

# WHAT PALLIATIVE PATIENTS AND THEIR CARERS NEED AT HOME AND WHAT A PRIMARY HEALTH CARE TEAM CAN OFFER - FIRST PILOT STUDY IN SLOVENIA

## KAJ POTREBUJEJO PALIATIVNI BOLNIKI IN NJIHOVI OSKRBOVALCI NA DOMU IN KAJ LAHKO PONUDI TIM OSNOVNEGA ZDRAVSTVA - PRVA SLOVENSKA PILOTNA RAZISKAVA

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Received: Sep 3, 2022  
Accepted: Nov 21, 2022

Original scientific article

### ABSTRACT

#### Keywords:

palliative care, home care, primary health care, needs assessment

**Introduction:** Spending one's last days and dying at home is a common wish of people with a life-limiting illness. Home-based palliative care is essentially organised at the primary level to meet the needs of palliative patients and their carers. The aim of this study was to identify the characteristics of home-based palliative care, focusing on those who identify palliative patients, what their needs are and how this affects their length of life and site of death.

**Methods:** This retrospective cohort study analysed routinely collected notes of patients enrolled in home-based palliative care between 2015 and 2021. Palliative care was provided by a primary health care team in a predominantly rural area.

**Results:** This study included 107 palliative patients, aged 71±11.4 years, 94% of whom had cancer. They were enrolled in palliative care by their primary care team or by hospital staff. The enrolment by hospital staff (3%) resulted in significantly shorter survival ( $p=0.008$ ). Patients lived an average of 66 days, and 65% of patients died at home. Home-based palliative care was found to respond to both basic and complex palliative medical needs, but was weaker in addressing socio-economic, psychological or spiritual issues.

**Conclusion:** This exemplary primary-level palliative team provided home-based palliative care that has improved over the years in terms of all the observed quality indicators: early enrolment, the proportion of patients dying at home and the ability to address needs. Specialised mobile palliative teams, hospitals and other palliative care settings complement home-based palliative care.

### IZVLEČEK

#### Ključne besede:

paliativna oskrba, oskrba na domu, osnovno zdravstvo, prepoznavanje potreb

**Uvod:** Neozdravljivo bolni ljudje si pogosto želijo preživeti zadnje obdobje svojega življenja doma in doma tudi umreti. Paliativno oskrbo na domu pretežno pokriva osnovno zdravstvo, ki se odziva na potrebe paliativnih bolnikov in njihovih oskrbovalcev. Namen raziskave je bil ugotoviti značilnosti paliativne oskrbe na domu s poudarkom na tem, kdo prepozna paliativne bolnike, kakšne so njihove potrebe in kako to vpliva na njihovo dolžino življenja in kraj smrti.

**Metode:** V retrospektivni kohortni študiji smo analizirali rutinsko zbrane zapise o oskrbi paliativnih pacientov, vključenih v paliativno oskrbo na domu v letih 2015-2021. Paliativno oskrbo je zagotavljal tim osnovnega zdravstva v pretežno ruralnem okolju.

**Rezultati:** V raziskavo je bilo vključenih 107 paliativnih bolnikov, starih 71 ± 11,4 let, od katerih je imelo 94 % raka. V paliativno oskrbo jih je vključil primarni zdravstveni tim (tj. družinski zdravnik, patronažna medicinska sestra, dežurna/nujna služba) ali bolnišnično osebje. Pri bolnikih, ki jih je v paliativno oskrbo vključilo bolnišnično osebje, je bilo statistično značilno krajše preživetje ( $p = 0,008$ ). Bolniki so v povprečju živeli 66 dni in 65 % bolnikov je umrlo doma. Paliativna oskrba na domu zagotavlja oskrbo večine osnovnih in kompleksnih zdravstvenih potreb paliativnih bolnikov, a je šibkejša pri obravnavi socio-ekonomskih, psiholoških ali duhovnih potreb.

**Zaključek:** V opazovanih letih se je kakovost paliativne oskrbe na domu v tem primeru dobre prakse izboljšala v vseh preučevanih kazalnikih: pri zgodnjem vključevanju, deležu pacientov, ki umirajo doma, ter odzivu na potrebe paliativnih bolnikov in oskrbovalcev. Specializirani mobilni paliativni timi, bolnišnična in druge oblike institucionalne paliativne oskrbe dopolnjujejo paliativno oskrbo na domu.

