this background, the study aims to determine the coping strategies of caregivers of cancer patients. The study aims were as follows:

1. To determine the coping strategies using the stress coping behavior scale (SCBS) in caregivers of cancer patients [7].
2. To determine the factors associated with coping strategies among the caregiver.

Participants and methods

Study design and settings

It was a hospital-based, cross-sectional study, which was conducted at the oncology wing (outpatient and inpatient department) of a tertiary care hospital of a social security organization in district Faridabad, Haryana, India. It caters to insured persons and their dependents under the Employees' State Insurance (ESI) Act [8]. It is a contributory scheme where a worker who earns less than or equal to 21,000 INR (252.69 USD) per month in an establishment contributes a monthly amount along with his employer to the ESIC corpus fund. In turn, he/she and dependents are entitled to primary, secondary, and tertiary medical care in the designated ESI dispensaries or hospitals or empaneled hospitals for super specialty care. India's healthcare system is diverse and complex, comprising both public and private sectors. The Public Healthcare System has three levels: primary, secondary, and tertiary. Primary healthcare is at the grassroots level, primary healthcare is provided through a network of primary health centers (PHCs), sub-centers, and community health centers (CHCs). Secondary and tertiary healthcare facilities include district hospitals and medical colleges, which provide more specialized care. These are also primarily funded and operated by the government. Private healthcare system ranges from small clinics to large corporate hospitals. These cater to a significant portion of the population, especially in urban areas. Private hospitals often offer advanced medical technologies and facilities, but the cost of treatment can be high, making it inaccessible for many. Health insurance coverage in India is growing, but still relatively low compared to many developed countries. Both public and private health insurance options are available. Government schemes like the Employees State Insurance Scheme and Ayushman Bharat aim to provide health coverage to economically vulnerable sections of society.

Study population

The participant of this study was the caregiver of cancer patients, responsible for attending to the needs of cancer patients. They were either family members or distant relatives, providing unpaid, nonprofessional care and met the following criteria: (a) a care provider of a cancer patient who was diagnosed by a clinician; (b) ≥ 18 years old; and (c) able to participate in the study both physically and mentally. One caregiver of one cancer patient was recruited.

Operational definition

Caregivers of cancer patients are family members or distant relatives, providing unpaid, nonprofessional care to their cancer-diagnosed relatives (related by blood, marriage, or adoption).

Sample size and sampling strategy

The sample size was calculated based on the previous study done by Kim and Schuz [9], in which the proportion of caregivers with high burden was found to be 67.3%. Using the formula:

Sample size = $Z_{1-\alpha/2}^{2}\, p\, (1-p) / d^{2}$

taking 10% as the relative precision (d) and 95% confidence interval, the sample size comes to be 189; assuming 10% as the non-response rate, 209 caregivers were approached. A convenient sampling strategy was used to recruit patients admitted to oncology or surgery departments.

Study tool

A structured questionnaire consisting of 3 sections i) Socio-demographic data, ii) Clinical history of caregiver and his patient, iii) Stress Coping Behavior Scale (SCBS) was used [7]. SCBS consisted of a 28-item questionnaire that assesses coping in 14 coping scales. It was translated in many languages including Hindi and is found reliable and valid for the Indian population by Janghel and Shrivastav [7]. The coping scale used in the present study is a Likert scale that measures the type of coping mechanism a person exhibits. The scale can determine participant's primary coping styles on the following three subscales:

1. Problem-Focused Coping (Cope P) (Items 2, 7, 10, 12, 14, 17, 23, 25) — this coping style characterizes the person using informational support and planning, and has a positive frame of mind. A high P score indicates coping strategies that are aimed at changing the stressful situation, indicative of psychological strength, grit, and a practical approach to problem-solving.
2. Emotion-Focused Coping (Cope E) (Items 5, 9, 13, 15, 18, 20–22, 24, 26–28) — this coping style characterizes the person as dependent on emotional support, humor, acceptance, self-blame, and religion. A high score indicates coping strategies that aim to regulate emotions associated with the stressful situation. High or low scores are not uniformly associated with psychological health or ill health but can be used to inform a wider formulation of the respondent's coping styles.
3. Avoidant Coping (Cope A) (Items 1, 3, 4, 6, 8, 11, 16, 19) — this coping style characterizes the person in the facets of self-distraction, denial, substance use, and behavioral disengagement. A high score indicates physical or cognitive efforts to disengage from the stressor and Low scores are indicative of adaptive coping. Fourteen subscales have also been decoded by the researcher [7].

Scores are presented for three overarching coping styles as average scores (sum of item scores divided by number of items), indicating the degree to which the respondent has been engaging in that coping style. 1 — I haven't been doing this at all; 2 — a little bit, 3 — a medium amount, and 4 — I've been doing this a lot. Consistently low scores on all subscales may indicate either: (A) the respondent does not feel they have many stressors to cope with. For example, that life is stress-free; (B) a lack of reflective capacity or resistance to disclose personal information; (C) the respondent does not have many coping skills [7].

Data collection

The caregivers of diagnosed cancer patients visiting the oncology ward were approached to take part in the study between July–October 2023. After explaining the aim and objectives of the study in their local language and obtaining written informed consent, they were included in the study. If the caregiver of the patient denied consent, then the next patient's caregiver was approached. The questionnaire was filled out using the interview method in their local language. The privacy and confidentiality of the study subjects was maintained. The data was tabulated in Microsoft Excel.

Data and statistical analysis

The continuous variables like age and scores were checked for normality of distribution. Data was analyzed using Epi info version 7 (CDC). The continuous variables were normally distributed and summarized as mean and standard deviation. Count and percentages were presented for categorical variables. The three subscales' average scores as outcomes were individually subjected to linear regression analysis with socio-demographic factors and clinical history variables as independent variables. P value ≤ 0.05 was considered statistically significant.

Ethical considerations

The study was approved by the Institute ethics committee: EC File No: 134 X/11/13/2023–IEC/DHR/67. Study participants were provided with a patient information sheet (PIS) in bilingual (Hindi and English) format. A written informed consent was obtained in the informed consent form (ICF) from the study participants with the option to withdraw from the study at any time without giving any reasons thereof. All the details of the study participants were kept confidential. The study was conducted in accordance with the Declaration of Helsinki.

Results

A total of 210 caregivers of cancer patients were approached for the personal interview, out of which 190 caregivers gave consent and participated in the study. The mean age of the participants was 38.48 ± 13.89 years, most of the caregivers were males (52.1%) and were close family members of the patient (99.5%), living in a nuclear family (42.1%). A minimum of 2 and maximum of 18 (mean = 6.4 ± 2.8) caregivers are taking care of their cancer relatives. The socio-demographic profile of the study participants is in Table 1.

Medical history of the cancer patients revealed that most of the patients were of gastrointestinal cancer (25.3%) followed by head and neck cancers (20.5%). Most of the patients (64.2%) were on chemotherapy. The duration of diagnosis for the majority (48.4%) was less than one year (Table 2).

The mean score of the three main coping styles and 14 subdomain coping styles is shown in Table 3. The highest mean of avoidant coping was that of self-distraction, which is 2.2. The highest mean of problem-focused coping was active coping such as by making constant efforts to overcome the problem. Religious and spiritual questions scored the highest mean in emotion-focused coping.

The highest mean score for avoidant type of coping style that is denial and substance abuse was found in the 19–29 year age group whereas the highest problem-focused and emotional focused mean score was found in 30–39 year age group caregivers. The male caregivers had a more avoidant coping style whereas females had more of a problem and emotional-focused coping style. Two or more than two caregivers have less avoidant and more problem-focused coping styles. Married participants living in joint families, educated and with good socio-economic status had more problem-focused coping strategies as compared to their counterparts. Participants whose patients had been diagnosed with cancer less than a year back had a more avoidant type of coping as compared to participants whose patients had been diagnosed in more than one year had more problem-focused coping (Table 4).

On subjecting the three coping scores to the linear regression model it was observed that male gender was significantly negatively related to emotion-focused coping style: coefficient −0.19 (95% CI: −0.35, −0.03). Illiteracy, education up to high school, and intermediate school of caregivers were significantly negatively correlated with problem-focused coping styles as compared to those with graduation degrees and above. Being an unmarried caregiver was significantly negatively correlated with problem-focused: coefficient −0.27 (95% CI: 0.52, −0.01) and emotion-focused coping style: coefficient −0.27 (95% CI: −0.45, −0.01) as compared to the married caregiver. Age and employment status of caregivers were not significantly correlated with any of the coping styles. Surgery as a treatment modality of cancer was negatively correlated with a problem-focused coping style as compared to those who received mixed treatment modalities. Hours spent in caregiving were inversely correlated with emotion-focused coping style (−0.01, 95% CI: −0.02, 0.0) (Table 5).

Discussion

The findings from this study provide valuable insights into the coping strategies employed by caregivers of cancer patients at a tertiary care center in North India. In the current study, family members served as the major informal caregivers to their relatives with chronic health conditions during the management, treatment, and recovery of this finding which goes with the finding of a study by Akpan-Idiok et al. [6]. However, this role of caregiving consequently places a huge demand on the caregiver's social, financial, and personal resources which becomes onerous. The financial aspect has not been studied in this study as all patients are insured under the ESI Act and their treatment is covered under this insurance. However, another coping study mentioned financial burden as an important determinant of coping [10]. Hence, for continuous caregiving of cancer patients, it has become imperative for caregivers to adopt suitable coping strategies that would serve as an impetus for optimal caregiving.

Gender differences in coping styles

The study suggests that male caregivers were more likely to exhibit avoidant coping styles, while female caregivers were inclined towards problem-focused and emotion-focused coping strategies. These findings are consistent with studies by Akpan-Idiok et al. [6], Long et al. [10] and Sheroun et al. [11]. Research has often shown that men tend to use more avoidant strategies, such as denial, whereas women tend to be more expressive of their emotions and seek solutions actively [10].

Age-related coping strategies

The results indicate that younger caregivers (aged 19–29) were more likely to employ avoidant coping

Table 1. Socio-demographic characteristics of the caregiver

Characteristics		Caregiver (n = 190)	Percentage [%]
Age (in years)	≤ 18	5	2.6
	19–29	56	29.5
	30–39	46	24.2
	40–49	39	20.5
	50–59	20	10.5
	≥ 60	24	12.6
Number of caregivers	One	77	40.5
	Two	66	34.7
	More than two	47	24.7
Gender	Male	99	52.1
	Female	91	47.9
Marital status	Married	152	80
	Unmarried	38	20
Religion	Hindu	187	98.4
	Muslim	3	1.6
Education	Illiterate	36	18.9
	Less than primary school	9	4.7
	High school complete	66	34.7
	Intermediate complete	35	18.4
	Graduate and above	44	23.2
Socio-economic scale (Modified BG Prasad scale 2022) [16]	Upper class	8	4.2
	Upper middle class	58	30.5
	Middle class	76	40
	Lower middle class	45	23.7
	Lower class	3	1.6
Employment status	Employed	109	57.4
	Unemployed	14	7.4
	Homemaker	67	35.3
Type of family	Nuclear	80	42.1
	Three generation	38	20.0
	Joint	72	37.9
Relation to patient	Children	82	43.2
	Parent	17	8.9
	Sibling	18	9.5
	Spouse	73	38.4
H/O chronic illness	Yes	38	20
	No	152	80
Mean hours spent per day on caregiving (± SD)	19.5 ± 6.3		

SD — standard deviation

strategies, while those in the 30–39 age group tended to use problem-focused and emotion-focused coping methods. This aligns with a study done by Sheroun et al. [11] that suggests coping strategies may evolve with age and life experiences. Younger individuals may still be developing their coping mechanisms,

Table 2. Clinical history of cancer patient (n = 190)

Variables		Patients (n = 190)	Percentage [%]
Type of cancer	Breast	18	9.5
	Gastrointestinal	48	25.3
	Gastro urinary	30	15.8
	Head and neck	39	20.5
	Lung	12	6.3
	Blood	28	14.7
	Others	15	7.9
Duration of diagnosis	Less than 1 year	92	48.4
	1–2 years	63	33.2
	More than 2 years	35	18.4
Type of treatment modality	Surgery	17	8.9
	Chemotherapy	122	64.2
	Mixed	51	26.8

Table 3. Coping score of the study participants (n = 190)

Domain	Mean	Standard deviation
Avoidant coping	1.64	0.37
Self-distraction, items 1 and 19	2.28	0.73
Denial, items 3 and 8	1.61	0.67
Substance use, items 4 and 11	1.23	0.55
Behavioral disengagement, items 6 and 16	1.46	0.62
Problem-focused	2.52	0.52
Active coping, items 2 and 7	3.05	0.75
Use of informational support, items 10 and 23	2.60	0.89
Positive reframing, items 12 and 17	2.37	0.86
Planning, items 14 and 25	2.51	0.79
Emotional focused	2.18	0.37
Emotional support, items 5 and 15	2.91	0.84
Venting, items 9 and 21	1.85	0.79
Humor, items 18 and 28	1.09	0.36
Acceptance, items 20 and 24	2.97	0.82
Religion, items 22 and 27	3.02	1.03
Self-blame, items 13 and 26	1.47	0.71

while those in their thirties may have more established strategies. Most of the caregivers in the current study were children or spouses. This is of importance as most cancers are prevalent or detected in old age.

Marital status and coping

Almost 80% of the respondents were married and 67% were middle-aged. These results are in accordance with another study that confirmed that most caregivers to patients with chronic health problems are middle-aged [12]. The study reveals that unmarried caregivers were more inclined towards avoidant coping styles and less likely to use problem-focused and emotion-focused strategies compared to married caregivers. The probable reason could be that married individuals often have more extensive support networks and, consequently, may be more likely to use problem-focused strategies [13]. The problem-focused coping facilitates emotional coping. The reason that married caregiver obtain advice and help from their immediate network; it reduces their stress to some extent hence increasing their emotional coping too [14].

Education and coping styles

The research demonstrates that caregivers with lower levels of education (illiterate or up to high school) tended to use problem-focused coping styles less frequently than those with a higher level of education (graduation degree and above). This result echoes previous findings (cite relevant studies) indicating that individuals with higher education may have better problem-solving skills and access to more resources [6, 15].

Treatment modality and coping

The study suggests that caregivers of cancer patients who underwent surgery as a treatment modality

Table 4. Mean coping scores among different socio-demographic factors of the caregiver

Socio-demographic profile	Parameters	Avoidant coping Mean score (SD)	Problem coping Mean score (SD)	Emotional coping Mean score (SD)
Age in years	< 18	1.40 (0.24)	2.25 (0.41)	1.92 (0.35)
	19–29	1.69 (0.37)	2.55 (0.52)	2.18 (0.38)
	30–39	1.66 (0.37)	2.64 (0.49)	2.28 (0.41)
	40–49	1.71 (0.41)	2.46 (0.55)	2.13 (0.34)
	50–59	1.59 (0.23)	2.45 (0.52)	2.12 (0.35)
	≥ 60	1.48 (0.38)	2.38 (0.57)	2.17 (0.34)
Gender	Male	1.68 (0.42)	2.51 (0.52)	2.10 (0.37)
	Female	1.60 (0.31)	2.53 (0.53)	2.27 (0.36)
Number of caregivers	One	1.65 (0.37)	2.48 (0.56)	2.18 (0.38)
	Two	1.65 (0.40)	2.60 (0.50)	2.20 (0.34)
	More than two	1.60 (0.35)	2.46 (0.50)	2.16 (0.41)
Relation to the patient	Children	1.62 (0.39)	2.55 (0.48)	2.17 (0.39)
	Parent	1.64 (0.34)	2.35 (0.46)	2.02 (0.22)
	Sibling	1.81 (0.40)	2.63 (0.69)	2.20 (0.39)
	Spouse	1.63 (0.35)	2.49 (0.54)	2.23 (0.37)
Marital status	Married	1.65 (0.38)	2.53 (0.53)	2.22 (0.37)
	Unmarried	1.62 (0.35)	2.47 (0.49)	2.04 (0.35)
Religion	Hindu	1.64 (0.38)	2.51 (0.52)	2.18 (0.37)
	Muslim	1.83 (0.07)	2.83 (0.63)	2.50 (0.52)
Education	Illiterate	1.61 (0.41)	2.40 (0.55)	2.20 (0.32)
	Less than primary school	1.43 (0.29)	2.42 (0.45)	2.07 (0.37)
	High school complete	1.68 (0.38)	2.53 (0.50)	2.22 (0.38)
	Intermediate complete	1.62 (0.37)	2.69 (0.54)	2.22 (0.42)
	Graduate and above	1.67 (0.37)	2.68 (0.54)	2.22 (0.42)
Employment	Employed	1.69 (0.40)	2.51 (0.52)	2.13 (0.38)
	Unemployed	1.56 (0.30)	2.54 (0.58)	2.14 (0.35)
	Homemaker	1.58 (0.32)	2.52 (0.53)	2.28 (0.34)
Type of family	Nuclear	1.65 (0.38)	2.51 (0.51)	2.15 (0.36)
	Three generation	1.63 (0.27)	2.41 (0.48)	2.14 (0.38)
	Joint	1.64 (0.41)	2.58 (0.56)	2.24 (0.38)
SES	Upper class	1.50 (0.30)	2.75 (0.51)	2.17 (0.09)
	Upper middle class	1.65 (0.39)	2.59 (0.51)	2.21 (0.40)
	Middle class	1.66 (0.29)	2.47 (0.56)	2.16 (0.42)
	Lower middle class	1.64 (0.49)	2.46 (0.48)	2.19 (0.29)
	Lower class	1.42 (0.07)	2.63 (0.45)	2.03 (0.25)
Location of cancer	Blood	1.70 (0.39)	2.67 (0.57)	2.19 (0.41)
	Breast	1.63 (0.30)	2.56 (0.53)	2.09 (0.37)
	Gastrointestinal cancer	1.56 (0.38)	2.47 (0.44)	2.19 (0.31)
	Genitourinary	1.62 (0.29)	2.48 (0.51)	2.23 (0.37)
	Head and neck	1.66 (0.37)	2.48 (0.51)	2.23 (0.37)
	Lung	1.76 (0.33)	2.36 (068)	2.17 (0.53)
	Other	1.73 (0.53)	2.47 (0.53)	2.15 (0.41)

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Table 4. cont. Mean coping scores among different socio-demographic factors of the caregiver

Socio-demographic profile	Parameters	Avoidant coping Mean score (SD)	Problem coping Mean score (SD)	Emotional coping Mean score (SD)
Duration since diagnosis	< 1 year	1.69 (0.39)	2.55 (0.55)	2.23 (0.39)
	1–2 years	1.59 (0.35)	2.54 (0.49)	2.19 (0.33)
	> 2 years	1.57 (0.36)	2.36 (0.49)	2.04 (0.36)
Treatment modality	Chemotherapy	1.66 (0.36)	2.52 (0.55)	2.16 (0.37)
	Surgery	1.61 (0.43)	2.20 (0.44)	2.09 (0.33)
	Mixed	1.62 (0.40)	2.62 (0.45)	2.26 (0.39)

SD — standard deviation; SES — socio-economic status

Table 5. Linear regression analysis of avoidant, emotional, and problem-focused coping with various socio-demographic parameters of the caregivers

Variables		Avoidant coping		Problem-focused coping		Emotion-focused coping	
		Coefficient (95% CI)	p-value	Coefficient (95% CI)	p-value	Coefficient (95% CI)	p-value
Age of caregivers (in years)		−0.01 (−0.01, 0.0)	0.06	−0.01 (−0.01, 0.01)	0.32	−0.01 (−0.01, 0.0)	0.07
Gender of caregivers	Male	−0.04 (−0.21,0.13)	0.65	−0.06 (−0.29–0.16)	0.57	−0.19 (−0.35, −0.03)	**0.017**
	Female	Ref					
Education of caregivers	Illiterate	0.03 (−0.18, 0.24)	0.8	−0.33 (0.62, −0.04)	**0.03**	−0.12 (−0.32, 0.08)	0.23
	Up to primary school	−0.17 (−0.46, 0.11)	0.23	−0.22 (0.61, 0.17)	0.27	−0.21 (−0.48, 0.06)	0.13
	Up to high school	−0.002 (−0.17, 0.17)	0.98	−0.26 (0.49, −0.03)	**0.03**	-0.11 (−0.27, 0.05)	0.19
	Up to intermediate school	−0.06 (−0.23,0.11)	0.45	−0.30 (0.52, −0.07)	**0.01**	−0.18 (−0.34, −0.03)	**0.02**
	Graduate and above	Ref					
Employment status of caregivers	Currently Employed	0.19 (−0.01, 0.38)	0.06	−0.04 (−0.31, 0.22)	0.76	0.02 (−0.16, 0.20)	0.82
	Unemployed	0.17 (−0.11, 0.45)	0.22	0.24 (−0.14, 0.62)	0.21	0.20 (−0.06, 0.46)	0.14
	Homemaker	Ref					
Relation of caregivers with patient	Children	−0.16 (−0.33, 0.01)	0.07	−0.01 (−0.25–0.22)	0.91	−0.07 (−0.23, 0.09)	0.40
	Parent	−0.06 (−0.27, 0.14)	0.54	−0.22 (−0.50, −0.05)	0.12	−0.18 (−0.38, 0.01)	0.06
	Sibling	0.04 (−0.17, 0.25)	0.72	0.11 (−0.17, 0.40)	0.45	−0.07 (−0.27, 0.12)	0.46
	Spouse	Ref					
Marital status of caregivers	Unmarried or Widowed or Divorced	−0.13 (−0.32,0.06)	0.18	−0.27 (−0.52, −0.01)	**0.04**	−0.27 (−0.45, −0.10)	**0.002**
	Married	Ref					
Religion	Hindu	−0.24 (−0.66,0.18)	0.26	−0.06 (−0.63, 0.51)	0.83	−0.07 (−0.46, 0.32)	0.73
	Muslim	Ref					

