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Challenges of palliative care identified by stakeholders in resource-limited settings: A multi-regional study in Kazakhstan

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ABSTRACT

Introduction: In Kazakhstan, a country of 19 million residents, more than 100,000 patients need palliative care. Since at least one family member is usually involved in the care of a terminal patient, more than 200,000 people would benefit from high-quality palliative care services in the country. However, with only 45 physicians and 101 nurses attending to 1925 palliative beds, Kazakhstan seeks to develop palliative services that meet the national needs in resource-limited settings and international standards.

The objectives of this study are to explore the challenges faced by stakeholders involved in palliative care in Kazakhstan and to subsequently provide recommendations that can guide policymakers towards further developing palliative care services in the country.

Methods: This cross-sectional descriptive study collected narrative data with in-depth interviews from n= 29 palliative stakeholders (family caregivers n= 12, healthcare professionals =12, administrators n= 5) across five regions of Kazakhstan. Verbatim transcripts of interviews were analyzed using content analysis to identify needs and challenges of stakeholders involved in palliative care.

Results: Our analysis identified seven main challenges of palliative care stakeholders: high out-of-pocket expenditures; lack of mobile palliative care services for home-based care; severe shortages of opioids to prevent pain suffering; poor formal palliative care education; absence of practical skills training for family caregivers; lack of awareness about palliative care in the society, and lack of state support.

Conclusion: Implementation of national palliative care strategies and policies require a large-scale coordinated involvement of all stakeholders. Our recommendations are based on the idea that coordinated, targeted, and tailored stakeholder engagement is preferred to a one-size-fits-all strategy.

1. Introduction

About 60 million people worldwide are presently in need of palliative care.^{1,2} Nearly 80% of them live in low-to middle-income countries (LMICs) where only 12% of people who require palliative care services have access to it [1,2]. Although the demand for palliative care in LMICs is estimated to double by 2060, these countries lack the necessary

resources, infrastructure and guidelines for launching palliative care programs and making them widely available [3,4].

There are 107,000 people needing palliative care in Kazakhstan. Since at least one family caregiver is usually directly involved in the care of a terminal patient, more than 200,000 individuals would benefit from high-quality palliative care services [5,6]. However, with only 45 physicians and 101 nurses attending to 1925 palliative beds, Kazakhstan

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seeks to develop palliative services that meet its national needs and international standards [6]. In 2015 the Quality of Death Index ranked Kazakhstan 50th out of 80 countries investigated [4,7]. However, in 2021 Quality of Death and Dying Index excluded Kazakhstan due to the absence of data collection mechanisms and reliable statistics for evaluating the country's palliative care status [8]. As a relatively young nation, Kazakhstan tries proactively to anticipate the trends, consequences, and problems caused by the rise of chronic non-communicable diseases such as cancer, diabetes and cardiovascular diseases [9,10]. Rapid demographic change in (LMICs) portends a significant increase in the ageing population similar to that previously experienced in high-income countries (HICs), albeit with some challenges due to the simultaneous weakening of traditional family care systems and underdeveloped policies for the care of older persons [1,2]. This rapid demographic shift requires urgent policy and systemic action to strengthen long-term and palliative care infrastructure to provide accessible and affordable care for the growing number of older and terminally ill individuals whose care needs will only increase in the coming decades [1, 2].

Although palliative care requires a holistic, multidisciplinary, family-centered approach, roles of palliative stakeholders, and, importantly, the demands and challenges they face are not clearly understood, especially in LMICs [6,11]. LMICs typically lack the data collection systems needed to evaluate how palliative care is provided, how much it costs, and how well it works [2]. Stakeholders such as NGOs, health professionals, and family caregivers have not been involved in recent initiatives and developments in palliative care, such as the development of the National Palliative Strategy in Kazakhstan [6]. Therefore, it is essential to perform a formal stakeholder analysis to systematically collect and analyze information pertaining to policymakers, healthcare providers, and family caregivers [12]. Formal stakeholder analysis methods are well-suited to guide health policy, program development and implementation [13].

Thus, the primary objective of this paper is to explore stakeholders' challenges related to providing palliative care in Kazakhstan. The secondary aim is to provide recommendations for policymakers to guide further development of palliative services. No comprehensive analysis of the needs of palliative care stakeholders has been carried out in Central Asia; therefore, by demonstrating the needs and challenges encountered by palliative stakeholders in limited-resource settings, findings may help other LMICs in their efforts to establish their palliative care services.

2. Methods

2.1. Study design

This cross-sectional descriptive study is based on narrative data collected with semi-structured interviews from 29 palliative care stakeholders representing the perspectives of family caregivers, healthcare professionals, and non-governmental organizations (NGOs). The interview guides were designed to inquire their perspectives on palliative care services and challenges they have encountered. The study was conducted according to the Consolidated Criteria for Reporting Qualitative research (COREQ) checklist [14] and is aligned with the Medical Research Council good research practice guidelines [15].

2.2. Settings

Inpatient palliative care in Kazakhstan is provided by hospices, general hospitals, and palliative units of cancer centers [6]. General hospitals were excluded from the study as they usually have less than 5 palliative beds [6]. To achieve a broader perspective, three hospices and three cancer centers located in five regions of Kazakhstan (Pavlodar, Astana, Almaty, Semey, and Kostanay) were approached by the research team, based on recommendations of the Kazakh Association of Palliative Care. The following criteria guided the selection of appropriate settings:

hospices with 60 or more beds for patients with terminal cancer; cancer centers with designated palliative care units with at least 20 beds for patients with terminal cancer; facilities that allow family caregivers to provide daily palliative procedures during inpatient care (massage, hygiene, prevention of bedsores, etc.). Data collection was carried out from August 2021 to April 2022.

2.3. Participants and procedures

Eligible family caregivers had to be at least 18 years old, caring for a patient with terminal cancer who had received inpatient palliative care for a minimum of 14 days in the respective facility. Family caregivers were identified by health professionals at recruiting facilities based on their degree of involvement with practical tasks related to daily palliative caregiving. Eligible family caregivers were contacted by head physicians and a researcher who explained the study and obtained written consent.

