

# Palliative Care in Kosovo

Preliminary Policy Recommendations for a National Program



Presented to the National Board for Cancer Control and  
the Ministry of Health of the Republic of Kosovo

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## **KEY TERMS & ABBREVIATIONS**

AMC	Action for Mothers and Children
ASK	Agency of Statistics of Kosovo
EHR	Electronic Health Record
ELMK	Essential List of Medicines for Kosovo
FMC	Family Medicine Clinic
LMIC	Low- and middle-income country
MoH	Ministry of Health
NBCC	National Board for Cancer Control
NCD	Non-Communicable Disease
NCR	National Cancer Registry
NGO	Non-Governmental Organization
NIO	National Institute of Oncology
NIPH	National Institute of Public Health
NSAID	Non-Steroidal Anti-Inflammatory Drug
PHA	Professional Health Association
SHS	Serious Health-Related Suffering
UCCK	University Clinical Center of Kosovo
UNFPA	United Nations Fund for Population Activities
WHO	World Health Organization

# EXECUTIVE SUMMARY

Each year, thousands of citizens of Kosovo with cancer and other chronic illnesses die without the benefits of comprehensive palliative care. Palliative care is offered only in limited forms in the country and is not integrated, comprehensive, or multidisciplinary. Nevertheless, the emergence of palliative care as a priority of the National Board for Cancer Control (NBCC) and other stakeholders provides a great opportunity for the promotion and implementation of a national palliative care program.

The research team at the Dartmouth Global Health Policy Lab examined the current state of palliative care delivery in Kosovo, and developed preliminary key findings, policy recommendations, and a conceptual framework for delivery of these policy options. The team first spent ten weeks conducting research at Dartmouth College in order to develop a scope of work and an initial literature review. From June 19th through August 20th, 2018, the research team carried out fieldwork in Kosovo. The team conducted a mixed methods study consisting of interviews with various health system leaders and health care providers in addition to an analysis of existing data and literature. This research and fieldwork was utilized to develop the key findings and delivery framework that are presented in this report.

## CURRENT STATE OF PALLIATIVE CARE DELIVERY

Palliative care is currently delivered in limited forms at all levels of the health care system in Kosovo. At the primary care level, home care teams specializing in chronic care deliver palliative care to home-bound patients. In regional hospitals, patients can seek out “supportive care” treatments between rounds of therapy at UCCK or when they no longer have curative options. In clinics at UCCK, doctors provide palliative care treatments to patients in need, but must do so as a secondary focus. In some areas of Kosovo, NGOs have started providing palliative care and home care to patients in need to close some of the gaps in palliative care provision. However, not all gaps in palliative care can be filled by NGOs, leaving many Kosovars without the appropriate palliative care options.

Though the provision of palliative care is limited, positive aspects of the current system include home care teams at the primary level, supportive care at the secondary level, and the inpatient palliative care unit at the tertiary level at UCCK. These components represent areas of care that can be strengthened and expanded as a foundation for a national palliative care program.

## KEY OPPORTUNITIES

The research team identified five key opportunities that would facilitate the establishment of a national program for palliative care. These five key opportunities are summarized below:

1. **Improve continuity of care for pain and symptom management.** Palliative care patients require continuous care. To provide this, the health system in Kosovo would benefit from 24-hour care services for patients in both home-based and inpatient settings, invest in medical equipment and pharmaceuticals that provide extended pain and symptom relief, and strengthen the existing referral system to create more formal pathways of care for palliative care patients.
2. **Increase access to the essential medicines for palliative care.** Increasing access to the essential medicines for palliative care is a critical step in improving palliative care in Kosovo. Accordingly, health system leaders should work toward adding all essential medicines for palliative care to the ELMK

(particularly oral morphine), standardizing the use of opioid analgesics for palliative care, and reforming the procurement process to eliminate gaps in the availability of essential medicines.

