

Original Article

Gaps between Supportive Care Needs and Services in Korea: Experiences and Preferences of Patients with Advanced Cancer and Their Caregivers in the Hospital and at Home

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Abstract

Purpose

With longer survivals in advanced cancer, the need for supportive care is increasing. However, in Korea, these services remain limited, and many patients rely on long-term care hospitals. We investigated the supportive care experiences of patients with advanced cancer and their caregivers, and preferred place of care (pPOC) by performance status (PS).

Materials and Methods

A cross-sectional survey was conducted at a tertiary hospital in Seoul, Korea, targeting patients hospitalized only for supportive care and their caregivers. PS was assessed using the Eastern Cooperative Oncology Group scale [good (0–1) or poor (2–4)]. Hospital and home care experiences and pPOC were compared by PS. Logistic regression analysis was used to identify factors associated with pPOC.

Results

This study included 200 participants (117 patients, 83 caregivers). Among patients, 72% had good PS and 28% had poor PS. Main reasons for hospitalization were symptom control (51.2%), assistance with daily living (36.5%), and device or wound management (22.5%). Overall, 60.5% of participants reported discomfort during hospitalization, mostly related to hospital life, and 34.5% noted that care was insufficient at home, particularly those in the poor PS group (27.1% vs. 53.6%). Concern about emergencies was the most common home-care difficulty. Despite these challenges, 60% of participants chose home as their future pPOC, with no significant differences by PS or other demographic/clinical factors.

Conclusion

Although most patients with advanced cancer and their caregivers preferred home for supportive care, many relied on hospitals. Structured home-based medical care programs are urgently required in South Korea.

Keywords Neoplasms, Palliative care, Home care services, Long-term care, Quality of life

Accepted Article

Introduction

With increasing survival among patients with advanced cancer, the demand for supportive care is growing. In South Korea (hereafter Korea), the National Health Insurance Service (NHIS) provides universal coverage and access to medical services for all citizens [1]. However, despite the strong infrastructure for disease treatment, access to supportive care services, particularly for patients with serious illnesses such as cancer, remains limited [2,3].

Home-based medical care (HBMC), a potentially important model of supportive care, is still in the early stages of implementation in Korea. Most services are focused on primary care; thus, aside from home hospices for terminally ill patients eligible for hospice care, home-based supportive care services for diseases such as cancer are limited [4,5]. As a result, many patients with advanced cancer requiring supportive care are admitted to long-term care hospitals (LTCHs), not because these facilities are ideally suited to their needs, but because alternative options for supportive care, particularly in the home or community, are limited within the current healthcare system [6,7].

While previous studies have shown that terminally ill patients often prefer to receive care at home [8-10], most have focused on end-of-life situations where curative treatment is no longer being pursued. In contrast, many patients with advanced cancer have substantial supportive care needs even while undergoing active treatment. Supportive care for these patients includes management of cancer symptoms as well as treatment-related side effects, and care of daily life owing to deterioration in general condition. However, little is known about patients' preferences for place of care when such supportive needs arise, or whether these preferences vary according to patient performance status (PS), caregiving burden, or other contextual factors. Understanding these dynamics is especially important in Korea, where LTCHs are often the only practical option for providing supportive care outside the home.

The aim of this study was to investigate the experiences of patients with advanced cancer and their caregivers in Korea, including their use of supportive care during hospitalization and at home, the challenges and emotional distress they encounter in the caregiving process, and their preferences regarding the place of care.

Materials and Methods

1. Study design and population

This cross-sectional survey was conducted at a tertiary hospital in Seoul, Korea, with over 1,700 beds, 550,000 inpatients, and 2.4 million outpatients annually. Participants included adults aged ≥ 20 years with advanced cancer (defined as locally advanced, metastatic or recurrent disease not amenable for curative treatment) who had been admitted to a hospital other than the hospital receiving anti-cancer treatments such as chemotherapy, radiotherapy, or surgery for supportive care within the last 6 months and their primary caregivers. The study included patients admitted solely for supportive care to hospitals that did not provide anti-cancer treatments. Patients who were admitted exclusively for anti-cancer treatment and had never been hospitalized solely for supportive care were excluded.

