



Research Paper

The type and amount of care provided by older adult caregivers to a spouse with cancer: Results from a mixed methods study

Valentina Donison^{a,*}, Katherine S. McGilton^a, Shabbir M.H. Alibhai^{b,c}, Assia Konsoulova^{d,e}, Martine Puts^a

^a Lawrence Bloomberg Faculty of Nursing, University of Toronto, Toronto, Canada

^b Department of Medicine, Institute for Health Policy, Management and Evaluation, University of Toronto, Canada

^c Department of Medicine, University Health Network, Toronto, Canada

^d Medical Oncology Clinic, University Specialized Hospital for Active Oncology Treatment, Prof. Ivan Chernozemski, Sofia, Bulgaria

^e Burgas University Prof. Assen Zlatarov, Bulgaria

ARTICLE INFO

Keywords:

Cancer caregiver
Older adults
Spousal caregivers
Geriatric oncology

ABSTRACT

Introduction: Spouses of older adults with cancer provide most long-term informal care, and those receiving treatment for cancer rely on this care, but few studies have examined this in Eastern Europe. Therefore, this study aims to understand the type and amount of care provided by older adult caregivers to their spouses during active cancer treatment in Bulgaria, and how patient and caregiver sociodemographic and health variables influence the care provided.

Materials and methods: This study used an exploratory mixed-methods convergent parallel research design comprising a cross-sectional survey ($n = 90$) and in-depth qualitative interviews ($n = 13$). Older adult caregivers (≥ 65 years) to a spouse receiving active cancer treatment were recruited from the USHATO Hospital, Sofia, Bulgaria from November 2024 to April 2025. The type and amount of care were measured using the National Study of Caregiving (NSOC) scales. Multivariable logistic regression models were used to assess the impact of sociodemographic factors (e.g., age, sex, number of comorbidities, education, income, duration of care in months, supports received, and patient cancer stage) on caregiving hours per week. Caregivers were purposively recruited from the survey sample, and face-to-face interviews were conducted. Open-ended interviews were analyzed using Braun and Clarke's method. The qualitative and quantitative results were integrated using a convergence joint display table.

Results: The mean age of caregivers was 70.3 (SD = 4.8) years and 70.6 (SD = 6.1) years for patients. Most caregivers were female (58.9%) and of Bulgarian ethnicity (96.7%). Patients had varied cancer and treatments but mostly advanced disease (62.2%). Over 80% of caregivers provided full-time caregiving in the past month, with a median of 8 h per day caregiving. Most caregivers primarily provided support with activities of daily living and instrumental activities of daily living. Caregivers with higher education (OR = 0.30, 95% CI 0.10–0.86) were less likely to provide more hours of caregiving. Themes included: caregivers providing around the clock care and personal and emotional support, not defining themselves by the role, and not asking for additional resources.

Discussion: Caregivers provided full-time care, mainly assisting with personal support, and caregivers with higher education were less likely to spend more time on caregiving.

1. Introduction

In the European Union (EU), cancer disproportionately affects older adults, with 60% of the estimated new diagnoses and 73% of deaths occurring in persons aged 65 years or older [1]. Bulgaria has 7.1 million

inhabitants and one of the EU's oldest and most rapidly aging populations [2,3]. While informal caregiving across Western and Eastern Europe and North America is similarly defined as unpaid assistance by family or friends, differences may exist in the cultural and social obligations, as well as in the health care settings in which care is provided

* Corresponding author at: Lawrence Bloomberg Faculty of Nursing, University of Toronto, 155 College Street Suite 130, Toronto, ON M4E 2N5, Canada.

E-mail address: valentina.donison@utoronto.ca (V. Donison).

<https://doi.org/10.1016/j.jgo.2026.103059>

Received 8 January 2026; Received in revised form 10 April 2026; Accepted 2 July 2026

Available online 8 July 2026

1879-4068/© 2026 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

[4–7]. Even though the provision of caregiving tasks (assistance with activities of daily living [ADLs]/ instrumental ADLs [IADLs]) may be similar across countries, in Bulgaria, informal caregiving is more strongly influenced by cultural and social familial obligations and by limited formal long-term care services [3,6,7]. Furthermore, since the fall of communism, the idea of self-reliance has become ingrained across all social settings, including healthcare [6].

Additionally, pensioners, particularly in Bulgaria, where the average monthly pension in 2025 was approximately 500 EUR, face economic constraints that limit their ability to pay for formal care [8]. Given that Bulgaria's health expenditure is among the lowest in the EU (2391 EUR vs. 5177 EUR EU average per capita in 2021), formal support and palliative care services are nearly nonexistent [9–11]. Because of the inadequate number of formal services for older adults and high poverty rates in the country, the majority of informal care is placed on family members, including spouses [3,9].

Although there has been previous research looking at caregivers to older adults with chronic conditions such as cancer [12,13], to date there is no research looking at caregivers who are older adults themselves, who are the primary caregivers to a spouse in active cancer treatment in Bulgaria.

Therefore, the research questions were: [1] What caregiving tasks (type of care provided, amount of care) do older adults ≥ 65 years of age provide to their spouse with cancer? (2) How do sociodemographic and health variables of the patient and caregiver influence the care provided by the caregiver? [3] What are the caregiving experiences of older adults in providing care to their spouse with cancer, related to the type and amount of care provided? (4) How do the qualitative interview data reporting participants' views align with the quantitative results about the type and amount of care provided?

2. Methods

2.1. Study design

The study was guided by a conceptual model based on the framework of Pearlin et al. [14], adapted by Stolz-Baskett et al. [15], and further revised by the principal investigator (PI) for this study (Supplemental File S1). This framework conceptualizes caregiving as a stressful experience, with perceived stress influenced by stressors such as the care context (sociodemographic characteristics, family network, caregiving history) and care recipient characteristics (i.e., ADL/IADL dependencies) [14,15].