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Table 5. cont. Linear regression analysis of avoidant, emotional, and problem-focused coping with various socio-demographic parameters of the caregivers

Variables		Avoidant coping		Problem-focused coping		Emotion-focused coping	
		Coefficient (95% CI)	p-value	Coefficient (95% CI)	p-value	Coefficient (95% CI)	p-value
Type of family of caregivers	Nuclear	0.01 (−0.12, 0.14)	0.87	−0.06 (−0.23, 0.11)	0.48	−0.09 (−0.21, 0.03)	0.15
	Three generation	−0.05 (−0.21, 0.11)	0.56	−0.19 (−0.41, 0.03)	**0.01**	−0.09 (−0.24, 0.06)	0.23
	Joint	Ref					
Socio-economic status (BG Prasad scale)	Class I	0.01 (−0.49, 0.52)	0.96	0.01 (−0.67, 0.69)	0.90	0.03 (−0.44, 0.50)	0.90
	Class II	0.21 (−0.23,0.64)	0.35	0.07 (−0.52, 0.66)	0.80	0.17 (−0.24, 0.57)	0.42
	Class III	0.25 (−0.18, 0.68)	0.26	0.02 (−0.56, 0.60)	0.90	0.18 (−0.22, 0.59)	0.37
	Class IV	0.19 (−0.24,0.62)	0.39	−0.05 (−0.63, 0.53)	0.86	0.16 (−0.25, 0.56)	0.45
	Class V	Ref					
Type of cancer	Blood cancer	0.03 (−0.21,0.27)	0.82	0.20 (−0.12, 0.52)	0.22	0.12 (−0.11, 0.34)	0.30
	Breast cancer	−0.01 (−0.29, 0.26)	0.92	0.08 (−0.29, 0.45)	0.66	0.04 (−0.21, 0.30)	0.74
	Gastrointestinal cancer	−0.10 (−0.33, 0.12)	0.38	−0.05 (−0.36, 0.25)	0.72	0.04 (−0.17, 0.25)	0.69
	Genitourinary cancer	−0.01 (−0.26, 0.23)	0.92	0.01 (−0.32, 0.33)	0.97	0.05 (−0.17, 0.28)	0.65
	Head and neck cancer	−0.02 (−0.26, 0.21)	0.88	−0.05 (−0.35, 0.26)	0.77	0.05 (−0.16, 0.26)	0.65
	Lung cancer	0.05 (−0.24, 0.34)	0.73	−0.36 (−0.75, 0.03)	0.07	−0.02 (−0.29, 0.25)	0.87
	Other	Ref					
Type of treatment being given for cancer	Chemotherapy	−0.02 (−0.14, 0.11)	0.79	−0.10 (−0.27, 0.07)	0.25	−0.09 (−0.21, 0.03)	0.11
	Surgery	−0.01 (−0.21, 0.19)	0.95	−0.47 (−0.74, −0.20)	**0.001**	−0.17 (−0.36, 0.02)	0.08
	Mixed treatment	Ref					
Duration since diagnosis of cancer	< 1 year	0.11 (−0.04,0.26)	0.15	0.20 (0.0, 0.41)	0.05	0.24 (0.09, 0.38)	**0.001**
	1–2 year	0.01 (−0.15.0.16)	0.94	0.04 (−0.17, 0.26)	0.69	0.09 (−0.06, 0.24)	0.23
	> 2 years	Ref					
Number of caregivers of the patient	One	0.06 (−0.10, 0.22)	0.48	0.03 (−0.19, 0.25)	0.79	0.02 (−0.13, 0.17)	0.75
	Two	0.04 (−0.12, 0.19)	0.65	0.07 (−0.14, 0.28)	0.49	0.03 (−0.12, 0.17)	0.70
	More than two	Ref					
	Hours spent in caregiving per day	−0.01 (−0.02, 0.004)	0.26	−0.01 (−0.02, 0.0)	0.08	−0.01 (−0.02, −0.0)	**0.006**

CI — confidence interval; p-value < 0.05 is considered as statistically significant were less likely to employ problem-focused coping strategies compared to those who received mixed treatment modalities. These results show that the choice of treatment modality can impact caregivers' coping mechanisms. Mixed treatment like a mix of surgery, chemotherapy, and/or radiotherapy requires multiple times of visits and multi-site visits of patients and hence requires problem-solving strategies from the caregiver for proximal goals.

Hours spent in caregiving and coping

The study found that the hours spent in caregiving were inversely correlated with emotion-focused coping, meaning that caregivers who spent more time caregiving were less likely to employ emotion-focused strategies. This result is somewhat unique and warrants further investigation, as it may be indicative of the emotional toll and burnout experienced by caregivers who spend extended hours in caregiving.

Overall, this study contributes to the growing body of research on the coping strategies of caregivers for cancer patients. The results align with many previous findings, highlighting the influence of factors like gender, age, marital status, education, and treatment modalities on coping styles. However, it also raises some intriguing questions, such as the inverse relationship between caregiving hours and emotion-focused coping. Future research should delve deeper into these areas to provide a more comprehensive understanding of caregiver coping strategies in the context of cancer care.

Limitations

This study has several limitations that need to be considered. First, due to the cross-sectional nature of the study, it was not examined whether the relationships are a result of reciprocity or causality. Longitudinal studies can be conducted to overcome this limitation. Secondly, potential selection bias could have occurred due to the convenience sampling technique utilized, which could affect the generalizability of the study results. In addition, this is a hospital-based study, therefore, the following findings might not be representative of all caregivers of patients with cancer in India. Further studies can be conducted to explore any possible changes in the coping styles of caregivers of patients with cancer throughout the cancer treatment journey.

Conclusions

Caregiver of cancer patients are mostly their blood relatives or close family members. A positive or negative coping strategy adopted by these caregivers is influenced by gender, marital and educational status, type of family and number of caregivers, duration of cancer, and treatment modality. Utilizing positive coping strategies by caregivers will not only enhance their quality of life but will even improve the caregiving of their diseased relatives. With the rapid urbanization and societal shift in family structures, healthcare facilities should focus on these burnt-out caregivers for their improved physical and mental health, thereby improving the quality of life of their cancer-diagnosed relatives.

Article information and declarations

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Data availability statement

Data can be made available upon reasonable request from the corresponding author with a data access agreement and with the permission of the participating hospital.

Ethics statement

The study was approved by the Institute (ESIC Medical College and Hospital, Faridabad, Haryana, India) ethics committee vide letter no: EC File No: 134 X/11/13/ /2023-IEC/DHR/67. Study participants were provided with a patient information sheet (PIS) in bilingual (Hindi and English) format. A written informed consent was obtained in the informed consent form (ICF) from the study participants with the option to withdraw from the study at any time without giving any reasons thereof. All the details pertaining to the study participants were kept confidential.

Author contributions

SS, PG, and HD formulated the research question and designed the study. MS and AY developed the study methods. HD, Ks, and ST supervised and monitored the study implementation. MS and SS did the statistical analysis. SS, PG, and HD interpreted the findings. HD and SS developed the first draft. All authors had full access to the data and reviewed and approved the final manuscript.

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Conflict of interest

The authors declare no conflict of interest.

Supplementary material

None.

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The mental health of family caregivers: do the complementary roles of personality trait, social support, and resilience matter?

Abstract

Background: Caregivers form an integral informal workforce that is usually overlooked, undervalued, and faces challenges such as maintaining optimal well-being and caring roles. This present study investigated the roles of personality, social support, and resilience in the mental health of family caregivers.

Participants and methods: The study based on self-report measures of the Big Five Personality Inventory, Social Support Scale, Resilience Scale, and General Health Questionnaire adopted a descriptive cross-sectional design. The participants in the study were 250 caregivers. Hierarchical multiple regression was used for data analysis.

Results: Results showed that the dimensions of the big five personality traits neuroticism ($\beta = -0.15$, $p < 0.05$), extraversion ($\beta = 0.16$, $p < 0.05$), openness to experience ($\beta = 0.17$, $p < 0.05$), conscientiousness ($\beta = 0.15$, $p < 0.05$) and agreeableness ($\beta = 0.13$, $p < 0.05$) significantly associated with family caregivers' mental health. In addition, social support ($\beta = 0.13$, $p < 0.05$) and resilience ($\beta = 0.13$, $p < 0.05$) were positively associated with the mental health of caregivers.

Conclusions: Families, providers of health care, hospital management, and policymakers in the health care sector should take cognizance of these endogenous and exogenous factors (*e.g.*, social support, personality traits, and resilience) in the development of intervention and support services for both existing and potential health caregivers. This is pertinent since their mental health is dependent on the positive correlation among these variables of interest.

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Introduction

Caregivers are becoming increasingly common as populations age in various regions of the world and ailments increase, with less attention given to such needs [1]. This is because caregivers form an integral part of the healthcare system in the informal workforce [2]. The concept of caregiving revolves around providing support, assistance, and care to individuals who are unable to fully care for themselves due to various reasons such as age, illness, disability, or other challenges [3]. Caregiving encompasses a wide range of activities and responsibilities, and it is often driven by a sense of responsibility, compassion, and empathy for those in need [4]. Caregiving refers to any sort of direct care, including labor done by paid and unpaid workers such as nurses, social workers, family members, significant others, and counselors [5]. Caregivers are individuals who provide various forms of support, assistance and care to people who are unable to fully care for themselves due to age, illness, disability, or other challenges. Caregiving can encompass a wide range of tasks and responsibilities, and caregivers can be family members, friends, or hired professionals. However, the emphasis in the present study is on family caregivers rather than professional caregivers. Family caregivers provide direct unpaid care to their family members because they are emotionally invested in the act of caregiving obligation as a result of the bond they share with the significant person [6]. Corollary, family caregivers perform a variety of tasks such as personal care, medical care, emotional support, household management, mobility assistance, and advocacy depending on the needs of the person they are rendering caring for [7]. In essence, family caregiving embodies the idea of offering help and support to family individuals who require assistance due to their unique circumstances [8]. It is a fundamental aspect of human compassion and interconnectedness, aiming to improve the well-being and dignity of family members who need care. Thus, family caregivers play an indispensable role in society, offering crucial support to those in need. Interestingly, the rapid increase in caring obligation has made informal caregivers critical stakeholders in the sustainability of social protection, healthcare, and the well-being of the care recipients [9]. This is pertinent because informal caregivers (family members), play a vital and distinctive role in providing care assistance.

Invariably, there is an urgent quest for studies on family caregiving among developing nations. For instance, in Nigeria, more than two-thirds of the population provides solicited and unpaid support to their sick ones [6], which shows that informal caregivers need support. Family caregivers are overlooked and undervalued in Nigeria due to the notion that it is culturally assumed that the family would care for their sick ones [6, 10]. This is pertinent because Nigerian culture has characteristics that are akin to influence caregiving and its attendant consequences. For instance, most of the tribes in Nigeria have norms or values that family members should provide unpaid caregiving common to their family members who are in need [11]. This is in contrast to what is obtained in Western societies, where caregivers have a right to “have a life” and are honored for their work [12]. In addition, family caregivers in Nigeria experience difficult role demands due to the huge stress related to caregiving because of a lack of infrastructure, manpower, unsupportive government policies, and limited resources [13]. This leads to poor mental health, depression, and anxiety caused by limited resources, lack of governmental support, and the individualistic nature of the Nigerian society, where every household takes care of its concerns [14]. Thus, to maintain optimal mental health among family caregivers, they must synchronize their caring obligations with their work, resources, physical and emotional health, and overall quality of life [15]. This is pertinent because effective service delivery among family caregivers is dependent on their mental health.

Furthermore, mental health plays a significant and interconnected role in caregiving, both for the care recipients and the family caregivers [16]. Mental health refers to a person’s emotional, psychological, and social well-being [17]. It encompasses various aspects of an individual’s life, including their thoughts, feelings, behaviors, and the quality of their relationships. Mental health is a crucial component of overall health and can significantly affect a person’s ability to lead a fulfilling and productive life. Its multifaceted nature encompasses the emotional, psychological, and social well-being of an individual, which is essential for overall health and quality of life. Thus, the challenges and demands of caregiving such as caregivers’ mental health (*e.g.*, emotional well-being, cognitive impairment, isolation and loneliness, stress and burnout, depression and anxiety, social isolation, guilt and self-neglect can affect the mental well-being of both the caregiver and care recipients [18]. However, raising awareness about the mental health challenges family caregivers face is critical because they are the key stakeholders in the healthcare journey of caring obligation [19]. This is pertinent because caregivers deserve recognition, understanding, and comprehensive support as they navigate the intricate balance between caregiving and mental health [20]. Nonetheless, there is a dearth of research in the body of literature that may be used to drive evidence-based planning for understanding the psychological, social, and personal elements that influence the mental health of family caregivers, especially in a neglected context like sub-Saharan Africa (*e.g.*, Nigeria).

Studies [17, 20] have shown the precipitating factors that influence and contribute to caregivers' mental health. However, these prior studies [*e.g.*, 13, 17, 20] have shown the correlation between social support and mental health, resilience and mental health, and personality and mental health, all in isolated situations and contexts with regard to Western culture and societies, with greater emphasis on professional caregivers rather than family caregivers [5, 17]. However, the roles of personality traits (big five), social support, and resilience in influencing the mental health of family caregivers remain understudied, especially in a neglected context like Sub-Saharan Africa (*e.g.*, Nigeria). Thus, the current research aimed to examine the unique complimentary roles and contributions of personality traits (big five), social support, and resilience in fostering mental health among family caregivers in this neglected context. To achieve this, the present study answers the calls of previous researchers [4, 9] on the need for cross-cultural validation and transportation of findings to diverse contexts. Based on this premise, the researchers examined the relationships between resilience, social support, and personality traits on the mental health of family caregivers with particular emphasis on the neglected context of sub-Saharan Africa, using Nigeria as a reference point.

Literature review

Personality trait and mental health

Personality and mental health are closely intertwined, with certain personality traits influencing an individual's susceptibility to mental health challenges and their ability to cope with stressors [21]. Personality refers to enduring patterns of thoughts, emotions, and behaviors that shape how an individual perceives and interacts with the world [22]. These traits remain relatively consistent over time and across various situations, shaping an individual's behavior, reactions, and preferences. Furthermore, the interaction between personality traits and mental health can be complex and dynamic, whilst certain traits may predispose individuals to specific mental health vulnerabilities, they can also be leveraged as strengths to promote well-being [23]. Understanding these connections can aid in early intervention, personalized treatment, and the development of coping strategies tailored to an individual's personality profile. Thus, certain personality traits can affect how family caregivers perceive and respond to their caregiving responsibilities, which may have a subsequent impact on their mental health. These personality traits include; neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness [24]. Neuroticism refers to the tendency to experience negative emotions such as anxiety, depression, and mood swings). Individuals high in neuroticism are more likely to be sensitive to stressors and experience emotional instability leading to poor mental health. Extraversion on its part encompasses qualities like sociability, assertiveness, and positive emotions [25]. Extraverted individuals tend to be outgoing, energetic, and enthusiastic in social situations. Extant studies [*e.g.*, 26] have evidenced that extraversion can act as a protective factor against certain mental health issues because of their larger social networks, which can provide emotional support and buffering against stress. Openness to experience refers to an individual's inclination toward creativity, curiosity, and appreciation for new experiences [27]. People high in openness are imaginative, open-minded, and receptive to unconventional ideas. Whilst openness itself is not directly linked to mental health, individuals high in this trait may be more open to seeking and engaging in human interaction. Agreeableness involves characteristics like kindness, empathy, and cooperation. Those high in agreeableness are considerate of others' feelings and tend to avoid conflict [28, 29]. Even though agreeableness generally contributes to positive social interactions, extremely high levels may lead to difficulties in asserting personal boundaries, potentially affecting mental well-being. The fifth trait, which is Conscientiousness, encompasses traits like organization, self-discipline, and goal-oriented behavior. Thus, conscientious individuals are responsible, dependable, and focused, with better mental health outcomes. People high in conscientiousness tend to engage in healthy behaviors, adhere to treatment plans, and effectively manage stress. These traits may help family caregivers manage their caregiving roles efficiently and reduce the likelihood of feeling overwhelmed or burned out.

Social support and mental health

Another pertinent factor that affects family caregivers' mental health is the level of perceived social support they enjoy. Social support refers to the assistance, comfort, empathy, and resources provided by one's social network of friends, family, peers, and community members [30]. It encompasses various forms of emotional, instrumental (practical assistance, such as help with caregiving tasks or access to community resources, which can alleviate the burden on caregivers and positively impact their mental health) informational (receiving guidance, advice, and information related to caregiving that can empower caregivers and reduce uncertainty), and companionship support that individuals receive during times of need or in daily life [31]. Family caregivers who have access to emotional support from family, friends, support groups, or healthcare professionals may experience reduced levels of stress, depression, and anxiety [32]. Furthermore, Shiba et al. [33] and Kort-Butler [34] asserted that social support from significant figures increases pro-active health-related behaviors among individuals. This is pertinent since human beings are inherently social creatures, and interactions with others have a profound impact on psychological, emotional, and even physical health. Extant studies have shown a strong link between close relationships, the quality of relationship experience, and mental well-being [35, 36]. Previous studies [30, 32] have suggested that social support contributes to a higher quality of life, meaningful connections, and interactions, which enrich daily experiences and provide a sense of purpose and fulfillment. Thus, seeking support from friends, family, and support groups is essential in reducing the vulnerability of family caregiver's mental health. This is pertinent because family caregivers with strong social support networks often experience lower levels of stress, depression, and anxiety. This is because the demands of providing care can affect caregivers' well-being. Thus, social support provides a safe space for family caregivers to express their emotions, receive validation, and gain emotional resilience through friends, family, and support groups; thereby improving family caregivers' mental health [35].

Resilience and mental health

Furthermore, to maintain optimal mental health among family caregivers, resilience should be construed among caregivers. Resilience is the psychological and emotional capacity to adapt, bounce back, and thrive in the face of adversity, challenges, and significant life stressors [37]. It is the ability to maintain mental and emotional well-being despite encountering difficult situations. Resilience involves a combination of personal traits, coping strategies, and external supports such as adaptability, positive mindset, problem-solving, self-efficacy, emotional regulation, and coping strategies that help individuals navigate and overcome setbacks and hardships [38]. Caregiving can be emotionally and physically demanding, leading to increased risks of mental health challenges for caregivers. Thus, resilience acts as a protective factor, enabling family caregivers to adapt, cope, and maintain their mental health in the face of these challenges. This is evidenced in Block and Block's [39] model of ego control and ego resilience theory, which suggests that integrating the recognized dynamics of healthy attachments such as permeability and elasticity, facilitates individual well-being. Thus, resilient individuals often possess characteristics such as optimism, problem-solving skills, flexibility, and the ability to seek support when needed [40]. Past studies [*e.g.*, 41] have demonstrated that a variety of factors, including individual variations (such as personal strengths), environmental elements (such as social support), and life experiences, can contribute to mental health. In other words, these elements increase people's capacity to adapt to and successfully handle difficulties in the face of adversity or stressful circumstances. Hence, in the demanding role of family caregiving, resilience acts as a buffer in reducing the risk of mental health issues such as depression, anxiety, and burnout.

However, the findings of the present study have vital implications for family caregivers and recipients of family caregiving since the study findings provide a vital framework and springboard into the inherent factors that influence and contribute to the mental health of family caregivers. Thus, the current study was guided by the following hypotheses:

- H1: Personality traits (extroversion, neuroticism, openness to experience, agreeableness, and conscientiousness) significantly associates with the mental health of family caregivers;
- H2: Social support is significantly associated with the mental health of family caregivers;
- H3: Resilience is significantly associated with the mental health of family caregivers.

Figure 1 gives a summative expression of the expected associations among personality traits, social support, and resilience on the mental health of family caregivers.

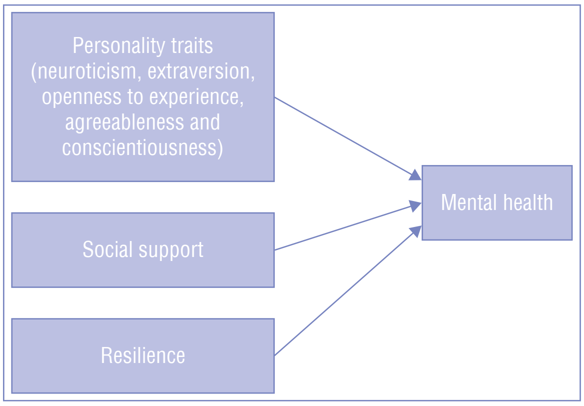

Figure 1. The hypothetical model of study the variables

Participants and methods

Study design

The present study was a descriptive cross-sectional design conducted in Nigeria in 2023. The STROBE guidelines for reporting observational studies were strictly followed.

Participants and setting

The participants for the study were 250 family caregivers comprising 147 (58.8%) males and 103 (41.2%) females drawn from different federal government-owned hospitals in Southeast Nigeria. The federal government owed hospitals were chosen because of their specialized nature and wider coverage in terms of infrastructure, staff, specialty, and human resources. The sample size was calculated with a 5% margin error, a 95% confidence interval, and an estimated sampling population of 405 both in and outpatients enlisted as patients in the hospital under study, with attendant family caregivers. The recommended minimum sample size using the Raosoft online sample calculator [42] was 198 participants. Thus, the sample size utilized in the study was above the threshold level. The age of the participants ranged from 18–60 years (mean age = 33.42; SD = 11.06). With respect to marital status, 108 (43.2%) were married, while 142 (56.8%) of the participants were single. For the participants' educational qualifications, the majority of the participants, 119 (47.6%) have WACE/GCE, 79 (31.6%) have degrees, and 52 (20.8%) have FSLC. The inclusion criteria include: both married and unmarried male and female family caregivers (age between 18–60 years); with at least primary education and must be a primary caregiver to a particular patient at the hospital or home and not just a person who visited the patient. Exclusion criteria include caregivers above 60 years, without any educational qualification, and not a primary caregiver to a particular patient.