2. Data collection

A self-administered survey was conducted from May 10 to 27, 2022, using convenience and purposive sampling. Participants were recruited from the oncology outpatient department of the study hospital. Trained investigators asked patients and their caregivers in the outpatient clinic waiting area about their willingness to participate and screened them for eligibility. If a person who met the eligibility criteria agreed to participate, they were given a questionnaire to complete immediately. Depending on the patient's condition, either the patient or caregiver responded.

3. Measures

Data were collected on (1) patient demographics and primary caregiver, (2) cancer-related details (duration of cancer and patient's physical PS, (3) hospitalization experience for supportive care (reason for admission, length of hospital stay [days], and whether respondent felt discomfort during hospitalization and if so, the reason for discomfort), (4) home care experience (care time per day, care area at home, perceived sufficiency of patient care at home, need for medical advice, depression of respondents, difficulties experienced at home care), (5) preferred place of care (pPOC) in the future.

Patient demographics included age, sex, residential region, and monthly household income. PS was assessed using the Eastern Cooperative Oncology Group performance status (ECOG PS), scored on a scale of 0 (fully active) to 5 (dead) [11] and classified as good PS (ECOG PS 0–1) and poor PS (ECOG PS 2–4) [12–15].

Reasons for supportive care-related hospitalization were classified into seven categories: symptom control, routine check-up, medical device management or wound care (e.g., nasogastric tube and central-line catheter), assistance with activities of daily living (ADL), alternative medicine, concern about home care, and others. Reasons for discomfort during hospitalization were also examined in seven categories: discomfort of hospitalization itself, misunderstanding of the patient's condition, feeling that cancer treatment was not helpful, feeling that the reason for hospitalization was not resolved, financial burden, discomfort of caregiver hospital stay, and other.

Regarding home care experience, care time was defined as the total amount of time spent caring for patients out of 24 hours a day. Areas of home care were classified into eight categories: meal preparation, check-ups for the patient's condition, exercise and self-

rehabilitation, medication management, washing and bathing care, wound care and position change, medical device management, and other. Perceived sufficiency of patient care was assessed using a 5-level Likert scale to determine whether respondents felt supportive care at home was sufficient and how often they needed advice from medical professionals, reported as number of times per week and per month. Resources used for medical advice were also investigated (multiple choice): oncology outpatient clinic visit to the hospital, online website search, patients and caregiver communities, primary care clinic visits, phone calls to the hospital providing cancer treatment, friends or relatives, and medical books or papers.

Depression related to home care was assessed using the Patient Health Questionnaire-9 (PHQ-9) (0–4, no depression; 5–9, mild depression; 10–19, moderate depression; and 20–27, severe depression) [16]. Difficulties experienced in home care were assessed using eight items: concern about emergency situations, assistance with ADL, difficulty understanding the patient's condition owing to lack of medical knowledge, emotional and psychological distress, pain management, financial burden, challenges with caregiving shifts, and medication and medical device management. pPOC was defined as respondents' preference for a future care location (home, hospital, or indeterminate).

4. Statistical analysis

Descriptive analysis was conducted to examine the demographics and care experiences of patients by PS group. Categorical variables are presented as counts and proportions, and continuous variables as medians and interquartile ranges (IQRs). Statistical differences by PS group were assessed using the χ^2 test for categorical variables and Wilcoxon rank sum test for continuous variables. Multivariate logistic regression analysis was performed to investigate factors associated with pPOC. Variables were selected based on a previous study on pPOC [17].

Statistical significance level was set at $p = 0.05$. All statistical analyses were performed using STATA version 16.0 (StataCorp LLC, College Station, TX, USA).

Results

1. Characteristics of patients and caregivers

A total of 200 respondents were recruited, including 117 (58.5%) patients and 83 (41.5%) caregivers of patients with advanced cancer. The proportions of patients with good and poor PS were 72.0% and 28.0%, respectively. Most primary caregivers were spouses (50.5%), followed by children (30.0%) and parents (10.5%). The Poor PS group had a longer cancer duration of 3–5 years (11.1% vs. 19.6%) and over 5 years (22.2% vs. 35.7%) ($p=0.04$) (Table 1).