Eligible to participate were healthcare professionals with a clinical role (e.g., physician, nurse, psychologist) with at least 3 years of experience in providing inpatient palliative care. Potentially eligible healthcare professionals were identified by facility administrators. Eligible administrators had to have a minimum of 5 years of experience in administration of palliative care services for a thorough understanding of palliative care policy, advocacy, recent developments, and future directions.

Participants received information sheets and consent forms in Russian, the official language of Kazakhstan. A demographic survey was administered to all participants to ascertain the characteristics of the sample. Authors had no pre-existing relationships with the individuals participating in the study. No monetary compensation or other forms of incentives were offered to encourage participation.

2.4. Data collection and analysis

All semi-structured interviews were conducted face-to-face in a meeting room of the corresponding facility. Interviews were audio-recorded with participants' explicit written consent and lasted, on average, 50 minutes, ranging from 30 to 180 minutes. Interview transcripts were de-identified during the transcription and verification process. All data were linked to a unique participant identification number and were stored in the authors' office. Sample characteristics were descriptively analyzed using IBM SPSS Statistics (Version 26). Transcripts were translated from Russian into English before being imported into NVivo Qualitative Research Data Analysis Software, Version 12. Thematic analysis identified patterns, based on which we create codes and arranged them into themes. The research team familiarized themselves with the data by repeatedly reading the transcripts and listening to the interview recordings. Memos were created to document the initial analysis of every interview. Two researchers independently coded the transcripts, compared, and aligned their coding categories to maintain qualitative rigor. Themes were developed and refined through ongoing analysis.

3. Results

3.1. Sample characteristics

The final sample consisted of 29 key stakeholders (Table 1). Among them, 12 were family caregivers, 12 were healthcare providers, and 5 administrators. The majority of family caregivers were female, with a median age of 45 (range: 24–58) years, primarily providing care for patients diagnosed with breast cancer. Most of these caregivers were the patients' daughters and provided palliative care in hospice settings. Most healthcare providers were also female, with an average work experience of 19 (range: 3–30) years. All administrators were associated with NGOs and had a median experience of 19 (range: 3–30) years in the

Table 1
Characteristics of study participants.

		Family Caregivers	Health professionals	Administrators
	Category	% (n) or Median (Range) n=12	% (n) or Median (Range)	% (n) or Median (Range)
Gender	Female	92% (11)	92% (11)	60% (3)
	Male	8% (1)	8% (1)	40% (2)
Age (years)		45 (24–58)	50 (23–59)	49 (38–56)
Settings	Hospice	58% (7)	58% (7)	
	Cancer Center	42% (5)	42% (5)	
Specialty	Physician		42% (5)	
	Nurse		42% (5)	
	Psychologist		17% (2)	
	NGO			60% (3)
	Health consulting			20% (1)
	Palliative facility			20% (1)
Experience (years)			19 (3–30)	10 (9–25)
Relationship to patient	Wife	17% (2)		
	Daughter	58% (7)		
	Mother	8% (1)		
	Niece	8% (1)		
	Son	8% (1)		
Type of cancer	Breast	33% (4)		
	Bowel	25% (3)		
	Lung	25% (3)		
	Uterus	8% (1)		
	Other type	8% (1)		
Length of time since diagnosis of terminal cancer	1–≤ 3 months	17% (2)		
	3–≤ 6 months	8% (1)		
	6–≤ 12 months	17% (2)		
	>12 months	58% (7)		

healthcare sector.

3.2. Main findings

We identified seven themes that were initially brought forward by different groups of stakeholders. The most common challenges highlighted by family caregivers were high out-of-pocket expenditures, the lack of mobile palliative care services, and shortages of opioids to prevent pain suffering. Physicians, nurses, and psychologists highlighted that the most common challenges they encounter in their daily practice are poor palliative care education and absence of practical trainings for family caregivers. Major challenges for administrators included lack of societal awareness about palliative care, and lack of financial support from the State. Table 2 provides a description of each theme, subthemes, and corresponding quotes.

3.3. High out-of-pocket expenditures

Family caregivers noted very high expenses associated with palliative care even in inpatient settings. A diagnosis of a terminal illness often makes it impossible for patients and their family caregivers to work, resulting in a loss of income for the family (Quote 1). Some families could afford more expensive consumables and equipment for their patients than others, increasing inequality of the care provided (Quote 2). Health professionals confirmed that they often ask family caregivers to buy lacking medicines and consumables (Quotes 3). Moreover, to hide the fact that their facilities do not have necessary medicines, nurses buy them at their own expense (Quote 4).

Table 2
Summary of main themes, subthemes, and quotes from study participants.

Theme	Subtheme	Quote
1) High out-of-pocket expenditures.	Out-of-pocket expenditures of family caregivers.	Quote 1: "We have bought many consumables ourselves, and that, day after day, takes a lot of money. Especially now that I'm a student and my mother is no longer working, not only does she not get a salary, but we are now also spending 200 dollars a month on her treatment." (Family caregiver)
	OOP and inequality of care.	Quote 2: "When my husband was admitted, physicians asked me if he used an oxygen concentrator. He did not. Then I've bought him an oxygen concentrator for 700 dollars. I understand that our cancer centers do not have it because it is very expensive equipment." (Family caregiver)
2) Lack of mobile palliative care services for home-based care.	Inability to cover actual costs.	Quote 3: "Of course, there is not enough funding, I can say with certainty that the funding that we have today covers about 70% of the actual costs, which is already not bad. In addition, we rely on family caregivers, charity or sponsors." (Physician)
	Home care after discharge.	Quote 4: "Low funding also affects the range of medicines in our unit. We are forced to ask family caregivers to buy certain medicines, it is very embarrassing for us, and sometimes we buy medicines ourselves, out of our pocket." (Nurse)
Mobile teams are unavailable.		Quote 5: "It is very strange that after some time these patients are discharged; they are still terminally ill, they are not cured, why are they discharged as if they have already been cured? In this case, why are there no home-based care to continue palliative care until the end of the life?" (Family caregiver)
		Quote 6: "We would really like to be supervised at home. Better at home than here. Home is familiar environment, psychologically it is better. It would be easier for all of us and my mother. I would prefer my mother to be monitored by a mobile service that visits us several times a week to give us advice and to be in touch with us at all times." (Family caregiver)
		Quote 7: "Many families prefer receiving palliative care at home. They might just wish dying at home, where their children are around them. But that doesn't mean