3. **Increase human resource capacities and competencies.** Workforce availability and training is a crucial pillar of any medical system. Given that Kosovo currently lacks a formal palliative care program, creating and expanding such a program will require an increase in trained health providers. Consequently, Kosovo will need to invest in and prioritize palliative care training for doctors and nurses, begin creating a palliative care specialty program, and consider the integration and expansion of provider roles in palliative care.
4. **Improve health education and health literacy.** The success of a national palliative care program relies on patient knowledge and awareness of their rights as patients and their treatment options, both curative and non-curative. To ensure that patients understand both their rights and treatment options, health system leaders may consider investing in patient education regarding palliative care options and promote communication about palliative care issues to reduce stigma for patients and their families
5. **Integrate social, emotional, and spiritual care.** For palliative care patients, medical treatments for pain and symptom management must be complemented by social, emotional, and spiritual support. To meet these holistic needs, health system leaders will need to develop integrated care guidelines for providers dealing with palliative care patients, incorporate spiritual care into palliative care, and educate all health care providers on multidisciplinary care at university level.

## **DELIVERY FRAMEWORK**

In order to create a comprehensive palliative care system, health care leaders must build capacity across each level of the health care system and make system-wide changes over time. The research team has developed a series of three stages for the delivery of palliative care; this system is explained in detail in Section 5: Delivery Framework. This framework provides a timeline for creating a palliative care system, with the ultimate goal of developing multidisciplinary, integrated, comprehensive care.

The first stage is defined by reallocating current resources and making system-wide changes to formalize palliative care provision pathways. The second stage is defined by capacity building activities, particularly focused on human resources and the beginning steps of integration of social and emotional care. The third stage is defined by comprehensive, multidisciplinary care that reaches full need through the introduction of standalone inpatient centers, in addition to the other sites of care developed in stages 1 and 2. Palliative care is a crucial part of the development of the health care system of Kosovo and this three-stage delivery framework serves as a preliminary model for the creation of a national program.

## **CONCLUSION**

The Dartmouth team has provided policy options and a three-stage delivery framework that together offer comprehensive strategies for promoting and implementing a national palliative care program. Based on these recommendations and framework, the NBCC and other key stakeholders can work towards developing integrated, comprehensive, and multidisciplinary palliative care in Kosovo.

# 1. BACKGROUND

## DEFINITION AND IMPORTANCE OF PALLIATIVE CARE

The World Health Organization definition of palliative care states that palliative care:

- “provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the illness of a family member and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”<sup>1</sup>

Palliative care is by definition multidisciplinary; it requires the integration of different health systems actors to provide treatment. In palliative care, pain and symptom management, emotional and spiritual support, and social support are combined to address the physical, sociological, and spiritual needs of patients and their families. These components allow for the development of holistic treatment plans which improve the quality of life and death for patients.

Trends in medical advances and population demographics in Kosovo have led to an emergence of chronic illnesses and noncommunicable diseases.<sup>2</sup> As the rates of non-communicable diseases (NCDs) and chronic illnesses rise, the numbers of patients with terminal diagnoses, including late stage cancers, will also increase. Palliative care is a crucial part of treatment for these types of serious illnesses and the need for palliative care will rise as the rates of these serious illness rise. Currently, there is no formal palliative care system or policy in Kosovo. Accordingly, the system-wide development of a palliative care program represents an important opportunity for improving medical care for the population of Kosovo.

## GLOBAL CONTEXT

In 2017, the *Lancet Commission on Palliative Care* estimated that more than 61 million people globally are affected by serious health-related suffering (SHS): pain or other suffering that cannot be relieved without medical intervention and compromises normal life.<sup>3</sup> Many of these people lack access to adequate care and are unable to get relief from their symptoms. Palliative care allows for this suffering to be alleviated through pain and symptom management, emotional and spiritual support, and bereavement and social support for the family and loved ones of the patient.<sup>4</sup>

Countries around the world are facing a shift in disease burden, with the burden of communicable diseases such as tuberculosis decreasing and the burden of NCDs such as diabetes and cancer increasing.<sup>5</sup> NCDs are now the leading cause of death globally, and their treatment is critical in all health care systems.<sup>6</sup> Many NCDs are chronic conditions that lead to a slow decline, and, in many cases, are incurable. These conditions therefore cause significant amounts of SHS which can be addressed through palliative care.