This study used an exploratory mixed-method study utilizing a convergent parallel research design to enable a more comprehensive understanding of an under-studied topic in a population that is often underrepresented in research, which will further help strengthen the validity of the findings [16,17]. Quantitative and qualitative data were gathered concurrently, analyzed separately, and the results were compared to see if they confirm or disconfirm each other through a joint display table.

2.2. Participants

The study was conducted at the medical oncology department at the USHATO Hospital (University Specialized Hospital for Active Treatment in Oncology, Prof. Ivan Chernozemski, Sofia, Bulgaria). Informal spousal caregivers aged ≥ 65 to a spouse undergoing systemic treatment (chemotherapy, immunotherapy, targeted therapy) for at least two months were invited to participate in the study. To reduce selection bias, nurses screened potential caregivers against predefined recruitment criteria, and all patients who met the criteria were approached consecutively throughout the recruitment period. If the participant was interested in hearing more, the PI (VD) approached eligible caregivers to explain the study.

2.3. Survey

2.3.1. Measurements

2.3.1.1. Sociodemographic. Information collected included caregivers' age, sex, place of residence, employment, number of children/grandchildren, income, years of education, and health status using the Older Americans Resources and Services Questionnaire (OARS 1-item) [18]. The chronic conditions question asks if the person has any of 11 listed chronic conditions (yes/no). The caregiver was asked to provide sociodemographic and cancer-related information on their spouse, such as age, sex, diagnosis, stage of disease, and type of treatment received (chemotherapy, immunotherapy, targeted therapy, combination therapy).

2.3.1.2. Type and amount of care. The US National Study of Caregiving (NSOC) scales and subscales [19] were used to measure the type and amount of care [19]. Questions measured the hours of care provided (per day/month), the care activities subscale measured the care provided (i.e., based on the ADL and IADL items). The medical activities subscale measured the types of medical assistance the caregiver provides (e.g., injections, wound care, skin care, dental care, foot care).

As no validated instrument was available in Bulgarian to measure the type and amount of care provided by caregivers, the PI and an independent, medical-certified translator (AK) translated the NSOC scales and subscales, OARS 1-item, ADL, and IADL scales into Bulgarian using the World Health Organization (WHO) forward-backward translation technique [20].

2.4. Analysis

Descriptive statistics such as means and frequencies were used to describe the number and type of care provided and the time spent caregiving. As our questionnaire did not include a question specifically asking about the hours per week caregivers spent providing care, we estimated weekly caregiving hours by multiplying the number of caregiving days in the prior month by the daily hours of care and dividing by 4.35 to obtain a weekly amount [21].

To examine which sociodemographic and health variables of the patient and caregiver influenced the care provided by the caregiver, all variables (age, sex, number of comorbidities, income, level of education, living with children/grandchildren, disease stage, caregiving duration in months, supports received) were first entered in the main multivariable logistic regression model using a 40-h-per-week caregiving cutoff as outcome. We then conducted a sensitivity analysis using a 55-h weekly caregiving threshold, entering all variables simultaneously. The dichotomization of the outcome (hours of care per week) was based on the mean hours caregivers spent on care per week and on available data quantifying the average time and effort family caregivers spend providing care to a person with cancer [22–24]. Next, we repeated both analyses after varying the caregiver duration predictor from 12 to 24 months. Finally, additional sensitivity analyses including univariate analyses were performed, and predictors with $p < 0.20$ were retained for inclusion in four models to obtain the most parsimonious models.

The assumptions for the linear regression analysis were met. All models had acceptable discrimination and good calibration (non-significant Hosmer-Lemeshow tests). We utilized IBM SPSS version 31 for data analysis.

2.5. Qualitative interviews

2.5.1. Data collection and analysis

The PI (a nurse) conducted 13 face-to-face semi-structured interviews with caregivers. A purposive sample of participants was chosen to allow for maximum variation based on sex and time spent caregiving.

Furthermore, caregivers were selected to represent the varying disease stages and various treatments to account for the diverse systemic symptoms that could impact the type and amount of care provided. Caregivers were asked open-ended questions using a topic guide (Supplemental File S2), underpinned by the study's conceptual framework. All interviews were audio recorded and transcribed verbatim by the PI. Open-ended interviews were analyzed using Braun and Clarke's approach [25,26].

Data saturation was achieved when no new themes emerged during the data analysis. This was accomplished through ongoing discussions among the research team (VD, MP, KM). Triangulation of the findings was undertaken through independent analysis of the transcripts by the PI and the supervisor, followed by discussion to reach consensus. QSR NVivo software version 14 was used to support the data analysis.

2.6. Data integration

Triangulation of the findings occurred after the quantitative and qualitative data were separately analyzed and integrated during the interpretation phase using a joint display table [27] and we used The Good Reporting of a Mixed Methods Study (GRAMMS) Checklist [28] (Supplemental File S3). *Ethics.*

The study was approved by the institutional review boards at USH-ATO Hospital, Sofia, Bulgaria and the University of Toronto Health Sciences Research Ethics Board (#46831). All participants in this study provided written informed consent.

3. Results

3.1. Sociodemographic information

A total of 121 eligible caregivers were invited to participate; 31 declined and 90 (74%) participated. The main reasons for declines included not being interested, not having enough time, and being too stressed to participate (Supplemental File S4). The mean age was 70.3 years (standard deviation [SD] = 4.9, range = 65–85), and most were female (58.9%) (Table 1). The mean age of patients was 70.6 years (SD 6.2, range 58–93), and the majority were male (58.9%). Most patients had head and neck cancers (23.3%), followed by breast (18.9%) and gastrointestinal (18.8%). Over half had advanced disease (62.2%), and chemotherapy (45.6%) and combination (35.6%) treatments were the most common treatments. Caregivers rated their health as good (60%), and they had a median of two comorbidities.

3.2. What care (type of care provided, hours per week) do older adults ≥ 65 years of age provide to their spouse with cancer?