(continued on next page)

Table 2 (continued)

Theme	Subtheme	Quote
3) Severe shortages of opioids to prevent pain suffering.	Recommendation: Mobile teams as a supplement to family caregivers.	we shouldn't take care of them. We must provide them with best home-based care possible, which is currently available only in some regions". (Nurse) Quote 8: "Our mobile team is a great help for hospices and cancer centers, it reduces their workload, its efficiency is not less than in the hospice. Our team visits around 8 patients every day and we receive very positive feedback from families. But as strange as it may sound, we have only one mobile palliative care team for a city of two million people, can you imagine that?" (Physician)
		Quote 9: "The availability of qualified and equipped mobile teams can be a very effective measure in conjunction with trained family members. For example, a mobile team visits patients, adjusts treatments, and stays in touch with a family member who is trained and prepared to provide palliative care at home". (Physician)
	Short list of analgesics.	Quote 10: "The list of opioid analgesics is very short: the weak opioid tramadol, short-acting injectable morphine, and the fentanyl patch. These are the only medicines we were given for severe pain management." (Family caregiver) Quote 11: "Physicians require us to return empty opioid ampoules before prescribing new ones. They must prescribe opioids to all patients in severe pain. Until we solve this problem, an increase of morphine imports makes no sense". (Family caregiver) Quote 12: "Before discussing shortage of opioids, we need to raise the issue of widespread opiophobia among physicians. Many patients in our country die in painful agony. Why? Because physicians are literally afraid to prescribe opioids, and when they do, they force patients to return old ampoules to get new dosages. Or even worse, to get a dose of opioids, the patient has to be admitted to hospice." (Administrator)
	Opiophobia among physicians.	Quote 13: "Primary reason of severe shortage of morphine in Kazakhstan is the very low volume of its imports. The overcontrol of opioids arises from the state's fear of its non-medical use
	Excessive control of opioids.	

Table 2 (continued)

Theme	Subtheme	Quote
4) Poor formal palliative care education	Lack of faculty members.	and trafficking, which results in sufferings of the most vulnerable population. We are trying to reach out to both the Ministry of Health and the Ministry of the Interior. Oral morphine is still the gold standard of pain relief, and we don't have it at all." (Administrator) Quote 14: "It is simple to introduce new courses, but where are we going to find faculty? Palliative faculty. We do not have qualified teaching workforce, that is why we invite international experts and organize webinars, but it's still a drop in the ocean". (Physician)
	Lack of training abroad.	Quote 15: "I also take part in organizing international advanced trainings and courses for health professionals from Kazakhstan, but for all these years I haven't seen any single palliative care specialist sent for such trainings abroad". (Administrator) Quote 16: "The quality of palliative education is poor and hours not sufficient. Nurses start their practice in palliative care right after graduation without knowing its basics (...) To put it bluntly, they learn as they work with terminal patients by trial and error." (Physician)
	Learning by trial and error	Quote 17: "Colleges do not teach us palliative care at all. Often, we hire nurses who have just graduated from college. We spend much time teaching them here. They learn a lot in the first months from older nurses. Then they quickly, (...) how to say, get the hang of it, and soon leave for another job in oncology or intensive care; And then, a new nurse takes a vacant position, and everything starts all over again". (Nurse)
	Experienced nurses teach new nurses.	Quote 18: "Absolutely all physicians and nurses, regardless of specialty, and even us, family members, we all should have basic palliative care and pain management skills. This should be a priority in all settings: hospices, palliative units, big cities, and small villages". (Family caregiver) Quote 19: "We already have advanced postgraduate courses. But for broader coverage and availability, the introduction of palliative online courses could be an affordable and effective solution to the improve
	Recommendation: Ubiquitous palliative training.	

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Table 2 (continued)

Theme	Subtheme	Quote
5) Absence of practical skills training for family caregivers.	Critical role of family caregivers.	palliative literacy even in remote regions of our vast country". (Administrator) Quote 20: "Teaching families the principles of patient care is one of the most important needs in home and inpatient settings. Our palliative care system relies heavily on family caregivers, but it takes training and support to prepare families to the process of caregiving. To do that, we have to teach them, and make this knowledge and skills available to all". (Psychologist) Quote 21: "...I would say, they're the ones that hold everything together. They represent a critical pillar of palliative care which we must strengthen and support with all our might. And giving them access to courses and education is the first thing we must do in our setting." (Administrator)
	Training for family caregivers.	Quote 22: "Our nurses show them everything in detail: how to take care of a patient, how to prevent bedsores, how to change a diaper, how to install a colostomy bag. It really depends on family involvement. If a relative asks, we teach, if they don't, we can't make them come and take care." (Physician)
	Training for rural population.	Quote 23: "Hospice patients represent just a small proportion of the total palliative needs in the country, while thousands of patients are hidden from our eyes because they are at home or live in rural areas. Reaching these families should be a priority when discussing family caregiver training because palliative illiteracy there is widespread." (Nurse)
	Recommendation: Online training courses for family caregivers.	Quote 24: "It would be very helpful to have access to online educational resources, where I could get information about how to provide care to my mom at home, or at what stage I should seek hospice care; and most importantly, what is the outcome of palliative care". (Family caregiver) Quote 25: "It would be very helpful for us if families would have access to certain educational courses... maybe online... where they are taught some palliative skills and given information in a clear and detailed way. Our nurses would complement it here by demonstrating some procedures". (Physician)

Table 2 (continued)