Increasing awareness of the burden of SHS has led to the development of palliative care programs around the world, with more countries creating national palliative care systems and international organizations calling for more attention to palliative care. In 2014, the WHO released a resolution calling on all member nations to



improve access to palliative care as a core component of health care, thereby promoting palliative care on a global level.<sup>7</sup> Palliative care has also become a core component of Universal Health Coverage as defined by the WHO.<sup>8</sup>

Many high-income countries have already faced the rise of SHS, and consequently have experienced an emergence of hospice movements and specialized palliative care delivery.<sup>9</sup> In contrast, palliative care has not yet become a focus for health care systems in many low- and middle-income countries. Instead, governments have focused their efforts on communicable diseases and curative care. However, as the burden of disease shifts to NCDs, more LMICs are beginning to implement palliative care programs.<sup>10,11</sup>

### Palliative Care Systems in the Balkans

Palliative care programs have emerged in many Balkan countries in recent years, with a range of countries implementing nation-wide programs. Many countries now have public provision of palliative care incorporated within national systems, linking palliative care provision to national resources and referral networks. These programs take a variety of forms, ranging from day hospice services to dedicated inpatient units to mobile palliative care units based in regional hospitals that provide home care. Multiple delivery models are implemented in most countries, with some combination of clinics providing palliative care to the population.<sup>12,13</sup>

While the implementation of palliative care services differs between Balkan countries, many share a pattern in the history and emergence of palliative care. In several countries, including Macedonia, Croatia, and Slovenia, palliative care emerged as an issue through the hospice movement, with international NGOs such as Sue Ryder stepping in to provide hospice and home care to patients at the end of life. As these movements expanded and became more widely recognized, they were able to work with governments in these countries to make palliative care a national priority. In many countries, this approach succeeded and palliative care was added to national health care plans, leading to nationwide palliative care programs.<sup>14,15</sup>

Another model for palliative care development in the Balkans is the creation of a national system in response to the need for palliative care by patients with terminal cancers. This need has led to a push for formalized palliative care programs and the inclusion of palliative care in cancer control plans and national laws.

More information about specific palliative programs in the Balkans is available in Appendix A.

## **HEALTHCARE IN KOSOVO**

### Health System Context

The health system in Kosovo has progressed greatly in recent years, especially with regards to the diagnosis and treatment of cancer. Patients who were once unable to receive treatment for cancer in Kosovo now have the opportunity to receive chemotherapy, radiation therapy, and surgery at UCCK. This substantial development has improved access to care and in doing so it has opened the discussion for greater improvements in the health system in Kosovo.

The National Board for Cancer Control (NBCC) has identified three priorities for strengthening the cancer care pathway in Kosovo. The first priority is to establish sustainable screening programs for cervical, breast, and colorectal cancers. Cervical screenings and mammography clinics have been implemented throughout the country, greatly increasing early detection of cervical and breast cancers. The second priority of the NBCC is to establish and fortify a National Cancer Registry (NCR). The NCR is key in understanding cancer trends and ensuring continuous care for patients. The final priority of the NBCC is to establish a national palliative care program as part of a comprehensive national cancer program. There is currently no formal palliative care provided through the public health system in Kosovo.