Measures

Four instruments were used in the present study namely the Big Five Personality Inventory, Social Support Scale, Resilience Scale, and General Health Questionnaire.

Big Five — personality inventory

A 44-item Big Five Inventory developed by John and Srivastava [43] was used to assess the five-dimensional perspectives of personality — openness, conscientiousness, extroversion, agreeableness, and neuroticism. It was developed to represent a prototype definition of an observer's personality ratings to allow efficient and flexible assessment of the five personality dimensions. Sample items include; "someone who has an active imagination" (openness to experience), "someone who tends to be lazy" (conscientiousness), "I see myself as someone talkative" (extraversion), "someone who has a forgiving nature" (agreeableness), and "someone who can be moody" (neuroticism). Openness to experience has 10 items; conscientiousness — 9-items; extraversion — 8-items; agreeableness — 9-items and neuroticism — 8-items. The response format is scored on a 5-point Likert format ranging from 1 "strongly disagree" to 5 "strongly agree". Items scored directly were responded to in the scoring range of 1–5 and reverse items scored in the range of 5–1. A high score indicates a high personality trait on the spectrum. John and Srivastava [43] obtained a Cronbach alpha of 0.90 for extroversion and agreeableness, while 0.92 were reported for conscientiousness, neuroticism, and openness to experience, and an overall score of 0.75. The researchers reported an overall Cronbach alpha coefficient of 0.79 and internal consistency reliabilities of the sub-scales ranged from 0.79 (neuroticism), 0.81 (extraversion), 0.71 (conscientiousness), 0.72 (openness to experience) and 0.75 (agreeableness) respectively. The scale has been validated and used in a similar context with acceptable reliability [44].

Multidimensional Scale of Perceived Social Support

The scale was developed by Zimet et al. [45] to measure perceived social support across cultures among adults. The Multidimensional Scale of Perceived Social Support (MSPSS) provides an assessment of three sources of support: family support, friends support, and significant others' support. It is scored on a 7-point Likert-type scale, ranging from (1) "strongly disagree" to (7) "strongly agree". Sample items include "I get the emotional help and support I need from my family", "I can count on my friends when things go wrong", and "There is a special person who is around when am in need". Zimet et al. [45] reported a Cronbach's alpha of 0.91, 0.87, and 0.85 for family, friends, and significant others' support respectively, and 0.85 as the reliability value of the total score. Zimet et al. [45] asserted that the scale can be used as a single construct, as used in the present study. The scale has been used in a similar study and context as a single construct with an acceptable reliability coefficient [46]. The present study reported α 0.74.

Resilience scale

This is a 14-item scale developed by Wagnild and Young [47] to measure the capacity to withstand life stressors in a bid to thrive and make meaning from life's challenges. The items of the Resilience scale (R-14) are scored using a 7-point response format ranging from 1 "strongly disagree" to 7 "strongly Agree". Sample items include; "I usually take things in stride", and "my life has a meaning". A higher score on the RS-14 scale indicates more resilient characteristics. Wagnild and Young [47] reported a Cronbach's alpha coefficient of 0.83. In the present study, the researchers reported a reliability coefficient of 0.83. The scale has been validated and used in a similar context with acceptable reliability [48].

Positive Mental Health Scale

The Positive Mental Health Scale (PMH-Scale) developed by Lukat [49] was used to assess the mental health of family caregivers. It is a 9-item standardized self-administered screening test to measure mental health. The items in the instrument are scored on a 4-point response format ranging from 1 (not true) to 4 (true). Sample items include "I am in good physical and emotional condition", and "I am a calm and balanced human being". A higher score indicates high mental health. Lukat [49] reported a Cronbach alpha coefficient of 0.93. The researchers reported a Cronbach alpha coefficient of 0.89 in the current study. The scale has been validated and used in a similar context with acceptable reliability [50].

Data collection

The study was conducted between August and November 2023. Participants were met in the in- and outpatients wards. The researchers established rapport with the participants by introducing themselves (with the trained research assistants who were nurses in the hospitals used in the study) and explained the purposes of the research before seeking their participatory consent. The participants were expected to indicate their participatory consent by ticking the consent box in the questionnaire. All participants were duly informed that their participation was voluntary and that their data would remain confidential, which is ensured by the non-inclusion of any means of identification. Those who consented to participate in the study were asked to fill the copies of the questionnaire. The questionnaire could be completed between seven to fifteen minutes. The copies of the questionnaire that were filled immediately were collected back, while those copies of the questionnaire not filled immediately were collected subsequently after they were administered, especially for participants who were not disposed to give immediate attention to the questionnaire. The data collection lasted barely four months. After completion and collection, properly filled copies of the questionnaire were used for data analysis. Two hundred and seventy-seven copies of the questionnaire were returned, twenty-seven were discarded as a result of improper completion while two hundred and fifty (250) valid copies were used for data analysis, yielding a valid response rate of 87.1%, out of two hundred and eighty-seven (287) copies of the questionnaire that were initially distributed.

Ethical considerations

Approval for the study was granted by the Ethical Committee Board, Department of Psychology, University of Nigeria, Nsukka (D.PSY.UNN/REC/2023-07--1RB000021). Informed consent was obtained from the participants. All the ethical standards according to the Helsinki Declaration of 1975, as revised in 2000 (5) concerning human experimentation (institutional and national), were followed.

Statistical analysis

Pearson's correlation (r) was conducted to test the relationship among the study variables while hierarchical multiple regression analysis was used for data analysis. Mendenhall et al. [51] posited that hierarchical multiple regression analysis allows researchers to concurrently use several independent (or predictor) variables. By using more than one independent variable, one should do a better job of explaining the variation in the criterion (dependent variable) and hence be able to make more accurate predictions. Hence, hierarchical multiple regression was used to test the hypotheses.

Results

In Table 1, some variables were added as control over the criterion variables. Invariably none of the control variables correlated with mental health. The addition of personality dimensions directly below the control variable in the statistical equation showed that extraversion ($r = 0.27$, $p < 0.01$), openness ($r = 0.28$, $p < 0.01$), and agreeableness ($r = 0.24$, $p < 0.01$) positively correlated with mental health. Conscientiousness did not correlate with mental health whereas neuroticism was negatively associated with mental health ($r = -0.11$, $p < 0.05$). Social support also correlated positively with mental health ($r = 0.14$, $p < 0.05$). Resilience was also found to correlate positively with mental health ($r = 0.12$, $p < 0.05$).

In Table 2, step 1, personality traits, extraversion ($\beta = 0.16$, $p < 0.05$), openness ($\beta = 0.17$, $p < 0.05$), consciousness ($\beta = 0.15$, $p < 0.05$), and agreeableness ($\beta = 0.13$, $p < 0.05$) respectively associated positively with mental health. This implies that an increase in

Table 1. Correlations matrix among demographic factors and the study variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Gender	–																
2. Maritalstatus	0.20	–															
3. Age	0.06	0.69	–														
4. Educational qualification	0.08	0.52	0.49	–													
5. Employment status	−0.07	−0.61	−0.55	−0.41	–												
6. Extraversion	0.02	0.11	0.02	0.04	−0.01	0.023	0.01	−0.01	−0.11	–							
7. Openness	0.02	0.003	−0.01	0.05	0.05	0.06	0.02	−0.06	−0.06	0.68**	–						
8. Neuroticism	0.00	0.14*	0.03	0.07	−0.05	−0.03	−0.08	−0.06	−0.09	0.11*	0.09	–					
9. Conscientiousness	0.06	0.09	0.09	0.04	−0.08	0.06	−0.10	−0.08	−0.04	−0.20**	−0.24**	−0.08	–				
10. Agreeableness	−0.01	0.05	0.01	0.05	−0.01	0.05	−0.011	0.01	−0.02	0.35**	0.37**	0.12	−0.03	–			
11. Social support	0.01	−0.04	0.05	−0.08	0.07	−0.16**	−0.12*	−0.09	−0.01	−0.03	−0.01	−0.14*	0.11	0.03	–		
12. Resilience	−0.02	−0.01	0.05	−0.02	−0.03	−0.02	−0.06	−0.10	−0.09	−0.05	−0.16**	−0.02	0.05	−0.02	0.18**	–	
13. Mental health	−0.01	0.01	−0.02	−0.03	−0.05	0.12*	0.04	−0.01	0.07	0.27**	0.28**	−0.11*	0.09	0.24**	0.14*	0.12*	–

**$p < 0.01$; *$p \leq 0.05$; gender (0 = male, 1 = female); educational qualification: 1 — FSLC, 2 — WACE/SSCE, 3 — degree

these traits leads to the experience of positive mental health among family caregivers, whereas neuroticism is negatively associated with mental health ($\beta = -0.15$, $p < 0.05$). This shows that there is an inverse relationship between this trait and mental health, implying that neuroticism leads to decreased mental health among family caregivers. Thus, hypothesis 1 was supported. The result also indicates that personality traits contributed 15% variance in mental health.

Social support when added in step 2 of the equation positively associated with mental health ($\beta = 0.13$, $p < 0.05$); thus, hypothesis 2 was supported. This shows that an increase in social support experienced by family caregivers leads to an increase in their mental health. Social support contributed 16% variance in mental health.

Resilience when added in step 3 of the equation positively associated with mental health ($\beta = 0.13$, $p < 0.05$); thus, hypothesis 3 was supported. This implies that an experience of increase in resilience among family caregivers invariably increases their mental health. The contribution of resilience in explaining variance in mental health was 17%.

Discussion

This study investigated the roles of the big five personality traits, social support, and resilience on the mental health of family caregivers. In other words, the researcher explored first, whether each dimension of the big five personality traits (neuroticism, extraversion, agreeableness, conscientiousness, and openness to experience) were associated with mental health; second, whether social support was associated with mental health and third, whether resilience was associated with mental health of family caregivers.

The findings of the study showed that personality traits (extraversion, conscientiousness, openness to experience, agreeableness, and neuroticism) were significantly associated with the mental health of family caregivers, thus hypothesis 1 was supported, which states that personality traits (extraversion, conscientiousness, openness to experience, agreeableness, and neuroticism) significantly associates with the mental health of family caregivers. Thus, the findings of the study showed that personality traits (extraversion) were positively and significantly associated with the mental health of family caregivers. This finding is consistent with previous findings [25, 26], which revealed that extraversion was positively associated with mental health. This is pertinent because extraversion is characterized by high levels of activity, sociability, and a greater tendency to experience positive outcomes [16].

Table 2. Hierarchical multiple regression of personality, social support and resilience as predictors of mental health

Variable Predictors	Step 1		Step 2		Step 3	
	β	t	β	t	β	t
Extraversion	0.16	2.17^*	0.16	2.27^*	0.15	2.07^*
Openness	0.17	2.22^*	0.15	2.11^*	0.19	2.55^*
Neuroticism	−0.15	-2.83^*	−0.13	-2.48^*	−0.13	-2.52^*
Conscientiousness	0.15	2.75^*	0.14	2.47^*	0.13	2.52^*
Agreeableness	0.14	2.38^*	0.13	2.29^*	0.12	2.25^*
Social support			0.13	2.45^*	0.11	1.97^*
Resilience				0.13	2.45^*	
Adjusted R^2	0.15		0.16		0.17	
ΔR^2	0.15		0.02		0.02	
ΔF	10.88^{**}		6.01^*		6.03^*	

* $p < 0.05$; ** $p < 0.01$; β — beta coefficient; t — t-statistic

In addition, highly extroverted individuals appear to have better perception and orientation to mental health, lower rate of depression, and negative emotion. Equally, Rastami et al. [26] postulated that individuals with extraversion traits are more prone to adaptive coping strategies, lower burden and stress, and better mental and physical health due to their disposition towards life orientation. Thus, it could be affirmed that family caregivers with such personality disposition maintain a sense of their own well-being through social relationships, and involvement in activities that have the potential of enhancing their self-worth, which aids in managing psychological tension [37].

In addition, the personality trait of openness to experience was positively associated with the mental health of caregivers. The result agrees with the findings of Löckenhoff et al. [27], which showed that openness to experience is a positive indicator of mental health. This is pertinent because greater mental flexibility of open-minded individuals facilitates adjustment to novel situations and thus, promotes cognitive, emotional, and physical well-being. Thus, it could be affirmed that family caregivers with traits of openness to experience exhibit greater in-depth knowledge and complexity to mental life experiences, coupled with their willingness to explore novel things and ability to think widely amid challenges. This gives them a wider perspective in handling work-role demands with undue pressure on their mental health.

In the same vein, neuroticism was negatively associated with family caregivers' mental health. This aligns with extant studies [52], which found that neuroticism is negatively associated with negative emotions and feeling easily overwhelmed by stressful experiences that affect mental health. Thus, increased vulnerability of stressors among family neurotic caregivers may have grave deleterious effects on such individuals' hassles of daily life as a result of their caregiving obligations. Hence, it could be affirmed that family caregivers with neurotic traits of personality are associated with greater sensitivity to caregiving-related stressors, burden and distress, maladaptive coping strategy, worse physical and subjective mental health, and fewer health-promoting behaviors [53].

Conscientiousness equally has a positive association with the mental health of family caregivers. Previous studies [54, 55] have evidenced that conscientiousness is linked to greater health-promoting behaviors, better subjective and objective health, lower risk of mortality, and cognitive impairment because they are highly disciplined and organized. In addition, highly conscientious caregivers report a sense of competence and confidence, which is a recipe for better mental health. Lewis and Cardwell [56] asserted that caregivers with conscientiousness personality traits have a better relationship with the care recipient because of their adaptive coping strategy and high level of organization and confidence in the face of challenges.

In the same vein, agreeableness is positively associated with family caregivers' mental health. The finding aligned with Day et al. [29] and Rastami et al. [26] studies, which found a significant positive relationship between agreeableness and mental health. These studies evidenced that people with higher levels of agreeableness exhibit higher levels of mental well-being. It could be contended that family caregivers with agreeableness trait of personality tend to have more positive reassessment in different situations which facilitates effective coping skills and strategy, thereby giving them greater control over life; which in turn expands their interaction and quality of life with increased positive mental health [28]. Furthermore, self-determination theory [57] gives credence to the direction of the results on personality traits. The theory is based on the premise that people have natural inclinations towards growth and actively seek to control their environment and interactions by integrating novel experiences into their sense of being, based on their individual dispositions. To achieve this, different orientations in individual personality traits (causality orientation model) affect their response to environmental stimuli and influence the impact of such stimuli on their behavioral response patterns in terms of decision-making and behavior regulation. However, family caregivers' ability to maintain optimal health through satisfaction of their needs and carrying out their work-role demands is dependent on the combination of internal, external, and contextual factors. Thus, it could be argued that family caregivers' ability to maintain optimal mental health is dependent on their ability to navigate through the internal, external, and contextual factors in their job context; based on their varied causality of orientations model (personality traits) developed through active environmental control, interactions and integration of novel experiences.

Furthermore, there was a strong positive association between social support and the mental health of family caregivers; thus, hypothesis 2 was supported, which states that social support is significantly associated with the mental health of family caregivers. This implies that an increase in perceived social support received by family caregivers invariably enhances their mental health. Social support is fundamental in caregiving because caregiving has been considered a prototypic example of negative health and a consequence of chronic stress [58]; where a caregiver is sometimes described as the hidden patient. Based on the premise that there is considerable variability in individual experiences with regard to unequal risk for adverse health outcomes among caregivers; promoting resources such as social support is imperative among caregivers. The finding agreed with previous studies [*e.g.*, 35], which suggest that mental health is dependent on the correlation between psychosocial factors or characteristics (*e.g.*, social support) and contextual factors. However, family caregivers who have access to perceived social support when needed exhibit a higher level of emotional stability and satisfaction and are responsive to environmental and contextual challenges. Equally, family caregivers with social support believe that they are loved and cared for, esteemed and valued which shows that the quality of social relationships is dependent on one's mental health [37]. In addition, it could be argued that social support experienced by family caregivers facilitates a higher quality of life and adaptation of specific coping skills that serve to maintain emotional stability and function, with less report of distress [33]. Equally, this finding supports the tenets of social support theory [34], which centers on the analogy that instrumental, informational, and emotional support from significant figures increases pro-active health-related behaviors among individuals. This is pertinent because social support reduces negative emotions, stress, and mental health-related issues with prompt and apt responsiveness to contextual and environmental challenges [30]. Corollary, social support facilitates caregivers' health status, health behaviors, and use of health services. Thus, family caregivers with perceived supportive societies and supportive relationships experience positive health-related behaviors that improve their mental health.

Corollary, resilience was significantly and positively associated with family caregivers' mental health; thus, hypothesis 3 was supported, which states that resilience is significantly associated with the mental health of family caregivers. This is in agreement with previous studies [38, 39], which revealed that individuals with higher resilience reported fewer instances of mental health-related issues because resilience strengthens positive indicators of mental health while attenuating the negative ones. The finding can be explained by a salutogenic model of resilience [40], which looks beyond the whole idea of risk exposure as a pre-requisite for being tagged "resilient" and rather emphasizes factors that contribute to health and well-being such as coherence and resistance. The model focuses on coping resources that could contribute to resilience and adjustment, notwithstanding adversities and risk. More so, family caregivers with attributes of resilience can navigate their way to the psychological, social, cultural, and physical resources that sustain their well-being due to their coping skills [38]. Therefore, resilience promotes succor and adequate coping under threats of various health-related stressors. Thus, maintaining higher resilience levels among caregivers is of great importance in keeping them protected from mental health-related problems [38].

This finding supports the tenets of Block and Block's [39] model of ego control and ego resilience, which suggests that integrating the recognized dynamics of healthy attachments such as permeability and elasticity facilitates individual well-being. This portrays that resilience is instrumental in effective resourceful adaptation to transition, change, conflict, and growth. Thus, family caregivers with resilience prototypes are associated with prosocial and self-regulatory behaviors [40], which encourage greater cognitive flexibility, increased engagement, goal-directed activities, and optimal mental health. In addition, Biswas et al. [38] posited that elements of human dynamics such as tenacity, decisiveness, self-control, innovativeness, optimism, honesty, and integrity are apt in the ability to cope, learn, and grow from different situations. Hence, it could be argued that caregivers with such resilient attributes tend to maintain optimal mental health irrespective of the challenging work demands they encounter; since they can adapt effectively in the face of life adversities.

Implications of the findings

The present research has some practical implications for practice. First, the findings showed that personality, social support, and resilience influence mental health, especially the family caregivers; thus, highlighting the need for personality assessment, social cohesion, fusion, and integration of family caregivers at the beginning of the caregiving relationship. This is pertinent because empirical evidence has shown that personality trait as an underlying factor is an important predictor of mental health. Corollary, personality assessment will aid in developing and designing supportive services and programs that will enhance family caregivers' psychological, emotional, and health needs, needed for caregiving relationships and outcomes.

In addition, families and management of healthcare providers should take cognizance of the importance of social support services in the healthcare delivery system. Evidence has shown that the caregivers' mental health is dependent on the level of perceived social support received by them in the discharge of their duties.

Furthermore, caregivers should be enlightened on the techniques to build resilience (*e.g.*, perseverance, self-control, interpersonal connectedness, innovativeness) for coping ability from different experiences due to the nature and dynamics of their work-role demands. This is imperative because the maintenance of relatively stable, healthy levels of psychological and physical functioning and the ability to generate new experiences and positive emotions is required over time among the caregivers, in order to achieve optimal mental health. These ideals can be achieved through familial support, collegial support, self-care, and growth experience.

Empirically, this research has added to the literature on mental health among caregivers in the neglected African context. Based on the review of the literature, this present study appears to be one of the first attempts to empirically test the big five personality traits (neuroticism, extraversion, conscientiousness, openness to experience, and agreeableness) on mental health among family caregivers in Africa context *vis-à-vis* social support and resilience. Thus, the study has opened future research areas in this direction.

Limitations of the study

Although the methodology deals adequately with the manifest variables, critical latent variables cannot be suitably accounted for by the use of a purely quantitative approach; due to the complex and multi-faceted nature of personality. Thus, a deeper understanding of the roles of personality, social support, resilience, and mental health can be attained using both quantitative and qualitative approaches. Thus, the mixed-method approach in investigating mental health among informal caregivers is worthwhile and should be considered by future researchers. In addition, the present study is based on self-reported data. This may be prone to the risk of social desirability responses, even though the possible problem of common error bias was reduced through confidentiality and anonymity in participants' responses.

Conclusions

The findings suggest that personality traits (neuroticism, conscientiousness, extraversion, openness to experience, and agreeableness), have a diverse influence on caregivers' mental health. Thus, the imperativeness of these personality attributes to the well-being of caregivers is *sine-qua-non* in treatment outcomes among recipients of caregiving. Equally, the finding illuminated the importance of social support as being pivotal in caregivers' maintenance of optimal mental health. This is pertinent since the quality of social relationships is dependent on one's mental health, since it facilitates positive social communication and support, reduces anxiety and depression, and develops the feeling of self-worth and security.

Furthermore, the findings revealed that resilience is an effective mechanism for the resourceful adaptation to transitions of life challenges in the discharge of work-role demands by family caregivers. This is pertinent because the elements of resilience akin to human dynamics such as tenacity, decisiveness, honesty and integrity, self-control, innovativeness, and optimism; strengthen positive indicators of mental health and buffer their general well-being. Designing intervention and support services for caregivers who may be susceptible to poor mental health will provide an avenue for such caregivers to adapt, improve treatment outcomes of the recipient of caregiving, and actualize their career goals.

