



## Number of palliative care nurse home visits and duration of palliative care associated with domains of the Good Death Inventory: A national survey of bereaved family caregivers in a middle income country

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### ABSTRACT

**Background:** In the lower-middle-income country of Kazakhstan, palliative care services are in the early stages of integration into healthcare services. No prior studies have investigated associations between palliative care service factors and a good death in lower-middle-income countries, nor explored how palliative care nurses contribute to a good death. In this paper, a good death is referred to as the control of pain and symptoms, clear decision-making, a sense of closure, being recognized and perceived as an individual, preparation for death, and still being able to contribute to others, all taken together.

**Objectives:** To identify new opportunities for palliative care service nurses by investigating associations between palliative care service factors and a good death, as measured by the Good Death Inventory.

**Methods:** Family caretakers of deceased patients from palliative care units and hospices were surveyed across six different regions of Kazakhstan. Data collected included demographics for patients and caregivers, palliative care service data, and Good Death Inventory items. Poisson regression analysis with  $r$  variance and linear regressions were conducted to identify determinants for achieving a Good Death and for the 18 Good Death Inventory domains.

**Results:** Two hundred and eleven family caregivers participated in the survey. Bivariate analysis revealed five statistically significant associations ( $p \leq 0.05$ ) with the outcome of a good death. In multivariate linear regression analyses, a palliative care duration of greater-than-6-months, compared to less-than-1-month, was associated with improvements in 10 out of 18 domains of the Good Death Inventory ( $p \leq 0.05$ ). More-than-once-weekly palliative care home visits by nurses, compared to no visits, were also associated with improvements in four domains ( $p \leq 0.05$ ).

**Conclusion:** We provide new directions for improvements in palliative care services in low-middle-income countries, giving impetus for resource allocation to palliative care home visits by nurses for achieving a good death for greater numbers of patients.

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### What is already known?

- Nurses are the primary professional palliative care givers in the nascent national palliative care system of the middle-income country of Kazakhstan.
- Palliative care specializations for nurses and physicians do not exist in this resource-limited setting.

### What this paper adds?

- Increased number of palliative care visits to patient homes by nurses prior to in-patient palliative care services and longer duration of palliative care both provided positive associations for achieving a Good Death.
- Added value of more frequent palliative care home visits by nurses was found to be uniquely associated with assisting patients to choose favorite place to die, improving patients' relationships with family members, and promoting patients' feeling that their lives were worth living to the time of their death, whereas duration of care was not associated with any of these domains.
- Both more frequent home visits and longer duration of care were independently associated with enhanced environmental comfort, improved relationships with medical staff, elevated patients' feelings of not being a burden to others and more control over patient's future.

## 1. Introduction

Non-communicable diseases account for most deaths globally, with cancer as a leading cause of death and disability in low- and middle-income countries (Bray et al., 2018; Farmer et al., 2010). In 2019, there were an estimated 23.6 million new cancer cases and 10 million cancer deaths worldwide (Global Burden of Disease 2019 Cancer Collaboration et al., 2022). The global burden of cancer cases is projected to increase to 28.4 million by 2040, a 47 % increase over that found in 2020, with disproportionate increases in lower income countries (Sung et al., 2021). This disproportionate increasing burden in resource-limited regions highlights the future demand for palliative care services in these countries.

The Worldwide Hospice Palliative Care Alliance estimated that globally in 2017, 76 % of all adults needing end-of-life care lived in low- and middle-income countries (World Health Organization, 2020). More than 80 % of all people worldwide with serious health-related conditions live in low- and middle-income countries with limited or no access to palliative care (Knaul et al., 2018), with the prevailing number of cancers having been diagnosed at later stages of disease (Shah et al., 2019). With the substantially disproportionate burden of cancer prevalence in low- and middle-income countries, some professionals have declared a call-to-action to respond to this crisis in these countries (Farmer et al., 2010).

The nursing care paradigm of providing holistic care aligns itself with addressing the core demands for provision of palliative care (Fitch et al., 2015). Non-specialized nurses have increasingly taken on the primary responsibilities of professional palliative care providers in low- and middle-income countries, where there is both a severe shortage of mental health specialists (Poudyal and Adhikari, 2022) and palliative-care specialized healthcare professionals (Abu-Odah et al., 2020) to address the increasing demand.

Limited access to palliative care services in low- and middle-income countries is associated with poor integration into national healthcare systems (Soto-Perez-de-Celis et al., 2016; Fadhil et al., 2017; Hannon et al., 2016; Basu et al., 2013). Researchers in low- and middle-income countries have focused on access to palliative care, with little attention on quality of services, contributing only 1.3 % of studies in all palliative care publications, with most studies being descriptive (Hannon et al., 2016). Palliative care in low- and middle-income countries is understudied, with one group of reviewers finding that no palliative care study directly collected data from patients or families of patients from low- and middle-income countries (Rao et al., 2022).