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## 1 INTRODUCTION

Spending one's last days and dying at home is a common end-of-life preference of people enrolled in palliative care (1, 2). To provide high-quality palliative care in a home setting, the primary health care system must address the basic needs of palliative patients and their carers to an equal or greater extent than the hospice or hospital setting. This includes early identification of palliative patients, appropriate identification and management of their complex needs, and multidisciplinary support for both patients and their carers at all stages of the illness and after death (3). These requirements are reflected in international and national palliative care recommendations and plans (3, 4)

Palliative care in Slovenia is provided at the primary, secondary or tertiary health care level, depending on the complexity of a patient's needs (5). As the needs of patients and their carers change over time, the level of palliative care changes accordingly. Palliative care at home is provided by an extended family medicine practice team: family doctor, community nurse, and an out-of-hours and emergency service (OOH/ES). In some Slovenian regions, specialised mobile palliative teams have been established to support primary care palliative teams and to address complex and technically demanding palliative care issues at home. Support services such as social services, hospice volunteers and home care services are often involved in palliative care (5, 6). Together with carers, they form an informal palliative team (6, 7). When the need for palliative care exceeds the capacity of primary care, hospital-based palliative care services are required.

Early identification of palliative patients is a cornerstone of advanced care planning (3). However, palliative patients with non-cancer conditions, such as end-stage organ failure (e.g. heart or lung disease) or frailty syndromes (e.g. dementia), are usually identified very late in the course of their illness (8). Many palliative care patients remain unrecognised until they require medical intervention at home due to acute deterioration, e.g. a home visit by an outpatient service or an emergency service (9).

Some palliative care needs are easier to recognise at home, where one has insight into the broader social context of patients' living conditions. On the other hand, many needs cannot be met at home because of a lack of diagnostic, therapeutic and care-giving opportunities. This is reflected in patients' preferences regarding the preferred site of care and the preferred site of death. For about three quarters of people enrolled in palliative care, their own home is the preferred site of death, and only one fifth of patients change their preference as their illness progresses (2). Even patients admitted to hospital continue to express the wish to die at home, but the majority of patients experience an institutional death

(10). This argues for a focus on home-based palliative care for patients with advanced illness, but urges policymakers to secure hospice and other palliative care facilities for those who think otherwise or who change their minds (2). The aim of this study is to determine the characteristics of home-based palliative care in Slovenia, focusing on who identifies palliative patients, what their needs are and how this affects their length of life and site of death.

## 2 METHODS

### 2.1 Population

This retrospective cohort study was conducted at Vrhnika primary health care centre in Slovenia, which provides health care to approximately 26,000 people in a suburban and rural area. The study included data on all deceased patients enrolled in palliative care between 2015 and 2021 who were living at home at the time of inclusion. Palliative patients living in nursing homes at the time of inclusion were excluded from the study. This yielded a total of 107 patients included in the analysis.

Vrhnika primary health care centre began enrolling patients to palliative care in 2017. Enrolment of an individual patient to palliative care was done pragmatically, when the patient needed medical assistance. Enrolment was suggested by their family doctor, community nurse, OOH/ES or hospital specialists. The family doctor made the decision as to whether the patient would benefit from palliative care. Palliative care always begun in agreement with the patient and their carer. As the enrolment of patients was not systematic, there was the potential for missing certain patient groups, which is further discussed in the section on limitations.

### 2.2 Data collection

A retrospective analysis of routinely collected notes on palliative care from the Vrhnika palliative care registry was conducted (Appendix 1). The forms were filled in by family doctors, community nurses and the OOH/ES, and were routinely collected to build a home-based palliative care registry.

Two researchers (UP and VH) independently analysed the palliative care notes of all patients. The notes were analysed for a) demographic data, b) data on enrolment and duration of palliative care, c) data on palliative needs d) data on the site of death. Numerical data (demographic data, date of enrolment, date of death, leading condition, services involved in care) were first collected from notes and then double-checked using the computer registry.