Theme	Subtheme	Quote
6) Lack of awareness about palliative care in society	Negative attitude towards palliative care	Quote 26: "Also, our population is not even aware of the existence of hospices. Thousands of suffering families could have benefit from it, but they do not know what palliative care means. Those who know, have a negative attitude to it... the word "hospice" is stigmatized". (Administrator) Quote 27: "I am sure that people in rural areas have never even heard the word "hospice" in their lives and do not know what palliative care is, so care for terminal patients there lies solely on shoulders of family members". (Administrator)
	Conflicts with family members	Quote 28: "Often we have to deal with patients and families who think that we treat cancer. Very often we are asked why we don't do chemotherapy, surgery, or radiotherapy.... people are very often discontent about it... we had so many conflicts with families because of this confusion". (Psychologist) Quote 29: "People do not understand the meaning and importance of palliative care. You know... I see how families feel... as if they betrayed their loved one by bringing him here. Often, they are angry at us ... because we care, not cure" (Physician)
	Recommendation to promote palliative care	Quote 30: "It is hard for me to say but social ads, like posters, talks, or publicity campaigns could help. Sometimes we organize open days or volunteer days to raise people's awareness of palliative care. But all these efforts could be made in vain if there are no clear recommendations given to patients by their physicians, oncologists or polyclinics." (Nurse) Quote 31: "Every year on World Hospice and Palliative Care Day we organize events dedicated to palliative care awareness. Many people participate, we walk the streets, hand out bulletins, conduct surveys and explain the meaning of palliative care to all." (Administrator)
	Poor referral by oncologists	Quote 32: "Who diagnoses terminal cancer? Us? No! Oncologists do that. And it is their responsibility to inform patients and their families that we, palliative care units and hospices, are ready to help 24/7. But often they don't do it and patients with terminal cancer go home. The

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Table 2 (continued)

Theme	Subtheme	Quote
7) Lack of the State support.	Collaboration with the State.	same is true for other specialists, those who diagnose terminal stages of HIV, tuberculosis, stroke, and so on. They must inform and refer patients to us immediately after a terminal diagnosis." (Physician) Quote 33: "One of the issues lies outside of the scope of palliative care, and it is how oncologists communicate to terminal patients about stopping cancer treatment, as it becomes useless or even harmful, and how they talk about transitioning to palliative care. I see that the problem is there, and I know it." (Administrator) Quote 34: "Better cooperation between palliative stakeholders and the state is the key to getting the state to support palliative care. We are already working on this. There were several meetings with the Minister of Health, and she has promised to support palliative care. The roadmap for the development of pediatric palliative care is being developed and we have a lot of work to do". (Administrator)
	Importance of the State support.	Quote 35: "The state should be a locomotive of palliative care development, and we, NGOs, sponsors, charity, we are like carriages, from behind we help the locomotive to move further. All these years palliative care in Kazakhstan has been developing independently, without a big role of the state, but we are about to exhaust these abilities, it's time for the state to come on stage and play its role." (Administrator)
	Frustration by the state support.	Quote 36: "After all the difficult experiences I had with my mother, I got the feeling that government authorities are not concerned with these patients, they would rather focus on the strong and healthy. It's as if they have a consumerist attitude toward people; in other words, why should they help fund and assist these patients if they're going to die soon anyway?" (Family caregiver)
	Low salaries and high turnover.	Quote 37: "Palliative nurses have a salary of around \$250. Every month they fight for shifts to get a little more money. They often take more shifts than the Ministry of Labor allows. As a result, their productivity falls, and burnout increases. Moreover,

Table 2 (continued)

Theme	Subtheme	Quote
	Future of palliative care.	our hospice has received fines for exposing nurses to this kind of burnout, and we have even less money left over. What is the bottom line? The nurses just leave the job." (Administrator) Quote 38: "As an oncologist, I often attend oncology conferences and congresses, and I notice that palliative care is getting more attention in Kazakhstan. It seems to me that we still have everything ahead of us, I am sure the government will help, and we are just at the beginning of our way." (Physician)

3.4. Lack of mobile palliative care services for home-based care

Most family caregivers emphasized advantages of home-based care not only as an alternative to inpatient care, but also as continuous support if a patient prefers to be discharged and continue to receive palliative care at home. However, they acknowledged that mobile palliative care teams remain mostly unavailable (Quotes 5–7). According to a physician who mans a mobile team, their team serves hundreds of palliative patients annually, effectively reducing the workload on hospices. For example, one mobile team serves the palliative care needs of a city with a population of two million (Quote 8). Physicians noted that the optimal scenario can be achieved when a well-equipped mobile team conducts regular visits to a patient who receives daily care from a family caregiver (Quote 9).

3.5. Shortage of opioids to prevent and alleviate pain and suffering

The shortage of opioids to alleviate pain and suffering in palliative patients is a significant concern that has been raised by family caregivers. They pointed out that the list of available medicines is limited, consisting mainly of weak opioids with minimal quantities of morphine (Quote 10). Caregivers expressed frustration over the strict control imposed by physicians and oncologists when prescribing morphine ampules (Quote 11).

Administrators shed light on the primary cause of this opioid scarcity, attributing it to a pervasive fear of opioids (opiophobia) within society. This fear may be associated with an increased number of hospitalizations, as patients might be more inclined to seek admission to hospices or palliative units to access opioid pain relief (Quote 12). There was a consensus among participants that palliative patients in Kazakhstan endure severe pain without adequate access to opioids. According to participants, a significant contributing factor to this issue is the excessive governmental control over opioids, driven by efforts to combat illicit drug trafficking. Administrators indicated that they are actively engaging with authorities in an attempt to address this problem (Quote 13). The collective goal is to ensure that palliative patients receive the pain relief they require.

3.6. Poor formal palliative care education

Many healthcare professionals have voiced concerns about the insufficient quality and quantity of educational courses offered in medical universities and colleges. They explained that introducing new courses in palliative care is hindered by the shortage of teaching professionals specialized in the field (Quote 14). To address this issue, the government has allocated funding for the training of health professionals abroad. However, administrators and health professionals

reported limited experience and subsequently engagement with overseas training programs (Quote 15).

Physicians specifically highlighted the adverse impact of subpar palliative education for nursing staff on the quality of care. They noted that newly hired and inexperienced nurses often gain essential knowledge and skills only through on-the-job experience (Quote 16). Physicians and nurses underscored the critical importance of education, emphasizing the link between inadequate education, high turnover rates, and substandard palliative care (Quote 17). Administrators suggested that free online courses could serve as an effective intervention to enhance palliative literacy in resource-limited settings and remote areas of Kazakhstan (Quotes 18–19).