Kazakhstan is a middle-income former Soviet Union country in Central Asia. Its palliative care services are at a preliminary stage of integration into mainstream healthcare services (Clark et al., 2020). The introduction of the Public Health Code 2009 (Code of the Republic of Kazakhstan No. 193-IV ZRK, 2009) and the adoption of the Kazakhstan National Cancer Control Program for 2012–2016 (Decree of the Government of the Republic of Kazakhstan No. 366, 2012) provided palliative care services with a legal framework. This nascent national palliative care system attempted to focus on hospice palliative care, which has shown to be more cost-effective than palliative care units in hospital-based cancer centers (Salikhanov, Kunirova and Aitbaeva, et al. 2023). However, in a 2023 assessment of palliative care services in Kazakhstan, researchers found a disproportionately-larger number of beds in hospital palliative care units than in hospices providing palliative care services (Salikhanov, Connor and Kunirova et al., 2023). They further found an absence of specializations in palliative care in nursing and medical education and found only one elective course on the topic, an advanced training course on hospice palliative care that was offered only to physicians. No elective courses were offered only to nurses. Given the severe shortage of physicians working in palliative care services in Kazakhstan, the assessment found that “nurses represented the main workforce in palliative care”. In 2020, basic elective palliative care courses were introduced into educational programs for physicians and nurses at undergraduate and postgraduate levels. However, these courses do not meet international standards, and currently there are no palliative care specialists in Kazakhstan who can provide training that meets these standards (Salikhanov, Connor and Kunirova et al., 2023). By default, nurses in Kazakhstan are the primary professional providers of the multicomponent palliative care services, for addressing physical, social, psychological, and spiritual needs (Bassah, Vaughn and Salas, 2023).

There is currently no study evaluating the associations of palliative care service factors with a good death in low- and middle-income countries like Kazakhstan, nor how palliative care professionals improve the quality of a good death for palliative care patients. Based on a systematic review, common core elements for a good death were identified as “control of pain and symptoms, clear decision-making, feeling of closure, being seen and perceived as a person, preparation for death, and being still able to give something to others” (Krikorian et al., 2020). This definition of a good death is reflected in the validated instrument, Good Death Inventory, from the family caregiver perspective (Miyashita, Morita and Sato, et al., 2008). The family caregivers have uniquely intimate connections with the patients, and palliative care services in Kazakhstan are heavily dependent on family caregivers (Salikhanov et al., 2023b). We selected the Good Death Inventory for our study, given it scored high in psychometric properties for both quality of care and quality of dying and death (Kupeli et al., 2019).

The aim of this study was to identify and characterize new opportunities for palliative care service professionals to improve the quality of a good death, utilizing the Good Death Inventory, for end-of-life patients. To address this aim, the research questions include the following:

- 1) To identify and characterize associations between palliative care service factors and a good death, as measured by the Good Death Inventory.
- 2) To identify and characterize the associations of specified palliative care service factors with the 18 domains for a good death, the component domains as defined by the Good Death Inventory.

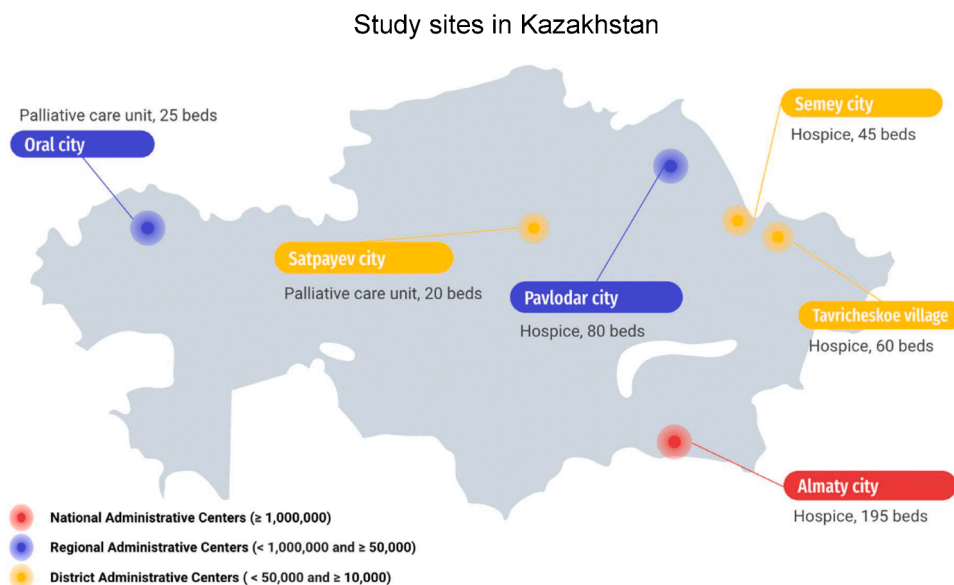
We designed our study to provide a roadmap for palliative care professionals for improving palliative care services in resource-limited settings.

## 2. Methods

### 2.1. Setting and study design

Kazakhstan, the ninth largest country in the world by area, is a landlocked middle-income country of 19 million people that declared its independence in 1991 with the collapse of the Soviet Union. We received ethical approval of our study by the Nazarbayev University Institutional Research Ethics Committee (NU-IREC-407/13,052,021) in 2021. The Ministry of Healthcare of Kazakhstan granted us official permission to conduct the study and provided us with an official national list of approximately 50 facilities that were reportedly providing the nascent government-legislated palliative care services. On contact with the facilities on the list, we found that the majority had no beds or only one or two beds assigned for palliative care patients; none were hospices. After excluding these facilities, we identified the remaining 10 geographically dispersed full-service palliative care centers that included hospices and hospital palliative care units.