To determine palliative care needs, a raw text analysis was conducted independently by both researchers. The text was searched for different indicators of needs: a) direct description of the need (e.g. nausea management),

b) therapy for a specific need (e.g. analgesics for pain), c) description of a medical procedure (e.g. wound care), d) instructions for other team members (e.g. 'Preferences about preferred site of death need to be discussed with the patient and carers') or e) other meaningful information (e.g. 'The patient lives alone'). The needs were categorised in the groups listed in Table 3.

The results of the needs analysis were compared. Any discrepancy was discussed and a joint team decision on the content was made.

### 2.3 Ethical considerations

In this study, routinely collected records of palliative care of patients were analysed. The data was anonymised. We did not attempt to obtain informed consent from relatives. The Slovenian National Medical Ethics Committee granted ethical approval for this study (approval no 0120-550/2021/3).

### 2.4 Statistical analysis

The observed characteristics were analysed using descriptive and comparative statistics, the t-test, and the one-way ANOVA for data with normal distribution and the chi-square test for discrete data. A Kaplan-Meier plot was used to present survival. Statistical analysis was performed using Minitab® Statistical Software (version 20.3, Minitab LLC, 2021, United States).

## 3 RESULTS

### 3.1 Demographic data

The palliative care notes of 107 patients were analysed.

The cohort consisted of adults aged between 45 and 90 (mean  $71 \pm 11.4$  years), predominantly male (60 males, 57%), all of Caucasian origin (Table 1).

Table 1. Characteristics of palliative patients and palliative care.

		N (%)	Survival (days) mean $\pm$ SD	p	Died at home N (%)	p
Gender	Male	61 (57%)	65 $\pm$ 119	0.882	33	0.484
	Female	46 (43%)	68 $\pm$ 109		28	
Age (years)	45-54	11 (10%)	45 $\pm$ 63	0.771	4	0.296
	55-64	18 (17%)	55 $\pm$ 124		11	
	65-74	32 (30%)	76 $\pm$ 142		16	
	75-84	31 (29%)	59 $\pm$ 85		20	
	85-90	14 (13%)	91 $\pm$ 130		10	
Leading condition	Cancer	101 (94%)	63 $\pm$ 111	0.467	57	0.623
	Non-cancer	6 (6%)	117 $\pm$ 164		4	
Enrolment by	Family doctor	48 (45%)	76 $\pm$ 110	0.009	1	0.267
	OOH/ES	36 (34%)	53 $\pm$ 113		32	
	Community nurse	20 (19%)	72 $\pm$ 137		17	
	Hospital team	3 (3%)	21 $\pm$ 11		11	

OOH - out-of-hours care; ES - emergency service; SD - survival days

Cancer was the most common medical condition for palliative care enrolment (n=101, 94%), followed by progressive neurological disease (dementia, amyotrophic lateral sclerosis, Parkinson's disease), heart failure and chronic obstructive pulmonary disease (Table 1).

### 3.2 Identification of palliative patients and enrolment in palliative care

Admission of patients to palliative care was suggested by family doctors, community nurses, OOH/ES or hospital teams. In the first year, the identification of palliative patients was most often done by OOH/ES. In subsequent years, more palliative patients were identified by their GPs and community nurses (Figure 1).