3.7. Lack of training on practical skills for family caregivers

Healthcare professionals and administrators highlighted a significant reliance on family caregivers within the palliative care system in Kazakhstan, whose role was deemed crucial in both outpatient and inpatient settings. However, they pointed out that family caregivers often lack the knowledge and practical skills necessary for providing essential patient care (Quotes 20–21). Physicians acknowledged that, in some cases, nurses may provide sporadic demonstrations of basic procedures in inpatient settings (Quote 22). On the other hand, nurses stressed the importance of initiating training efforts in rural areas, where the level of education tends to be lower, and where a significant portion of the population is likely to require palliative care (Quote 23). They highlighted that online courses would serve to enhance palliative care skills among family caregivers and provide them with the necessary information and support to better care for their loved ones (Quotes 24–25).

3.8. Lack of societal awareness about palliative care

Administrators raised concerns about the low societal awareness surrounding palliative care, highlighting a phenomenon they referred to as "family betrayal." This term encapsulates the negative attitude of families toward entrusting their terminally ill loved ones to palliative care staff (Quote 26). Additionally, there were worries about the lack of awareness among the rural population, which constitutes a half of Kazakhstan's population which may not possess even basic palliative skills (Quote 27). Healthcare professionals noted that the lack of awareness often leads to conflicts when family members confuse palliative care with cancer treatment, insisting on requesting treatments like radiotherapy or chemotherapy (Quotes 28–29).

Healthcare professionals conducted local events in hospices and palliative units, while administrators organized outdoor events where they disseminated written and verbal information about palliative care

services (Quotes 30–31). However, there was a belief that oncologists should inform patients and their families about the benefits of palliative care immediately after making a diagnosis (Quotes 32–33). This coordinated effort would improve understanding and acceptance of palliative care among both patients and their families.

3.9. Lack of state support

Administrators underscored the importance of fostering better cooperation between palliative care stakeholders to enhance the involvement of the government in palliative care initiatives (Fig. 1). They acknowledged that some progress had already been achieved through active collaboration with the Ministry of Health (Quote 34). However, they also admitted that palliative care in Kazakhstan has, to a large extent, developed without significant involvement from the Ministry of Health, even though such involvement is deemed crucial for further advancement (Quote 35).

From the perspective of some families, past experiences have led them to believe that the government prioritizes life-prolonging treatments over care for terminally ill patients nearing the end of life (Quote 36). Nurses highlighted the challenges they face, including low salaries equivalent to \$250 a month, which is nearly half of the national average. To compensate for this, staff members often take on additional shifts, resulting in increased workload, conflicts, and a high turnover rate (Quote 37). In contrast, physicians held more optimistic views and pointed out a significant increase in attention from the State. They believe that the government plays an active role palliative care development (Quote 38). This positive outlook suggested a potential shift towards greater governmental support for palliative care in Kazakhstan.

4. Discussion

Our study explored the challenges encountered by diverse groups of palliative care stakeholders within resource-limited settings of Kazakhstan. The insights derived from this research could provide valuable support to the ongoing development of palliative care systems in LMICs. According to the Lancet Commission Report, the integration of palliative care into universal health coverage in LMICs could be advanced by research [1]. Involvement of key stakeholders is crucial for further palliative care development and better understanding of the context in which palliative care is organized, provided, and received [16,17]. Previous research has emphasized the need to capture the challenges faced by different palliative stakeholders, especially in LMICs [12,17,18]. Despite different experiences and the use of different palliative care settings, stakeholders in five regions of Kazakhstan identified common challenges related to palliative care.

Some participants in our study had catastrophic out-of-pocket

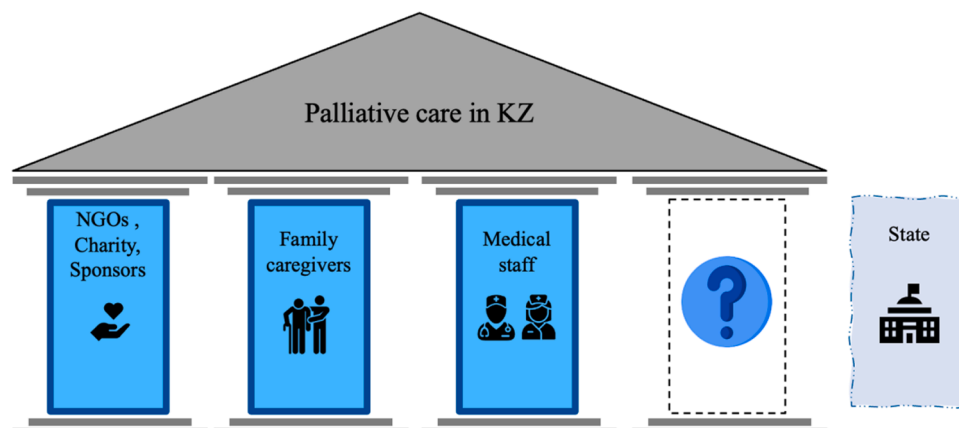


Fig. 1. The pillars on which palliative care in Kazakhstan rests.

expenses related to their caregiving duties. The need for their "financial risk protection" is emphasized, especially in LMICs where families must choose between the suffering of a loved one and crippling health care expenses [19,20]. Studies show that home-based mobile palliative services help prevent unnecessary hospitalizations, support families, and reduce the overall costs of care [21]. Therefore, mobile home-based care in Kazakhstan could be considered in conjunction with the training for family caregivers. This measure can also reduce the burden on inpatient care and the overall healthcare system, which is relevant in LMIC settings [22].

The topic that elicited the most emotional debate pertained to the necessity for opioids—specifically, oral morphine. The issue of opioid scarcity in Kazakhstan comprises two distinct facets: external and internal. On the external front, the heavy-handed regulation of narcotics by the police department and the national security committee manifests itself in the meager volumes of morphine imported into the country [5, 6]. While dialogues to increase morphine imports are currently underway between the Ministry of Health and the police department, mitigating opiophobia demands a more intricate and sustained effort. Participants emphasized the futility of augmenting morphine imports if the medication is not administered to those who are most in need. Research underscores that overregulation of opioids fosters a detrimental cycle of limited access and underestimated needs, with LMICs bearing the brunt of these challenges [23].