2. Care experience during hospitalization for supportive care

The most common reasons for admission were symptom control (51.2%), assistance with ADL (36.5%), and medical device management and wound care (22.5%). Median (IQR) length of hospital stay in the last 6 months was 14 (7–43.5) days. Approximately one-third of patients (34.5%) were hospitalized for over 30 days in the last 6 months, particularly in the poor PS group (31.3% vs. 42.9%). More than half of participants (60.5%) reported feeling discomfort during hospitalization for supportive care, with the most common reason being hospitalization itself (57.9%), followed by a perceived lack of understanding of the patient's condition by hospital staff (10.7%), the feeling that hospitalization was not helpful for cancer treatment (9.9%), and unresolved reasons for admission (9.9%) (Table 2).

3. Care experience at home for supportive care

Median (IQR) care time was 3 (1–5) hours on weekdays and 3 (2–6) hours on

weekends. The poor PS group spent significantly more time both on weekdays (2 (1–4) vs. 3 (2–5) hours, $p < 0.01$) and weekends (3 (2–5) vs 6.5 (4–12) hours, $p < 0.01$). The most common areas of home care were meal preparation (83.5%), checkups for the patient's condition (80.5%), and exercise or self-rehabilitation (31.0%), particularly in the poor PS group (all $p < 0.01$). A perceived insufficiency of supportive care at home was reported by 34.5% of respondents, with a higher proportion in the poor PS group (53.6% vs. 27.1%, $p < 0.01$).

The need for medical advice at least once weekly was reported by 34.5% of respondents, including 53.6% in the poor PS group. The most common sources of medical advice were outpatient clinic visits (82.5%) and websites (40.0%). Additionally, 20.5% of the patients consulted support groups, and only 13.0% visited primary care clinics.

Moderate or higher levels of depression during home care were reported by 26.5% of patients, particularly in the poor PS group (47.4% vs. 22.4%, respectively), and by 31.3% of caregivers, particularly in the poor PS group (54.1% vs. 13.0%) (Table 3).

Regarding difficulties encountered during home care, the most common response for both patients and caregivers was concern about emergency situations (53.8% and 59.0%, respectively), followed by assistance with ADL (32.5%) and difficulty understanding the patient's condition owing to lack of medical knowledge among caregivers (33.7%) (Table 4).

4. Preferred place of care

Home was the pPOC for 60.0% of respondents, comparable with the proportion in the poor PS group (57.1%) (Fig. 1). Multivariate analysis revealed no significant associations between preference for home care and ECOG PS, patient sex, type of primary caregiver, or cancer duration (Table 5).

Discussion

In this cross-sectional study of patients with advanced cancer and their caregivers, we found that the majority of those admitted to the hospital for supportive care reported discomfort during hospitalization and preferred home as the site of future care. Admissions were most often for symptom control, assistance with ADL, medical device management, and wound care. However, more than half of the patients reported discomfort during hospitalization, most commonly due to hospitalization itself and a perceived lack of understanding of the patient's condition. Considering that many patients living with advanced cancer and their caregivers prefer to stay at home but choose hospitalization for supportive care owing to concerns about emergencies and the need for frequent medical advice, expanding home-based supportive care programs for these patients is necessary.

The strength of this study is that we investigated the preferred places of supportive care for patients with advanced cancer undergoing active cancer treatment and their caregivers. The majority (60%) reported a preference for receiving supportive care at home, and this proportion remained high even among those with poor PS. While previous research has shown that patients near the end of life often wish to remain at home [17,18], our findings extend this evidence to patients who are still undergoing active treatment but require supportive care. Notably, multivariable analysis revealed no significant association between preference for home care and PS, age, sex, type of primary caregiver, or cancer duration. This indicates that the preference for home is a broadly shared value across diverse demographic and clinical subgroups, rather than being confined to those with specific characteristics.

Although many patients and caregivers expressed a preference for home, supportive care in practice was often delivered through hospitals such as LTCHs. In the past six months, more than one-third of patients who had been hospitalized for supportive care stayed longer

than 30 days, underscoring the frequent reliance on hospitalization for supportive needs. The most common reasons for admission—symptom control, assistance with ADL, and medical device or wound management—are types of care that could be provided in the home setting if appropriate HBMC programs were available. This suggests that, in the current system, hospital admission frequently substitutes for the lack of an accessible home-based supportive care system. Importantly, this reliance on hospitals did not necessarily translate into a satisfactory experience: more than half of respondents reported discomfort during hospitalization, most frequently citing the discomfort of the hospital environment itself and a perceived lack of understanding of the patient's condition.