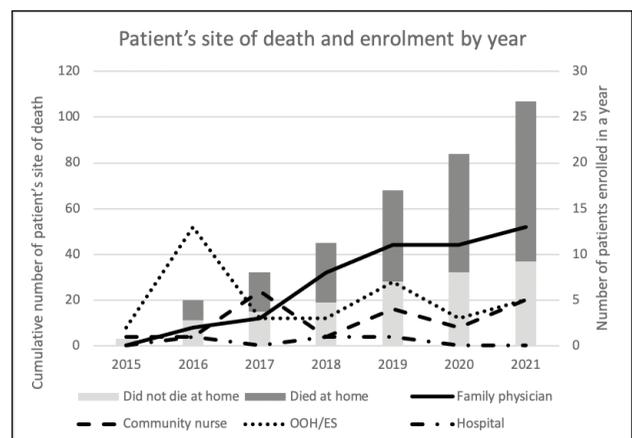


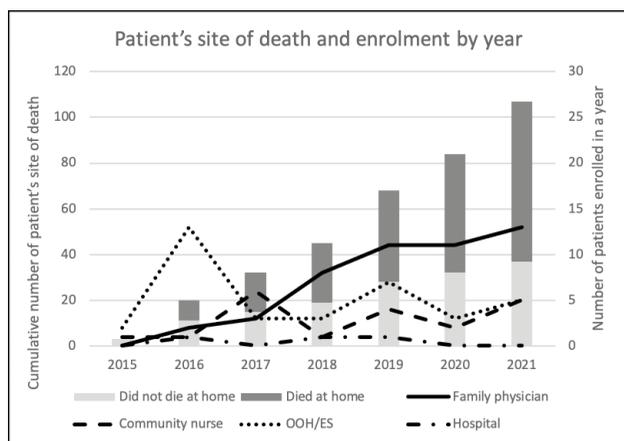
Figure 1. Cumulative patient enrolment and their site of death by year (bars) and enrolment by different primary care services (lines).

**Table 2.** Enrolled patients in years and their site of death.

Year	No of patients enrolled	Died at home	Did not die at home
2015	3	0 (0%)	3 (100%)
2016	17	9 (53%)	8 (47%)
2017	12	8 (67%)	4 (33%)
2018	13	9 (69%)	4 (31%)
2019	23	14 (61%)	9 (39%)
2020	16	12 (75%)	4 (25%)
2021	23	18 (78%)	5 (22%)

### 3.3 Survival and site of death

The average survival time from enrolment to death was 66 days, with the shortest survival time being 0 days and the longest being 636 days (Figure 2).



**Figure 2.** Survival of palliative patients in time.

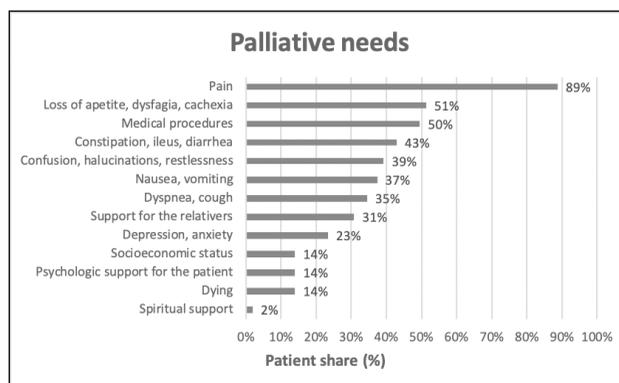
Palliative patients died at home in 65% of cases (N=70), in hospital in 30% of cases (N=32), in a hospice in 3% of cases (N=3) and in a nursing home in 2% of cases (N=2). The proportion of patients who died at home increased over the years from 0% to 78% in 2021 (Figure 1, Table 2). Survival was significantly shorter in patients who were enrolled in palliative care by a hospital team compared to those enrolled by family doctors ( $p=0.009$ ). All other variables (gender, age, leading condition, enrolment) did not result in a statistically significant difference in survival duration or site of death (Table 1).

### 3.4 Palliative needs

The categories of palliative needs are presented in Table 3. Pain was the most frequently addressed palliative need at 89% (N=95), followed by other common medical needs: nutritional and digestive problems, breathing difficulties, psychological and cognitive changes, and the need for medical procedures (e.g. wound care, subcutaneous therapy, etc.). Psychological support was offered more

**Table 3.** Categories of palliative needs.

Category
Pain
Dyspnoea, heavy breathing, cough
Loss of appetite, dysphagia, cachexia
Nausea, vomiting
Constipation, ileus, diarrhoea
Confusion, hallucinations, delirium, restlessness
Anxiety, depression
Dying
Medical procedures
Psychological support to patients
Psychological support to carers
Socio-economic status
Spiritual support



**Figure 3.** Needs addressed by primary-level palliative team.

frequently to caregivers than to patients (N=34 vs. N=14 or 32% vs. 12%). Socio-economic needs were addressed in less than 15% of cases and spiritual support was documented in only one case. Needs related to the process of dying were documented by 16 patients (15%).

A more detailed list of palliative needs addressed is shown in Figure 3. The inter-rater agreement in determining which palliative needs were recognised and addressed was 96.4%.