It has been documented that beyond physicians and nurses, specialists at all levels of healthcare must be competent in caring for terminal patients and their families [24]. Experiences of LMICs show that better palliative care education results in higher accessibility and expansion of palliative care services [25,26]. The importance of education cannot be underestimated; therefore, to make palliative care a public health concern, palliative education should be made available for all health professionals [27,28]. The basic palliative competence should be promoted among the entire health workforces [29].

The need for training family caregivers is of particular importance in the context of resource-limited settings of Kazakhstan, where families do not have the skills to care for loved ones at the end of life [2]. In the United States, the economic value of unpaid care provided by family caregivers is estimated to be around \$470 billion annually [30]. In the US, family caregivers are recognized as a central part of long-term care, where all health professionals are encouraged to integrate family caregivers into the care team and provide better support to families [29]. The Kazakh palliative care system relies heavily on families due to the close family ties in the Kazakh society and a voluntary desire to take care of a loved one at the end of life. The sense of coherence, the rituals and traditions, and the long-term mutual support that families and communities provide to those who die or grieve cannot be replaced by healthcare professionals [2]. Moreover, the lack of a family caregiver is strongly linked to hospital readmissions, leading to increased healthcare costs [29]. Researchers identify a complex mix of physical and psychosocial variables that influence the will to live, where absence of a spouse correlated with a lower 'will to live' score [31]. Online education platforms for family caregivers of dementia patients have already demonstrated the feasibility of achieving significant enhancement in the well-being of patients and their family caregivers [32–35].

Rural and remote areas should be given special attention when addressing the issue of palliative training for family caregivers as they struggle with inadequate healthcare infrastructure and lack of qualified healthcare staff [36]. Poor public awareness may serve as an underlying factor for other challenges in palliative care, as it affects the general population, patients, families, medical professionals, and the State [37]. Our findings indicate the necessity of public education and awareness-building campaigns that inform society of the goals of palliative care [38]. Research indicates that public education about palliative care and pain relief is the key to expanding its accessibility [1]. International experience demonstrates effective community engagement, mobilization, and death-literacy initiatives that are used in a

variety of public engagement strategies, such as public events, art exhibits, etc. [39].

Finally, the need for State's support was a painful point for all participating administrators, also noted by health professionals and family caregivers. Expanding bed capacity and access to pain medications in Kazakhstan has been achieved largely due to the advocacy of NGOs over last 7 years [5]. Insufficient funding negatively affects salaries of palliative staff which earn substantially less than staff in other medical specialties. Palliative care is of significant benefit to the State and could reduce the strain on the health budget by preventing unnecessary hospitalizations and interventions and by freeing economically active family members and improving the image of healthcare [40,41].

4.1. Recommendations

Based on the in-depth analysis of interviews, we propose seven recommendations to address challenges expressed by palliative care stakeholders. Reflecting of the Road Map of Palliative Care Development in Kazakhstan, we further categorized these recommendations into short-, mid-, and long term:

1. Increase the volume of imported opioids and advocate against their excessive control (short-term).
2. Introduce pilot projects on free online/on-site training courses for family caregivers to build awareness and explain basic palliative procedures (pain relief, hygiene, feeding, etc.) (mid-term).
3. Promote palliative care and home-based services in remote rural areas which represent almost 50% of the population (long-term).
4. Revise the policy of funding cuts based on lower quality of care in palliative facilities in favor of more transparent mechanisms when the quality could be incentivized rather than punished (mid-term). Fig. 2 demonstrates the vicious circle between the policy and lower quality of palliative care.
5. Reconsider the broad distribution of single palliative beds in hospitals in favor of established palliative care facilities, that could promote homogeneity of quality of care and facilitate the implementation of future reforms (long-term).
6. Promote awareness-raising campaigns advocating for palliative care and explaining its benefits for society (long-term). Fig. 3 represents the factors associated with decisions to receive palliative care in Kazakhstan.

4.2. Strengths and limitations

Our study included family caregivers of cancer patients, while palliative care is also provided to patients with other terminal diagnoses,

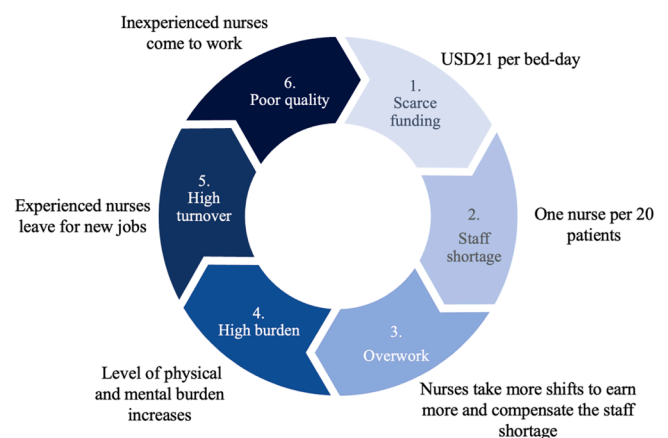


Fig. 2. Vicious cycle representing cause and effect links between the funding, staff burden, and quality of care.

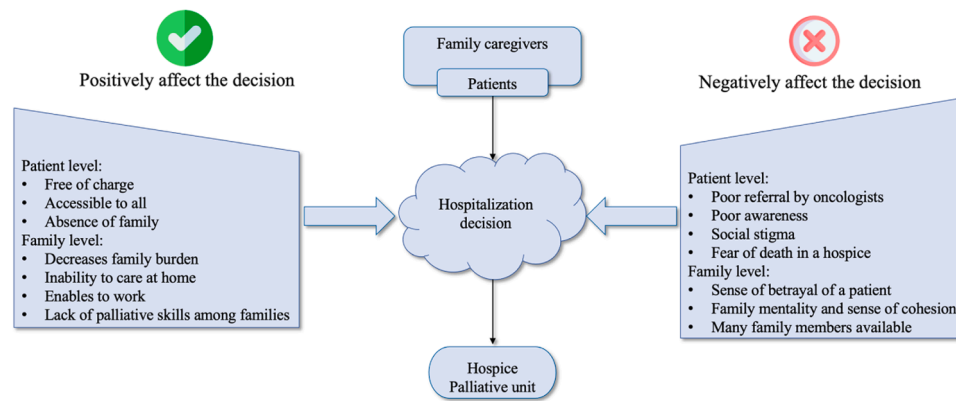


Fig. 3. Factors associated with the decision to receive inpatient palliative care.

such as HIV, tuberculosis, stroke, etc. Moreover, the study did not collect data from participants from rural areas, which represent almost 50% of the population of Kazakhstan. Future research will need to extend beyond cancer care, to consider multiple disease groups, and to include rural population to form a comprehensive palliative strategy in resource-limited settings of Kazakhstan.