On the other hand, in the home setting, both patients and caregivers most frequently reported being worried about emergent situations, and more than one-third indicated the need for medical advice at least once a week. However, in the absence of accessible home-based services for patients with advanced cancer, most relied on oncology outpatient clinic visits or websites. A previous study showed a strong association between unmet information needs and higher levels of anxiety and depressive symptoms among caregivers of patients with cancer [19]. Psychological distress was also common in our study, with nearly one-third of patients and caregivers reporting moderate or severe depression, and the proportion was particularly high among caregivers of patients with poor PS. In this group, both the heavier responsibility for assisting with ADL and the heightened uncertainty due to insufficient professional support may have contributed to their greater psychological burden.

Previous studies have shown that family-provided home care, while strongly preferred, can place considerable psychological strain on families. High levels of anxiety and depression and reduced quality of life have been reported in this context [20,21]. These findings underscore the importance of structured HBMC, which involves multidisciplinary teams and supports

patients and families across the disease trajectory. With these features, HBMC is well-positioned to address not only medical needs but also psychosocial challenges, thereby mitigating the psychological burden often experienced in family caregiving at home [22-25].

It is noteworthy that the study population exhibited an uneven sex distribution, with females accounting for 72.5% of the respondents. Although the lack of data on specific cancer type limit ability to determine if this imbalance is disease-specific, the recruitment of patients with a history of hospitalization for supportive care may have influenced this distribution. In Korea, traditional gender roles often dictate that women, particularly those in middle-aged and older cohorts, bear primary responsibility for household and caregiving duties [26,27]. These social expectations frequently persist even after a cancer diagnosis, creating a 'double burden' where female patients must manage both their treatment and domestic obligations. To alleviate these burdens and prioritize self-care, an increasing number of female patients with cancer are opting for admission to nursing hospitals rather than remaining at home [28]. While sex was not a statistically significant predictor of home care preference in the logistic regression model, the proportion of male patients preferring home care (65.5%) was slightly higher than that of female patients (57.9%). Considering that the burden of housework and caregiving in Korea is concentrated on women—and that these domestic roles often remain unchanged even following a cancer diagnosis—it is plausible that female patients increasingly opt for facility-based supportive care, such as nursing hospitals, to focus on self-care. This tendency for women to seek hospitalization to alleviate domestic responsibilities may have contributed to the higher proportion of female respondents observed in this study. This imbalance in sex distribution should therefore be considered when interpreting the results and represents a potential limitation of the study.

Furthermore, it also noted that while 60% of respondents preferred home care, the

remaining 40% expressed a preference for facility-based care or remained undecided regarding their care setting. The absence of statistically significant factors associated with home care preference in logistic regression model aligns with previous findings, which show no clear determinants distinguishing patients who prefer home discharge from those who favor institutional care [29]. This lack of distinct predictors suggests that the choice of care place is influenced by a complex interplay of diverse factors and highly individualized needs [30]. Previous systematic review reported that a patient's preference for a care place is shaped not only by their symptom burden but also by family-related factors, such as the presence of cohabiting family members and caregiving capacity [30]. To establish a preference-sensitive care model that ensures patients receive care in their desired setting, a more various support system is required to honor and facilitate individual patient preferences.

Patients with advanced cancer inevitably require supportive care because of various uncomfortable symptoms and decreased performance during anticancer treatment. This study shows that patients with advanced cancer and their caregivers who prefer home care in an environment without such appropriate HBMC experience discomfort from avoidable hospitalization for supportive care. Therefore, it is necessary to design targeted home-based supportive care programs for these patients.

This study has several limitations. First, this study was conducted at a single tertiary hospital using convenience sampling, which may limit the generalizability of the findings. In addition, the study population consisted of patients who had experienced hospitalization solely for supportive care, which may represent a subgroup with relatively high supportive care needs. Therefore, the findings should be interpreted with caution when applied to the broader population of patients with advanced cancer. Second, self-reported surveys are inherently prone to recall and reporting bias. However, the questionnaires were administered face-to-face by

trained investigators, which likely reduced such errors. Third, although the survey has the strength of including responses from both patients and caregivers and covering multiple domains of supportive care experiences, the questionnaire was developed specifically for this study and was not a validated supportive care needs instrument. Therefore, direct comparisons with studies using validated tools should be interpreted with caution. To aid conceptual comparison, we provide a qualitative mapping of our items to SCNS-SF34 domains (S1 Table) [31]. Future studies using validated supportive care needs instruments are warranted. Fourth, this study did not collect detailed information on primary cancer types. Because symptom burden, treatment complexity, and supportive care needs may differ across cancer types, examining supportive care needs according to cancer type may provide more nuanced insights into patients' supportive care experiences and preferences.