## 4 DISCUSSION

This study identified the characteristics of the home-based palliative care service provided by one exemplary primary-level palliative team. Palliative patients are typically adults and elderly people with cancer who have been enrolled in palliative care by their primary care team. With advanced care planning, they live for an average of two months, with most of them dying at home. Primary care services were found to respond to a wide variety of palliative medical needs, but were weaker in addressing socioeconomic, psychological or spiritual issues.

The prevalence of palliative patients with advanced chronic conditions is estimated at 1.5% in the general population, with a cancer to non-cancer ratio of 1 to 7 (11). In the population of 25,000 people we observed, one would expect more than 350 people to be enrolled in palliative care each year, of whom about 50 would be cancer patients. In our study, the annual prevalence was up to 23 patients, mainly cancer patients. This shows that about half of cancer patients and the majority of non-cancer palliative care patients remain unidentified. Even taking into account nursing home and hospice residents, who were not included in the study (4.5% of the Slovenian population aged 65 live in nursing homes (12)), there are still many patients who would benefit from inclusion in home-based palliative care.

Several tools have been developed to facilitate the early identification of patients in need of primary palliative care (13): the PIG tool, (14), the SPICT tool (15), the NECPAL tool (16) and the RADPAC tool (17). None of these tools were systematically used in our population. Health care workers relied on the 'surprise question' (18, 19) (i.e. 'Would you be surprised if this patient died in days/weeks/months?') and on an individual prediction of illness trajectory. The use of assessment tools would probably result in more identified palliative patients, especially among people with terminal organ failure conditions and frailty syndromes (13). Computer search tools that can be used on existing primary care databases and identify those patients who might be in the last phase of life (e.g. EARLY identification tool, UK National Health Service) are an alternative to individual assessment.

Patients are enrolled in palliative programmes by various members of primary-care or hospital medical teams. Our data shows a trend of increased enrolment of patients by their family doctors and a fall in enrolment by OOH/ES. Over the years, family doctors have enrolled more palliative patients in response to extensive national initiatives to integrate end-of-life care into all levels of health care (4-6) and to the evident benefits of shared, home-based palliative care. This has caused a decline in patients recognised by OOH/ES, which is an important achievement towards advanced care planning. Of course, the role of OOH/ES in coping with sudden deteriorations and unexpected needs still remains, and a 24/7 service is essential for high-quality palliative care (20). The share of patients enrolled by community nurses appears stable over the years. Their insight into patients' living conditions and social networks is invaluable for detecting palliative care needs sooner and among the most vulnerable patients (21). Hospital initiatives to enrol patients in home-based palliative care were scarce and carried out too late. Most patients began with home-based palliative care after discharge from the hospital and lived at home for a very short time. This is reflected in a significantly

shorter survival time compared to patients enrolled by their GPs. Palliative patients would benefit from a uniform palliative care registry and a uniform system of home-based palliative care. This compromises the transfer of information on palliative care needs between the primary and secondary/tertiary levels.

The goal of early palliative care enrolment is not only to identify patients with palliative care needs, but also to enrol them early enough. Our results show a mean survival of 66 days, with a median of 23 days. The difference between mean and median indicates that some patients were indeed enrolled early, but more than half of them received palliative care for less than one month, and some of them only on the last day. A qualitative study among family doctors in Belgium showed the same trend: that they more often paid attention to the palliative care needs of patients in the terminal phase (22). This is another signal that a systematic and proactive search for patients with palliative needs is justified.

Direct enquiry and identification of preferences for end-of-life care is associated with patients achieving their preferred site of death, and patients whose preferred site of death was unknown were more likely to be admitted to hospital for end-of-life care (23). Our results show a major improvement in increasing the share of patients dying at home, starting from none in the first year to 78% in the last observed year. The increase in the proportion of people who died at home in 2020 and 2021 might be higher due to the Covid-19 pandemic and the reduced access to hospital services and nursing home placements. Furthermore, there was a decline in the proportion of patients who were enrolled in palliative care by community nurses and OOH/ES. The proportion of patients enrolled by their GPs increased, which could indicate a better accessibility of GPs during the pandemic compared to other services.