In sum, the researchers suggested that people are susceptible to poor mental health, due to the absence of social support, resilience, and variation in personality traits. Therefore, in light of the present findings, personality, social support, and resilience may have a protective effect on the psychological, physical, and physiological state of the family caregivers in the course of discharging their work roles. Thus, having a nuanced understanding of these constructs will help caregivers improve problem-solving management, and acquire coping strategies and life skills needed to reduce emotional burdens associated with caregiving in order to maintain optimal mental health.

Article information and declarations

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Data availability statement

The datasets generated and analyzed during the current study will be available from the corresponding author upon reasonable request.

Ethics statement

Ethical approval No D.PSY.UNN/REC/2023-07--1RB000021. All procedures followed were under the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5).

Author contributions

Conceptualization, project administration, supervision, resources, methodology, and writing of the original draft, review, and editing — OOI; conceptualization, methodology, draft, formal analysis, software, validation, review, and editing — IJN; methodology, draft, formal analysis, project administration, supervision, resources — PCA.

Conflict of interest

The authors declare no known conflicts of interest.

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Supplementary material

None.

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Original article

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Attitudes towards death among the nursing staff in oncology departments and hospices

Abstract

Background: Attitude towards death is the way people perceive the process of dying, as well as related emotions, moods, and one's own assessment of death. The attitude towards life transience, particularly among the nursing staff dealing with terminally ill patients in their daily practice, is of key importance for the way of perceiving the purposefulness and validity of their work. This study aimed to analyze attitudes towards death among the nursing staff in hospices and oncology departments.

Participants and methods: Overall, 159 members of the nursing staff in stationary hospices and oncology departments participated in the study. The Death Attitude Profile-Revised (DAP-R) was used to collect research material. A statistical analysis of the findings was conducted using the Student's t-test, ANOVA, Mann–Whitney U test, and the Kruskal–Wallis test.

Results: The median (Me) results for the particular dimensions were as follows: approach acceptance: Me = 42, fear of death: Me = 27, neutral acceptance: Me = 29, death avoidance: Me = 17, and escape acceptance: Me = 21. Concerning neutral acceptance, the median values for the oncology hospital and hospice staff members were Me = 29 and Me = 26, respectively.

Conclusions: Oncology nurses show a higher tendency towards neutral acceptance compared to the hospice staff. The respondents with a secondary level education demonstrated a higher tendency towards escape acceptance and death avoidance. Nurses with previous experience in oncology, hospice, or palliative care in addition to their current job demonstrate a higher tendency towards fear of death.

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Keywords: nursing staff, attitude, death, hospice, oncology

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Introduction

The attitude towards death determines personal feelings associated with the transience of human life (individual and referring to other people). It describes various moods or psychological dispositions that appear while dealing with death as well as its assessment [1]. There are two primary institutional care models related to dying: hospital and hospice models. It has been shown that the factors associated with nurses' spiritual care competence include their death attitudes in terms of approach acceptance and escape acceptance [2]. Care provided to patients in their terminal phases is particularly demanding for the nursing staff to be in constant and direct contact with these individuals. The attitude toward death appears to be an important issue in addition to the required knowledge and skills. The way its perception affects the view on caring for a dying patient and subsequently influences the quality of care provided as well as the mental and physical health of the nursing staff [1, 3, 4]. A negative attitude towards the transience of human life involves fear of death, death avoidance or escape acceptance. Fear of human life ending is a common and complex issue manifested by perceiving death as a departure to the unknown, by the sense of loss, or the religion-related dilemmas. Concerning death avoidance, the feeling of anxiety diminishes in the defense mechanism of its wiping from the mind while escape acceptance emerges when individuals are overwhelmed by their suffering and existential dilemmas together with the sense of ineffectiveness [5]. These experiences shape the psychosocial condition of the medical staff and affect patient management.

Improper ways of coping with the dying process result in nurses being tired of demonstrating empathy and a lower level of job satisfaction, which compromises the quality of care provided [6]. Negative attitudes are also associated with the phenomenon of occupational burnout [7]. Patient care in their end-of-life phase and the suffering observed in oncology departments and hospices pose a high risk of developing this problem. Concerning the palliative care team, the data show that the highest levels of emotional exhaustion (19.5%) and depersonalization (8.2%) are seen among nurses [8]. A high or critical level of burnout syndrome was observed in 9.75% and 2.43% of oncology nurses, respectively [9]. The research findings confirm that the burnout prevalence is higher among oncology nurses compared to those involved in palliative care [10, 11].

A positive view on death stands in contrast to the deterioration of the care quality and the poorer emotional state of the health professionals caused by the negative death attitude. This positive attitude includes approach acceptance and neutral acceptance. Approach acceptance is associated with the belief in a joyful afterlife which helps accept death. A similar attitude is neutral acceptance when an individual is not afraid of death but accepts it as an integral part of life and feels indifferent to it [5]. Maintenance of optimism while facing the process of transience results in a lower risk of occupational burnout [7]. In addition, an appropriate view on death improves the subjective well-being of the medical staff which, together with a good scientific attitude to dying, helps improve the quality of care provided [1]. Therefore, it is important to determine the attitudes toward death among the nursing staff whose job involves dealing with dying patients regularly and facing the discomfort typical of oncology departments and hospices. Moreover, factors associated with a particular view (especially those that can be modified) are worth identifying to provide support to the staff dedicated to palliative and cancer care and to reduce or prevent adverse consequences of the negative attitude towards death.

Participants and methods

Data design and collection

This cross-sectional study was conducted in the National Research Institute of Oncology in 11 clinics and two stationary hospices in Warsaw. Questionnaires and secured boxes for their collection were provided to the charge nurses by the principal investigator following a phone call. The questionnaires were collected by the principal investigator on the scheduled day. The study participants were selected based on the purposive sampling and the inclusive criteria involved the nursing staff members working in oncology departments or adult hospices as the primary workplaces, with at least three years of professional experience overall and at least one year's experience in the current workplace, who gave their consent to participate. The consent to conduct the study was obtained from the directors of the above institutions. The study was conducted between September and November 2023.

Ethical considerations

The study was carried out by the Declaration of Helsinki principles. The Bioethics Committee at the Medical University of Warsaw acknowledged the study design (No. AKBE/313/2023). The questionnaire contained information about the purpose of the study, voluntariness, confidentiality, and anonymity of the data collected as well as the information they will only be used for the research purpose. Each participant could withdraw from the study at any time without giving reasons.

Measurement

A questionnaire consisting of two parts was applied to the study. The first part contained the sociodemographic and professional data: age, gender, marital status, education level, religion, the workplace and the form of employment, the number of working years, and additional postgraduate education. Moreover, the nurses were asked about their personal experiences related to disease and death. The other component was the Death Attitude Profile-Revised (DAP-R) by Wong et al. [5] in the Polish adaptation by Brudek et al. [12]. The questionnaire contains 32 statements referring to attitudes toward death in 5 dimensions: fear of death (7 items), death avoidance (5 items), neutral acceptance (5 items), escape acceptance (5 items), and approach acceptance (10 items). The overall score ranges from 32 points to 224 points. The respondents were asked to declare how they agree with each statement by selecting the answer on a 7-point scale where 7 points refer to "strongly agree" while 1 point means "strongly disagree". Each subscale (1 to 7 scoring points) represents one of five attitudes towards death. A higher score indicates a stronger tendency to demonstrate a particular attitude. The reliability of the DAP-R questionnaire was validated using Cronbach's alpha. The internal consistency was satisfactory, with $\alpha = 0.863$.

Statistical analysis

The assumed significance level was $p \geq 0.05$. For the analysis of quantitative data presented in groups, non-parametric tests (the Man–Whitney U or the Kruskal–Wallis with *post-hoc* tests) were applied. For the analysis of correlations between quantitative variables, the Spearman test was used. The tests were selected based on the distribution of variables which was verified using the Shapiro–Wilk test. The calculations were performed in the SPSS Statistics and MS Office 2019 programs. Results were presented as medians and interquartile range.

Results

Participants

Overall, 310 and 50 members of the nursing staff in the National Research Institute of Oncology and in the stationary hospices, respectively, were invited to participate in the study. The questionnaire was completed by 196 respondents (62.2% return rate), of which 35 questionnaires were not included in the analysis due to incomplete items or double answers. As the number of stationary adult hospices was limited and they usually employ a small number of nurses, a comparison of the staff attitudes between both kinds of institutions revealed a numerical diversity.

In total, 159 respondents participated in the study, including 127 nurses who declared a hospital or a cancer institute as the primary workplace and 32 nurses employed in stationary hospices. In the study group of the medical staff, the largest subgroup included the female personnel (87.4%), with a bachelor's (40.5%) or master's (41.1%) degree, having a personal relationship (65.4%), being a member of the Roman Catholic Church (61.0%), with the employment agreement (81.8%) (Table 1).

The mean age of the respondents was 43.58 (SD = 12.81) years, the mean number of their overall working years was 17.94 (SD = 13.16), and the mean number of their working years in the oncology department or the hospice was 12.51 (SD = 9.86). Concerning the attitudes towards death, the median results for the particular dimensions were as follows: approach acceptance: Me = 42, fear of death: Me = 27, neutral acceptance: Me = 29, death avoidance: Me =17, and escape acceptance: Me = 21 (Table 2). There were no correlations with significant p values between the particular death attitude dimensions and the respondents' age, the overall number of working years, and the number of working years in the oncology department or the hospice.

The analyses of relationships between the attitude towards death and sociodemographic and professional variables show that there were differences with significant p values between neutral acceptance and the workplace of the respondents ($p = 0.001$). Higher values in this median were observed among the members of the oncology hospital staff (Me = 29). No differences were shown between fear of death, death avoidance, approach acceptance, death acceptance, and the respondents' workplace were confirmed. The differences were demonstrated between fear of death ($p = 0.02$), approach acceptance ($p = 0.008$), escape acceptance ($p = 0.04$), and the respondents' gender. There were no differences between the nursing staff's attitudes towards death and their marital status. The differences were confirmed between escape acceptance ($p = 0.006$), death avoidance ($p = 0.049$), and the respondents' education levels. Differences with significant p values were observed between fear of death ($p < 0.001$) as well as death avoidance ($p < 0.001$) and the sense of comfort during a conversation about death (Table 3).

Table 1. Characteristics of the study group

Characteristic	N	[%]
Gender		
Female	139	87.4
Male	20	12.6
Marital status		
In a relationship	104	65.4
Not in a relationship	55	34.6
Education		
Secondary-level medical degree	28	17.7
Bachelor degree	64	40.6
Master degree	66	41.7
Primary workplace		
Oncology hospital	127	79.9
Hospice	32	20.1
Religion*		
Does not state religion	30	18.9
Roman Catholicism	97	61.0
Christianity	14	8.8
Other	3	1.8
Palliative care specialty		
Yes	22	13.9
No	125	79.1
In the process	11	7.0
Cancer nursing specialty		
Yes	45	28.3
No	103	64.8
In the process	11	6.9
Additional postgraduate education		
Yes	39	24.7
No	111	70.3
In the process	8	5.1
Previous experience in oncology, hospice, or palliative care in addition to the current work		
Yes	58	36.5
No	101	63.5
Form of employment		
Contract of employment	130	81.8
Mandate contract	13	8.2
Self-employment	15	9.4
Family history of a serious cancer		
Yes	94	59.1
No	65	40.9
Caring for a terminally ill family member		
Yes	92	57.9
No	67	42.1
Previous participation in a life-threatening incident		
Yes	58	36.5
No	101	63.5
Sense of comfort during a conversation about death		
Definitely yes	33	20.9
Probably yes	60	38.0
Difficult to asses	34	21.5
Probably no	23	14.6
Definitely no	8	5.1

* Atheism was indicated by 15 (9.4%) nurses

Table 2. Median scores of DAP-R

Dimensions	Q25	Me	Q75
Fear of death	22.00	27.00	35.00
Death avoidance	11.00	17.00	22.00
Approach acceptance	34.00	42.00	55.00
Escape acceptance	17.00	21.00	26.00
Neutral acceptance	25.00	29.00	32.00

DAP-R — Death Attitude Profile-Revised; Me — median; Q25 — first quartile; Q75 — third quartile

This study did not confirm any differences between the attitude towards death and the palliative care or cancer nursing specialty. It was demonstrated that the nurses participating in the postgraduate courses manifested neutral acceptance ($p = 0.005$) significantly more frequently than the other respondents.

No differences were confirmed between the particular death attitude dimensions and a family history of serious cancer or experience in caring for a terminally ill family member. The nursing staff members who had been involved in a life-threatening incident demonstrated higher scores ($p = 0.03$) concerning fear of death compared to the staff without such experience 26.4.

Discussion

The aim of this study was an analysis of attitudes towards death among the nursing staff in hospices and oncology departments. Concerning approach acceptance and escape acceptance, the overall findings of the study revealed far higher scores compared to those obtained by Cardoso et al. [13] among nurses employed in various hospital departments, divided into two groups: nurses taking care of COVID-19 patients (with a high risk of death) and nurses working in other units. The mean results for the study participants regarding approach acceptance and escape acceptance were 37.16 (SD = 11.675) and 15.42 (SD = 6.010), respectively [13]. Compared to the findings of the present study, far lower scores for each attitude dimension were observed in the study conducted by Zhang et al. [1] among nurses working in various hospital departments. In the analysis of data collected in the group of Polish nurses, the most common attitudes were fear of death and natural acceptance of death while the least frequent dimension was death avoidance [14].

It was confirmed that neutral acceptance was more common among the nursing staff in oncology departments compared to the nurses working in hospices. The literature data concerning studies

Table 3. **The differences between attitudes towards death and the workplace, gender, education, the sense of comfort during a conversation about death**

	Fear of death	p-value	Death avoidance	p-value	Approach acceptance	p-value	Escape acceptance	p-value	Neutral acceptance	p-value
Primary workplace†										
Oncology hospital	27 (22–37)	0.12	16 (11–23)	0.53	42 (34–55)	0.64	21 (17–27)	0.81	29 (26–32)	0.001**
Hospice	25 (19.5–31)		19 (13–21.5)		42.5 (34.5–59.5)		22 (18.5–23.5)		26 (18.5–29.5)	
Gender†										
Female	28 (22–37)	0.020	18 (11–22)	0.42	43 (36–56)	0.008*	21 (18–26)	0.043	29 (25–32)	0.85
Male	22.5 (18–28.5)		14 (11.5–19.5)		38 (22–45.5)		18.5 (12.5–23)		29 (27.5–31)	
Education††										
Secondary-level medical degree	31.5 (22–38)	0.27	20.5 (11–28.5)	0.049	45.5 (39.35)	0.079	24 (20–31)	0.006*	29.5 (26.5–32)	0.055
Bachelor degree	27 (22.5–34.5)		18 (12–21)		44 (37.5–56.5)		20.5 (16.5–24.5)		27.5 (23.5–30.5)	
Master degree	26 (21–35)		15 (10–21)		40 (31–54)		20 (17–25)		29 (25–32)	
							Secondary level > Bachelor degree (p = 0.016) Secondary level > Master degree (p = 0.005)			
Sense of comfort during a conversation about death††										
Definitely yes	21 (16–29)	0.001**	11 (8–20)	0.001**	39 (28–50)	0.34	20 (15–23)	0.56	29 (22–33)	0.069
Probably yes	24.5 (21–34)		14 (9–20.5)		45.5 (36.5–60)		21.5 (16.5–26.5)		29.5 (27.5–32)	
Difficult to asses	28.5 (24–33)		18 (14–22)		42 (36–55)		22 (19–25)		28 (25–31)	
Probably no	39 (25–43)		22 (17–26)		42 (38–55)		20 (19–26)		27 (23–30)	
Definitely no	42 (32.5–49)		30.5 (29.5–35)		48.5 (24–65)		25 (18–33)		27.5 (25.5–31)	
	Definitely yes *vs.* difficult to assess (p = 0.009) Definitely yes *vs.* probably no (p < 0.001) Definitely yes *vs.* definitely no (p < 0.001) Probably yes *vs.* probably no (p < 0.001) Probably yes *vs.* definitely no (p = 0.002) Difficult to assess *vs.* probably no (p = 0.027) Difficult to assess *vs.* definitely no (p = 0.031)		Definitely yes *vs.* difficult to assess (p = 0.037) Definitely yes *vs.* probably no (p < 0.001) Definitely yes *vs.* definitely no (p < 0.001) Probably yes *vs.* probably no (p < 0.001) Probably yes *vs.* definitely no (p < 0.001) Difficult to assess *vs.* definitely no (p < 0.001) Probably no *vs.* definitely no (p = 0.022)							

† U Mann–Whitney test; †† ANOVA Kruskall–Walis with *post-hoc* tests; * p < 0.01; ** p < 0.001

involving only oncology nurses show it was a prevailing attitude [2, 15]. Zheng et al. [15] confirmed the lowest median score for escape acceptance in the group of oncology nurses. In a study aiming to assess the relationship between the attitude toward death and oncology nurses' spiritual care competence, Li et al. [2] obtained a mean score of 27.67 (SD 6.65) for approach acceptance.

The study conducted by Peters et al. [3] shows that palliative care nurses usually demonstrated a positive attitude towards death and dying while emergency care nurses reported higher scores for death avoidance and far poorer skills in coping with death compared to palliative care nurses. The palliative care nurses demonstrated high acceptance of death reality (neutral acceptance 82%). The most common attitudes revealed in studies with the nursing staff of various departments (including nurses in oncology units and palliative care institutions) were approach acceptance and neutral acceptance [16, 17]. Oncology and hematology nurses demonstrated significantly higher scores for fear of death, death avoidance, and escape avoidance compared to palliative care nurses in the study conducted by Gama et al. [18].

The study found that female nurses significantly more frequently demonstrated fear of death, approach acceptance and escape acceptance. Few studies indicated escape acceptance as a more common attitude among males [19]. Male nursing students reported higher scores for approach acceptance but lower scores for fear of death and death avoidance compared to female students [20]. It was observed that the attitudes adopted by females and males were natural acceptance and fear of death, respectively [14]. It is worth mentioning that the male group in this study constituted only 12% of the respondents so it cannot be a representative group.

It was shown that the participants' age and marital status were not associated with the nursing staff's attitudes towards death. In the study by Duran et Polat [4], hospital nurses demonstrated positive death attitudes and a low level of fear of death. Approach acceptance was high among younger nurses while a strong escape approach was observed among single individuals. Younger and older respondents more commonly reported fear of death and neutral acceptance, respectively, in the study conducted by Cybulska et al. [14] concerning marital status, a correlation with natural acceptance of death was observed.

Professional experience and continuing education are also important issues in the process of creating nurses' attitudes toward death. The study did not confirm any correlation between the duration of nurses' working lives and their attitudes towards death. Previous experience in oncology, hospice, or palliative care in addition to the current work was associated with a higher tendency towards fear of death. A positive correlation between the duration of nurses' working life and escape acceptance was observed in the study by Duran and Polat [4]. This may suggest that the nurses developed strategies for coping with dying and death based on emotions. Consistent reports indicate that nurses who are at the beginning of their job careers demonstrate stronger fear of death and more negative attitudes toward caring for patients during their terminal stages of life than more experienced nurses [21]. The present study demonstrated that the nursing staff with the secondary-level medical degree more commonly demonstrated the attitudes of escape acceptance and death avoidance. In a study involving the nursing staff with a similar education level distribution (excluding the PhD degree), diverse attitudes toward death were not confirmed [14]. The fact that lower education and experience levels may be associated with negative attitudes was demonstrated in the study conducted by Cevik and Kav [17] among nurses working in various hospital departments (12.3% of the study participants in oncology units).

Having oncology and palliative care specialties was not connected with the participants' attitudes towards death while additional education frequently resulted in adopting neutral acceptance among the staff. The findings of the study by Gama et al. [18] show a higher level of escape acceptance among nurse specialists. Moreover, palliative care nurses reported a weaker fear of death, death avoidance and escape acceptance compared to oncology care specialists.

Death-related personal experience appears to be a factor that facilitates coping positively with new situations at work and in personal life. This suggests that longer professional experience results in a weaker fear of death and a more positive attitude to nursing care. No correlation was observed between the attitude towards death and a family history of serious cancer or the experience of caring for a terminally ill family member. Compared to the nursing staff with no experience in providing care to dying patients, the more experienced nurses demonstrated higher scores for natural acceptance in the study by Xie et al. [20]. A study aiming to analyze nurses' attitudes towards death as well as death-related experience and care provided to dying patients confirmed a less positive attitude towards delivering care to dying patients among nurses with a stronger fear of death [17]. Another factor associated with the attitude towards death that was found was the sense of comfort during a conversation about death. The highest scores were reported for fear of death which correlated with a lack of freedom in a discussion and for death avoidance analogically associated with death fear.

The discussed issue is very important for nursing practice and further development. This study helps better understand the factors related to nurses' attitudes towards death, which is useful for planning effective nursing training strategies at the pre-and postgraduate stages.

However, the present study has its limitations. This study involves a small sample of palliative care specialists compared to oncology nurses. A purposive sampling was used which is prone to researcher bias. The study group was fairly homogenous in terms of gender. A small number of respondents participated in the study, which limits the potential to generalize the study findings for the overall population of the nursing staff in oncology departments and stationary hospices. No data were collected concerning the work environment of the nursing staff.