We sent an official invitation letter to each administrative head of these palliative care service centers, requesting permission from them to conduct our anonymous survey to family caregivers or guardians of deceased patients who received their palliative care



**Fig. 1.** In Kazakhstan, there are three levels of government administration. Cities with a population of more than or equal to one million people are designated National Administrative Centers. Cities with a population of more than or equal to 50,000 people and less than one million people are Regional Administrative Centers. Towns with a population greater than or equal to 10,000 people and less than 50,000 people are designated as District Administrative Centers [20].

services. Six of these centers (four hospices and two hospital palliative care units) provided us with permission to conduct the survey. Those six participating centers included one in the National Administrative Center of Almaty (the largest city in Kazakhstan), one each in the Regional Administrative Center cities of Pavlodar and Oral, and one each in the District Administrative Centers of Satpayev and Semey and Tavricheskoe village (Fig. 1).

Inclusion criteria for caregivers being invited to participate in the survey were as follows: (1) a family caregiver or legal guardian of a deceased cancer patient who received palliative care services, (2) the caregiver had no mental or physical impairments that could unduly affect answering the survey questions, (3) the caregiver could respond to a self-administered online survey in the Kazakh or Russian languages, and (4) had internet access to take the survey. The study excluded (1) a family caregiver or guardian of a patient who died more than 2 years before or less than 3 months prior to the survey, and (3) a family caregiver or guardian of a deceased patient who was younger than 18 years old.

In each participating palliative care center (including the four hospices and the two hospital palliative care units), one contact person was assigned by the administrative head of that center as a research liaison who was in contact with the deceased patients' family caregivers or guardians. The liaison was usually a palliative care unit/hospice worker who had regularly communicated with the patients and their families during the palliative care service period.

Each participating hospice and palliative care unit was visited by research team members during the period from the start of July 2021 to the end of May 2022. During this time, each center's research liaison was trained by the research team, with scheduling based on the liaison's availability. Each of the hospice and palliative care unit research liaisons were trained on how to contact the family caregiver or guardian with sensitivity, to deliver detailed information about the survey research, to check for inclusion/exclusion criteria, and to provide the electronic URL link to the anonymous survey for potential caregiver participants who showed interest. If the family caregiver or guardian followed-up on the URL link for the survey, then a full consent form was presented online. If the caregiver provided consent to participate, then that participant was provided access to the anonymous online survey.

## 2.2. Demographic characteristics and palliative care service factor data

In the survey, family caregiver participants were asked to provide demographic data on the deceased patient's age at time of death, sex, marital status, level of education, place of death, and the city/town where the patient received palliative care services. In our study, place of death variable includes deaths that occurred in both hospice and palliative care units. We also collected data on the caregiver participant's age, sex, health status, relationship to the patient, and frequency of visits with the patient. Family caregiver participants were also asked to provide data on the care received by deceased patients; this included frequency of visits to the patient's home by professional palliative caregivers during the lag time following cancer prognosis and prior to admission to a palliative care center or death. These professional palliative care home visits by mobile units were conducted by nurses but at times may have also included social workers, psychologists, nurse aides, and physicians. Frequency of palliative care home visits were limited by availability of palliative care mobile units and geographical constraints. We have explored this issue more thoroughly in the qualitative research component of our larger study, being prepared as another manuscript. Data was also collected from the family caregiver on the patient's main place of care, duration of care since diagnosis, length-of-stay during last admission, and whether the patient stayed at home for the last 30 days before their death.

## 2.3. Good death inventory

To measure the quality of death and dying among terminally ill patients in Kazakhstan, we selected the Good Death Inventory, a tool that was first developed and validated in Japan (Miyashita et al., 2008a; Hirai et al., 2006, 2007). The Good Death Inventory evaluates end-of-life care from the bereaved family members' perspective. The Good Death Inventory tool has been validated in various countries (Shin et al., 2011; Zhao et al., 2019) and in a comprehensive systematic review, the Good Death Inventory was identified as one of two instruments with the best psychometric properties measuring quality of death, dying, and care for end-of-life out of 67 instruments reviewed (Kupeli et al., 2019). The large majority of these 67 instruments acquire their data from family caregivers, while the remaining instruments acquire data from professional palliative care providers.

We applied the Good Death Inventory with 18 domains for the measure of a good death (10 core domains and 8 optional domains), with three items in each domain. The core 10 domains include physical and psychological comfort, dying in a favorite place, maintaining hope and pleasure, good relationships with medical staff, not being a burden to others, good relationships with family, independence, environmental comfort, being respected as an individual, and life completion. Meanwhile, the 8 optional domains include receiving enough treatment, natural death, preparation for death, control over the future, unawareness (awareness) of death, pride, and beauty (dignity and physical experience), feeling that one's life is worth living, and religious and spiritual comfort. We asked participants to evaluate each attribute on a 7-point Likert scale (1 - absolutely disagree, 2 - disagree, 3 - somewhat disagree, 4 - unsure, 5 - somewhat agree, 6 - agree, and 7 - absolutely agree). The possible scores range from 18 to 126, with a high score indicating the achievement of a good death. The Japanese version of the Good Death Inventory was translated into Kazakh and Russian languages and back-translated for accuracy.

We utilized a standard approach of setting a cut-off point to dichotomize the Good Death Inventory into categories of *Achieved a good death* and *Not Achieved a good death* to formulate the outcome for multivariate logistic regression analysis. We dichotomized by computing the overall mean average of all Good Death Inventory items for each deceased patient as provided by their family caregiver, then assigned an *Achievement of a good death* designation if the overall mean of Good Death Inventory items was 4.5 or more (rounding up to 5, where 4 represented the neutral "unsure" selection on the Likert scale) or assigned a *No Achievement of a good death* designation

for a mean less than 4.5 (rounding down to 4).