In summary, this study revealed that the majority of patients with advanced cancer receiving active cancer treatment and their caregivers expressed a preference for supportive care at home. Despite this preference, many relied on hospitals for supportive care needs, reflecting both limitations in family-led home care, such as a lack of information and professional support, and the absence of structured alternatives. These findings highlight the importance of developing targeted HBMC in Korea to support patients and families not only at the end of life but also throughout the cancer journey. Developing HBMC models adapted to the Korean healthcare context and testing them through pilot studies is essential for creating systems capable of meeting the physical, psychological, and social needs of patients living with advanced cancer and their families.

Ethical Statement

This study was approved by the Institutional Review Board of Seoul National University Hospital (IRB No. 2201-132-1294), and informed consent was obtained from all study participants.

Author Contributions

Conceived and designed the analysis: Jang MS, Hwang IG, Yoo SH, Kim MS, Lee SY.

Collected the data: Jang MS, Hwang IG, Yoo SH, Cho B, Keam B, Kim YJ, Baek SK, Kim MS, Lee SY.

Contributed data or analysis tools: Jang MS, Hwang IG, Kim MS, Lee SY.

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Conflicts of Interest

Conflict of interest relevant to this article was not reported.

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Table 1. Characteristics of patients living with advanced cancer and their caregivers

	Total (n=200) n (%)	Good PS (n=144) n (%)	Poor PS (n=56) n (%)	p value
Respondents				<0.001
Patient	117 (58.5)	98 (68.1)	19 (33.9)	
Caregiver	83 (41.5)	46 (31.9)	37 (66.1)	
Patients' information				
Age				0.08
<50	49 (24.5)	42 (29.2)	7 (12.5)	
50–60	59 (29.5)	38 (26.4)	21 (37.5)	
60–70	52 (26.0)	37 (25.7)	15 (26.8)	
≥70	40 (20.0)	27 (18.8)	13 (23.2)	
Sex				0.11
Male	55 (27.5)	35 (24.3)	20 (35.7)	
Female	145 (72.5)	109 (75.7)	36 (64.3)	
Residential region				0.20
Metropolitan	129 (64.5)	89 (61.8)	40 (71.4)	
Non-metropolitan	71 (35.5)	55 (38.2)	16 (58.6)	
Monthly household income (\$)				0.94
<1500	38 (19.0)	27 (18.8)	11 (19.6)	
1500–4500	102 (51.0)	72 (50.0)	30 (53.6)	
>4500	52 (26.0)	39 (27.1)	13 (23.2)	
N/A	8 (4.0)	6 (4.2)	2 (3.6)	
Duration of cancer				0.04
< 1 year	74 (37.0)	59 (41.0)	15 (26.8)	
1–3 years	47 (23.5)	37 (25.7)	10 (17.9)	
3–5 years	27 (13.5)	16 (11.1)	11 (19.6)	
≥5 years	52 (26.0)	32 (22.2)	20 (35.7)	
Primary caregiver				0.20
Spouse	101 (50.5)	72 (50.0)	29 (51.8)	
Children	60 (30.0)	39 (27.1)	21 (37.5)	
Parents	21 (10.5)	18 (12.5)	3 (5.4)	
Others	18 (9.0)	15 (10.4)	3 (5.4)	

Values are presented as number (%). N/A, not applicable.