Over 80% of caregivers provided daily or near-daily (30 days) caregiving in the last month (Table 2). A median of eight hours per day was spent caregiving, and 64.4% spent over 40 h per week caregiving. The duration of caregiving varied, with most caregivers being a caregiver for less than six months (28.9%), followed by 6–12 months (26.7%). Over 80% of caregivers did not have paid help to assist. Most caregivers reported providing support primarily with IADLs; over 70% reported providing daily assistance with shopping. Furthermore, over 70% helped with cleaning and preparing meals daily. The highest percentage categories of assisting with ADLs include feeding (20%) and support with dressing/grooming (20%). Many caregivers (55.6%) helped with making appointments with medical providers. Other frequent tasks included assisting with skin-related wounds or sores (41.1%), logging into an online patient account (38.9%), and helping with preparing a special diet (31.1%).

Most caregivers (86.7%) reported having family or friends with whom they could discuss important aspects of life (Table 2), and 33% reported having friends or family to help with daily activities, such as errands or housework. Furthermore, 2% of caregivers attended a

Table 1

Description of the sample characteristics.

Demographic Variables	Characteristics	N/Percentage (%)
Caregivers		
Sex	Male	37 (41.1)
	Female	53 (58.9)
Age (years)	Mean (SD)	70.34 (4.9)
Education Level	Less than high school diploma	6 (6.6)
	High school diploma or equivalent	50 (55.6)
	University degree or higher	34 (37.8)
Perceived Income Sufficiency	Yes	46 (58.1)
	No	44 (48.9)
Residence	City	67 (74.4)
	Small town	12 (13.3)
	Village	11 (12.2)
Ethnicity	Bulgarian	87 (96.7)
	Turkish	2 (2.2)
	Roma	1 (1.1)
	Other	0
Does the caregiver have any children/grandchildren living with the caregiver?	Yes	28 (31.1)
	No	62 (68.9)
Number of Children/Grandchildren	Children	27 (30)
	Grandchildren	6 (6.7)
Employment	Yes	14 (15.6)
	Retired/No	76 (84.4)
Self-Rated Health Rating (OARS-1)	Excellent	6 (6.7)
	Very good	11 (12.2)
	Good	54 (60.0)
	Fair	10 (11.1)
	Poor	9 (10.0)
Comorbidities	Musculoskeletal	38 (42.2)
	Lung/Respiratory	12 (13.3)
	Urogenital	14 (15.6)
	Cardiovascular	44 (48.9)
	Diabetes	21 (23.3)
	Gastrointestinal	15 (16.7)
	Ear/Nose/Throat	12 (13.3)
	Neurological	11 (12.2)
	Median Number of Comorbidities	2 (N/A)
Patients		
Sex	Male	53 (58.9)
	Female	37 (41.1)
Age	Mean (SD)	70.58 (6.2)
Time of Diagnosis	Less than 6 months ago	22 (24.4)
	6 months to 1 year ago	20 (22.2)
	1 to 2 years ago	15 (16.7)
	2 to 5 years ago	19 (21.1)
	More than 5 years ago	14 (15.6)
Initiation of Cancer Treatment	2 to 4 months ago	22 (24.4)
	4 to 6 months ago	7 (7.8)
	6 to 12 months ago	22 (24.4)
	More than 12 months ago	39 (43.3)
Cancer Type	Head and neck	21 (23.3)
	Breast	17 (18.9)
	Gastrointestinal	17 (18.8)
	Lung	12 (13.3)
	Gynecologic	10 (11.1)
	Skin	8 (10.9)
	Genitourinary	4 (4.4)
	Other	1 (1.1)
Cancer Stage	Early/localized	34 (37.8)
	Advanced/Metastatic	56 (62.2)
Current Systemic Treatment Type	Chemotherapy	41 (45.6)
	Targeted Therapy	4 (4.4)
	Immunotherapy	13 (14.4)
	Combination	32 (35.6)

* SD: standard deviation; OARS-1: Older Americans Resources and Services Self-Rated Health Rating Item.

Table 2

Amount of care provided and supports received.

Characteristic	Category	Frequency (n)/ Percentage (%)
Caregiving Duration	Less than 6 months	26 (28.9)
	6–12 months	24 (26.7)
	1–2 years	8 (8.9)
	2–5 years	21 (23.3)
	More than 5 years	11 (12.2)
Regular Schedule	Yes	78 (86.7)
	No	12 (13.3)
Does the care recipient have paid help	Yes	12 (13.3)
	No	78 (86.7)
Days Assisted (Last Month)	Full-time caregiving (26–30 days)	75 (83.3)
	Frequent caregiving (16–20 days)	3 (3.3)
	Moderate caregiving (11–15 days)	7 (7.8)
	Occasional caregiving (6–10 days)	4 (4.4)
	Minimal caregiving (0–5 days)	1 (1.1)
	Full-time caregiving: 13–24 h	19 (21.1)
Hours Per Day Assisted	Intensive caregiving: 9–12 h	24 (26.7)
	Moderate caregiving: 5–8 h	23 (25.6)
	Short-term caregiving: 1–4 h	24 (26.7)
	Low Caregiving Hours (>40 h/wk)	32 (35.6)
Hours (Per Week)	High Caregiving Hours (≥ 40 h/wk)	58 (64.4)
Supports Received		
Did the care recipients' medical providers give you the training you needed to help with health treatments	Yes	42 (46.7)
Do you have friends or family that you talk to about important things in your life?	Yes	78 (86.7)
Do you have friends and family that help you with daily activities such as running errands or helping you with things around the house?	Yes	33 (36.7)
Do you have friends and family that help you care for the care recipient?	Yes	30 (33.3)
In the last year, have you gone to a support group for people who provide care?	Yes	2 (2.2)
Have you used any service that took care of the care recipient so you could take some time away from helping?	Yes	1 (1.1)

* wk: week.

support group in the last year, and 1% used a type of service to take time away from caregiving (Supplemental File S5).

3.3. How do sociodemographic and health variables of the patient and caregiver influence the care provided by the caregiver?

The main analysis (Table 3) and the sensitivity analyses (Tables 3–5) yielded consistent results. Across all analyses, education level was the only significant predictor of the number of weekly caregiving hours. Caregivers with higher education (more than high school) were less likely to provide more hours of caregiving.