## 2.4. Data analysis

Family caregiver characteristics and deceased patients' demographics, clinical characteristics, and the total scores of the Good Death Inventory were described with frequencies and percentages. Cronbach's alpha measure was applied to test for internal consistency of the Good Death Inventory overall and Good Death Inventory domains for this data (Table 1). Preliminary bivariate analysis was conducted using Fisher's exact test (Wong, 2011) to compare demographic and clinical characteristic category counts between those deceased patients who had achieved and those who had not achieved a good death. Factors that showed statistical significance in the bivariate analysis with a  $p$ -value < 0.05 were further explored in multivariate analysis utilizing a Poisson regression with robust variance (Table 3), a preferred regression when outcomes are common (Barros and Hirakata 2003). The covariates in the Poisson regression with robust variance model for the good death outcome (including those that were not statistically significant in the final Good Death Inventory model to control for any residual confounding) were then introduced into separate multivariate linear regression models for the 18 domains of the Good Death Inventory as individual outcomes to characterize the specific associations between palliative care service factors and Good Death Inventory domains. The statistically significant level was set at  $p \leq 0.05$  where  $\alpha=0.05$  for all statistical testing. Statistical analyses were conducted using STATA version 17 software.

## 3. Results

### 3.1. Internal consistency of the good death inventory

The Cronbach's alpha for the overall Good Death Inventory indicated good internal consistency (Table 1).

### 3.2. Descriptive data

The study surveyed 376 caregivers, of which 227 participated after providing consent. After excluding incomplete data, the final analysis included 211 family caregivers. Most caregivers were female, as were half of the deceased patients. Patients typically received palliative care in hospices or at home, with many passing away in palliative care units or hospices. Caregivers visited patients frequently, with 41 % visiting daily and 35 % visiting 1–3 times weekly. Professional palliative care visits varied in frequency, with nearly half of deceased patients receiving care for 1–6 months and a third receiving care for less than 1 month.

### 3.3. Bivariate and multivariate factors associated with achieving a good death

The bivariate analysis (Table 2) identified five statistically significant associations with the outcome achieving or not achieving a good death. These variables include "marital status", "main place of care", "city administrative division level", "frequency of home visits by palliative care professionals", and "care duration".

Variables with statistical significance in the bivariate analysis were introduced in the multivariate Poisson regression with robust

**Table 1**  
Internal consistency of the GDI overall and GDI domains.

GDI <sup>a</sup> subscales	Mean $\pm$ SD <sup>b</sup>	Cronbach's alpha
Physical and psychological comfort	3.40 $\pm$ 1.41	0.843
Dying in a favorite place	4.29 $\pm$ 1.32	0.684
Maintaining hope and pleasure	4.38 $\pm$ 1.30	0.741
Good relationship with medical staff	5.68 $\pm$ 1.06	0.759
Not being a burden to others	4.47 $\pm$ 1.25	0.703
Good relationship with family	5.45 $\pm$ 1.29	0.850
Independence	3.28 $\pm$ 1.60	0.861
Environmental comfort	5.38 $\pm$ 1.24	0.875
Being respected as an individual	5.42 $\pm$ 1.10	0.688
Life completion	4.55 $\pm$ 0.93	0.519
Receiving enough treatment	5.17 $\pm$ 1.16	0.705
Natural Death	5.70 $\pm$ 2.81	0.607
Preparation for death	4.99 $\pm$ 1.31	0.777
Control over the future	4.35 $\pm$ 1.21	0.727
Unawareness of death	4.31 $\pm$ 1.25	0.724
Dignity and physical appearance	3.90 $\pm$ 1.15	0.684
Feeling that one's life is worth living	4.57 $\pm$ 1.09	0.629
Religious and spiritual comfort	4.45 $\pm$ 1.39	0.809
<b>GDI<sup>a</sup> overall</b>		<b>0.863</b>

<sup>a</sup> Good Death Inventory (GDI) provides a measure for evaluating good death from the bereaved family member's perspective.

<sup>b</sup> Standard Deviation (SD) is a measure of how dispersed the data is in relation to the mean.

**Table 2**  
Differences in demographics and clinical characteristics between participants who achieved good death and those who did not.