Table 2. Care experience during hospitalization for supportive care

Variables	Total (n=200)	Good PS (n=144)	Poor PS (n=56)	p-value
	n (%)	n (%)	n (%)	
Reason for admission*				
Symptom control	103 (51.2)	71 (49.3)	32 (57.1)	0.32
Assisting with activities of daily living	73 (36.5)	54 (37.5)	19 (33.9)	0.64
Medical device management and wound care	45 (22.5)	30 (20.8)	15 (26.8)	0.37
Worry about home care	39 (19.5)	31 (21.5)	8 (14.3)	0.25
Alternative medicine	37 (18.5)	23 (16.0)	14 (25.0)	0.14
Routine condition check-up	36 (18.0)	29 (20.1)	7 (12.5)	0.21
Others	3 (1.5)	3 (2.1)	0	0.28
Length of hospital stay within the past 6 months				
days, median (IQR)	14 (7-43.5)	11 (7-30.5)	16.5 (7-135)	0.08
< 30 days	131(65.5)	99 (68.8)	32 (57.1)	
≥ 30 days	69 (34.5)	45 (31.3)	24 (42.9)	
Uncomfortable experience with admission	121 (60.5)	85 (59.0)	36 (64.3)	0.50
Reason for discomfort*				
Discomfort of hospitalization itself	70 (57.9)	52 (61.2)	18 (50.0)	0.60
Lack of understanding of the patient's condition by hospital staff	13 (10.7)	8 (9.4)	5 (13.9)	0.39
Feeling of hospitalization was not helpful for cancer treatment	12 (9.9)	7 (8.2)	5 (13.9)	0.28
Unresolved reasons for admission	12 (9.9)	9 (10.6)	3 (8.3)	0.81
Financial burden	6 (5.0)	5 (5.9)	1 (2.8)	0.53
Discomfort of caregiver's hospital stay	3 (2.5)	2 (2.4)	1 (2.8)	0.84
Others	5 (4.1)	2 (2.4)	3 (8.3)	0.11

PS, performance status; IQR, interquartile range. Values are presented as numbers (%) unless otherwise noted. *Multiple choices were possible.

Table 3. Care experience at home for supportive care

Variables	Total n (%)	Good PS n (%)	Poor PS n (%)	p-value
Care time (hours/day), median (IQR)				
Weekdays	3 (1-5)	2 (1-4)	3 (2-5)	<0.01
Weekends	3 (2-6)	3 (1-5)	6.5 (4-12)	<0.01
Care area at home				
Meal preparation	167 (83.5)	113 (78.5)	54 (96.4)	<0.01
Check-up for patient's condition	161 (80.5)	108 (75)	53 (94.6)	<0.01
Exercise and self-rehabilitation	62 (31.0)	36 (25)	26 (46.4)	<0.01
Managing of medication	52 (26.0)	25 (17.4)	27 (48.2)	<0.01
Washing and bathing care	22 (11.0)	3 (2.1)	19 (33.9)	<0.01
Wound care and position change	7 (3.5)	4 (2.8)	3 (5.4)	0.37
Medical device management	5 (2.5)	1 (0.7)	4 (7.1)	0.01
Others	7 (3.5)	6 (4.2)	1 (1.8)	0.411
Perceived sufficiency of patient care at home				<0.01
Average, sufficient, and very sufficient	129 (64.5)	103 (71.5)	26 (46.4)	
Insufficient	52 (26.0)	31 (21.5)	21 (37.5)	
Highly insufficient	17 (8.5)	8 (5.6)	9 (16.1)	
N/A	2 (1.0)	2 (1.4)	0	
Need for medical advice				
Frequency				0.01
Rarely	56 (28.0)	47 (32.6)	9 (16.1)	
1~2times/month	68 (34.0)	51 (35.4)	17 (30.4)	
1~2times/week	54 (27.0)	36 (25)	18 (32.1)	
3~4times/week	18 (9.0)	8 (5.6)	10 (17.9)	
Everyday	4 (2.0)	2 (1.4)	2 (3.6)	
Method*				
Oncology outpatient clinic visit	165 (82.5)	118 (81.9)	47 (83.9)	0.74
Online web searching	80 (40.0)	57 (35.6)	23 (41.1)	0.85
Patient group asking	41 (20.5)	29 (20.1)	12 (21.4)	0.84
Primary care clinic	26 (13.0)	19 (13.2)	7 (12.5)	0.90
Phone call to oncology outpatient clinic	23 (11.5)	17 (11.8)	6 (10.7)	0.83
Friends or relatives	8 (4.0)	5 (3.5)	3 (5.4)	0.54
Books or journals	2 (1.0)	1 (0.7)	1 (1.8)	0.49
Patient depression assessed by PHQ-9				0.12
No (0-4)	47 (40.2)	42 (42.9)	5 (26.3)	
Mild (5-9)	39 (33.3)	34 (34.7)	5 (26.3)	
Moderate (10-19)	30 (25.6)	21 (21.4)	9 (47.4)	
Severe (20-27)	1 (0.9)	1 (1)		
Caregiver depression assessed by PHQ-9				<0.01
No (0-4)	36 (43.4)	25 (54.4)	11 (29.7)	