3.4. What are the caregiving experiences of older adults providing care to their spouses with cancer, related to the type and amount of care provided?

A total of 13 face-to-face interviews were conducted with five male and eight female caregivers. Four main themes were identified: caregivers providing around the clock care, caregivers providing personal and emotional support, caregivers not defining themselves by the role, and caregivers not asking for additional resources. Table 5 shows exemplary quotes.

3.5. Caregivers providing around the clock care

Caregivers expressed that caregiving for their spouse is constant and around-the-clock, with many sharing that they are available to help their spouse 24/7 with whatever support they may need, with little to no time left for their personal needs. This theme exemplifies how caregivers perceive their time spent caregiving as nonstop and feel as though they are under constant surveillance, ensuring they are available to provide care for their spouse at any time of the day or night.

3.6. Caregivers providing personal and emotional support

Caregivers articulated that they provided care mainly with ADLs/IADLs, including domestic tasks such as meal preparation, cooking, cleaning, and grocery shopping. Personal support was provided with bathing, dressing, mobility, personal hygiene, and accompanying spouses to appointments. Emotional support included encouraging their spouse and engaging them in social interactions to create a sense of normalcy in the situation.

3.7. Caregivers not self-identifying as caregivers

Most caregivers reported not identifying as caregivers. Participants stated that the help they provide is natural and comes from within, that they feel a sense of duty and obligation as spouses, and that it's something they must do to help each other prolong their lives together. Also, caregivers discussed the reciprocal nature of the relationship and how spouses are already used to helping each other when needed.

3.8. No additional resources asked for by caregivers

When asked about the types of resources caregivers may need and find helpful, many caregivers said they had not even thought about what they need and are self-reliant in providing care to their spouse. Some stated that they have support from family, friends, and neighbours in terms of receiving social support and advice about the diagnoses and disease trajectory; however, when asked what they may need to help provide care for their spouse, the majority could not think of anything. Furthermore, some caregivers reported financial struggles, including difficulties with income and receiving minimal to no social assistance to help support their spouse during treatment.

3.9. Data integration

There was concurrence between the two data sets regarding the type of care provided with IADLs/ADLs, the amount of care provided, and the supports and resources. While there was agreement, the qualitative data provided more in-depth information about the emotional and social support provided. Caregivers mentioned providing emotional stability to spouses by offering encouragement and ensuring that spouses still had some sense of normalcy by encouraging social interaction with friends and family. Education level was the only significant predictor of hours of care provided per week. Caregivers with higher education (more than high school) were less likely to provide more hours of caregiving. The discrepancies in emotional support and educational level could be explained by differences in measurement between the quantitative and

Table 3

Multivariable logistic regression main analysis model and sensitivity models for predictors on hours of care per week.

Characteristic	Main Analysis Results Model 1 (40 h/12mths) AUC: 0.74 HL p-value: 0.57	Sensitivity Analysis Results Model 2 (55 h/12mths) AUC: 0.71 HL p-value: 0.93	Sensitivity Analysis Results Model 3 (40 h/24mths) AUC: 0.74 HL p-value: 0.24	Sensitivity Analysis Results Model 4 (55 h/24mths) AUC: 0.71 HL p-value: 0.90
Age (years)	0.96 (0.87–1.06)	0.95 (0.86–1.05)	0.96 (0.80–1.06)	0.95 (0.86–1.05)
Sex (female)	2.19 (0.72–6.68)	0.76 (0.27–2.12)	2.04 (0.65–6.33)	0.72 (0.25–2.04)
Number of comorbidities (n)	0.73 (0.44–1.20)	1.12 (0.71–1.78)	0.70 (0.42–1.17)	1.11 (0.70–1.76)
Income	0.53 (0.16–1.68)	0.71 (0.25–2.01)	0.55 (0.17–1.74)	0.74 (0.26–2.09)
Education ($\leq$ HS; $>$ HS)	0.30 (0.10–0.86) *	0.37 (0.13–1.04)	0.27 (0.09–0.81) *	0.36 (0.13–1.01) *
Cancer stage (Advanced/Non-Advanced)	1.96 (0.68–5.61)	2.21 (0.81–6.03)	2.10 (0.72–6.14)	2.20 (0.80–6.03)
Living with children/grandchildren	0.71 (0.23–2.20)	2.14 (0.75–6.10)	0.76 (0.24–2.38)	2.15 (0.75–6.19)
Caregiving duration (12 mths or 24 mths)	0.50 (0.17–1.43)	0.52 (0.19–1.39)	0.37 (0.12–1.13)	0.51 (0.18–1.44)
Supports Received	2.0 (0.69–6.35)	1.00 (0.37–2.72)	2.16 (0.71–6.58)	0.96 (0.35–2.59)

Values are odds ratio (95% confidence intervals). Models represent combinations of caregiving hours per week (40 or 50 h) and duration (12 or 24 month) cut-offs. Significance: * $p < 0.05$; $p < 0.01$. AUC: Area Under the Curve Model Discrimination Results, HL: Hosmer-Lemeshow Model Calibration Results, HS: high school, mths: months.

Table 4

Multivariable logistic regression reduced entry sensitivity analysis models for predictors on hours of care per week.