Conclusions

Oncology nurses show a higher tendency towards neutral acceptance compared to the hospice staff. The respondents with a secondary level education demonstrated a higher tendency towards escape acceptance and death avoidance. Nurses with previous experience in oncology, hospice, or palliative care in addition to their current job demonstrate a higher tendency towards fear of death.

Article information and declarations

Acknowledgments

None.

Data availability statement

The datasets used and/or analyzed in the current study are available from the corresponding author upon reasonable request.

Ethics statement

The study was carried out by the Declaration of Helsinki principles. The Bioethics Committee at the Medical University of Warsaw acknowledged the study design (No. AKBE/313/2023).

Author contributions

Study concept and design — KK (60%), EK (40%); data collection — KJ (100%); data analysis — KJ (60%), EK (40%); preparation of the original version of the manuscript: KJ (100%); literature review — KJ (60%), EK (40%); preparation and approval of the final version of the manuscript: KJ (60%), EK (40%).

Conflict of interest

The authors declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

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Supplementary material

None.

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Review

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Unravelling the landscape of image-guided radiotherapy: a comprehensive overview

Abstract

Image-guided radiation therapy (IGRT) is essential to modern radiation therapy. It ensures precise radiation delivery to tumor targets, sparing healthy cells and tissues. IGRT techniques upgraded themselves to a level where the technology allows for tracking the real-time image of the tumor during treatment and significantly improves the accuracy and precision of radiation therapy. By integrating advanced imaging modalities such as cone beam computed tomography, magnetic resonance imaging, and positron emission tomography, clinicians can visualize the tumor and surrounding tissues in three dimensions. It also can account for intrafraction variations, such as organ motion and changes in tumor size or shape, which can occur throughout treatment. Using IGRT techniques, clinicians can adapt the treatment plan in real-time to ensure optimal radiation delivery to the tumor while sparing healthy tissues. Moreover, IGRT is crucial in managing systematic and random errors during radiation therapy. These errors could lead to underdosing of the tumor or overdosing of healthy tissues, compromising treatment efficacy and patient safety. To mitigate these errors, imaging and frequent verification of the treatment are necessary throughout the treatment. This review paper offers a comprehensive summary of IGRT, its diverse modalities, clinical integration, quality assurance tests performed, and the role of artificial intelligence (AI) in IGRT.

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Keywords: image-guided radiation therapy, cone beam computed tomography, surface-guided radiation therapy, magnetic resonance linear accelerator, artificial intelligence

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Introduction

Accurate determination of the target volumes of radiotherapy is of utmost importance for improving local tumor control and minimizing toxicity. To achieve this, the set-up of a patient's anatomy concerning the treatment beams is used to enhance the accuracy of the set-up from the point of systematic and random error. Anisotropic margins expand the gross tumor volume (GTV) to a clinical target volume (CTV) [1]. The CTV is then enclosed by a planning target volume (PTV), which adds an extra margin to the CTV to consider positional and delineation uncertainties [2]. However, it is to be noted that, to manage less toxicity, smaller margins may underdose the CTV [3]. Therefore, advanced imaging techniques during image-guided radiation therapy (IGRT) are essential to enhance the accuracy and precision of treatment delivery.

Image-guided radiation therapy techniques, as is known, allow the user to confirm the set-up and match the target before treating the patient with high-energy radiation to deliver the dose precisely. These treatment modalities are especially beneficial in cases where the tumor is located near critical organs or structures, as they can shape the radiation beam to match the desired target contours of the tumor, minimizing radiation exposure to nearby sensitive tissues.

Several techniques are used for position verification, such as megavoltage electronic portal imaging device (MV-EPID) and megavoltage cone beam computed tomography (MV-CBCT). Imaging based on kilovoltage cone-beam computed tomography (kV-CBCT) is preferred as it provides additional anatomical information compared to EPID imaging [4]. Nowadays, linear accelerators (LINAC) have imaging devices that produce high-quality images, simplifying the set-up verification process. The set-up error is determined using sophisticated software by comparing the image taken immediately before or after the treatment session with the planned image [5].

Image-guided radiation therapy rationale and hypothesis

"Increasing the precision and accuracy of radiation delivery will reduce toxicity with potential for dose escalation and improve tumor control" is the basic hypothesis [6]. Hence, to significantly reduce set-up error, it is essential to use high-precision techniques to ensure that the daily anatomy and position of the patient match or surpass the treatment plan at every stage. In current clinical practice, verification is primarily employed to guide the radiation beam to a predefined limit by repositioning the patient correctly and eliminating the misalignment. By imaging before treatment, set-up errors and uncertainties in positioning can be reduced. Images acquired in between or along with the treatment provide information on positional changes due to organ motion during the treatment. This can increase confidence in the effectiveness of treatment and avoid potential mistargeting incidents [7].

The recent advancements in imaging and treatment delivery provide accurate tumor localization and repositioning of patients. The concept of IGRT has dramatically improved the management of geometric uncertainties, thus providing precise information on the patient and tumor position, allowing for verification of planned and actual treatment geometry, resulting in improved dose delivery. However, it must be addressed that IGRT delivers an extra dose in addition to the treatment dose, though it helps to reduce toxicity and allows improved tumor control [8].

IGRT is an imaging tool used in radiotherapy to correct geometrical mismatch, delineate target volumes and organ-at-risk (OARs), determine biological attributes, *etc.* It is commonly known as image-based radiotherapy, more focused on imaging with radiation treatment, improving the precision of radiotherapy for advanced techniques like 3D-CRT, IMRT, and stereotactic radiosurgery/radiotherapy (SRS/SRT) [9].

Definition and different IGRT modalities

IGRT is a radiotherapy procedure that uses image guidance in various stages [10]. It is the central pillar in advancing radiotherapy, and imaging information has been adopted and integrated to facilitate various treatment modalities. The following are the different technologies used in radiation therapy.

Planar

Two-dimensional (2D) images, both kV and MV, generated from modern accelerators, are produced by two sets of imaging systems. The kV image is obtained from a conventional X-ray tube mounted orthogonally to the MV radiation gantry and opposes a flat panel detector. In contrast, the second detector that opposes the gantry, the so-called electronic portable imaging device (EPID), to obtain 2D MV images is the other type. The flat-panel detectors are matrices of solid-state amorphous silicon photodiodes. KV-KV, MV-MV, or KV-MV image acquisition methods acquire the images [11]. EPID is generally used when image quality is not a factor. An EPID image in the prostate may be an example where corrections are made based on the bony anatomy and radio-opaque fiducials [12].

Another type of room-mounted planar imaging system is a two-unit system. Two units from different directions define the target. Such a system uses fiducial markers, bony anatomy, or direct visualization for accuracy and localization [13]. Notably, ExacTrac [14], Cyberknife [15], and Vero [16] are some examples of such systems.

The application of a planar imaging system offers multiple picture-matching options. After converting the 3D CT simulation image to a 2D (digital radiographic reconstruction) image, the matching X-ray images acquired before, during, or after the treatment are compared with these DRRs to determine their maximum resemblance to the relevant X–ray images. The patient is then set up according to the manual match and DRR to eliminate rotational errors. Finally, the algorithm decides the region of interest to fuse and filters out structures that provide more ambiguity to the fused image [14].

Cone beam computed tomography system

The imaging system's flat panels produce orthogonal planar projections, are suitable for fluoroscopy, and can complement 3D and 4D images. CBCT plays a vital role in IGRT by providing high-quality, three-dimensional imaging of the treatment area. CBCT allows for accurate visualization of the target volume and surrounding structures, enabling precise alignment and positioning of the patient before each treatment session. This technology helps detect anatomical changes, such as tumor size and shape, bladder and rectum fillings, and allows for immediate adjustments to the treatment plan, ensuring optimal dose delivery [17].

Radiotherapy planning done in a three-dimensional platform is a new concept and is growing rapidly, although the techniques of CBCT existed long ago. Besides verifying the patient's position in 3D, CBCT has potential benefits for dose verification and adaptive planning in the future. CBCT systems are available in the MV and kV range, and the choice depends on several factors, including the extra dose the patient receives depending on the frequency of its use [17].

Elekta's X–ray volume imaging (XVI) and Varian's On-Board Imager (OBI) are the kV–CBCT imagers mounted orthogonally to the MV treatment beam, used as an IGRT system that uses a kV X-ray source composed of an amorphous silicon flat panel detector. Amorphous silicon flat-panel detectors are well suited to mount on the linear accelerator because of their low optical scattering and high-resolution properties [18].

Fan beam

Helical tomotherapy can best explain fan beam radiotherapy. The basic idea of helical tomotherapy is to integrate a linear accelerator or other radiation-emitting device into a CT-like ring gantry configuration that can be used for both imaging and delivering therapeutic radiation. The machine is designed to treat the patient in slices, and the couch moves in the cranio-caudal direction of a CT [19]. The treatment unit includes a radiation detector system at the beam exit side, which is generally a Xenon-filled ionization chamber used for easy and fast acquisition of MVCT scans of the patient in the treatment position [20]. The main advantage of tomotherapy is that it uses the same beam for treatment and imaging. The image acquired from a fan beam CT has an advantage in its properties and has better image qualities with low artifacts and noise. It has a better spatial and contrast resolution than CBCT [21].

Non-ionizing visualization systems

All the imaging modalities mentioned above use ionizing radiation for imaging purposes. Such modalities incorporate an extra dose to the treatment dose. Imaging modalities like magnetic resonance imaging (MRI), ultrasonography, and surface-guided radiation therapy (SGRT) can eliminate these excess doses because they do not contribute to the treatment plan and use non-ionizing radiation, a non-harmful, real-time imaging technology [22].

In situations where the visualization of soft tissue was required, ultrasonography was found to be a handy and attractive tool for IGRT [24]. Imaging modalities like kV or MV X-ray imaging provide excellent localization for bony structures but lack adequate soft-tissue contrast to visualize organs such as the prostate. Ultrasonography imaging is a less expensive, real-time imaging modality that enables the visualization of soft tissue structures and can be used as a complementary imaging modality to other imaging systems. Ultrasonography uses high-frequency sound waves with a frequency above the audible level of human hearing; used for imaging in diagnostic radiology for a long time and is considered one of the safest methods in diagnostic imaging [18].

Magnetic resonance imaging is another non-ionizing visualizing tool used in IGRT. This technology has recently integrated with a linear accelerator and has been categorized as MR-LINAC. It can acquire an image the same as a kV-CBCT. The main advantage of MR-guided over kV-CBCT-guided is that it has better visualization ability of soft tissue and can help improve target localization and organ at risk (OAR) delineation [23] for several sites, such as the brain, prostate, and pelvis, thus reducing the possibility of geographical miss and enabling dose escalation [24]. MR images are often registered with CT images for treatment planning in radiotherapy to provide precise delineation of target volumes and OARs due to their superior soft-tissue contrast [25]. Changes in the shape and size of the tumor during the treatment can be further visualized using real-time tracking. Elekta Unity and ViewRay MRIdian are two examples of MRI LINAC used [26]. These two units facilitate rapid adaptive planning and treatment delivery by integrating MRI and LINAC.

Optical surface scanning or SGRT is another non-ionizing image-guided radiotherapy tool effective in intra-fractional motion, respiratory gating techniques, and patient positioning with the help of a light projector and a few camera units to register the real-time 3D surface of the patient [22]. It is an effective tool for patient positioning as it considerably reduces overall set-up time, and no radiation dose is involved [27]. Three systems are commercially available for surface guidance and to enhance system accuracy. The AlignRT (VisionRT) SGRT system, The Catalyst/Sentinel system of C-RAD, and the Identify system now acquired by Varian are in clinical use. These SGRT systems use multiple structured light projections, which are detected by cameras placed in different positions to obtain an image of the patient's surface [28].

Image-guided radiation therapy workflow

The set-up deviation is calculated by comparing and correcting the positional mismatch of the treatment with the reference image acquired at the time of simulation with the help of the image. It accounts for both random and systematic deviations. Systematic deviations refer to the differences between the planned set-up on the simulator and the actual set-up during treatment. These deviations may occur due to daily variations in the movement of skin marks about bones. On the other hand, random errors can result from various sources, including the simulator itself. To minimize geometric uncertainties, IGRT helps to adjust the patient's position or modifies the treatment plan based on anatomical changes. The image of the patient acquired immediately before a treatment offers opportunities for a more precise set-up [29].

IGRT follows two methods for image registration, *i.e.* online and offline. Online methods are known to be more effective than offline methods in reducing geometric uncertainties, but they require more work, longer treatment times, and higher radiation doses. Online approaches are generally preferred for cases where the high-dose area is close to critical anatomical structures, for dose-escalation programs, or hypo-fractionated treatments. However, recent studies have shown that offline procedures can achieve similar effectiveness [30]. Consequently, the radiation oncologist in charge of the patient must evaluate each case individually and determine the best method for correcting the target area. Regardless of the chosen method, a tolerance margin needs to be established for each disease and target location, considering factors such as the priority of PTV coverage, the importance of organs at risk, organ motion, and patient characteristics [5]. Patient immobilization and positioning in IGRT are essential factors in its success. Various immobilization devices, such as thermoplastic masks or customized body VacLok, ensure patients are in the correct position during treatment. These devices restrict the patient's movement and ensure optimal target volume throughout treatment.

Quality assurance

The introduction of the IGRT system in radiotherapy has improved the accuracy of treatment delivery. However, the components used in IGRT also ensure safety, geometric accuracy, and image quality. Thus, a rigorous quality assurance (QA) program should be conducted before clinical implementation to provide confidence that the imaging system is operating within acceptable limits.

Advanced IGRT technologies need to perform a QA program to ensure the system's performance is established at the time of commissioning [31]. The QA program concerning IGRT has three major components, *viz.* safety, geometry, and image quality, and these three components are applicable for radiographic and tomographic image guidance. The evaluation of geometric accuracy for repositioning patients before, during, or after treatment is the major test in IGRT [32]. Quality assurance of IGRT includes geometric accuracy tests, image quality checks, scale and distance accuracy, low contrast resolution, spatial resolution, uniformity and noise, image dose, accuracy in CT numbers, image registration, accuracy in remote control couches, and daily operational issues [33].

Artificial intelligence in image-guided radiation therapy

Artificial intelligence (AI) has the potential to optimize radiotherapeutic procedures, resulting in an improvement in the quality, safety, accuracy, and timeliness of radiotherapy. Recently, AI can contour organs and targets previously done by the oncologist manually, making their work easy. With the help of AI, the treatment target accuracy and minimal harm to the normal tissue have become easier, as well as quality assurance [34]. AI-based IGRT techniques can monitor tumor motion, reduce treatment uncertainty, and improve precision. Advanced techniques like intensity-modulated radiotherapy (IMRT), volumetric modulated arc therapy (VMAT), and stereotactic ablative radiotherapy (SABR) require comparatively more precision; AI in IGRT can ensure a precise distribution of the radiation dose around the tumor volume, detects the change in position or shrinking of the tumor, thereby creating adaptive plans, minimizing the amount of healthy tissue irradiated. Advancements and upgrades in machine and deep learning have significantly impacted radiotherapy workflow and have the potential to provide high–quality treatment for cancer patients, which has grown exponentially in recent years [35].

Varian Ethos is an example that utilizes an intelligent optimization engine (IOE) designed for plan automation. This system adjusts radiotherapy treatment plans daily according to the anatomical changes. The system creates an adapted plan using artificial intelligence, thus speeding up the workflow [36]. The new feature IOE and its innovative workflow in generating the reference plan is designed to streamline the treatment planning process by automating the insertion of optimization parameters based on the physician's planning directives. It supervises modifying inputted goals and priority ranks before the final plan generation. The physicians or physicists are not able to control the optimizer. Instead, they set "clinical goals" to guide the IOE indirectly. It was found that utilizing an advanced AI-guided approach produces superior plan quality in the Varian Ethos IOE system [37].

Conclusions

The evolution of radiotherapy is advancing day by day to a new scenario, and IGRT plays an essential role in this field. IGRT is a vital tool in radiotherapy for verification and delivering a more conformal dose to the target. The technological advancements in IGRT have improved the delivery by integrating different imaging modalities in the treatment room to minimize the geometrical uncertainties. This tool verifies the consistency of planned and actual geometry, resulting in better dose administration. One of the issues with the IGRT is the extra dose a patient receives for imaging. On the other hand, however, more precision and accuracy of radiation administration are predicted to reduce toxicity.

Article information and declarations

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Author contributions

Conception, design, critical review — GS; manuscript preparation, literature review — HK; literature review, supervision — PPM; manuscript preparation, data collection — RK; design, manuscript preparation, data collection, literature review — DL.

Conflict of interest

The authors declare no conflicts of interest.

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Review

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Facebook counseling in the field of complementary and alternative medicine among Polish breast cancer patients: a narrative review

Abstract

Introduction: Breast cancer (BC) patients often use complementary and integrative therapies as supportive care as suggested by online sources during cancer treatment and when coping with the side effects of treatment. However, the evidence for the effectiveness of such therapies is limited. This review aimed to critically analyze Facebook's advice to women with BC regarding the use of complementary and alternative medicine (CAM) and assess their safety and effectiveness.

Methods: Narrative review.

Results: The search yielded 1,300 pieces of advice provided by the community of Facebook groups. These were analyzed, and their safety and effectiveness were assessed. Many different CAM therapies were identified, which were grouped into five categories.

Conclusions: Currently, searching for information on CAM on Polish-language Facebook groups by breast cancer patients poses a risk of obtaining advice of unproven effectiveness. Patients are exposed to suggestions that they should take products that may interact with conventional treatment or that they may be persuaded to give up conventional treatment. Cancer care providers should consider the complexity and implications of the unmet need for information and support for breast cancer patients that result in seeking CAM advice on Facebook groups. Measures should be taken to ensure that breast cancer patients can find reliable evidence on CAM online and on social media.

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Keywords: complementary and alternative medicine, breast cancer, online health information-seeking, social media, misinformation

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Introduction

Complementary medicine includes therapies used in addition to conventional medicine. Alternative medicine includes therapies used in place of conventional medicine, while integrative medicine is the coordinated use of evidence-based complementary practices and conventional care [1]. Integrative oncology refers to complementary and integrative therapies with conventional oncology care [2]. In oncological diseases, patients use complementary and integrative therapies intending to improve well-being, improve quality of life (QOL), and alleviate the symptoms of the disease and the side effects of conventional treatments. The most common types of complementary and alternative medicine (CAM) include herbal products and dietary supplements such as vitamins and minerals [3–6]. Breast cancer (BC) patients often use complementary and integrative therapies as supportive care during cancer treatment and when coping with the side effects of treatment [7, 8]. However, the evidence for the effectiveness of such therapies is limited [9]. CAM among patients is perceived as safe and is usually self-administered without prior consultation with a physician. Despite the widespread belief among patients that vitamins or plant-derived therapies are inherently safe, there is growing evidence that caution should be exercised [10]. Some CAM methods, especially herbal products, vitamins, and minerals, can hurt the treatment process of patients, leading to disease complications, the omission of conventional treatment toxicity, and drug interactions [5, 11, 12]. Herbal products contain many natural chemicals that share metabolic pathways with some anti-cancer drugs, potentially leading to under- or over-exposure to these drugs and consequently to treatment failure or increased toxicity. Therefore, CAM-drug interactions are a significant concern when treating cancer patients [11, 13, 14]. The potential interactions between CAM and anticancer drugs are estimated to be around 55–85% in patients taking both types of treatment [15]. These results may be underestimated because patients rarely inform healthcare professionals about the use of CAM.

During the COVID-19 pandemic, cancer patients experienced particular difficulties and barriers in using the services of formal healthcare facilities, which undoubtedly could have influenced the increased interest in CAM methods among this group of patients and the transfer of their activity towards the use of social media to meet therapeutic needs and expectations [16]. Social networks allow greater access to health-related information and provide a point of free communication between people living with similar chronic diseases [17]. The results of a systematic review examining the use of social media by healthcare professionals suggest that healthcare providers see social media platforms as valuable tools to help patients self-manage chronic conditions [18]. When patients access health-related information on Facebook, their primary motives are to receive social support, exchange advice and increase knowledge [19]. In addition, the exchange of information regarding specific diseases and related problems occurs in Facebook groups. Nowadays, social media has become an important and common mechanism for providing support in self-management, coping, and treatment of chronic diseases [20].

Previous research has shown that Facebook groups are a communication tool used by patients seeking information or support for BC [21]; however, there is a gap in research examining what self-healing and self-management content is communicated on Facebook groups related to CAM therapies for BC.This review aimed to critically analyze Facebook's advice to women with BC regarding the use of CAMs and assess their safety and effectiveness.

Methods

Facebook data search design and procedure

The procedure of searching for groups on Facebook for the selection of groups involved creating a new account on the Facebook platform after deleting all browsing history and cookies from the internet browser (Google Chrome). Two researchers individually then entered terms related to complementary and alternative medicine (alternative medicine, complementary medicine, natural medicine, natural therapies, herbs, herbal medicine, Chinese medicine, homeopathy, and Ayurvedic medicine) in the Facebook group category. After searching for each term, the first five groups found in the browser, the members of which exceeded 50 thousand people, were joined. The next step was to send a request to the administrator of each group regarding the possibility of searching posts in the group for CAM advice.

Inclusion/exclusion criteria for Facebook groups

The analysis was limited to all public and closed Facebook groups related to CAM, where the content was posted in Polish. Secret Facebook groups or those that did not appear in the Facebook group search were excluded from the analysis because only individual Facebook users who were invited by the Secret

Group admin or a current Facebook member can see the group title, description, members, and content. In addition, any closed group that did not accept the researchers' request to join the Facebook group before data collection began was excluded, as group posts can only be viewed by members alone.