Mild (5-9)	21 (25.3)	15 (32.6)	6 (16.2)
Moderate (10-19)	24 (28.9)	6 (13)	18 (48.7)
Severe (20-27)	2 (2.4)		2 (5.4)

PS, performance status; IQR, interquartile range; PHQ-9, patient health questionnaire-9. Values are presented as numbers (%) unless otherwise noted. *Multiple choices were possible.

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Table 4. Difficulties while caring for patients at home

Rank	Difficulties	n (%)
Patients		
1	Worry about emergent situation	63 (53.8)
2	Assisting with activities of daily living for patients	38 (32.5)
3	Difficulty understanding the patient's condition due to lack of medical knowledge	34 (29.1)
4	Emotional and psychological difficulties	27 (23.1)
5	Pain management	21 (17.9)
6	Financial burden	17 (14.5)
7	Difficulties with caregiving shifts	8 (6.8)
8	Managing medication and medical devices	2 (1.7)
Caregivers		
1	Worry about emergent situation	49 (59.0)
2	Difficulty understanding the patient's condition due to a lack of medical knowledge	28 (33.7)
3	Assisting with activities of daily living for patients	25 (30.1)
4	Pain management	24 (28.9)
5	Emotional and psychological difficulties	14 (16.9)
6	Financial burden	9 (10.8)
7	Difficulties with caregiving shifts	7 (8.4)
8	Managing medication and medical devices	4 (4.8)

Multiple choices were possible.

Table 5. Multivariate logistic analysis of associated factors for preferred care at home

	Prefer home			Crude Model		Model 1		Model 2	
	n	n	%	OR	95% CI	aOR	95% CI	aOR	95% CI
Total	200	120	60.0						
ECOG PS									
Good PS (0-1)	144	88	61.1	1.00		1.00		1.00	
Poor PS (2-4)	56	32	57.1	0.85	(0.45-1.59)	0.91	(0.47-1.74)	1.00	(0.51-1.99)
Patient age									
<50	49	36	73.4			1.00		1.00	
50~60	59	35	59.3			0.51	(0.22-1.17)	0.63	(0.26-1.54)
60~70	52	29	55.8			0.40	(0.17-0.95)	0.55	(0.21-1.44)
≥70	40	20	50.0			0.31	(0.12-0.78)	0.46	(0.16-1.36)
Patient sex									
Male	55	36	65.5			1.00		1.00	
Female	145	84	57.9			0.57	(0.29-1.13)	0.63	(0.31-1.30)
Primary caregiver									
Spouse	101	64	63.4					0.73	(0.31-1.75)
Child	60	27	45.0					0.46	(0.16-1.29)
Others								1.00	
Duration of cancer									
<1year	74	43	58.1					1.00	
1-3 years	47	32	68.1					1.88	(0.84-4.24)
3-5years	27	11	40.7					0.63	(0.24-1.63)
>5years	52	34	65.4					1.37	(0.64-2.96)

ECOG, Eastern Cooperative Oncology Group; PS, performance status; OR, odds ratio; aOR, adjusted odds ratio; CI, confidence interval. Model 1: Crude. Model 1: Adjusted for patient age and sex. Model 2: Adjusted for patient age, patient sex, primary caregiver, and duration of cancer.