Variable	Not Achieving a Good Death		Achieving a Good Death		p-value <sup>b</sup>
	n <sup>a,c</sup>	%	n <sup>a,c</sup>	%	
<b>Patients</b>					
Marital Status					
Single/Divorced	26	49.06	27	50.94	<b>0.05</b>
Married	29	31.52	63	68.48	
Sex					
Female	26	32.91	53	67.09	0.25
Male	33	42.31	45	57.69	
Age					
≤ 59 years	14	37.84	23	62.16	0.44
60–69 years	20	42.55	27	57.45	
70–79 years	11	35.48	20	64.52	
≥ 80 years	7	24.14	22	75.86	
Education					
High school education	16	51.61	15	48.39	0.15
Specialized secondary education	24	37.50	40	62.50	
Higher education	17	30.36	39	69.64	
Place of death					
Home	17	34.00	33	66.00	0.28
Hospice/PCU <sup>d</sup>	33	36.26	58	63.74	
Hospital	9	56.25	7	43.75	
Main place of care					
Home	17	34.00	33	66.00	<b>&lt;0.01</b>
Hospice	32	48.48	34	51.52	
Hospital	7	41.18	10	58.82	
PCU	2	8.00	23	92.00	
City administrative division level					
National administrative centers (≥1000,000)	13	21.67	47	78.33	<b>0.01</b>
Regional administrative centers (<1000,000 and ≥50,000)	37	47.44	41	52.56	
District administrative centers (<50,000 and ≥10,000)	7	41.18	10	58.82	
Frequency of visits by a family caregiver					
1 day weekly	11	61.11	7	38.89	0.13
1–3 days per week	16	32.00	34	68.00	
4–6 days per week	5	29.41	12	70.59	
Every day	19	32.76	39	67.24	
Frequency of palliative care home visits by nurse					
Never	23	57.50	17	42.50	<b>0.01</b>
Less than once weekly	5	38.46	8	61.54	
Once weekly	5	17.86	23	82.14	
More than once weekly	20	30.77	45	69.23	
Care duration					
< than one month	29	59.18	20	40.82	<b>&lt;0.01</b>
1–6 months	20	28.99	49	71.01	
> than 6 months	7	24.14	22	75.86	
Length of stay					
Two days or less	5	33.33	10	66.67	0.24
> 2 days to 2 weeks	12	46.15	14	53.85	
> 2 weeks to 4 weeks	13	39.39	20	60.61	
> 4 weeks to 8 weeks	6	19.35	25	80.65	
> 8 weeks	10	40.00	15	60.00	
The patient stayed at home within the last 30 days before their death					
Yes	21	32.31	44	67.69	0.31
No	37	41.11	53	58.89	
<b>Caregivers</b>					
Age					
16–35	13	35.14	24	64.86	0.77
36–45	12	33.33	24	66.67	
46–57	15	41.67	21	58.33	
58–80	11	29.73	26	70.27	
Relationship to the patient					
Spouse/partner	7	53.85	6	46.15	0.43
Parent	22	35.48	40	64.52	
Sibling	8	42.11	11	57.89	
Other	16	30.77	36	69.23	
Sex					
Female	49	37.40	82	62.60	0.83
Male	10	34.48	19	65.52	

(continued on next page)

Table 2 (continued)

Variable	Not Achieving a Good Death		Achieving a Good Death		p-value <sup>b</sup>
	n <sup>a,c</sup>	%	n <sup>a,c</sup>	%	
Health status at the moment of caregiving					
Poor	7	63.64	4	36.36	0.16
Fair	15	35.71	27	64.29	
Moderate	21	42.86	28	57.14	
Good	16	29.63	38	70.37	

<sup>a</sup> Several total n do not equal 211 due to missing values.

<sup>b</sup> p-value measures the strength of evidence against the null hypothesis.

<sup>c</sup> n - sample size.

<sup>d</sup> Palliative care unit (PCU) - are wards within hospital that provide care for terminally-ill patients.

variance model (Table 3). In the analysis, the likelihood of patients achieving a good death was significantly linked to the duration and frequency of palliative care. Patients with care lasting over 6 months were much more likely to achieve a good death compared to those with less than 1 month of care. Additionally, patients visited at home by palliative care professionals more than once a week had a higher likelihood of experiencing a good death compared to those who were never visited at home by such caregivers.

### 3.4. Palliative care service factors associated with achieving a good death for the individual 18 good death inventory domains

Table 4 shows a statistically significant positive association between palliative care duration and achieving a higher score for 11 out of 18 domains for the Good Death Inventory, including *physical and psychological comfort, environmental comfort, good relationship with medical staff, receiving enough treatment, maintaining hope and pleasure, independence, not being a burden to others, religious and spiritual comfort, control over the future, and preparation for death*.

Extended palliative care duration (over 6 months) compared to shorter durations (less than 1 month) is significantly associated with higher scores across various domains, including physical and psychological comfort, environmental comfort, relationship with medical staff, receiving sufficient treatment, life completion, maintaining hope and pleasure, independence, not being a burden to others, religious and spiritual comfort, control over the future, and preparation for death. Similarly, having a life-threatening illness for 1–6 months versus less than 1 month is significantly associated with increased scores for maintaining hope and pleasure, religious and spiritual comfort, and a good relationship with medical staff.

Statistically significant associations between higher frequency of home visits by palliative care professionals and achieving a higher score for 8 out of 18 domains of a good death were found for the following domains: *environmental comfort, dying in a favorite place, good relationship with medical staff, good relationship with family, not being a burden to others, control over the future, feeling that one's life is worth living, and preparation for death* (Table 4).

Table 3

Multivariate analysis of factors associated with the achievement of a good death.

Variable	Relative Risk <sup>a</sup>	95 % CI	p value
Marital Status			
Single/Divorced	Ref. <sup>b</sup>		
Married	1.29	0.95 - 1.76	0.11
City administrative division level			
District administrative centers (<50,000 and ≥10,000)	Ref. <sup>b</sup>		
Regional administrative centers (<1000,000 and ≥50,000)	0.72	0.44 - 1.2	0.21
National administrative centers (≥1000,000)	1.01	0.63 - 1.61	0.96
Main place of care			
Home	Ref. <sup>b</sup>		
Hospice	0.81	0.58 - 1.13	0.21
Hospital	0.95	0.53 - 1.72	0.88
PCU <sup>c</sup>	1.20	0.86 - 1.69	0.29
Palliative care duration			
< than one month	Ref. <sup>b</sup>		
1–6 months	1.34	0.9 - 1.99	0.15
> 6 months	1.92	1.29 - 2.84	<0.01
Frequency of palliative care home visits by nurse			
Never	Ref. <sup>b</sup>		
< than once weekly	0.98	0.55 - 1.75	0.94
Once weekly	1.32	0.86 - 2.03	0.21
More than once weekly	1.51	1.00 - 2.29	0.05

<sup>a</sup> Relative Risk (RR) measures the strength of association between exposure factor and outcome.