Characteristic	Sensitivity Analysis Results Model 5 (40 h/12mths) AUC: 0.69 HL: 0.64	Sensitivity Analysis Results Model 6 (55 h/12mths) AUC: 0.65 HL: 0.34	Sensitivity Analysis Results Model 7 (40 h/24mths) AUC: 0.69 HL: 0.23	Sensitivity Analysis Results Model 8 (55 h/24mths) AUC: 0.77 HL: n/a single predictor model
Age (years)	–	–	–	–
Sex (female)	2.22 (0.84–5.80)	–	1.94 (0.72–5.22)	–
Number of comorbidities (n)	–	–	–	–
Income	0.84 (0.31–2.24)	–	0.85 (0.32–2.28)	–
Education ($\leq$ HS; $>$ HS)	0.31 (0.11–0.83) *	0.34 (0.13–0.87) *	0.29 (0.11–0.84) *	0.31 (0.12–0.78) **
Cancer stage (Advanced/Non-Advanced)	–	–	–	–
Living with children/grandchildren	–	1.93 (0.75–4.96)	–	–
Caregiving duration (months)	–	–	0.57 (0.21–1.52)	–
Supports Received	–	–	–	–

Values are odds ratio (95% confidence intervals). Models represent combinations of caregiving hours per week (40 or 50 h) and duration (12 or 24 month) cut-offs. Variables with criterion of $p < 0.20$ were retained from univariate analysis and were included in the sensitivity analysis. The ‘–’ indicates variables not retained. Significance: * $p < 0.05$; $p < 0.01$. AUC: Area Under the Curve Model Discrimination Results, HL: Hosmer-Lemeshow Model Calibration Results, HS: high school.

qualitative approaches, with one capturing aspects that the other did not [15,27,29]. For example, the themes for participants with higher versus lower education were analyzed to determine whether there were differences in the amount of time spent caregiving. Yet, no consistent pattern emerged, highlighting a divergence between the survey and the interviews (Table 6).

4. Discussion

This study is the first to analyze the type and amount of care provided by older adult caregivers (≥ 65 years) to a spouse receiving active cancer treatment in the largest cancer center in Sofia, Bulgaria. Most caregivers provided care with IADLs, including grocery shopping, cleaning, and preparing hot meals. These findings are congruent with other research reporting that caregivers mainly provided care with tasks such as cooking, shopping, and other domestic tasks while spouses received systemic cancer treatment [30,31]. Providing emotional and social support was one of the findings reported by caregivers during the qualitative interviews. Similarly, researchers reported a protective effect of caregiving, in which caregivers provided emotional support and assisted with managing the patient's social life during cancer treatment [12,30,32].

A key finding in this study was that caregivers provided daily or near-daily, around-the-clock caregiving to their spouse. These findings are consistent with previous family cancer caregiving literature, which outlines that high-intensity caregiving often coincides with exceeding full-time employment [33,34]. Additionally, 60% of caregivers rated

their health as good. This finding is consistent with research in Bulgaria on older adults' self-rated health and aligns explicitly with the theory of socioemotional selectivity [35,36]. This theory suggests that as individuals age, they tend to shift their thinking toward a more positive outlook, and subjective well-being tends to improve with age [35,36]. Older adults may therefore focus on more positive aspects of their health as a form of self-preservation and as an adaptation mechanism. Furthermore, the study by Mourgova [37] on the health status of the older population in Bulgaria found that in 2014, over 89.3% of men ≥ 65 years reported their self-perceived health as good, as did 86.5% of women ≥ 65 years.

Level of education was the only significant characteristic associated with the amount of caregiving per week. This finding is consistent with the study by Harris et al. [38], which found that caregivers who provided higher-intensity caregiving (time spent per week) were more likely to be disadvantaged by social class and educational level. Furthermore, high-intensity caregiving was more likely among individuals who were retired and unemployed [38]. Because retired and unemployed individuals have fewer competing demands, they may have more time to provide high-intensity caregiving. Moreover, older adults often care for spouses due to their life-course position [39,40], social expectations [41], and reciprocal life-course ties [42], in which caring for a spouse becomes socially expected and common in older age. In this study, caregivers explicitly reinforced the reciprocal nature of caregiving and the economic constraints they experienced during the interviews.

The uniqueness of our study lies in its focus on the relationship

Table 5
Qualitative themes and exemplary quotes.

Theme	Quotes
Caregivers Not Self-Identifying as Caregivers	"No, no. I don't see myself as a caregiver. I just... I do it for my husband." (Female, 67 yrs., >40 h/week, Localized Disease) "No. Everything comes from me. I have to do this for him so we can prolong our lives together." (Female, 74 yrs., >40 h/week, Advanced Disease) "No... it just comes from within me. Character." (Male, 67 yrs., <40 h/week, Localized Disease)
No Additional Resources Asked for by Caregivers	"Well... I haven't thought about that because I rely entirely on myself." (Female, 67 yrs., >40 h/week, Localized Disease) "No, no. I think what we're doing is enough." (Male, 65 yrs., >40 h/week, Localized Disease) "We've always managed on our own... I can't say that someone takes care of us. My daughter just paid for the most recent surgery and for the selection of the team that conducted the surgery." (Female, 70 yrs., >40 h/week, Advanced Disease) "Yes. So, this is social assistance. Hers is 130 leva (66 EUR per month). Mine is 36 leva 18 EUR per month). No, this is absolutely nowhere near enough, even with medications, we compromise because there's just... nowhere to get it from; there's no other way." (Male, 68, >40 h/week, Advanced Disease) "No, no. The income.... If we have to pay for these things ourselves.... We are on...He earns 660 leva per month (337 EUR), and I earn 620 leva (317 EUR per month)." (Female, 70 yrs., > 40 h/week, Advanced Disease)
Caregivers Providing Around the Clock Care	"Well, basically 16 h every day. Every day! From waking up to going to bed. That's more or less the time. I don't even allow myself the most basic care and needs for myself." (Female, 68, >40 h/week, Localized Disease) "It's constant because there's always something to do." (Male, 68, >40 h/week, Advanced Disease) "Of course, 24 h a day, I am with him. Always. During the night, during the day, consistently. I am always under surveillance.The door is open. I am in the other room; he is sleeping on the bed. If I hear something, I immediately go." (Female, 74 yrs., >40 h/week, Advanced Disease) "Well, I'm by his side all the time, basically, 24 h a day. Very rarely, once or twice a month, I can go somewhere. That's once a month; the rest of the time, I'm with him all the time." (Female, 65 yrs., > 40 h/week, Advanced Disease) "I can't say exactly, but I'm available twenty-four hours a day. There are times when he's lying down, I can feel him, he's calm, and I lie down too and fall asleep. But after ten minutes, he rings the alarm, his stomach hurts, or he accidentally hits the button. My peace is broken." (Female, 65 yrs., > 40 h/week, Advanced Disease)
Caregivers Providing Personal and Emotional Support	"It is well known that after chemotherapy one does not feel well, then I took the most care of her. When moving around, when getting food, when going out in the second week, because chemotherapy was going on fortnightly. Because you have to move and of course the encouragement, which also everyone says is important and I also think it's extremely important." (Male, 72 yrs., <40 h/week, Advanced Disease) "I try to create some contacts for him because he is very communicative. This really scares him because we don't have any contacts. We were such a very social family." (Female, 65 yrs., > 40 h/week, Advanced Disease) "Morning involves getting up, changing his clothes, having breakfast, and taking medication. If he is able, he will walk outside, which implies getting dressed and preparing to go out. Then, he