Not all palliative patients want to die at home; indeed, for 16% of people, home is the least preferred place of death (24, 25). Routine and ongoing assessment of preferred site of death should therefore be included in home-based palliative care, and facilities for those who do not wish to die at home (hospices, nursing homes, hospitals) should be available (2, 24, 25).

Primary-level palliative care refers to the basic skills and competencies required of all doctors and other health care professionals (26). The results of this study show that the primary health care team recognised and managed the basic and more complex medical needs of palliative patients, but was weaker in addressing the psychological, socioeconomic and spiritual needs of palliative patients and their carers. There seems to be a perception among patients and carers that the family doctor is the person to appeal to in acute medical situations rather than for non-medical palliative care needs (22). A multidisciplinary palliative care team that includes social workers and

psychologists would probably bridge this gap. An important contribution can also be made by trained lay persons who help palliative patients on a voluntary basis, such as the Last Aid organisation (27).

Only 15% of patients were managed for symptoms related to the process of dying. This indicates that patients and relatives were prepared for the terminal phase. Some patients needed to be hospitalised due to complex conditions that could not be resolved at home (e.g., severe dyspnoea-related pleural effusion and ascites, pain resistant to therapy). Based on years of regional experience (28-31), Slovenia has been expanding the network of specialised mobile palliative teams that provide specialist consultation and specialist palliative care at home. Further progress in home-based palliative care is expected, especially for patients with complex palliative needs (30).

#### 4.1 Limitations

This study has several limitations. First, the study was conducted at a single centre and the results were not compared with other centres. To the best of our knowledge, there is no other home-based palliative care registry in Slovenia at the primary level. In many regions, palliative care is fragmented, with information on palliative care not being shared among primary care team members and hospital palliative teams. The results of this study better relate to what can be done in home-based palliative care. They do not allow generalisations to be made regarding overall home-based palliative care in Slovenia.

Second, the information for this study derived from patients' notes that were designed for sharing information and not for further research work. However, this provided us with untempered data on what was performed at home. Finally, the relatively small sample is an important weakness of this study. The most important reason for the relatively small number of palliative patients is that the population was not systematically screened for palliative care patients (patients were enrolled pragmatically). Therefore, this study does not provide any insight into the experience of people who were not involved in palliative care. The researchers are aware that the population that refuses to participate in palliative care programmes or patients who have not been identified as palliative patients by primary care providers may have the most unmet needs.

## 5 CONCLUSION AND FURTHER RESEARCH

This exemplary primary-level palliative team provided home-based palliative care, which was available at all times (24/7). The quality of palliative care has improved in recent years for all observed indicators: early admission to

palliative care, the proportion of patients dying at home, and the ability to address the basic and complex medical needs of palliative patients and their carers. Family doctors and community nurses identified the majority of palliative patients and enrolled them in palliative care. OOH/ES covered sudden deterioration and unexpected needs. The most commonly addressed palliative care need was pain and the least addressed was spiritual support. The study demonstrates that primary-level palliative teams are not a stand-alone service; rather, palliative care is one of the areas in which different primary medical professionals work together.

Further research into home-based palliative care should focus on the early identification of palliative patients, shifting from a recognition of patients who actively seek medical assistance to a systematic identification of potential palliative patients within a population. The benefits and risks of such systematic identification for palliative patients should be explored in detail. Furthermore, research should also focus on strategies for coping with unmet needs and a multidisciplinary approach to psychological, socioeconomic and spiritual support provided by services that complement primary-level palliative teams.

## CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

## FUNDING

The study was financed by Department of Family Medicine, Faculty of Medicine, University of Ljubljana.

## ETHICAL APPROVAL AND REGISTRATION

The authors of this paper hereby declare that the study complies with the Declaration of Helsinki and has been approved by the Slovenian National Medical Ethics Committee (0120-550/2021/3).

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#### Appendix 1: Palliative care assessment note.

Palliative Care in Healthcare Centre Vrhnika		
Name and surname of the patient Birth date		Palliative care: YES/NO
Address		Phone
Responsible relative		Phone
General practitioner		Phone
Community nurse		Phone
Diagnoses		
Medical, nursing, social problems		
Therapy		
Other		
Date		Medical professional