The combination of the efforts of the NBCC and the National Institute of Oncology (NIO) has opened doors for patients to receive care and has informed the health sector of the cancer burden in Kosovo. Kosovo currently has a very young population, but doctors describe the population as “aging quickly;” cancers and other diseases that increase the need for palliative care will soon develop in the younger sectors of the population. As of July 2017, 49.6 percent of the population of Kosovo was between 25 and 54 years old, while only 7.3 percent of the population was 65 years and older.<sup>16</sup> In addition to the aging population, a demographic and social change is taking place in Kosovo. Compared to families in the past, children are less likely to live with their parents into old age. Many young Kosovars have left the country for opportunities abroad. This has led to a population of “abandoned elderly,” a group of Kosovars over 65 who do not have any family members to take care of them. These elderly people are often in need of supportive care, assistance with daily tasks, and palliative care, thereby increasing the overall need for palliative care in Kosovo.

### Health System Structure

The health sector in Kosovo is separated into three levels; primary, secondary, and tertiary. Looking at cancer specifically, screening and supportive therapies are centered at the primary and secondary levels respectively. The burden of all direct cancer treatment is focused in Pristina at the NIO. All treatments provided through the public sector are free of charge for patients. The tertiary and secondary levels are funded by the Ministry of Health (MoH), while the primary care level is funded by the Ministry of Finance through payments to municipalities.

All medicines and medical equipment are procured through a central process, which differs based on the level of health care: primary care centers request medicines and equipment directly through the MoH at the municipality level, while regional hospitals and UCCK request medicines through the central pharmacy at UCCK. Only medicines on the Essential List of Medicines for Kosovo (ELMK) are available through this process in the public sector. Because of difficulties in procurement and resource constraints across the health system, many medicines on and off the ELMK must be purchased by patients out-of-pocket. Opportunities for capacity building related to the ELMK and the procurement process will be discussed further in Section 4.

The responsibility of palliative care is legally placed on the primary level of health care, and all family medicine physicians receive minimal palliative care training in their residency. Palliative care is specifically included in the mandate of primary care in Kosovo but is not included in the national health plan and is not prioritized or funded. There are no palliative care specialists in Kosovo. Any palliative care training doctors receive is not standardized and is often received through NGOs or through schooling and training outside of the country. Because of palliative care has not been standardized across Kosovo, there are gaps in care for many patients. In the next section we will outline the steps that have been taken to improve the quality of life and death for patients and provide a description of the current services offered and the patient populations served by the three levels of the health care system.

## 2. METHODOLOGY

The Dartmouth Global Health Policy Lab team in Kosovo aimed to support the goals of the NBCC by researching palliative care in Kosovo with the ultimate aim of providing policy recommendations on improving palliative care provision to both the NBCC and the MoH. The research methodologies focused on assessing current provision of palliative care, the level of need for palliative care in country, and capacity of the country to carry out a national palliative care program. The team undertook a mixed methods study that consisted of interviews with various health care actors and an analysis of existing literature and data, with a focus on global palliative care literature.

Research conducted for the first ten weeks of the project was based in Hanover, New Hampshire and included the preparation of the literature review and the scope of work. The research team drew on existing research on palliative care programs in resource-constrained settings and reports outlining the essential inputs of palliative care programs. Along with the literature review, the team conducted a comparative analysis of palliative care systems in similar countries. The research team also conducted initial informal interviews with the client to get a better sense of the priorities of the NBCC in this research project.

From June 19 to August 20, 2018, the Dartmouth team conducted more than 40 interviews with members of the NBCC, health workers, government officials, administrators, and other health care experts. These interviews were structured with goal of understanding how health care, and particularly palliative care, is provided both in the public health system and by actors outside of the public health system. The research team began its data gathering at the NIO as the majority of palliative care demand comes from cancer patients treated there. The research team visited regional hospitals to gain a better understanding of care at the secondary level and to examine regional discrepancies in care. The research team also conducted interviews at the primary care level, visiting sites of home care and palliative care provision in a range of municipalities. The research team spoke with actors involved in medicine procurement and with pharmacists, as well as health care systems leaders in the Chamber of Physicians and the Chamber of Pharmacists, the faculty at UCCK, and the officials at the MoH. In addition, the research team conducted interviews with representatives from NGOs that advocate for improved care and patients' rights to care, support improved health care delivery, and deliver health care as well. The team spoke to representatives of Smile International, Caritas, the Patients' Rights Organization of Kosovo, the Mother Teresa Society, the World Health Organization, UNICEF, and UNFPA. Lastly, analysis of data from National Institute of Public Health (NIPH) and the Agency of Statistics Kosovo (ASK) supplemented the interview findings, allowing the team to quantify the need for palliative care and the medical infrastructure available in Kosovo.