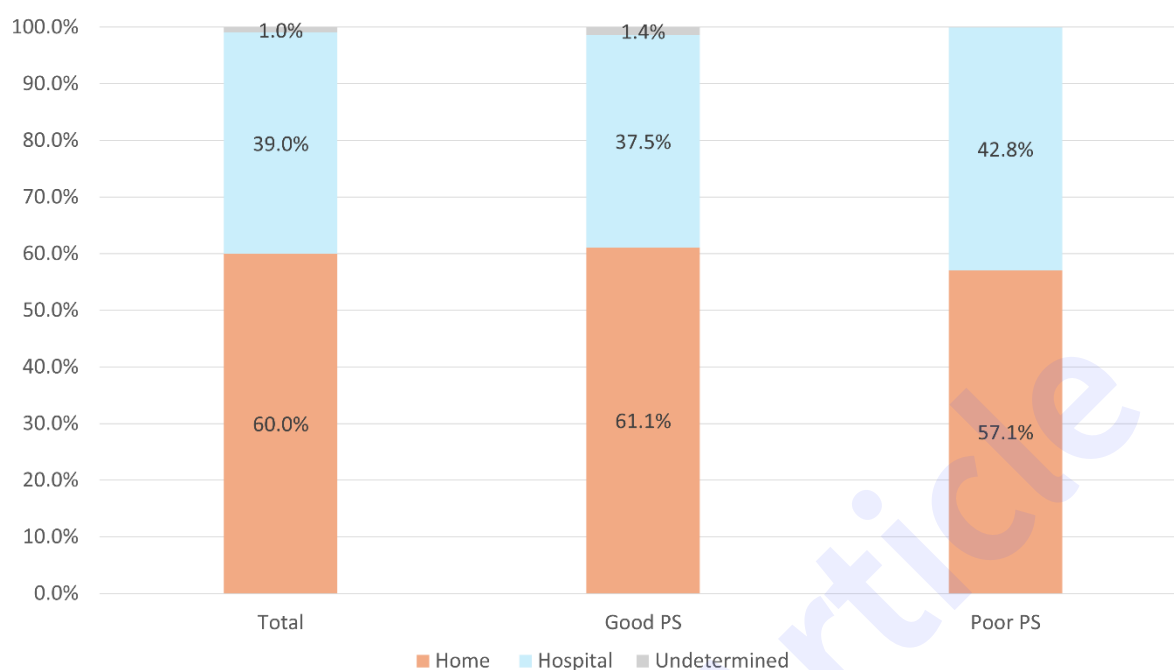


Fig. 1. Preferred place of care according to Eastern Cooperative Oncology Group performance status. * Good PS: (ECOG PS 0–1) and poor PS: (ECOG PS 2–4).

S1 Table. Survey domains and items in relation to 34-item Supportive Care Needs Survey (SCNS-SF34)

Domain	SCNS-SF34 domain	SCNS-SF34 items (abridged)	This study domain	This study items
Supportive care needs	Psychological	Anxiety; Depression; Fears about cancer spreading; Concerns about close others	Depression Difficulties in home care	PHQ-9 items Emotional and psychological distress
	Health system and information	Being given information about illness; Access to counselling; Having one staff to talk to	Difficulties in home care Need for medical advice	Difficulty understanding the patient's condition due to lack of medical knowledge Frequency
	Patient care and support	Staff attending promptly to physical needs	Reasons for discomfort during hospitalization	Misunderstanding of the patient's condition
	Physical and daily living	Pain; Unable to do usual things	Difficulties in home care	Assistance with ADL; Pain management
	Sexuality	Changes in sexual feelings		Not assessed in this study
Supportive care at hospital experience			Reason for admission	Symptom control; Assisting with ADL; Device and wound management; Worry about home care; Alternative medicine; Condition check-up; Others
			Discomfort during hospitalization	Yes/No
			Reasons for discomfort during hospitalization	Discomfort of hospitalization itself; Staff misunderstanding; Not helpful for treatment; Unresolved issues; Financial burden; Discomfort of caregiver's stay; Others
Supportive care at home experience			Care time at home	Daily caregiving time (hours/day).
			Perceived sufficiency of supportive care at home	5-level Likert scale
			Care area at home	Meal preparation; Condition check-up;

	Resources used for medical advice	Exercise; Medication management; Bathing; Wound care; Device management; Others
	Difficulties in home care	Outpatient clinic; Web searching; Patient group; Primary care clinic; Phone call to outpatient clinic; Friends or relatives
		Books or journals
		Emergency concerns; ADL assistance; Knowledge gaps; Distress; Pain; Financial burden; Caregiving shifts; Medication/device management
Preferred place of care	Preferred place of care	Home; Hospital; Indeterminate

SCNS-SF34, 34-item Supportive Care Needs Survey; PHQ-9, Patient Health Questionnaire-9; ADL, Activities of Daily Living.