Collection of data related to complementary and alternative medicineadvice

After obtaining the administrator's consent to join the group, two researchers independently searched for a specific group of content or entries related to BC employing the search engine, using terms such as "breast cancer", "breast neoplasm", "breast", and "breasts". Only posts regarding patients seeking help in the treatment and/or management of BC symptoms in 2020–2022 were analyzed. The analysis excluded posts concerning benign breast tumors, cysts, and posts in which the author indicated that she had not yet received a final diagnosis of a lesion in the breast. Advice posted in the comments by other members of the groups was then collected. The advice was selected in six categories: (a) herbs and plant products (*per os*), (b) vitamins and minerals, (c) mushrooms, (d) discouraging/encouraging conventional medicine, and (e) other.

Assessment of the safety and effectiveness of CAM therapies recommended by users in the form of advice on Facebook groups, taking into account the evidence-based medicine (EBM) guidelines.

Complementary and alternative medicine therapy advice provided on Facebook groups that appeared 20 or more times was found in the NatMed Pro database. Detailed information regarding the inclusion criteria of studies is provided in Table S1 and Table S2. A scoping review method is an approach that allows for the inclusion of diverse methodologies (*i.e.* experimental and non-experimental research) and has a significant impact on EBM. The approach can be used to map fields of a topic where it is difficult to visualize the range of material categories, contributing to the presentation of varied perspectives on a phenomenon of concern. The steps proposed by Arksey and O'Malley [22] were followed to conduct this review, which includes 5 stages: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarizing, and reporting the results. Complete further meta-analysis or sub-group analysis was not intended due to the heterogenicity of the study designs included in this review.This scoping review followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis extension for Scoping Reviews (PRISMA-ScR) checklist (Table S3).

Search strategies and study selection

A NatMed Pro database search was conducted by two investigators. NatMed Pro is a subscription database presenting up-to-date clinical data on natural medicines, herbal medicines, and dietary supplements used in the Western world [22]. Compiled by pharmacists and physicians, it is an online tool that collects evidence-based research from impartial, peer-reviewed sources. It enables the assessment of potential interactions between the drug and CAM, as well as the assessment of safety and effectiveness. The study inclusion criteria and search strategy are presented in the Supplementary Materials, Table S2.

In the first stage, the "Effectiveness Checker" tool was applied to check how effective the proposed CAM methods are in the treatment of breast cancer. In the second stage, the "Interaction Checker" tool was employed to analyze potential interactions between conventional treatment and CAM products. The data selection process is presented in Figure 1. Data including the authors' name, year of publication details of the interventions, and outcome measures or conclusions were compiled in Table S4.

Results

Advice on CAM for breast cancer

Of the 12 groups that met the inclusion criteria for the study, the administrators of 7 groups accepted the researchers' request to join the group, of which no posts regarding BC were found in the two groups. Detailed information on the groups is included in Table S1.

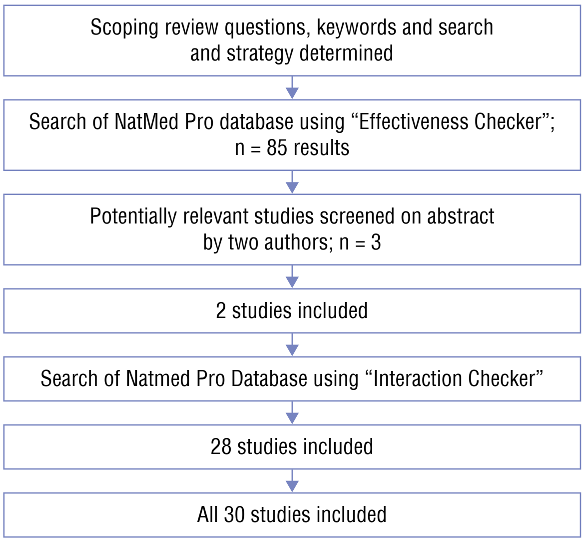

Figure 1. The data selection process

Table 1 presents the characteristics of advice recommending the use of CAM in BC therapy found on Facebook groups. Ultimately, 29 posts were analyzed, from which 1437 CAM advice offerings on BC were collected. The most common advice was to take herbs and plant products (N= 560; 39.01%) and vitamins and minerals (n = 351; 24.4%) (Table 1). The most frequently recommended herbs and plant products were beetroot (n = 70; 12.5%), dandelion (n = 51; 9.1%), cannabidiol (n = 44; 7.9%), flax seed (n = 36; 6.4%) and the fungus chaga (n = 19; 43.2%) (listed separately), with vitamins and minerals being: iodine (n = 132; 37.6%), vitamin D (n = 84; 23.9%) and vitamin C (n = 65; 18.5%). Other recommended therapies included castor oil compress (n = 85; 24.6%), amygdalin (n = 43; 12.5%), and baking soda compress (n = 36; 10.4%). Regarding recommendation of conventional medicine: encouragement (n = 102; 74.5%); discouragement (n = 35; 25.5%).

Effectiveness of complementary and alternative medicine therapy of advice posted on Facebook groups

Based on the NatMed Pro database search, information was found on the effectiveness of products such as flax seed and vitamin C in BC treatment. Studies on breast cancer prevention were excluded.

Flaxseed

A small clinical study shows that dietary flaxseed has the potential to reduce tumor growth in postmenopausal patients with breast cancer. Consuming a muffin containing ground flaxseed reduces markers of tumor cell proliferation [23].

Vitamin C

A meta-analysis results suggest that post-diagnosis vitamin C supplementation may be associated with a reduced risk of total mortality and breast cancer-specific mortality. Vitamin C supplementation is associated with a 15% lower risk of breast cancer-related mortality when compared to no supplementation [24]. On the other hand, a large observational study in patients with breast cancer undergoing radiotherapy shows that Vitamin C supplementation does not reduce the risk of breast cancer recurrence. Although the vitamin C group had notably less aggressive tumor types, recurrence-free survival was similar in both vitamin C and control groups [25].

Interactions between complementary and alternative medicine and conventional treatment

Based on the NatMed Pro database search, information was found on potential interactions with

Table 1.Characteristics of recommended CAMs for women with breast cancer by the community on Facebook groups

Type of CAM	n [%]
Herbs and plant products	**560 (100)**
Beetroot (*Beta vulgaris*)	70 (12.5)
Dandelion (*Taraxacum officinale*)	51 (9.1)
Cannabidiol (CBD)	44 (7.9)
Flax seed (*Linum usitatissimum*)	36 (6.4)
Urtica (*Urtica dioica*)	28 (5.0)
Turmeric (*Curcuma*)	27 (4.8)
Black seed (*Nigella sativa*)	19 (3.4)
Burdock (*Arctium*)	18 (3.2)
Common wormwood (*Artemisia absinthium*)	18 (3.2)
Evening-primroses (*Oenothera*)	17 (3.0)
Graviola (*Annona muricata*)	16 (2.9)
Delta-9-tetrahydrocannabinol (THC)	16 (2.9)
Cleavers (*Galium aparine*)	14 (2.5)
Greater celandine (*Chelidonium majus*)	14 (2.5)
Capsaicin	11 (2.0)
Swedish Bitters	10 (1.8)
Other	151 (26.9)
Vitamins and minerals	**351 (100)**
Iodine	132 (37.6)
Vitamin D	84 (23.9)
Vitamin C	65 (18.5)
Vitamin K	19 (5.4)
Selenium	18 (5.1)
Zinc	12 (3.4)
Other	21 (6.0)
Mushrooms	**44 (100)**
Chaga (*Inonotus obliquus*)	19 (43.2)
Other	25 (56.8)
Other therapies	**349 (100)**
Castor oil compress	85 (24.6)
Amygdalin	43 (12.5)
Baking soda compress	36 (10.4)
Recall healing	26 (7.5)
Yellow tulip bulb ointment	17 (4.9)
Other	138 (40.0)
Other	**137 (100)**
Encouraging the use of conventional medicine	102 (74.5)
Discouraging the use of conventional medicine	35 (25.5)

CAM — complementary and alternative medicine; n — the number of comments with a recommended product in a given category conventional treatment in such CAM products as black seed (*Nigella sativa*), cannabidiol (CBD), chaga (*Inonotus obliquus*), dandelion (*Taraxacum officinale*), evening primrose (*Oenothera biennis*), greater celandine (*Chelidonium majus*), delta-9-tetrahydrocannabinol (THC), selenium, turmeric (*Curcuma longa*), vitamin C and vitamin D. The analysis included drugs used in the treatment of breast cancer, such as tamoxifen, letrozole, exemestane, doxorubicin, cyclophosphamide, epirubicin, paclitaxel, docetaxel, carboplatin, methotrexate, mitomycin, and vincristine. Identified were 132 combinations of potential interaction of CAM products and anticancer agents. Among this n = 82 (62.9%) revealed no interaction risk, n = 45 (34.1%) hypothetical interaction risk, and 4 potential clinical interaction risk (3%). Table 2 presents potential interactions between herbal medicines and anticancer agents.

Black seed

Black seed may interact with tamoxifen and cyclophosphamide. *In vitro* researches suggest that black seed, especially thymoquinone, the main bioactive compound, may increase levels of drugs metabolized by CYP2C9 [26]. Black seed might also interfere with immunosuppressive therapy. The effect of black seed is unclear. Some animal studies suggest that it might stimulate immune function [27, 28] while others suggest that it may suppress [29, 30].

Cannabidiol

Cannabidiol might have interactions with tamoxifen, letrozole, exemestane, doxorubicin, cyclophosphamide, paclitaxel, docetaxel, and vincristine. *In vitro* studies show that cannabidiol (CBD) inhibits CYP2C9, CYP3A4, and CYP2C19 and suggest that it plays an essential role in herb-drug interaction [31]. CBD intake might also increase levels of drugs metabolized by CYP2C8 and increase levels of certain glucuronidated drugs. *In vitro* researches also show that cannabidiol inhibits uridine diphosphoglucuronosyl transferase (UGT) 1A9 and UGT2B7, enzymes responsible for glucuronidation [32]. That suggests that CBD could decrease the clearance and increase levels of glucuronidated drugs. Additionally, in one case report, women who were taking tamoxifen and cannabidiol were found to be presented with a 9.2% increase in N-desmethyl tamoxifen and an 18.8% increase in endoxifen levels after discontinuing cannabidiol for 67 days [33].

Chaga

Chaga may interact with cyclophosphamide. *In vitro* researches demonstrate that certain constituents of chaga (polysaccharides) stimulate immune function and might interfere with immunosuppressive therapy [34].

Dandelion

Dandelion could potentially interfere with Tamoxifen and Doxorubicin. Dandelion intake may increase the clearance of drugs that are UGP substrates. Studies conducted in female rats reveal that consumption of dandelion tea increases (244% of control) the activity of phase II detoxifying enzyme UGP [35].

Evening primrose

Evening primrose may interact with Tamoxifen. *In vitro* studies show that intake of evening primrose may increase the level and clinical effects of *CYP2C29* substrates [36].

Greater celandine

Greater celandine might have interaction with tamoxifen, cyclophosphamide, and methotrexate. *In vitro* researches indicate that consumption of greater celandine inhibits CYP2D6 enzyme activity and may increase levels of drugs metabolized by CYP2D6 [37]. Greater celandine intake can also affect the liver, it has been linked to many cases of hepatotoxicity [38–40]. Co-treatment with greater celandine and hepatotoxic drugs might, therefore, increase the risk of liver damage. Moreover, clinical research suggests that greater celandine might stimulate immune responses, so might decrease the effects of immunosuppressive therapy [41].

Delta-9-tetrahydrocannabinol

Delta-9-tetrahydrocannabinol (THC) could potentially interact with tamoxifen, letrozole, doxorubicin, cyclophosphamide, paclitaxel, and vincristine. *In vitro* researches show that THC moderately increases levels and adverse effects of CYP2C9 and CYP3A4 substrates [42, 43]. THC intake may also alter levels of drugs that are substrates of P-glycoprotein (P-gp). Most *in vitro* researches suggest that THC can inhibit P-gp and increase the accumulation of probe compounds by reducing P-gp-mediated drug efflux [44, 45].

Selenium

Selenium may interact with cyclophosphamide. Preliminary clinical studies suggest that selenium intake may stimulate the immune system and may reduce the effectiveness of immunosuppressant therapy [46].

Turmeric

Turmeric can theoretically interact with every drug selected in this review. *In vitro* and animal research

Table 2. Potential interactions between herbal medicines and anticancer agents

	Tamoxifen	Letrozole	Exemestane	Doxorubicin	Cyclophosphamide	Epirubicin	Paclitaxel	Docetaxel	Carboplatin	Methotrexate	Mitomycin	Vincristine
Black seed	CYP2C9				IMM							
CBD	CYP2C9 CYP3A4 UGT	CYP2C19 CYP3A4	CYP3A4	CYP3A4	CYP2C19 CYP3A4		CYP2C8 CYP3A4	CYP3A4				CYP3A4
Chaga					IMM							
Dandelion	UGT			UGT								
Evening primrose	CYP2C9											
Greater celandine	CYP2D6 HEP				HEP IMM					HEP		
THC	CYP2C9 CYP3A4 P-gp	CYP3A4		CYP3A4 P-gp	CYP3A4		CYP3A4 P-gp					CYP3A4 P-gp
Selenium					IMM							
Turmeric	CYP3A4 HEP P-gp	CYP3A4	CYP3A4	AE CYP3A4 P-gp	AE CYP4A4 HEP	AE	CYP3A4 P-gp	CYP3A4	AE	HEP	AE	CYP3A4 P-gp
Vitamin C				AE	AE	AE			AE		AE	
Vitamin D	CYP3A4	CYP3A4	CYP3A4	CYP3A4	CYP3A4		CYP3A4	CYP3A4				CYP3A4
▨	No expected interaction			☐	Theoretical interaction			🟧	Potential clinical interaction			

Red — inhibition; green — increase; violet — controversial in references

AE — antioxidant effects; CBD — cannabidiol; CYP2C9 — cytochrome P2C9 (etc.); HEP — might increase the risk of hepatoxicity; IMM — interfere with immunosuppressive therapy; THC — delta-9-tetrahydrocannabinol; UGT-UDP — glucuronosyltransferase show that consuming turmeric might increase levels metabolized by CYP3A4 [47, 48]. *In vitro* and animal studies show turmeric intake might also increase the absorption of P-glycoprotein substrates and hold potency to cause herb-food interactions [49, 50]. Turmeric has antioxidant effects. Theoretically, this may reduce the activity of chemotherapy drugs that generate free radicals. However, research is conflicting [51].

A small clinical trial in patients with breast cancer taking tamoxifen shows that co-treatment with curcumin could lower endoxifen concentrations below the threshold for efficacy (potentially 20–40% of the patients) [52]. Additionally, a few case reports show that turmeric consumption may increase the risk of liver damage when hepatotoxic drugs are prescribed, especially when taken in high doses [53, 54].

Vitamin C

Vitamin C could potentially interfere with doxorubicin, cyclophosphamide, epirubicin, carboplatin, and mitomycin. The antioxidant effects of vitamin C might reduce the effectiveness of antitumor antibiotics. More evidence is needed to determine the effects that vitamin C could potentially have on chemotherapy because there are many opinions about the risks or benefits of antioxidant supplementation [55].

Vitamin D

Vitamin D intake might interact with tamoxifen, letrozole, exemestane, doxorubicin, cyclophosphamide, paclitaxel, docetaxel, and vincristine. Vitamin D might affect CYP3A4 enzyme activity and reduce the bioavailability of CYP3A4 substrates. *In vitro* research suggests that vitamin D induces CYP3A4 transcription [56].

Discussion

Social networks such as Facebook provide access to health-related information and enable communication between people with similar health problems. However, the unmet needs of patients to manage their symptoms, coupled with a desire to use natural methods to improve their health, mean that patients seeking guidance on complementary health approaches may result in making decisions based on recommendations gathered from resources of varying credibility without any professional education. The Internet is a significant source of health misinformation that threatens public health because it hinders the delivery of evidence-based medicine, as well as negatively impacts the patient–doctor relationship, while the use of unproven therapies is associated with reduced survival [10, 57, 58].

Our research has shown that BC patients commonly seek information on CAM to treat their disease. Herbs, plant products (43.1%), and vitamins and minerals (27.0%) were the most frequently proposed CAM products. These results align with previous study reports on the most commonly used CAMs by patients [59, 60]. Natural compounds derived from plants have provided a range of useful chemotherapeutic drugs for malignant tumors due to their wide range of anti-cancer effects, and vitamin or mineral deficiencies are observed among BC patients. However, most of the evidence cited confirms that the CAMs recommended by Facebook users are not effective and most may lead to interactions with conventional drugs. The quality of herbal products and the lack of strong scientific evidence currently make integrating them into conventional cancer care practices difficult. A factor that complicates the assessment of the quality and safety of herbs and other plant products is their complexity and high variability.

Clinical studies reviewed in the present study citing in favor of CAM for BC show that products such as flaxseed [23] and vitamin C [24, 25] can be used to support the effects of conventional medicinal products. However, these products are not able to produce a therapeutic effect on their own as suggested by the group members. In addition, some of these products were effective or ineffective depending on the type of BC and whether the study patients were pre-menopausal or postmenopausal.

The results of the present study showed that the CAM products proposed by the community of Facebook groups can lead to interactions with conventional treatment. The results demonstrate that four of the CAM-drug interactions reveal potential clinical interaction and forty-five present hypothetical interaction risk. Additionally, proposed CAM treatments included methods such as castor oil poultice, yellow tulip bulb-ointment, recall healing, and baking soda poultice, for which the review found no credible scientific evidence of their effectiveness. It has also been observed that part of the Facebook group community discourages BC patients from using conventional medicine, which can result in a much lower chance of survival [58, 61].

The results ofthis research indicate that the CAM methods proposed by the Facebook community groups did not include mind-body practices such as yoga, meditation, acupressure, or relaxation techniques, which have proven effectiveness and safety in reducing the effects of common problems experienced by BC patients, including chemotherapy-induced nausea and vomiting (CINV) [62, 63], anxiety and depression [64, 65], pain [66–69] or which improve the quality of life [64, 65, 70–72]. In addition, it was observed that the advice posted by the community groups did not include information on potential CAM-drug interactions or questions about whether and/or what conventional treatment is currently used among respondents seeking additional treatment methods.

The search for additional information and the use of CAM methods to treat and manage the symptoms of the disease and/or meet the psychological needs of many patients (which is associated with improved optimism and prospects), can affect recovery and potential cancer treatment outcomes [73]. Therefore, healthcare professionals must discuss the use of CAMs with patients, not only by discouraging ineffective and unsafe methods but also by recommending CAMs, the effectiveness and safety of which are scientifically proven. It is also important to increase the social media activity of medical CAM specialists to promote integrative oncology — a patient-centered, evidence-based field of cancer care that uses mind-body practices, natural products, and/or lifestyle modifications in addition to conventional cancer treatment derived from different traditions [2].

Strengths and limitations

The strengths of these studies require further consideration. First, to the best of the authors' knowledge, this is the first study to assess the phenomenon of Polish BC patients seeking information on CAM on the Facebook platform. It is also worth noting that the analyzed posts came from the period of the COVID-19 pandemic, when anti-epidemic procedures were in force, blocking women's access to formal healthcare facilities, which probably allowed them only partially to assess the scope of seeking direct advice from BC patients. On the other hand, for patients, perhaps it was a period of increased activity on FB groups as a form of meeting their health needs due to social isolation procedures during the pandemic. Second, the present work is also the first to assess whether the proposed CAM advice in Facebook groups is safe and effective, and it was done so by utilizing the credibility of the EBM evidence.

Nevertheless, this study has several limitations. Firstly, the study's design does not allow us to determine exactly which of the recommended CAM methods will be employed by BC patients. Secondly, it was not possible to obtain information on what conventional treatment they were currently receiving from posts by BC patients, so it was impossible to assess the exact risk of an interaction between CAM and conventional treatment. Thirdly, the safety and efficacy analysis of the recommended CAM methods was not a systematic review; therefore, not all information about the individual methods was disclosed. In addition, only posts from groups that were visible in the Facebook search engine and in which the administrator allowed the analysis of posted content were considered in the data collection process. Finally, the analyzed content did not include information on fan pages and other portals or forums outside the Facebook platform.

Conclusions

Currently, searching for information on CAM on Polish-language Facebook groups by BC patients poses a risk of obtaining advice of unproven effectiveness. In addition, patients are exposed to suggestions to take products that may interact with conventional treatment or may be persuaded to give up traditional treatment. There is a need to improve communication between BC patients and healthcare professionals about safe and effective CAM methods and the risk of CAM-drug interactions.

Cancer care providers should consider the complexity and implications of the unmet need for information and support for BC patients that result in seeking CAM advice on Facebook groups. On the other hand, measures should be taken to ensure that BC patients can also find reliable evidence on CAMs online in online forums and groups. Incorporating evidence-based CAM practices can be an important component of interventions aimed at improving BC patients' quality of life and survival. Further research is needed to determine which CAM methods are safe and effective as an integrative adjunct to conventional cancer therapies. This research can be used as a framework to develop educational materials for providers and patients on integrative oncology.

Article information and declarations

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None.

Ethics statement

The study was conducted by the Declaration of Helsinki. The Bioethics Committee has issued its Ethical Approval at the Medical University of Lublin (decision number: KE-0254/29/02/2022).

Author contributions

Conceptualization: ABJ, BJŚ; methodology: ABJ; formal analysis: ABJ; data curation: ABJ, BJŚ; writing — original draft preparation: ABJ; writing — review and editing: BJŚ, GJN; supervision: BJŚ, GJN; project administration: BJŚ, GJN. All authors have read and agreed to the published version of the manuscript.

Conflict of interest

The authors declare no conflicts of interest.