## 3. CURRENT STATE OF PALLIATIVE CARE

### GROWING NEED FOR PALLIATIVE CARE

Around the world, LMICs like Kosovo are experiencing a demographic shift, with the burden of disease shifting from communicable diseases such as HIV and tuberculosis to NCDs such as cancer, diabetes, and hypertension.<sup>17</sup> These NCDs, especially cancer, cause significant amounts of SHS, especially at the end of life, and drive an increased need for palliative care. According to many models of estimating palliative care need, all cancer patients at the end of life need palliative care, due to the SHS caused by the disease. However, need for palliative care is not limited to cancer patients; it is generally accepted that more than 60 percent of all patients who die require palliative care in the last year of life.<sup>18</sup>

As Kosovo navigates the transition in disease burden from communicable diseases to NCDs, another transition is taking place. The young population of Kosovo is aging, and the number of citizens over 65 will increase in the coming years. Terminal cancers and other conditions that occur near the end of life are more common in older patients, increasing the need for palliative care as the size of the elderly population increases. This trend is compounded by a cultural change, with young Kosovars moving outside of the country or out of their family homes, leaving their parents without a caretaker.

#### Growing Cancer Burden in Kosovo

Cancer is becoming a much more common ailment in Kosovo, leading to the creation of the NBCC, national screenings for common cancers, the implementation of the NCR, and work to increase the types of available treatments at the NIO. In 2017, 2,902 new cases of cancer were found and recorded with the NCR, an incidence of 163 new cases per 100,000 citizens.<sup>19</sup> The most common new cases found were of breast cancer (16.6 percent),

digestive organ cancer (16.2 percent), melanomas (14.9 percent) and respiratory/thoracic cancers (12.2 percent).<sup>20</sup> These numbers represent new cases recorded with the NCR, and may include cases that were previously diagnosed but not yet reported. However, it is not possible to discern if this incidence is an underestimate or an overestimate of the true incidence in Kosovo, as previously diagnosed cases are included, but many existing cancer cases are not yet diagnosed and are not included in this number. In total, there are 4,729 recorded cases of cancer in Kosovo, or 265.7 cases per 100,000 citizens.<sup>21</sup> Increased screenings for cervical and breast cancers are expected to find additional cases, revealing the true extent of the burden of cancer in Kosovo. As more cases are discovered, the need for palliative care either alongside treatment or after treatment options have been exhausted is projected to rise.

#### Need for Palliative Care: 5,802 cases in 2017.<sup>22,23</sup>

To calculate the number of patients in need of palliative care in Kosovo, the research team reviewed multiple models of palliative care needs assessment. These models calculate need based on population size, the needs of patients with specific diseases, or a combination of the two methods. The Stjernsward model estimates 60 percent of all dying patients need palliative care services. The Higginson model estimates that all patients dying of cancer and two thirds of the remaining deaths would benefit from palliative care.<sup>24</sup> The *Lancet Commission* estimates that all patients with one of an established set of diseases that cause SHS are in need of palliative care.<sup>25</sup> Due to lack of information about the true burden of cancer in Kosovo and the use of the Stjernsward model as the minimum standard for needs assessment in similar European countries, the research team opted to use this model to calculate the base need for palliative care in Kosovo.<sup>26</sup> In 2017, there were 9,670 deaths in Kosovo.<sup>27</sup> Using the Stjernsward model to estimate need, 5,802 of these cases would have benefitted from palliative care in the last year of life.<sup>28</sup>