Table 5 (continued)

Theme	Quotes
	rests, and during this time, I must have shopped and cooked. I get up very early in the morning to cook so that I have something to give him to eat for lunch." (Female, 65 yrs., > 40 h/week, Advanced Disease) "Since the chemotherapy started, because it is a heavy therapy, the first fifteen, twenty days after the infusions with the appropriate preparations, I have helped with absolutely everything, including housework. Personal assistance with the service until she gets stronger and starts to take care of herself independently, including her personal hygiene, nutrition and so on." (Male, 71 yrs., >40 h/week, Advanced Disease)

between older adult spouses in a specific cultural setting (Bulgaria). Consideration needs to be given to the unique cultural context and setting, ingrained in Bulgarian culture and the mentality of an older generation. One consideration is that the majority of caregivers reported not receiving practical support, including formal services and respite care. Furthermore, most caregivers verbalized not wanting to bother or inconvenience their children to protect them from the situation, which aligns with the Bulgarian culture of taking the burden off children [43]. As the older generation in Bulgaria values strong community ties [44], we can see from the interviews that caregivers value the opinions of neighbours and friends when seeking social support throughout the caregiving trajectory.

Health care providers should routinely screen caregivers about the time they spend on caregiving to help identify caregivers at high risk of burden and reduced mental health-related quality of life. Future research should focus on developing valid instruments to capture the emotional caregiving provided by cancer caregivers in different cultural settings and how this type of care affects caregiver outcomes [45,46]. Moreover, as caregivers expressed the reciprocal nature of caregiving and providing emotional labour throughout the caregiving trajectory, the implementation of dyadic-based coping interventions in clinical practice, such as psychoeducational or communication-based interventions [47,48], has been shown to improve relationship quality and improve psychological well-being for both the caregiver and the spouse.

4.1. Limitations and strengths

In this study, we recruited older adult caregivers from one cancer center clinic in Sofia, Bulgaria. Because we used a recall-based measure of time spent caregiving, these measures are susceptible to under- or overestimation of caregiving hours [49,50]. As our study participants were spousal caregivers, who are mainly retired, it may be difficult for spouses to distinguish time spent on caregiving tasks from time spent on personal and social activities that are not entirely connected to caregiving but are reciprocally experienced with the spouse, potentially leading to an inaccurate overestimation of hours spent providing care. Also, the wide confidence intervals in this study for the sex variable likely reflect limited representation of males relative to females, resulting in insufficient power to detect meaningful sex differences.

In this study, we did not assess the construct validity of the NSOC in this population. However, we conducted face validity testing, using the WHO forward-backward translation process [20], which does not require full revalidation. Furthermore, future studies should assess the patient's functional status and disability that could add context to the findings, as this was not measured in this study. Even though, the interview questions were not formally piloted, the research team met throughout the study to adjust the guide based on the interviews, as is recommended for qualitative research [26]. We added clarifications and probes to the topic guide as we went along.

Our study did not explicitly assess whether caregiving tasks

Table 6
Convergence joint display table.

Quantitative Results	Qualitative Themes	Interpretation: Convergence, Complementarity, or Discrepancy
IADLs 97% helped every day/ most days with shopping and groceries 90% helped every day/ most days with cleaning 86% helped every day/ most days with preparing hot meals	Caregivers reported having “shopped and cooked,” and helping with “absolutely everything, including housework.” Providing emotional care was a common theme reported by caregivers. They provided emotional support through “encouragement” and creating social interaction for the spouse.	Convergence: The high frequency of support in IADLs aligns with caregivers’ interview reports of helping with domestic tasks, including meal preparation, cooking, cleaning, and grocery shopping. Discrepancy: There were no quantitative findings to support this theme because the survey lacked questions to capture the emotional and social support caregivers provided to their spouses.
ADLs 32% helped every day/ most days with showering/bathing 32% helped every day/ most days with mobility 29% helped every day/ most days with dressing/grooming 23% helped every day/ most days with eating	Caregivers reported helping with “absolutely everything,” including “dressing” and “personal assistance,” as well as “hygiene.”	Complementarity: A smaller percentage of caregivers reported providing help with ADLs quantitatively; however, the qualitative interviews show that caregivers often discussed helping with personal support, including bathing, dressing, mobility, and personal hygiene
Amount of Care 86% of caregivers provided care on a regular schedule (same days and hours in the previous month) 83% provided full-time caregiving (30 days in the previous month) 64% provided ≥40 h of care per week 8 h (median) per day were spent caregiving.	Caregivers expressed that caregiving for their spouse is constant and around-the-clock, with many sharing that they are available to help their spouse “24/7” with whatever support they may need. Caregivers reported being available day and night, under constant surveillance, and ready to respond to whatever was required of them, with little to no time left to attend to their own personal needs.	Convergence: The quantitative data align with the qualitative findings, indicating that caregivers perceive caregiving as “around-the-clock.”
Resources Used/Support Received 98% reported never attending a support group for caregivers in the last year. 99% have never used any respite service 86% reported having friends or family that they talk to about important things in life.	Many caregivers reported that they don’t use or need any resources. Numerous said they hadn’t even thought about what they need and are self-reliant in providing care to their spouse. Some stated that they have support from family, friends and neighbours in terms of receiving social support and advice about the diagnoses and disease trajectory.	Convergence: The quantitative data show that few caregivers received practical support with caregiving. Caregivers mainly reported being self-reliant and not requiring external support. However, the quantitative data show a high percentage of caregivers received emotional support from friends and family, with some reporting receiving social support from family, friends, and neighbours during the interviews.
Caregiver/Patient Sociodemographics Education level was the only significant predictor of hours of	This variable was not mentioned or discussed in the qualitative interviews.	Discrepancy: Education is a significant predictor of the amount of time spent providing care per week. However, the lack

Table 6 (continued)

Quantitative Results	Qualitative Themes	Interpretation: Convergence, Complementarity, or Discrepancy
care provided per week in the simultaneous and sensitivity analysis models. Caregivers with higher education (>HS) were less likely to provide more hours of caregiving.		of qualitative findings suggests that this variable was not captured during the interviews.