5. Conclusion

While the goals of prolonging life are prioritized and well-funded, they should be followed by the goal of reducing suffering by providing adequate pain and symptom relief. To join the group of countries where palliative care is available, accessible, and affordable, Kazakhstan aims to integrate palliative services into the mainstream healthcare system at all levels throughout the country, from primary care to hospices, and from large cities to remote villages [4]. Target 3.8 of the United Nations Sustainable Development Goals points to the need for achieving universal health coverage, including access to essential health services and financial risk protection by 2030. However, no country can achieve universal health coverage without including palliative care [1,42].

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Ethical statement

Ethical approval was obtained from the Nazarbayev University Institutional Research Ethics Committee on June 15th, 2021 (IREC № 413/24052021).

CRediT authorship contribution statement

Gulnara Kunirova: Supervision, Writing – review & editing. **Byron Lawrence Crape:** Project administration, Supervision, Writing – review & editing. **Fatima Khashagulova:** Formal analysis, Writing – review & editing. **Maria Katapodi:** Data curation, Formal analysis, Funding acquisition, Supervision, Writing – original draft, Writing – review & editing. **Yuliya Savinova:** Data curation, Supervision, Writing – review & editing. **Islam Salikhanov:** Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft. **Reka Schweighoffer:** Formal analysis, Methodology, Writing – review & editing. **Monica Aceti:** Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing.

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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References

- [1] F.M. Knaul, P.E. Farmer, E.L. Krakauer, et al., Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report, *Lancet* 391 (10128) (2018) 1391–1454, [https://doi.org/10.1016/S0140-6736\(17\)32513-8](https://doi.org/10.1016/S0140-6736(17)32513-8).
- [2] L. Sallnow, R. Smith, S.H. Ahmedzai, et al., Report of the Lancet Commission on the Value of Death: bringing death back into life (Published online February), *Lancet* (2022), [https://doi.org/10.1016/S0140-6736\(21\)02314-X](https://doi.org/10.1016/S0140-6736(21)02314-X) (Published online February).
- [3] K.E. Sleeman, M. de Brito, S. Etkind, et al., The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions, *Lancet Glob. Health* 7 (7) (2019) e883–e892, [https://doi.org/10.1016/S2214-109X\(19\)30172-X](https://doi.org/10.1016/S2214-109X(19)30172-X).
- [4] Connor S.R., Morris C., Jaramillo E. Global Atlas of Palliative Care 2nd Edition; 2020. (www.thewhpc.org).
- [5] G. Kunirova, A. Shakenova, Palliative care in Kazakhstan, *J. Pain. Symptom Manag.* 55 (2) (2018) S36–S40, <https://doi.org/10.1016/j.jpainsymman.2017.03.028>.
- [6] I. Salikhanov, S.R. Connor, G. Kunirova, et al., Challenges for developing palliative care services in resource-limited settings of Kazakhstan, *Public Health Rev.* 44 (2023), <https://doi.org/10.3389/PHRS.2023.1605672>.
- [7] The 2015 Quality of Death Index Ranking Palliative Care across the World.2015.
- [8] E.A. Finkelstein, A. Bhadelia, C. Goh, et al., Cross country comparison of expert assessments of the quality of death and dying 2021, *J. Pain. Symptom Manag.* 63 (4) (2022) e419–e429, <https://doi.org/10.1016/j.jpainsymman.2021.12.015>.
- [9] Arkhangelsky V., Denisenko M., Elizarov V., Zhusupov B., Moldakulova G. Population Analysis of the Republic of Kazakhstan.; 2019. Accessed May 31, 2022. (<https://kazakhstan.unfpa.org>).
- [10] United Nations Population Fund. Kazakhstan is at a relatively early stage of demographic transition - population ageing. Published October 1, 2020. Accessed May 30, 2022. (https://kazakhstan.unfpa.org/en/news/kazakhstan-relatively-early-stage-demographic-transition-population-ageing#_ftnref4).
- [11] S. Kaasa, J.H. Loge, M. Aapro, et al., Integration of oncology and palliative care: a Lancet Oncology Commission, *Lancet Oncol.* 19 (11) (2018) e588–e653, [https://doi.org/10.1016/S1470-2045\(18\)30415-7](https://doi.org/10.1016/S1470-2045(18)30415-7).
- [12] J. Xiao, C. Brenneis, K. Fassbender, Stakeholder perspectives towards implementing the national framework on palliative care in Canada (Published online), *Health Policy (N. Y.)* (2022), <https://doi.org/10.1016/j.healthpol.2022.01.011> (Published online).
- [13] C. De Forcrand, M. Flannery, J. Cho, et al., Pragmatic considerations in incorporating stakeholder engagement into a palliative care transitions study, *Med. Care* 59 (8 Suppl 4) (2021) S370, <https://doi.org/10.1097/MLR.0000000000001583>.
- [14] Tong A., Sainsbury P., Craig J. Hospital at Westmead, NSW 2145, Australia, and 3 Population Health. [doi:10.1093/intqhc/mzm042](https://doi.org/10.1093/intqhc/mzm042).