Deaths in Kosovo are distributed throughout the country, and the number of deaths in each municipality are relatively proportionate to the population: larger municipalities generally have more deaths than smaller ones. This pattern is disrupted by the large number of deaths occurring in Pristina, the site of the only tertiary level hospital in the country. Only 8.7 percent of deaths in 2017 were permanent residents of Pristina, but 23.8 percent of all deaths in Kosovo occurred in Pristina, a total of 2,304 cases.<sup>29</sup> According to data from the NIPH, 1,567 deaths occurred in the clinics at UCK in 2017, while 982 deaths occurred in all regional hospitals, together representing 29 percent of all deaths occurring in Kosovo.<sup>30,31</sup> Patients travel to major health care centers in Kosovo to receive advanced care, and some Kosovars travel abroad to receive medical treatments that are not available in the country. Approximately 9.3 percent of reported deaths occurred outside of Kosovo, and this percentage reflects patients who travel for health care and live outside of the country.<sup>32</sup>

## **STATUS OF PALLIATIVE CARE**

Palliative care has emerged as a pressing issue across Kosovo. In interviews with health care providers and administrators at all levels of the health care system, the research team found that most stakeholders recognized the need for formal palliative care services in Kosovo. Stakeholders often spoke of the burden of providing palliative care in a setting not designed to deliver this care and issues arising from lack of dedicated palliative care training. This feeling was especially strong in clinics that saw a high volume of patients in need of palliative care, most notably the NIO in Pristina.

NGOs such as Smile International, Caritas Kosova, the Professional Health Association (PHA), and the Mother Teresa Society have begun to address the unmet need for palliative care. These NGOs provide palliative care and home care, hold training conferences on palliative care and pain management for doctors and nurses, and work with international groups to establish new programs. Out of these contributions, the training conferences are particularly valuable. Both Smile International and the PHA hold accredited conferences, where attendees can receive continuing education credit for the re-licensing process. These conferences give attendees between five and ten points towards the 100 points needed every five years for both doctors and nurses. These conferences are attended by doctors and nurses from around the country, and have grown rapidly, with over 2,000 attendees

at a 2017 conference series put on by Smile International, according to their data. Speakers at the conferences often include international experts, including palliative care doctors from the United States and United Kingdom.

Palliative care has been on the radar of many health care providers for years, but it has only recently been incorporated into health policy planning. The NBCC has recently recognized the need for non-curative care for patients with terminal cancer cases and has identified a national palliative care system as an integral part of a comprehensive cancer control program. This officially marks palliative care as a national priority for cancer care, along with cancer screenings and curative therapies.

Overall, the provision of palliative care in Kosovo has increased but still does not match the needs of the population. The following section examines the different sites of care around the country. It is crucial to note that though there are many different initiatives, care is not coordinated, and the lack of a formal system impacts access to care for many citizens in need.

## **OVERVIEW OF CURRENT PALLIATIVE CARE DELIVERY**

### Primary Care Delivery

Legally, palliative care is under the jurisdiction of primary care which is administered on the municipal level. Because of this structure, the provision of palliative care varies by municipality and is dependent on the priorities of the current municipal government. Each municipality has a central family medicine center (FMC) with other clinics throughout the rest of the municipality. The FMCs are funded through the Ministry of Finance, based on the municipality's population size. The central clinic may have specialists such as gynecologists and pediatricians, while the other clinics usually only staff general practitioners and family medicine doctors, though this also varies by municipality. The family medicine staff is based on the population, with one doctor and two nurses allocated per 1,000 residents.