ADLs: activities of daily living; HS: high school; IADLs: instrumental activities of daily living.

represented new responsibilities adopted since taking on the caregiving role, or whether this was the couple’s pre-cancer role assignment. Future research should examine changes in role allocation and how this may influence existing roles. An explanatory sequential study design could be considered as a suitable option for future research. This type of design can be useful when divergent results emerge, as, based on the survey results, findings that were unanticipated can be followed up with specific questions during the qualitative interviews to provide a better understanding and context [17,51].

One strength of our study lies in its research design, which employs a convergent parallel mixed-methods approach, enabling us to gain and report a richer and more holistic understanding of participants’ experiences in caring for their spouses. **5. Conclusion.**

In this study, caregivers reported providing around-the-clock caregiving, including emotional support. Routine screening of the type and amount of care provided by caregivers, health care providers can better outline the supportive interventions that may support and help caregivers in providing care to their spouses with cancer.

Consent for publication

All authors have given their consent for this manuscript to be published in Journal of Geriatric Oncology

Ethics approval

The study was approved by the institutional review boards at USH-ATO (University Specialized Hospital for Active treatment in Oncology, Prof. Ivan Chernozemski, Sofia, Bulgaria) and the University of Toronto Health Sciences Research Ethics Board (#46831).

Authors’ contributions

Conceptualization: VD, SA, MP, KM, AK.
Data Curation: VD.
Formal Analysis: VD, MP.
Investigation: VD, MP, SA, KM, AK.
Methodology: VD, MP, SA, KM, AK.
Software: IBM SPSS Version 31. QSR NVivo Version 14.
Supervision: MP.
Validation: VD, MP, SA, KM, AK.
Visualization: VD, MP, SA, KM, AK.
Writing - Original Draft: VD, MP, SA, KM, AK.
Writing – Review and Editing: VD, MP, SA, KM, AK.
All authors have approved the final article.

Declaration of competing interest

None.

Acknowledgement

Funding: Ms. Valentina Donison is supported by the Ontario Graduate Scholarship, Queen Elizabeth II/University of Toronto Foundation Graduate Fellowship in Science and Technology. Dr. Puts is supported by a Tier 2 Canada Research Chair in the care for frail older adults.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jgo.2026.103059>.

Data availability

Not applicable.