<sup>b</sup> A reference group is a group of observations to which other groups are compared to.

<sup>c</sup> Palliative care unit (PCU) is a department with palliative care wards in a hospital or a cancer center where patients with terminal illness are hospitalized.

**Table 4**

Eighteen Individual multivariate linear regression models provided for the associations of the two covariates “palliative care duration” and “frequency of palliative care home visits by nurses” with each of the 18 domains for the Good Death Inventory as the outcomes. Values in bold indicate statistical significance with  $p$ -value  $\leq 0.05$ .

Good Death Domains	Palliative care duration <sup>a</sup>					Frequency of palliative care home visits by nurse <sup>a</sup>											
	< 1 month	1–6 months			> 6 months		Never	Less than once per week			Once per week		More than once per week				
		Coefficient	95 % CI <sup>c</sup> , $p$ -value <sup>b</sup>		Coefficient	$p^b$		95 % CI <sup>c</sup>	Coefficient	$p^b$	95 % CI <sup>c</sup>	Coefficient	$p^b$	95 % CI <sup>c</sup>	Coefficient	$p^b$	95 % CI <sup>c</sup>
<b>Physical and psychological comfort</b>																	
1. Physical and psychological comfort	Ref. <sup>d</sup>	−0.39 (−2.04, 1.26), $p = 0.64$			2.13	<b>0.04</b>	0.14–4.12	Ref. <sup>d</sup>	−0.68	0.62	−3.40–2.04	0.51	0.67	−1.81–2.82	1.59	0.09	−0.22–3.40
<b>Place of care</b>																	
2. Environmental comfort	Ref. <sup>d</sup>	0.07	0.93	−1.42–1.55	1.96	<b>0.03</b>	0.17–3.75	Ref. <sup>d</sup>	0.95	0.44	−1.50–3.40	1.91	0.07	−0.17–3.99	2.41	<b>&lt;0.01</b>	0.78–4.04
3. Dying in a favorite place	Ref. <sup>d</sup>	−1.14	0.18	−2.80–0.53	1.63	0.11	−0.37–3.64	Ref. <sup>d</sup>	−1.79	0.20	−4.53–0.96	0.48	0.69	−1.86–2.81	2.23	<b>0.02</b>	0.40–4.06
<b>Decision-making and relationship with medical staff</b>																	
4. Good relationship with medical staff	Ref. <sup>d</sup>	1.53	<b>0.01</b>	0.35–2.71	1.81	<b>0.01</b>	0.38–3.23	Ref. <sup>d</sup>	−0.37	0.71	−2.32–1.58	1.34	0.11	−0.32–3.00	1.97	<b>&lt;0.01</b>	0.67–3.27
5. Receiving enough treatment	Ref. <sup>d</sup>	0.20	0.77	−1.16–1.56	2.02	<b>0.02</b>	0.38–3.67	Ref. <sup>d</sup>	−1.00	0.38	−3.25–1.25	1.57	0.11	−0.34–3.48	1.25	0.10	−0.24–2.75
6. Unawareness of death	Ref. <sup>d</sup>	0.14	0.87	−1.53–1.81	0.83	0.42	−1.19–2.84	Ref. <sup>d</sup>	−1.56	0.26	−4.32–1.20	−1.05	0.38	−3.39–1.30	−1.33	0.16	−3.17–0.51
7. Natural death	Ref. <sup>d</sup>	0.67	0.38	−0.83–2.17	1.52	0.10	−0.29–3.32	Ref. <sup>d</sup>	−2.25	0.08	−4.72–0.23	−1.00	0.35	−3.10–1.11	−0.71	0.39	−2.36–0.93
<b>Family relationship</b>																	
8. Good relationship with family	Ref. <sup>d</sup>	0.11	0.89	−1.47–1.69	0.34	0.73	−1.57–2.25	Ref. <sup>d</sup>	−1.19	0.37	−3.80–1.42	1.09	0.33	1.13–3.31	1.96	<b>0.03</b>	0.22–3.70
<b>Psycho-existential issues</b>																	
9. Life completion	Ref. <sup>d</sup>	−0.30	0.62	−1.47–0.87	1.40	<b>0.05</b>	−0.01–2.82	Ref. <sup>d</sup>	0.03	0.98	−1.91–1.96	0.29	0.73	−1.35–1.94	1.19	0.07	2.48
10. Maintaining hope and pleasure	Ref. <sup>d</sup>	2.02	<b>0.01</b>	0.45–3.60	2.58	<b>0.01</b>	0.68–4.49	Ref. <sup>d</sup>	0.22	0.87	−2.39–2.82	1.40	0.21	−0.81–3.62	0.61	0.49	−1.13–2.34
11. Independence	Ref. <sup>d</sup>	0.64	0.54	−1.41–2.68	3.03	<b>0.02</b>	0.56–5.50	Ref. <sup>d</sup>	−1.44	0.40	−4.82–1.94	−0.95	0.52	−3.82–1.93	−0.24	0.84	−2.49–2.01
12. Not being a burden to others	Ref. <sup>d</sup>	0.78	0.31	−0.74–2.30	3.42	<b>&lt;0.01</b>	1.58–5.25	Ref. <sup>d</sup>	−3.11	<b>0.02</b>	−5.62– (−0.60)	1.44	0.18	−0.69–3.57	0.60	0.48	−1.07–2.27
13. Being respected as an individual	Ref. <sup>d</sup>	−0.27	0.70	−1.70–1.11	0.64	0.45	−1.03–2.31	Ref. <sup>d</sup>	−1.05	0.37	−3.33–1.24	1.36	0.17	−0.58–3.30	0.38	0.63	−1.15–1.90
14. Religious and spiritual comfort	Ref. <sup>d</sup>	1.98	<b>0.03</b>	0.20–3.77	2.18	<b>0.05</b>	0.03–4.33	Ref. <sup>d</sup>	−0.16	0.92	−3.10–2.79	2.25	0.08	−0.25–4.76	0.97	0.33	−0.10–2.93
15. Control over the future	Ref. <sup>d</sup>	1.05	0.12	−0.29–2.39	3.50	<b>&lt;0.01</b>	1.89–5.12	Ref. <sup>d</sup>	2.16	0.06	−0.05–4.37	2.69	<b>0.01</b>	0.81–4.56	2.77	<b>&lt;0.01</b>	1.30–4.24
16. Feeling that one's life is worth living	Ref. <sup>d</sup>	0.37	0.59	−0.99–1.73	1.13	0.18	−0.52–2.77	Ref. <sup>d</sup>	−0.63	0.58	−2.89–1.62	2.07	<b>0.03</b>	0.16–3.99	1.41	0.07	−0.09–2.91
17. Dignity and physical appearance	Ref. <sup>d</sup>	0.47	0.53	−0.98–1.91	−1.66	0.06	−3.41–0.09	Ref. <sup>d</sup>	1.37	0.26	−1.02–3.76	−1.86	0.07	−3.89–0.17	−0.77	−0.34	−2.36–0.82
18. Preparation for death	Ref. <sup>d</sup>	0.91	0.22	−0.54–2.35	3.00	<b>&lt;0.01</b>	1.26–4.75	Ref. <sup>d</sup>	−0.41	0.73	−2.80–1.98	2.60	<b>0.01</b>	0.57–4.64	2.38	<b>&lt;0.01</b>	0.79–3.97