- [15] MRC Ethics Series Good Research Practice: Principles and Guidelines.
- [16] E.A. Finkelstein, A. Bhadelia, C. Goh, et al., Cross country comparison of expert assessments of the quality of death and dying 2021 (Published online), *J. Pain. Symptom Manag.* (2022), <https://doi.org/10.1016/j.jpainsymman.2021.12.015> (Published online).
- [17] K.B. Nkhoma, B. Ebenso, D. Akeju, et al., Stakeholder perspectives and requirements to guide the development of digital technology for palliative cancer services: a multi-country, cross-sectional, qualitative study in Nigeria, Uganda and Zimbabwe, *BMC Palliat. Care* 20 (1) (2021), <https://doi.org/10.1186/s12904-020-00694-y>.
- [18] K. Hiatt, C. Stelle, M. Mulsow, J.P. Scott, The importance of perspective: evaluation of hospice care from multiple stakeholders, *Am. J. Hosp. Palliat. Med.* 24 (5) (2007) 376–382, <https://doi.org/10.1177/1049909107300760>.
- [19] Y. Goryakin, M. Suhrcke, The prevalence and determinants of catastrophic health expenditures attributable to non-communicable diseases in low- and middle-income countries: a methodological commentary, *Int. J. Equity Health* 13 (1) (2014), <https://doi.org/10.1186/s12939-014-0107-1>.
- [20] S. Verguet, J.J. Kim, D.T. Jamison, Extended cost-effectiveness analysis for health policy assessment: a tutorial, *Pharmacoeconomics* 34 (9) (2016) 913–923, <https://doi.org/10.1007/s40273-016-0414-z>.
- [21] S. Dhaliwal, M. Muckaden, Impact of specialist home-based palliative care services in a tertiary oncology set up: a prospective non-randomized observational study, *Indian J. Palliat. Care* 21 (1) (2015) 28, <https://doi.org/10.4103/0973-1075.150170>.
- [22] Roberts B., Robertson M., Ojukwu E.L., David, Wu S. Home Based Palliative Care: Known Benefits and Future Directions. *Curr Geriatr Rep.* 1:3. doi:10.1007/s13670-021-00372-8.
- [23] Anderson E.D., Davis C.S. Breaking the Cycle of Preventable Suffering: Fulfilling the Principle of Balance.; 2010. (<http://ssrn.com/abstract=2011197>).
- [24] Suikkala A., Tohmola A., Rahko E.K., Hökkä M. Future palliative competence needs—a qualitative study of physicians' and registered nurses' views. doi:10.1186/s12909-021-02949-5.
- [25] T. Pastrana, I. Torres-Vigil, L. de Lima, Palliative care development in Latin America: an analysis using macro indicators, *Palliat. Med.* 28 (10) (2014) 1231–1238, <https://doi.org/10.1177/0269216314538893>.
- [26] L. Gwyther, F. Rawlinson, Palliative medicine teaching program at the university of Cape Town: integrating palliative care principles into practice, *J. Pain. Symptom Manag.* 33 (5) (2007) 558–562, <https://doi.org/10.1016/j.jpainsymman.2007.02.018>.
- [27] P. Paal, C. Brandstötter, S. Lorenzi, P. Larkin, F. Elsner, Postgraduate palliative care education for all healthcare providers in Europe: results from an EAPC survey, *Palliat. Support Care* 17 (5) (2019) 495–506, <https://doi.org/10.1017/S1478951518000986>.
- [28] W.W. Li, J. Chhabra, S. Singh, Palliative care education and its effectiveness: a systematic review, *Public Health* 194 (2021) 96–108, <https://doi.org/10.1016/j.puhe.2021.02.033>.
- [29] C.L. Estes, E. Williams, *Health policy: crisis and reform*, Jones Bartlett Learn. (2013).
- [30] S.C. Reinhard, L.F. Feinberg, A. Houser, R. Choula, M. Evans, *Valuing the invaluable: 2019 update*, AARP Insight Issues (2015).
- [31] Khan L., Wong R., Li M., et al. Maintaining the Will to Live of Patients With Advanced Cancer. (www.journalppo.com).
- [32] Public Policy Institute A. Caregiving in the U.S. 2020 - AARP Research Report.; 2019. (www.greenwaldresearch.com).
- [33] P.C. Griffiths, M. Kovaleva, M. Higgins, A.H. Langston, K. Hepburn, Tele-Savvy: an online program for dementia caregivers, *Am. J. Alzheimers Dis. Other Dement.* 33 (5) (2018) 269–276, <https://doi.org/10.1177/1533317518755331>.
- [34] K. Rodriguez, M. Fugard, S. Amini, et al., Caregiver response to an online dementia and caregiver wellness education platform, *J. Alzheimers Dis. Rep.* 5 (1) (2021) 433–442, <https://doi.org/10.3233/ADR-200292>.
- [35] A. Langer, A. Meleis, F.M. Knaul, et al., Women and health: the key for sustainable development, *Lancet* 386 (9999) (2015) 1165–1210, [https://doi.org/10.1016/S0140-6736\(15\)60497-4](https://doi.org/10.1016/S0140-6736(15)60497-4).
- [36] J. Haier, J. Sleeman, J. Schäfers, Editorial series: cancer care in low- and middle-income countries, *Clin. Exp. Metastasis* 36 (2019) 477–480, <https://doi.org/10.1007/s10585-019-10003-4>.
- [37] A. Shalev, V. Phongtankuel, E. Kozlov, M.J. Shen, R.D. Adelman, M.C. Reid, Awareness and misperceptions of hospice and palliative care: a population-based survey study, *Am. J. Hosp. Palliat. Med.* 35 (3) (2018) 431–439, <https://doi.org/10.1177/1049909117715215>.
- [38] X. Lu, J. Liu, Factors influencing public awareness of and attitudes toward palliative care: a cross-sectional analysis of the 2018 HINTS Data, *Front Public Health* 10 (2022), <https://doi.org/10.3389/fpubh.2022.816023>.
- [39] MacDonald Susan, M.Herx Leonie, B.Boyle Anne. *A Case-Based Manual*, 4th edition, Oxford University Press, 2022. ISBN: 9780191873874.
- [40] Isenberg S.R., Lu C., et al. Impact of a New Palliative Care Program on Health System Finances: An Analysis of the Palliative Care Program Inpatient Unit and Consultations at Johns Hopkins Medical Institutions. Published online 2016. doi:10.1200/JOP.
- [41] I. Duncan, T. Ahmed, H. Dove, T.L. Maxwell, Medicare cost at end of life, *Am. J. Hosp. Palliat. Med.* 36 (8) (2019) 705–710, <https://doi.org/10.1177/1049909119836204>.
- [42] United Nations. SDG indicator metadata. Published online December 20, 2021. Accessed June 7, 2022. (<https://unstats.un.org/sdgs/metadata/?Text=&Goal=3&Target=3.8>).