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Supplementary material

The supplementary material (Tables S1–S4) for this article can be found online at https://journals.viamedica.pl/palliative_medicine_in_practice/article/view/100311.

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Subcutaneous drainage of chronic refractory edema in cancer patients: case presentation

Abstract

Edema is a frequent manifestation in patients with advanced diseases. There is little research on it. The symptomatic impact it generates, the functional limitation, and the decreased quality of life are often underestimated in those affected patients. Many strategies for their management are employed, but the therapeutic response and tolerance are limited in patients with advanced diseases. The following study presents the case of a patient with progressive retroperitoneal sarcoma who develops severe lower limb lymphedema of multifactorial etiology, refractory to treatment, in whom subcutaneous lymphatic drainage was performed with clinical improvement and impact on quality of life. Finally, there is a discussion of the topic and a review of the available literature on the presence of lymphedema in patients with cancer and the different available therapeutic options.

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Keywords: cancer pain, lymphedema, palliative care, quality of life, subcutaneous drainage

Introduction

Lymphedema is an accumulation of proteinaceous material in soft tissues affected by alteration of the lymphatic system for different causes, which favors skin lesions and infections, and affects wound healing [1, 2]. It frequently affects the limbs of patients with chronic oncological and advanced non-oncological diseases, mainly lower limbs, generating marked functional limitations and impact on their quality of life and that of their caregivers, which the medical team frequently underestimates [3]. Different studies have shown that patients with cancer and lymphedema have a greater functional impairment and psychological and social involvement than patients without lymphedema. Additionally, they have many limitations for exhaustive evaluations and conventional treatments [1, 4]. The World Health Organization and the different lymphedema consensus recommend palliative care for lymphedema management in cancer patients [1].

The diagnostic approach should include different etiologies, such as lymphatic obstruction, hypoalbuminemia

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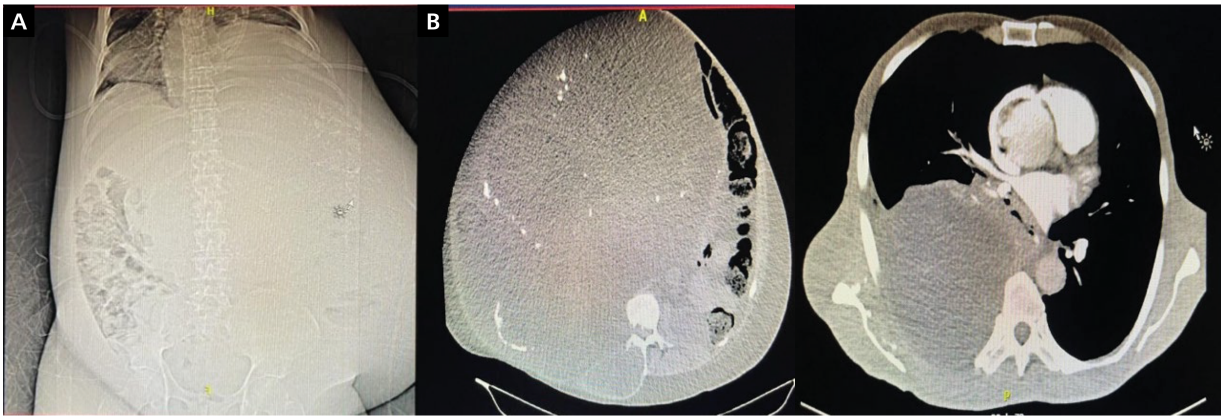

Figure 1. Radiograph (Rx) simple abdomen shows extensive abdominal occupation by tumor mass and displacement of other structures (**A**); computed tomography (CT) angiography of the chest and abdomen shows pleural and pericardial tumor involvement and associated right pleural effusion (**B**)

or diseases with protein loss, heart, kidney, or liver disease, infections, trauma, immobility, and medications. Etiologies such as previous pelvic surgery, radiation therapy, and metastatic lymphadenopathy stand out in cancer patients [5]. The therapeutic arsenal for lymphedema management includes options such as diuretic therapy, steroid use, and mechanical treatment with compressive drainage therapies. Although these types of strategies are often effective, in patients with multiple comorbidities and patients with advanced cancer, in terminal stages or palliative care, they may not be appropriate due to the increased risk of adverse effects and intolerance to them, which faces a more complex situation and requires an individualized and multidisciplinary management [5, 6].

A patient was reported with advanced retroperitoneal neoplasia in progression with severe lower limb lymphedema with marked functional limitation and impact on his quality of life, refractory to medical management, in whom was performed controlled subcutaneous drainage, achieving significant clinical improvement and overall quality of life. This type of intervention in patients with cancer and lymphedema is discussed.

Clinical case

A 48-year-old patient was presented, welder, separated, three children, and lived with a daughter. With a diagnosis of retroperitoneal liposarcoma of 3 years of evolution, he received oncological management with chemotherapy schema MAI (mesna, doxorubicine, ifosfamide). He presented tumor mass progression in 2021. He received a second line of chemotherapy with docetaxel and gemcitabine and later progressed again, and he started immunotherapy with pazopanib. It presented with somatic and neuropathic mixed pain in the abdomen, in place of a large tumor mass, referred to the lower extremities, sarcopenia, and sensation of progressive dyspnea of tumor origin that increased with effort. Chest computed tomography angiography and abdominal computed tomography (Figure 1) showed the absence of pulmonary embolism, 14 × 10 × 13 cm mass that involved right pleura and lung and caused right lower lobe atelectasis, left mediastinal displacement and compression of both atria, extrinsic compression of the source bronchi, intermediate and for the right lower lobe, compression of the inferior vena cava with decreased caliber and obliteration of the right inferior pulmonary vein. In the abdomen, he presented a giant tumor mass of 48 × 36 × 35.8 cm that moved all organs to the left with compression of the urinary tract with dilation of the renal pelvis and collecting groups.

Clinically, the patient with progressive functional decline and dependence associated with abdominal tumor mass growth and severe and progressive lymphedema in lower limbs, limiting, with impact on quality of life, difficulty with urination, and pain of oncological origin. Use of oral morphine at home without improvement. A multimodal hospital analgesic treatment was started with acetaminophen 1 g q8h, pregabalin 75 mg day, hydromorphone 0.4 mg IV 6 h, and rescues of 0.2 mg, supplemental oxygen for dyspnea management and desaturation. A bladder catheter was placed and furosemide 40 mg IV q8h was ordered. Achieved was an improvement of diuresis, better control of pain, and the sensation of dyspnea.

He persisted, however, with severe limiting edema in his lower limbs with a perception of disability. Was a burden to his family and had death wishes. Due to frailty, pain, and disability, no compressive measures were performed, and it was decided, with informed consent, to perform subcutaneous lymphocentesis

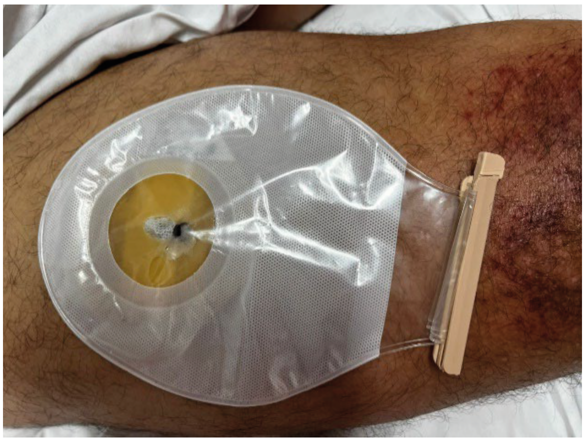

Figure 2. Subcutaneous needles inserted into the patient's thigh, and pediatric ostomy pouches for each needle

Table 1. Lymphoedema Quality of Life Tool (LYMPQOL LEG)

Dominions	Inicio	72 h
Functionality	4	2
Appearance/body image	4	2
Symptoms	4	1
Behavior/emotional	4	2
Overall quality of life	2	6

of lower limbs using a Yelco #18 through sterile technique, one on each thigh connected to pediatric ostomy bags (Figure 2), with drainage of abundant clear fluid and progressive decrease of edema 2 cm in the perimeter of the extremities, allowing to get up and move to the bathroom with support, decreased pain and mood improvement. There were no systemic or infectious adverse effects secondary to subcutaneous drainage. The patient was discharged from the hospital to continue home management with support from a home care plan, subcutaneous lymphocentesis at home, subcutaneous opioid medication with low-dose hydromorphone for pain and dyspnea control, and supplemental oxygen by nasal cannula. Lymphoedema Quality of Life Tool (LYMPQOL LEG) scale is performed before and 72 hours after the intervention, with an assessment of 1 to 4, where a lower score is worse to a higher, and overall quality of life from 0 to 10, where the higher value is the better quality of life. The results showed improvement in the different parameters. Table 1 summarizes the main domains of the scale and the results reported by the patient.

Outpatient follow-up was performed by phone. The patient reported adequate pain control and more comfort for him and his caregivers. He needed a change of the needles due to accidental loss. The patient died two months later.

Discussion

The presence of edema in patients with advanced diseases is generally multifactorial, lymphatic, vascular, hypoproteinemic, or permeability edema, and has been shown to negatively impact the physical and psychosocial well-being and quality of life of patients and caregivers. The prevalence of lymphedema in cancer patients is 10–19%, but with even higher rates in gynecological and breast cancer at 47% and 60%, respectively [7, 8]. In the study patient, a giant retroperitoneal liposarcoma generating compression of lymphatic and vascular structures led to refractory lymphedema in lower limbs. Clinical evidence supports that there is an increase in health costs and a great impact on the quality of life of patients with lymphedema, and it is even worse in the presence of cancer due to the high symptomatic burden, fragility, and deterioration of the general condition, and is also directly related to palliative treatment intent and survival [4, 5, 9, 10].

The diagnosis is essentially clinical. Clinical manifestations of lymphedema are associated with edema, increased perimeter, immobility, and distension of soft tissues. Patients report heaviness, soft tissue tension, somatic and neuropathic pain, paresthesia, and exudation. To these are added psychosocial symptoms such as hopelessness, depression, anxiety, disgust, and isolation, clearly described in the study patient, severely impacting his quality of life [1, 7, 8].

Multiple strategies exist for the management of patients with chronic lymphedema with acceptable response, including limb elevation, compressive bandages, physiotherapy, acualinphatic therapy, medicines such as diuretics and steroids, and surgical treatments, as well as the combination of these strategies [1, 4, 10, 11]. Cancer patients have a greater risk of adverse effects with these measures like renal failure and hypotension secondary to diuretics, infections, steroid immunosuppression, and deterioration of heart failure and dyspnea associated with manual decongestant therapy, and they have less satisfactory responses [4, 5]. In addition, physical, manual, and decongestant therapies require trained personnel to ensure the expected goals [1]. All this generates stress in the medical staff and impotence when the desired results are not achieved. It is essential to have clear information, with education, risk prevention strategies, clear goals to achieve, an adequate risk/benefit balance, early diagnosis and intervention, and an emphasis on quality of life over the complete resolution of lymphedema. All this has been shown to improve adhesion and outcomes [10, 12]. The study patient received pharmacological strategies with steroids and diuretics with poor response, foreseen by the anatomical involvement generated by the large tumor volume that involved intraabdominal vascular structures such as compression of the vena cava.

Several case reports of the use of subcutaneous drainage for the management of chronic lower limb lymphedema have shown benefits in fragile patients with advanced diseases, especially those refractories to conventional measures [2, 5, 8, 9]. Liao et al. [12] reported the therapy of controlled subcutaneous drainage in upper limb lymphedema refractory to decongestant therapy with adequate response in control of the symptoms and functionality.

Controlled subcutaneous lymphedema drainage was first reported by Clein and Purgachev [13] in 8 patients with advanced cancer and lower limb lymphedema, finding improvement in comfort and mobility without associated adverse effects. It is a measure reserved for patients who do not respond to other therapeutic strategies, achieving high success rates, and may also be an option in very fragile patients, prostrate, with poor accompaniment by the health team and absence of caregivers. Some factors that could be considered predictors of response are spontaneous fluid exudation and nonfibrotic lymphedema with fovea [5, 9].

Beck et al. [1] in a systematic review compared controlled subcutaneous drainage, manual lymphatic drainage and multiband decompression therapy, kinesio taping, and the mixture of these manual decompressive therapies in the management of lymphedema in patients with cancer, concluded that all strategies are safe and effective considered individually, notwithstanding the effectiveness cannot be established by the low quality of evidence-based only on case reports and retrospective studies. Grądalski [4] also reported the results of several cases of refractory edema, including cancer patients, managed with venous diuretic and decompressive therapy by trained physiotherapists, with remarkable improvement in the overall discomfort evaluation, improved edema, weight loss, and high adhesion.

Landers et al. [7] in a multicenter prospective observational study evaluated outcomes and impact on quality of life with the treatment of subcutaneous drainage in patients in hospice with refractory lymphedema, and they employed the LYMQOL scale, which is a validated scale to evaluate physical, emotional, and functional aspects in patients with lymphedema. They found improvement in edema, weight loss and perception of appearance, emotional symptoms, functionality, and pain control. The rate of adverse events was 20%, mainly erythema, 2 cases of erysipelas, and 2 cases of acute renal failure. The study patient reached favorable results of subcutaneous drainage in lymphedema management in the overall assessment of quality of life and domains such as self-care, pain, and psychosocial aspects, reported using the LYMPQOL-scale LEG is a validated scale for reporting outcomes and impact on the quality of life of patients with lymphedema [14]. The degree of dependence remains very important in the context of advanced disease without an option for oncological management. No systemic or infectious adverse effects occurred.

There are no standardized recommendations or guidelines about controlled subcutaneous lymphedema drainage in patients with advanced diseases, especially cancer patients, and multiple protocols are employed in case reports of patients with lymphedema with different types of cancer that do not respond to other measures [5]. A different number of needles, the size of needles, butterflies, and yelco of different calibers also varies, and from 1 to 10 subcutaneous catheters. Improved edema, mood and mobility, weight loss, pain control, and comfort were reported outcomes. Instead, the different studies described minimal adverse effects, acute renal failure secondary to abundant fluid drainage, transient subcutaneous fistula, and recurrence of edema after catheter removal. The infection rate varies between 6 and 30%, but is considered low, and in many cases, the presence of erythema as a diagnostic criterion is explained by lymphedema [5, 7]. In the study, the patient used two yelco connected to pediatric urostomy bags. The patient tolerated the procedure well, and no complications occurred.

More evidence is needed based on better methodological quality studies, especially in cancer patients and palliative care since patients with lymphedema in palliative care tend to have advanced and sometimes end-of-life diseases, high fragility index, high symptomatic load, cognitive alterations, rapid deterioration, which makes them have poor tolerance to conventional treatments and difficult to recruit, randomize and follow for clinical studies. From an ethical point of view, based on the limited evidence available, subcutaneous drainage should be considered an off-label strategy, individualized in well-selected patients, and should have informed consent and clarity in risk/benefit uncertainty [2, 10].

Palliative care can support the management of these patients based on their philosophy of comprehensive care for patients and caregivers, communication process, education, transition from care to home, multidisciplinary management, symptom control, and emphasis on quality of life.

Conclusions

Chronic lymphedema of lower limbs is a very prevalent symptom in patients with oncological diseases, and health personnel should be aware because this affects their quality of life negatively. They are also fragile patients and usually do not tolerate multiple treatments. For this reason, it is necessary to highlight the importance of subcutaneous lymphocentesis of the lower limbs, which impacts the patient`s symptomatology with minimal adverse effects. Although there is not enough published information, it creates the need for medical personnel to know this procedure as a therapeutic option in individualized patients with refractory chronic lymphedema in the lower limbs.

Article information and declarations

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Author contributions

All authors contributed to the development of the article.

Conflict of interest

All authors declare that they don’t have a conflict of interest.

Ethics statement

The article was reviewed and approved by the hospital’s ethical committee.

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Supplementary material

None.

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Case report

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Concurrent pleural and pericardial effusions in advanced lung adenocarcinoma

Abstract

Lung adenocarcinoma is a common malignancy that often spreads to different organs, such as the pleura and pericardium. The concurrent presence of pleural and pericardial effusions often signifies an advanced stage of the disease. This case report delineates the presentation of a 71-year-old male diagnosed with advanced lung adenocarcinoma complicated by concurrent pleural and pericardial effusions. Diagnostic imaging and cytological analysis confirmed the diagnosis, guiding subsequent treatment. Pericardiocentesis and thoracentesis were initiated to alleviate symptoms and improve quality of life. The case underscores the complexities involved in managing advanced lung adenocarcinoma accompanied by pleural and pericardial involvement.

Palliat Med Pract 2024; 18, 4: 250–254

Keywords: pleural effusion, pericardial effusion, adenocarcinoma of lung

Introduction

Lung cancer is a prevalent malignancy with a considerable risk of mortality and the potential to metastasize to various organs [1]. The concurrent occurrence of pleural and pericardial effusions is more frequently associated with malignancy than pericardial effusions alone [2]. The following description pertains to a patient diagnosed with stage IVA non-small cell lung cancer, specifically adenocarcinoma, along with left pleural effusion and pericardial effusion.

Case presentation

A 71-year-old male presented to the Emergency Department complaining of progressively worsening shortness of breath over the past week, particularly notable in the last 3 days. His breathlessness was

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Table 1. Laboratory results of complete blood count and blood chemistry upon admission

Parameter	Results	Reference range
White blood cell count (× 10^9/L)	11.0	4.0–11.0
Haemoglobin (g/dL)	11.1	12.0–16.0
Platelet count (× 109/L)	338	150–400
Random blood glucose (mmol/L)	5.4	7.8–11.1
Aspartate transaminase (U/L)	23	< 38
Alanine transaminase (U/L)	16	< 41
Sodium (mmol/L)	136	136–145
Potassium (mmol/L)	4.4	3.5–5.1
Urea (mmol/L)	4.9	2.5–7.8
Creatinine (μmol/L)	54.8	44–78

constant and unaffected by activity or weather. He reported a week-long cough with thick white sputum containing blood, along with hoarseness persisting for the past 6 months. Despite a history of weight loss amounting to 6 kg over the last 3 months and a smoking habit of 12 cigarettes per day since adolescence, there were no signs of bleeding, fever, night sweats, or black stools. On physical examination, he appeared moderately unwell and malnourished, with a body mass index (BMI) of 18 kg/m^2, a respiratory rate of 24 breaths per minute, and SpO_2 at 99% with 3 liters per minute of supplemental oxygen. Clinical examination revealed notable findings, including a firm, non-tender left supraclavicular gland enlargement, decreased left chest expansion, and diminished breath sounds in the left basal lung, among others. Abdominal examination was unremarkable.

The complete blood count and blood chemistry at admission were within normal limits (Table 1). Thoracic multislice computed tomography (MSCT) with contrast at admission revealed a left lung mass in the left upper lobe, bilateral pulmonary nodules, bilateral lymphadenopathy, left pleural effusion, pericardial effusion, and aortic dilatation and atherosclerosis (Figure 1). Cytomorphological evaluation of pleural fluid on the second day of treatment revealed reddish-yellow fluid totaling 70 mL (in 2 specimens). The malignant cells consisted of groups of cells with glandular and papillary formations, coarse nuclear chromatin, irregular nuclear edges, sufficient cytoplasm with a mesothelial background, and the presence of lymphocytes and erythrocytes. Malignant cells indicative of adenocarcinoma were identified at the conclusion of the smear. Echocardiography on the second day of treatment concluded massive pericardial effusion, approximately 850 mL in volume, with signs of impending cardiac tamponade, impaired right ventricle (RV) diastolic filling due to the massive pericardial effusion (volume sekitar 8,560 mL), normal left ventricle (LV) systolic function [with an ejection fraction (EF) of 62.3% by biplane], normal RV systolic function, TAPSE of 2.3 cm, and global normokinetics. Based on the medical history, physical examination, laboratory, and other supportive tests, and the results of the consultation with the cardiology department, this patient was diagnosed with adenocarcinoma of the lung, T2aN3M1a stage IVA, ECOG 3, with left pleural effusion and pericardial effusion secondary to malignancy.

On the second day of treatment, the patient underwent thoracentesis due to indications of right-sided pleural effusion, yielding 900 mL of cloudy yellow fluid, which was subsequently analyzed biochemically. The analysis resulted in classification as an exudate due to its yellow purulent nature, high protein content, high cell count, and elevated lactate dehydrogenase levels. On the third day of treatment, the patient was diagnosed with lung adenocarcinoma based on the results of pleural fluid cytology. The patient was referred to the cardiology department for management. Pericardiocentesis was performed with a single puncture and a drain was left in place, allowing for continuous drainage. For four days, a total of 850 mL of hemorrhagic fluid was removed. A second pericardiocentesis on the sixth day yielded an additional 109 mL of hemorrhagic fluid. Due to recurring effusions, it was decided to use a Robinson drain during a second thoracentesis performed on the twelfth day, successfully sparing the patient from further procedures by extracting 1,700 mL of cloudy yellow fluid. Samples of the pleural effusion were then examined for EGFR mutations. Following the second thoracentesis, the patient experienced reduced shortness of breath. At the next visit, this patient was scheduled for chemotherapy. EGFR testing revealed no mutations. The patient was prepared for chemotherapy with a regimen consisting of carboplatin 385.9 mg on day one and pemetrexed 747 mg on days 1 and 8.

Discussion

Lung tumors, primarily categorized into small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC), constitute 95% of all lung cancers. This classification assists in treatment selection and prognosis prediction. NSCLC, representing 85% of cases, includes adenocarcinoma, squamous cell carcinoma, and large cell undifferentiated carcinoma subtypes [3]. The revised classification now divides lung adenocarcinoma into three distinct groups: adenocarcinoma *in situ* (AIS), minimally invasive adenocarcinoma (MIA), and invasive adenocarcinoma. The term bronchoalveolar cell carcinoma (BAC) is no longer included [4].