<sup>a</sup> Only the two statistically significant variables in the multivariate Poisson regression model in Table 3 (“palliative care duration”, and “frequency of palliative care home visits by nurses”) were included in the 18 multivariate linear regression models for the domains of the Good Death Inventory.

<sup>b</sup>  $p$ -value measures the strength of evidence against the null hypothesis.

<sup>c</sup> CI is a range of values that you can be 95 % confident contains the true mean of the population.

<sup>d</sup> A reference group is a group of observations to which other groups are compared to.



When palliative care professionals visited a patient's home less than once per week compared to never, there was a significant decrease in the score for the "not being a burden to others" domain. Conversely, weekly home visits were associated with improvements in the scores for control over the future, feeling that life is worth living, and preparation for death. More frequent home visits, occurring more than once per week, were linked with increases in scores for environmental comfort, dying in a preferred location, having a good relationship with medical staff and family, as well as enhanced feelings of control over the future and preparation for death.

#### 4. Discussion

To our knowledge, our study is the first conducted in a nascent national palliative care system in a resource-limited setting. It assesses new opportunities for palliative care professionals to improve the quality of a good death, using the Good Death Inventory which has one of the best scores for psychometric properties for end-of-life measures (Kupeli et al., 2019).

In a closer look at the associations with individual Good Death Inventory domains, we found that longer palliative care duration was positively associated with 11 of the 18 Good Death Inventory domains, and more frequent palliative care home visits were positively associated with seven of the Good Death Inventory domains (Table 4). Consistent with our findings, researchers from Korea concluded that longer duration was associated with greater overall quality of life and higher scores in terms of environmental comfort, improved good relationship with family, maintaining hope and pleasure, preparation for death, and religious and spiritual comfort (Choi et al., 2018). Researchers from Japan also found that longer duration of care was associated with maintaining hope and pleasure and promoting the feeling that one's life is worth living (Miyashita et al., 2008b).

Our finding that more frequent palliative care nursing home visits were associated with promotion of environmental comfort for the patient may be attributed to the creation of a safe and supportive atmosphere, fostered not only by their families but also by the active involvement of palliative care professionals in their care. A positive impact of palliative care professional visits on environmental comfort for the patient may relate to the nurse's mediating role in the relationship between patient and family. A study conducted by the researchers at the University of Adelaide in Australia underscored the positive influence of palliative care professionals on the patient's environment, where the health care professional fostered an environment where patients actively participate in decisions on medical care and on choices of the preferred place of death (Sathianathan et al., 2021).

We found it important that when patients were visited by palliative care professionals more than once per week, there was an association with increased likelihood that the patient was choosing to die in a favorite place. The increased presence of palliative care nurses at the homes of patients before they enter care facilities (or choose to stay at home) may have a positive impact on assisting patients and their family caregivers in choosing the most safe and peaceful location for the patient's passing. A study conducted by researchers at King's College London suggested that optimal palliative care may facilitate dying in a preferred place (Gomes et al., 2008).