References

- [1] Dyba T, Randi G, Bray F, Martos C, Giusti F, Nicholson N, et al. The European cancer burden in 2020: incidence and mortality estimates for 40 countries and 25 major cancers. *Eur J Cancer* 2021;157:308–47.
- [2] Jeleva R. Labor market participation, informal caregiving and quality of life of elderly people in Bulgaria. *Probl Postmodernity* 2023;13(1):26–41.
- [3] Pithecock N. Aging in the Republic of Bulgaria. *Gerontologist* 2017;57(5):809–15.
- [4] Abed N, Knezevic B, Sousa P, Tella S, Srulovici E, Strametz R, et al. Defining informal caregivers by their characteristics safety roles and training needs in Europe. *Sci Rep* 2025;15(1):24375.
- [5] Bom J, Bakx P, Schut F, van Doorslaer E. The impact of informal caregiving for older adults on the health of various types of caregivers: a systematic review. *Gerontologist* 2019;59(5):e629–42.
- [6] Goncharova G, Karamelska T. Care of People Living with dementia in Bulgaria: between over-responsibility to the family and distrust in public health services and policies. *Comp Southeast Eur Stud (Print)* 2024;72(1):58–82.
- [7] Spasova S. Challenges in long-term care in Europe. A study of national policies. European Commission; 2018.
- [8] Average Pension in Bulgaria to reach €541.20 in 2026 [press release]. Bulgaria 13.11.2025. 2025.
- [9] Policies OEOHSA. Bulgaria: Country Health Profile 2021, State of Health in the EU. Brussels: Paris/European Observatory on Health Systems and Policies; 2021.
- [10] Zahariev BG, Lidia ESPN. Thematic report: Inequalities in access to healthcare Bulgaria. 2018.
- [11] Dimova R, Koeva Atanasova, Koeva-Dimitrova, Kostadinova Spranger. Bulgaria Health system review. 2018. Contract No.: 4.
- [12] Stolz-Baskett P, Taylor C, Glaus A, Ream E. Supporting older adults with chemotherapy treatment: a mixed methods exploration of cancer caregivers' experiences and outcomes. *Eur J Oncol Nurs* 2021;50:101877.
- [13] Wright KB, Bylund CL, Vasquez TS, Mullis MD, Sae-Hau M, Weiss ES, et al. Adult-child caregivers' family communication experiences after an older parent's blood cancer diagnosis: a survey exploring their openness, avoidance, and social support. *Cancers* 2023;15(12):3177.
- [14] Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30(5):583–94.
- [15] Stolz-Baskett P. Experiences of informal caregivers of older cancer patients a mixed methods study: Florence nightingale faculty of nursing and midwifery. 2017.
- [16] Creswell JW, Creswell JD. Research design: qualitative, quantitative, and mixed methods approaches. 5th ed. Los Angeles: SAGE; 2018.
- [17] Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. 3rd ed. Thousand Oaks, California: SAGE; 2018.
- [18] Fillenbaum GG, Smyer MA. The development, validity, and reliability of the OARS multidimensional functional assessment questionnaire. *J Gerontol (Kirkwood)* 1981;36(4):428–34.
- [19] National Health and Aging Trends Study (NHATS), the National Study of Caregiving (NSOC). [Internet]. Updated June 29, 2020. Accessed. Available from: <https://www.nhats.org/researcher>; 2020.
- [20] Process of translation and adaptation of instruments [Internet]. Available from: <https://terrance.who.int/mediacentre/data/WHODAS/Guidelines/WHODAS%20%20Translation%20guidelines.pdf>; 2023.
- [21] Meyer K, Gassoumis Z, Wilber K. The differential effects of caregiving intensity on overnight hospitalizations. *West J Nurs Res* 2021;44(6):528–39.
- [22] Hunt G, Longacre M, Kent E, Weber-Raley L. Cancer caregiving in the U.S.: an intense, episodic, and challenging care experience. 2017.
- [23] Kadambi S, Loh KP, Dunne R, Magnuson A, Maggioro R, Zittel J, et al. Older adults with cancer and their caregivers - current landscape and future directions for clinical care. *Nat Rev Clin Oncol* 2020;17(12):742–55.
- [24] Ketcher D, Otto AK, Vadaparampil ST, Heyman RE, Ellington L, Reblin M. The psychosocial impact of spouse-caregiver chronic health conditions and personal history of cancer on well-being in patients with advanced cancer and their caregivers. *J Pain Symptom Manag* 2021;62(2):303–11.
- [25] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101.
- [26] Braun V, Clarke V. Conceptual and design thinking for thematic analysis. *Qual Psychol (Washington, DC)* 2022;9(1):3–26.
- [27] O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;341(7783):1147–50.
- [28] O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. *J Health Serv Res Policy* 2008;13(2):92–8.
- [29] Moffatt S, White M, Mackintosh J, Howel D. Using quantitative and qualitative data in health services research – what happens when mixed method findings conflict? [ISRCTN61522618]. *BMC Health Serv Res* 2006;6(1):28.
- [30] Donison V, Toledano N, McGilton K, Alibhai SMH, Puts M. Care provided by older adult caregivers to a spouse in active cancer treatment: a scoping review. *Support Care Cancer* 2022;30(11):8679–88.
- [31] Pethybridge R, Teleni L, Chan RJ. How do family-caregivers of patients with advanced cancer provide symptom self-management support? A qualitative study. *Eur J Oncol Nurs* 2020;48:101795.
- [32] Lehto US, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. *Eur J Cancer Care* 2018;27(1).
- [33] Coughlin SS, Datta B. Predictors of unhealthy physical and mental days among informal cancer caregivers: results from the 2019 Behavioral Risk Factor Surveillance System survey. *Support Care Cancer* 2022;30(3):2163–71.
- [34] Semere W, Althouse AD, Rosland A-M, White D, Arnold R, Chu E, et al. Poor patient health is associated with higher caregiver burden for older adults with advanced cancer. *J Geriatr Oncol* 2021;12(5):771–8.
- [35] Carstensen LL, Isaacowitz DM, Charles ST. Taking time seriously: a theory of socioemotional selectivity. *Am Psychol* 1999;54(3):165–81.
- [36] Löckenhoff CE, Carstensen LL. Socioemotional selectivity theory, aging, and health: the increasingly delicate balance between regulating emotions and making tough choices. *J Pers* 2004;72(6):1395–424.
- [37] Mourgova M. Health status of old age population in Bulgaria. *Eur J Nat Sci Med* 2022;5(2):88–95.
- [38] Harris EC, D'Angelo S, Syddall HE, Linaker C, Cooper C, Walker-Bone K. Relationships between informal caregiving, health and work in the Health and Employment After Fifty study, England. *Eur J Pub Health* 2020;30(4):799–806.
- [39] Berg CA, Upchurch R. A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol Bull* 2007;133(6):920–54.
- [40] Eifert EK, Adams R, Morrison S, Strack R. Emerging trends in family caregiving using the life course perspective: preparing health educators for an aging society. *Am J Health Educ* 2016;47(3):176–97.
- [41] Morgan T, Ann Williams L, Trussardi G, Gott M. Gender and family caregiving at the end-of-life in the context of old age: a systematic review. *Palliat Med* 2016;30(7):616–24.
- [42] Pinquart M, Sörensen S. Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychol Aging* 2011;26(1):1–14.
- [43] Cahill E, Lewis LM, Barg FK, Bogner HR. You Don't want to burden them: older adults' views on family involvement in care. *J Fam Nurs* 2009;15(3):295–317.
- [44] Litwin H, Levinsky M, Schwartz E. Network type, transition patterns and well-being among older Europeans. *Eur J Ageing* 2020;17(2):241–50.
- [45] Hong J, Kim O. Development and validation of an emotional labour scale for nurses. *J Nurs Manag* 2019;27(3):509–16.
- [46] Jeung D-Y, Kim HR, Song H, Kim I, Yoon J-H, Koh S-B, et al. Emotional labor (KELS®11): scale development and validation in the Korean context. *Ann Occup Environ Med* 2025;37:e13.
- [47] Chen M, Gong J, Cao Q, Luo X, Li J, Li Q. A literature review of the relationship between dyadic coping and dyadic outcomes in cancer couples. *Eur J Oncol Nurs* 2021;54:102035.
- [48] Zhou J, Chen X, Wang Z, Li Q. Couple-based communication interventions for cancer patient-spousal caregiver dyads' psychosocial adaptation to cancer: a systematic review. *Healthcare (Basel)* 2023;11(2):236.
- [49] Freedman VA, Cornman JC, Carr D, Lucas RE. Time use and experienced wellbeing of older caregivers: a sequence analysis. *Gerontologist* 2019;59(5):e441–50.
- [50] Brenner PS. Investigating the biasing effect of identity in self-reports of socially desirable behavior. *Sociol Focus (Kent, Ohio)* 2011;44(1):55–75.
- [51] Fetter MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res* 2013;48(6pt2):2134–56.