Pleural metastases are characterized by direct invasion as the main feature, whereas pericardial metastases primarily appear as tumor cells floating within the cavity or as lymphatic emboli rather than by direct invasion of the underlying fibrous tissue [5]. Previous studies have shown that cytology is more accurate than histopathology in diagnosing pericardial effusion as pericardial metastases [6]. This is in contrast to pleural effusions, where pleural fluid cytology has a diagnostic yield of 60% for carcinoma, and medical thoracoscopy exceeds 93% for biopsy specimens [7]. The absence of mutations identified in a diagnostic sample obtained at initial presentation may change as the tumor progresses or in response to chemotherapy [8]. The initial diagnostic workup included MSCT with contrast, which revealed characteristic findings of advanced NSCLC, including a left lung mass, bilateral pulmonary nodules, and bilateral lymphadenopathy, along with left pleural and pericardial effusions. Cytomorphological evaluation of pleural fluid confirmed the presence of malignant cells indicative of adenocarcinoma, supporting the diagnosis. In the present case, EGFR testing was performed, but no mutations were identified in the diagnostic sample obtained at the initial presentation.

Pericardial effusion has emerged as an independent prognostic factor for mortality in lung cancer [9]. Among individuals diagnosed with NSCLC, patients with mild pericardial effusion typically exhibit better survival outcomes compared to those with significant pericardial effusion [10]. Furthermore, recent investigations have linked concurrent pleural effusion, positive cytology, and NSCLC to unfavorable prognostic outcomes through multivariate Cox regression analysis [11]. Recent studies have also suggested that local chemotherapy, with or without systemic chemotherapy, in conjunction with pericardiocentesis, may offer superior efficacy compared to other treatment modalities [12].

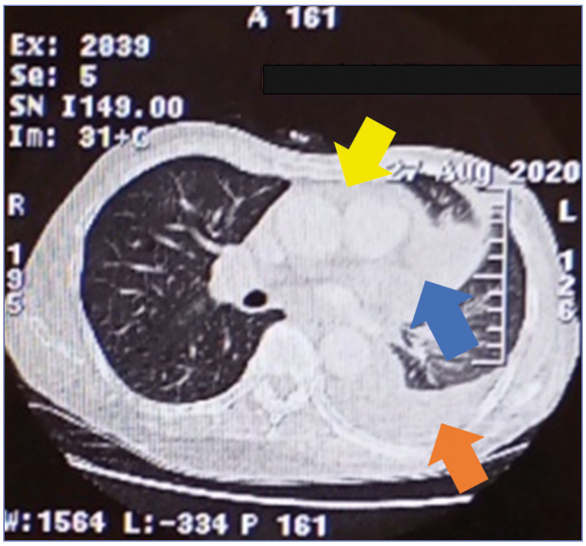

Figure 1. Thoracic multislice computed tomography (MSCT) with contrast at admission. The blue arrow indicates a left lung mass in the left upper lobe, the brown arrow indicates left pleural effusion, and the yellow arrow indicates pericardial effusion

In managing advanced or metastatic NSCLC, the NCCN tailors treatment plans based on patient performance. Those with performance statuses of 0–1 receive category 1 therapies, like pembrolizumab combos. Performance status (PS) 2 patients are directed to carboplatin/pemetrexed regimens. PS 3–4 prioritize supportive care. Pemetrexed is favored in maintenance, alongside category 1 choices such as bevacizumab, pemetrexed, or pembrolizumab combos [13]. Despite the presence of complications and concurrent medical conditions, elderly individuals with a favorable Eastern Cooperative Oncology Group performance status (ECOG PS) frequently have opportunities to continue chemotherapy. When considering treatments for elderly patients, preference is given to medications with minimal cardiovascular and renal toxicity, as well as those lacking significant adverse effects or notable drug interactions [14]. Theoretically, the combination of pemetrexed and carboplatin holds promise as an optimal regimen for elderly patients with advanced non-squamous NSCLC. Notably, there have been no significant disparities observed in the pharmacokinetics of pemetrexed across age groups ranging from 26 to 80 years [15].

The ECOG PS score of the study patient stands at 3, denoting the capability to execute only limited self-care activities. The treatment approach emphasizes delivering comprehensive supportive care meticulously customized to address their individual condition and requirements. Acknowledging the obstacles presented by their performance status, the authors have elected to pursue a treatment protocol incorporating a combination of chemotherapy with carboplatin and pemetrexed. Additionally, it is imperative to engage in discussions regarding therapeutic options specific to a given country and substantiate treatment choices within the framework of available resources and healthcare norms. Subsequent research endeavors could explore the efficacy of varied treatment regimens and their ramifications on patient outcomes.

Conclusions

Concurrent pleural and pericardial effusions in advanced lung adenocarcinoma pose diagnostic and therapeutic challenges. The present case underscores the importance of a comprehensive diagnostic approach, including cytological analysis, imaging modalities, and molecular testing, in guiding appropriate management strategies. Early recognition and intervention, such as pericardiocentesis and systemic chemotherapy, are crucial for optimizing patient outcomes and improving quality of life.

Article information and declaration

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Author contributions

The authors have contributed equally.

Conflict of interest

The authors declare that no conflict of interest.

Ethics statement

The patient's relative permitted the authors to publish the manuscript and signed the informed consent form.

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Supplementary material

None.

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Robert G. Twycross (1941–2024) — the pioneer of palliative care

> *…I've also recognized what Twycross repeatedly talked about — the importance of the small things.*
> Jacek Łuczak [1]

"Thank you very much for your letter of 5th April. I am most interested in your thought that perhaps this will eventually be your own field" [2] — this is what Dame Cicely Saunders wrote to the then 25-year-old Robert Geoffrey Twycross, a medical graduate from Oxford, whom she had met two years earlier while still a student. It was then that Twycross established the Radcliffe Christian Medical Society at his University so that he could invite Dame Cicely Saunders to give a lecture on her plans to organize modern care for the dying. The idea of Robert Twycross, which Saunders eagerly picked up, became a reality. He could write about himself at the end of his life: "I am one of the pioneers of hospice and palliative care in the UK" [3].

Just a few weeks ago, on 20th October 2024, Robert G. Twycross passed away peacefully at his home, surrounded by his loved ones. The funeral took place on 15th November at All Saints' Church in Headington. In addition to his family and friends, it was attended by colleagues and students of Dr. Twycross, and probably hundreds of doctors and nurses involved in palliative care in many places around the world watched it broadcast via the Internet. Dr. Robert G. Twycross was another representative of the outgoing generation of palliative and hospice care pioneers. His special relationship with Poland deserves commemoration [4].

When Robert G. Twycross came to Milan for the first Congress of the newly established European Association for Palliative Care (EAPC) in 1988, he met there three Polish doctors: the already known to him Dr. Zbigniew Żylicz, working in the Netherlands, Dr. Grażyna Zengteler from an informal voluntary home hospice (the third in Poland) established by the parish of St. John Cantius in Poznań, and Prof. Jacek Łuczak, a cardiologist and anesthesiologist who was just starting his palliative journey. In 1987, he succeeded in setting up the first Polish pain clinic for cancer patients — at the University Hospital in Poznań, where he worked, and then a palliative care team to provide multidisciplinary palliative care to patients and their

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families at home [1, 5, 6]. Two doctors from Poznań were able to come to Milan thanks to scholarships from the International School for Cancer Care established by Dr. Twycross a year earlier [1]. This was the beginning of a long friendship and very fruitful years of cooperation.

In 1988, Dr. Robert G. Twycross was already well-known in the world of palliative medicine, mainly as a researcher and a colleague of Dame Cicely Saunders. In the first half of the 1970s, he worked at St Christopher's Hospice in London established by Cicely Saunders in 1967 — the first modern hospice in the UK, which became the model for the worldwide hospice movement. Inspired by her, Dr. Robert Twycross conducted scientific research comparing the analgesic effectiveness of morphine and diamorphine (heroin) [7, 8]. The results of his studies led to the introduction of orally administered morphine to international standards for the treatment of pain in cancer patients. When, on the initiative of Jan Stjernswärd, the Working Group for the development of cancer pain relief standards at the WHO was established, Robert Twycross played a key role in that project. He is considered the author of the key principles in the recommendations first published in 1986 [9], which still form the basis of pain management theory today, not only in cancer patients but also in patients with chronic pain of non-cancer origin. The next 1990 edition was the basis of the Polish version — Cancer Pain Relief and Palliative Care. Report of the WHO Expert Committee, Geneva 1990, Polish edition Kraków, 1994.

In 1976, one of the first NHS-funded hospices in the UK — Sir Michael Sobell House — was established in Oxford. Dr. Robert Twycross was initially the Medical Director of the unit (until 1987), and from 1988 to 2005, he was the Director of the World Health Organization's Collaborating Centre for Palliative Care established at the Oxford Hospice. Dr. Robert Twycross was a tireless lecturer in the field of palliative care in Oxford, as well as in over 40 countries around the world, including Poland. He made Sir Michael Sobell House one of the most important centers of education in the field of palliative care and medicine at that time. Over the following years, palliative care pioneers from most European and many non-European countries would come to Oxford. In the mid-1990s, Dr. Robert Twycross organized pioneering international courses for palliative care leaders from all over the world. In line with the idea of multidisciplinary team work, nurses, physicians, psychologists, and other staff underwent joint theoretical and practical training at the patient's bedside, under the watchful eye of Dr. Twycross and his team. The lecturers from Sir Michael Sobell House Hospice were not only physicians but also nurses, psychologists, sociologists, and clergymen.

Robert Twycross, Jacek Łuczak, and lectures and participants in the international palliative care course, Ląd, 1992

The cooperation between Dr. Robert Twycross and Prof. Jacek Łuczak, initiated at the meeting in Milan, lasted more than 20 years. In November 1988, Dr. Twycross came to Poznań for the First National Congress of Palliative Care, organized by the newly formed team led by Prof. Jacek Łuczak [5, 10]. In 1989, the first Palliative Care and Intensive Oncological Therapy Department was established in Poland, within the structure of the Chair of Oncology of the Poznań University of Medical Sciences. Education of medical students began in 1990, and it was one of the first pre-graduate programs of that type in the world [11, 12]. Twycross and Łuczak signed a cooperation agreement between Sir Michael Sobell House and the Poznań University of Medical Sciences. This resulted in a series of post-graduate courses in palliative care (Advanced Courses in Palliative Care). From 1990 to 2002, they were organized in Ślesin, Ląd, Krasnobród, Olcza, and from 1994 in Puszczykowo [5, 10, 13].

The courses were run by Prof. Łuczak's Department and Robert Twycross was their scientific director, later with the assistance of Prof. Łuczak, Dr. Michael Minton, and Prof. Zbigniew Żylicz. The participants of the courses were physicians, nurses, psychologists, and healthcare managers, not only from Poland but also from many other countries, especially from Central and Eastern Europe (*e.g.* Lithuania, Slovakia, Hungary, Serbia, and Romania). Today, it is difficult to determine the exact number of international participants in these tiraining courses, which were meticulously prepared by Robert. The "paper" records have not survived. Approximately 40–80 people attended each course and many of them established the first palliative and hospice care units in their cities and countries in the following years. The training program was developed jointly by Dr. Twycross and Prof. Łuczak. New themes and educational plans for the following years were determined at each conference. Current topics that were addressed during the courses were based on first studies that were published in this developing field.

Particular attention was paid to difficult cases of pain treatment ("intractable pain"). During the courses, participants shared the experiences in the use of opioids (*e.g.* tramadol) and analgesic adjuvants (*e.g.* ketamine) in the treatment of cancer and non-cancer pain, which was a novelty at that time. Further experience gained by participants was discussed in consecutive years.

During the courses, Dr. Twycross took on the roles of scientific director, lecturer, discussion moderator, and… inquisitive student. He thoroughly analyzed every topic covered, paying attention to the smallest details. He was guided by the "attention to detail" principle — a basic rule in pain treatment. There was no place for inaccuracy. He was regarded by most participants as an excellent teacher. His lectures were systematic and clear. During informal discussions, he asked course participants for their opinions on the topics of his lectures. He encouraged undertaking research. He was truly respected. Thanks to him, the world's best experts in the newly emerging specialty were invited to lecture on the courses (*e.g.* Prof. Vittorio Ventafridda, Prof. Kathleen Foley, Prof. Irene Higginson, Prof. David Clark, Prof. Sam Ahmedzai, Prof. David Oliver, Dr. Michael Minton, Prof. Zbyszek Żylicz, Dr. Steven Passik, Prof. Ruben Bild, and Dr. Phyllis R. Silverman). Robert's enthusiasm for developing of palliative care was "contagious", inspiring, and energizing. Robert encouraged educating healthcare professionals, hospice staff, and students in the field of symptom management and palliative care. The courses organized in Puszczykowo were followed by local or wider-range programs managed by hospice associations and emerging palliative care teams. The subject "palliative care"/"palliative medicine", first taught at the University in Poznań, found its way to other universities where both physicians and nurses were educated. One can say that the current expertise in palliative care and education in palliative medicine in Poland would not be possible without Dr. Robert Twycross [12, 14, 15].

Dr. Robert Twycross spread the idea of palliative care, continuing and developing the work of Dame Cecily Saunders, lecturing at many international conferences in Europe, America, and Asia (*e.g.*, he participated in palliative care training courses in India for many years). In his late years, he supported the development of palliative care in the former Soviet Union countries. He visited Poland several times in the last decades of his life, including as a guest of honor at the conferences of the Polish Society of Palliative Medicine (PTMP) in 2008 and 2012; he was awarded the title of Honorary Member of the PTMP in 2011. In June 2016, Dr. Robert Twycross was a speaker at the 9th conference of the journal *Palliative Medicine in Practice* combined with the 20th Anniversary of the Department of Palliative Care of Collegium Medicum in Bydgoszcz. He was a Member of the Scientific Council of *Palliative Medicine in Practice* for several years.

Dr. Robert Twycross played a key role in the recognition of palliative medicine as a medical specialty in the UK (1987), and other countries (Poland was the third country to introduce a medical specialty in palliative medicine, in 1999, and the first specialists passed the exam in 2003) [16]. He developed the first curricula for medical students. He was the author of many books and articles on palliative care and pain management published in the years 1968–2024. The first publications on the treatment of patients with advanced cancer that appeared in Poland were translations of Dr. Robert Twycross's works. His lectures were translated by Prof. Zbigniew Żylicz [17], and the textbook of which Dr. Twycross was a co-author (together with Sylwia Lack), the first one in that field on the Polish market, was translated by the physicians from the Hospice Pallotinum in Gdańsk — Mr. and Mrs. Stolarczyk [18]. The most important collective work, initiated in 2000 and still being developed by the Doctor's colleagues — Dr. Andrew Wilcock and Dr. Sarah Charlesworth, seems to be the compendium of pharmacotherapy in palliative care — Palliative Care Formulary (latest 8th edition, 2022) [19].

Dr. Twycross, consequently, throughout his life, opposed euthanasia and decriminalization of the so-called assisted dying [3] — from his earliest articles written while still a student, through statements submitted to the British Parliament, to positions developed in hospice care communities. The last article written by Robert on the issue of assisted dying was published in April 2024 [20]. Robert was a very religious person, living according to the principles of the Bible. It is a little-known fact that after his retirement as a physician, he was involved in preaching in the Anglican Church for a few years [21].

Robert had an interesting view on the unique role that palliative care should have in medicine. He believed that, despite the significant development, there should remain the original enthusiasm and freshness: "In palliative care, the number of followers is no longer small, and routinization has already occurred in countries where palliative care has become established. However, palliative care continues to need the creative and disruptive influence of charisma. Most palliative care programs have not yet reached the goal of truly holistic care. If palliative care is to continue to develop, an ongoing creative tension between charisma and routinization is necessary. Otherwise, the palliative care movement of the late 20th century will degenerate, like so many other movements before it…" [22] — these words of Dr. Robert Twycross, written over twenty years ago, remain relevant today.

Dr. Robert Twycross never sought titles or honors. He approached each successive project with commitment and English sense of humor. Privately, he was a warm, understanding, and very hospitable man, a friend to many, husband to Deidre for 60 years, father to five children, and grandfather. The reminiscences and thanks published after his death prove how much he was appreciated and loved.

Article information and declaration

Conflict of interest

The authors declare that there is no conflict of interest.

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To the memory of Robert Geoffrey Twycross 1941–2024

On the evening of the 20th of October, at home, surrounded by his family, Robert passed away at the age of 83. He was one of the most inspiring clinical teachers we ever met. For many years, he was our mentor. He was always interested in what we were doing and what we were writing. Sometimes, we were writing something together, using his profound knowledge and experience in editing. He was somebody who was always learning, usually by writing.

One of us (Zbigniew Żylicz) met him for the first time in 1988, in Milan, Italy, at the first "unofficial" European Congress on Palliative Care. The other one of us (Małgorzata Krajnik) met Robert a couple of years later. After this Congress, the attendees founded the European Association of Palliative Care (EAPC). I (Zbigniew Żylicz) eagerly sought Robert to get acquainted with him. The idea was to invite Him to Poland to help develop palliative care there. And Robert agreed to this immediately and with great enthusiasm. Afterward, he visited Poland many times and inspired many doctors and nurses, among them us, to commit ourselves to a career in palliative care. Robert frequently invited us to participate in his courses at Oxford. It was his way to keep in contact with us. Initially, we were invited as students, but later, as speakers and members of expert groups, he was leading. There were fascinating discussions on pain and opioids, nausea and vomiting, pruritus, and many more.

After each such meeting, participants wrote a paper on the subject and presented a state-of-the-art paper that was published. Once, we were both intrigued by a patient in my (Zbigniew Żylicz) Dutch hospice, Rozenheuvel, who was suffering from severe itch and tried to commit suicide because of this. He responded to paroxetine given to him in anticipation of psychological depression. To our surprise, the patient responded to this treatment with a complete remission of the itch. When we shared this with Robert, he suggested collecting more similar cases and later doing a clinical trial. Robert spiked our interest in itch for many years. At a particular moment, we proposed Robert writing a textbook on itch. He then confessed that all his knowledge on this subject could be summarized in half a page. Despite this, he agreed to work on the textbook. He organized a meeting of renowned experts in Oxford to learn more about the subject. The Conference, again, resulted in a state-of-the-art paper, best-cited ever, and a book written by the experts and edited by us.

Of course, he was mentoring many more doctors worldwide, including India, Germany, Netherlands, Belgium, Russia, and Ukraine. He had unbelievable and inexhaustible energy for traveling and lecturing. Students and listeners were giving him power. They were winding him up. One of the most exciting journeys was to Chengdu, China in 2005. We were

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Figure 1. Walking through the Oxford fields — Deirdre Twycross, Robert Twycross and Małgorzata Krajnik

Figure 3. Tour of the Tatra mountains in Poland

Figure 2. Tour of the Tatra mountains in Poland — from right: Robert Twycross and Małgorzata Krajnik with two other course attendees

Figure 4. Tour of the Tatra mountains in Poland. On the foreground Michael Minton and Robert Twycross

teaching (Zbigniew Żylicz), with Robert as lead, a group of 250 palliative care physicians for a couple of days. Exhausting, but certainly rewarding.

We visited Oxford frequently, staying sometimes at His home in Headington, Oxford, welcomed by Robert and Deirdre. In 1994, I (Zbigniew Żylicz) opened a new hospice, Rozenheuvel, in the Netherlands. Although I was rather experienced as an internist in hospital medicine, I sometimes needed to call Robert and chat with him about my dilemmas and complex patients. He was always willing to help and to discuss, which was enormously helpful in a country (the Netherlands) just beginning to get interested in palliative care.

At a particular moment, from Roberts' students, we became teachers to others in our countries. We copied a lot from Robert's style of teaching. We shall always remember how Robert inspired us and helped us to develop our interests for the benefit of others. We shall miss him.

At the end, we want to share some photos of Robert showing Him in the different roles he played: as a mentor, teacher, and spiritual man who trusts God and contemplates life. I (Małgorzata Krajnik) will always remember those walks through the Oxford fields while Robert asked me about my work and different problems (Fig. 1). During that marvelous tour of the Tatra mountains in Poland, we had time for great fun and deep reflections (Fig. 2–4). I am especially grateful to him for his visit in 2016 to see our new location of the inpatient department (Fig. 5) and to celebrate the 20th anniversary of the Palliative Care Department (Fig. 6 and 7). And Robert as a teacher (Fig. 8). For me, especially since 1993, when I participated in the International School for Cancer Care in Oxford (Fig. 9). And during a course in Wisła. Poland in 2008 (Fig.10).

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Figure 5. A visit to the new location of the hospital department in Bydgoszcz, 2016. On the foreground: prof. David Currow, Anna Adamczyk and behind Robert Twycross

Figure 6. The 20th anniversary of the Palliative Care Department, Bydgoszcz 2016, In the front row: Robert Twycross, Małgorzata Krajnik, Piotr Sobański, Zbigniew Żylicz

Figure 7. The 20th anniversary of the Palliative Care Department, Bydgoszcz 2016. From the right: Wojciech Leppert, Robert Twycross, David Currow. 9th from the right Małgorzata Krajnik and other attendees

Figure 8. Robert Twycross as a teacher

Figure 9. International School for Cancer Care in Oxford, 1991

Figure 10. Conference in Wisła, Poland, 2008. From the left: Deridre Twycross, Robert Twycross, Małgorzata Krajnik and Aleksandra Kotlińska-Lemieszek

Article information and declaration

Conflict of interest

The authors declare that no conflict of interest.

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