We found that having palliative care professional visits more than once a week, as compared to never, was associated with more positive relationships with other medical staff. With more frequent home visits, palliative care nurses may build greater intimacy with patients and family caregivers, playing a moderating role in improving interpersonal relationships between patients and their medical providers. Similar findings highlighting a strong emotional bond between patients and medical staff were observed in a study of palliative medicine conducted in Iran. Those researchers concluded that palliative care had a positive impact on the relationship between the care team and cancer patients (Aghaei et al., 2020). Palliative care nurses can play a crucial role in establishing positive relationships between patients and their families with the medical staff, ultimately contributing to a good death.

Both more frequent palliative care patient home visits and palliative care lasting longer than 6 months were associated with patients less likely to feel themselves being a burden to others. The perception of burdening others, symptom burden, and functional dependence have been identified as predictors of severe depressive symptoms (Tang et al., 2016). Prior researchers have also shown that for in-patients with advanced cancer, anxiety and existential distress acted as intermediaries between self-perceived burden and quality of life (Xiaodan et al., 2022). In a study among Taiwanese cancer patients, self-perceived burden score escalated as patients neared the end of life (Tang et al., 2017). Palliative care nurse home visits may reduce patients' sense of being a burden and improve their quality of life.

Patients visited by palliative care nurses at home more than once per week experienced greater family support. This finding aligns with the palliative care professional cornerstones in comprehensive patient care: offering critical assistance in symptom management, addressing family members' questions and concerns, and providing valuable emotional support; these actions contribute to improving family engagement. Having a good relationship with the patient's family has been shown to be associated with lower risk of experiencing depressive symptoms among bereaved family members (Jho et al., 2016). The greater severity of patient symptoms has been shown to be associated with overall reduction in quality of life for family caregivers, including poorer sleep quality and greater caregiving strain (Valero-Cantero et al., 2022). These findings underscore the possible impact of increased frequency of home visits and the importance of holistic care and support for both patients and their families.

In our study, more frequent visits by palliative care professionals to the homes of patients when patients were still at home and longer duration of palliative care treatment were associated with improved preparation for death for the patient. More frequent earlier contact with patients may have contributed to this preparation. Some researchers have proposed that palliative care for patients at earlier stages of advanced illness reaps benefits (Lynn and Adamson, 2003). Earlier palliative care improves symptom management, quality of life, and increased satisfaction with care among terminally-ill patients (Zimmerman et al., 2014; Hannon et al., 2017). When quality of life is improved, both patients and family caregivers report greater opportunity preparing for death (Sarmiento et al., 2017).

Our finding of the association between more frequent home visits by palliative care nurses and patients' feeling that their lives were worth living may be explained by the transformational support of the nurses, reducing tension in the family. In an intervention study

(Norinder et al., 2017), family caregivers received support from palliative care professionals during their home visits. Patients reported feeling relieved because they felt this support enabled their family caregivers to openly discuss their grief, allowing their families to express their feelings.

We showed that more frequent visits by professional palliative care nurses were associated with being involved in decision-making regarding treatment, granting patients the feeling of being able to control their future. Previous researchers have found that patients preferred to know their diagnosis and be involved in decision-making (Datta et al., 2017; Murray et al., 2015). While this is a standard practice in higher income countries and is becoming widespread in many countries (Chatuverdi et al., 2014; Ichikura et al., 2015), many low-and-middle-income countries lag behind in patient-centric decision-making. Involvement in decision-making is an important component in achieving a good death. Chittam et al. (2015) showed that cancer patients in India who reported being unaware of their diagnosis were more likely to have more anxiety levels and depression. This finding underscores the importance of implementing diagnosis-related information disclosure and involving patients in decision-making.

## 5. Strengths and limitations

To our knowledge, our study is the first conducted in a nascent national palliative care system to assess new opportunities for palliative care professionals to improve the quality of a good death using the Good Death Inventory. One of the strengths of our study is that it is based on a national sample, with a broad range of centers providing palliative care services in Kazakhstan. Additionally, it includes palliative care patients from different geographic regions in both urban and rural areas.

The study had limitations. Our survey represents retrospective views of family caretakers. Because our data are based on family caretaker reporting, some nuanced differences between family caretakers' and deceased patients' perspectives may have existed. However, we believe that this limitation, given findings from other studies, was constrained given the intimacy between family caretakers and their deceased family member.

## 6. Conclusion

We have provided a potential roadmap for placing more resources in palliative care home visits by nurses in resource-limited settings for greater success in achieving a good death for more terminally-ill patients. Further studies on the cost-effectiveness of placing a greater emphasis on home visits during the period of the patient's home stay in resource-limited settings are necessary to explore feasibility.

## CRedit authorship contribution statement

**Byron Crape:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Makpal Akhmetova:** Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Formal analysis, Data curation. **Pana Akhmetniyaz:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation. **Faye Foster:** Writing – review & editing, Supervision, Investigation, Data curation, Conceptualization. **Kamalzhan Nadyrov:** Writing – review & editing, Writing – original draft, Project administration, Investigation, Data curation. **Lyazzat Toleubekova:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.ijnnsa.2024.100217](https://doi.org/10.1016/j.ijnnsa.2024.100217).

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