The research team identified limited palliative care provided in several municipalities using home visits. Specifically, the team was able to view these systems in Pristina, Suhareka, Ferizaj, and Fushe-Kosova. In these municipalities, mobile teams visit patients with identified palliative care and chronic care needs in their homes and provide frequent visits to administer treatments. These teams are not organized or intended to provide palliative care. Rather, they are chronic care teams that were implemented to provide home care to patients with chronic conditions, such as diabetes or hypertension, who cannot come to the FMCs. In Ferizaj, Fushe-Kosova, and Pristina, these teams emerged exclusively from FMC initiatives. In Suhareka, Mitrovica, Prizren, and other municipalities, the chronic care team emerged through a partnership with Caritas Kosova, an NGO dedicated to improving Kosovar quality of life, defending human rights, and peace-building in Kosovo.<sup>33</sup>

Chronic care teams are based at FMCs and respond to calls from patients and their families requesting an appointment. The majority of these home care teams work five days a week, eight hours per day. Many are unable to provide service in the evenings and weekends because of a lack of staff. Most home care teams described working at full capacity for the number of staff they currently have, visiting patients constantly during their working hours. For example, the Pristina team of two doctors and four nurses working at full capacity for the entire capital city serves an average of 22 patients per day.

### *Services Offered*

These chronic care teams visit patients in their homes as often as needed, sometimes visiting a patient every day the clinic is open. On patient visits, the teams provide various types of care, with palliative care patients and those with advanced cancers receiving IV fluids, injections, supplements, and some pain management. Other services include catheterization, blood tests, and glucose monitoring. The teams also check vitals, monitor disease progression, collect samples for necessary lab tests, and refer patients to specialists as needed. Bed-bound patients are sporadically provided with pressure relieving mattresses to prevent bed sores, but access to these mattresses is limited. As a result, mattresses are passed between patients after deaths. Pain management

is provided through a variety of methods, sometimes including subcutaneous and IV morphine, and NSAIDs. However, morphine is reserved for emergencies in some municipalities, limiting pain management capacity. These treatments are provided on home visits and are often not available when the teams are not present. In some cases, the teams are able to teach family members how to administer the treatments, allowing for more continuous pain management. It is crucial to note that these teams do not distinguish between chronic care and palliative care. Instead, all patients receive a range of services based on their specific needs.

Chronic care teams also play an important role in providing moral support for the patient and their family. Some nurses cite the emotional support and presence they provide as important in their care. This aspect of care has not been formalized in the chronic care teams in the public health care system, but in Suhareka and other municipalities, nurses are trained and employed by Caritas Kosova in providing emotional support and encouragement, as well as how to address social issues in their cases.

As in other parts of the health care system, a lack of resources impacts health care delivery. Gaps in the procurement cycle lead to patients paying for their own medical supplies and purchasing medicines from private pharmacies.

### *Providers*

The makeup of home care teams does not vary greatly between different municipalities and usually consists of a combination of nurses and doctors. The chronic care teams used at the primary care level consist of nurses and family medicine doctors, with the doctors taking a more active role in some teams than in others. In Fushe-Kosova, Ferizaj, and Suhareka, the chronic care teams primarily consist of nurses who deliver care to patients around the municipality. All nurses have training in providing home care through the nursing school curriculum, and have limited exposure to palliative care, but do not have specific trainings on how to provide palliative care. These nurses provide prescribed treatments and routine care but cannot diagnose new ailments or prescribe new medications. If these services are necessary, the nurses are joined by a family medicine doctor from a nearby FMC or Ambulanta.

In contrast, the Pristina chronic care teams are composed of two nurses and one family medicine doctor, who all go on all home visits. Family medicine doctors have some specific palliative care training, with a module on palliative care in residency. Both doctors and nurses on these teams supplement their trainings by attending conferences and trainings on palliative care held in Kosovo and nearby countries, and doctors and nurses working with Caritas receive additional home care trainings through the NGO.

In some cases, the doctors and nurses assigned to home care make up a specific “home care team.” For example, the home care team in Pristina is a set group of two doctors and four nurses. However, in other municipalities, such as Fushe-Kosova, there is not a dedicated team for home care delivery; rather all nurses and doctors work on home care provision in shifts based on need. The organization of the home care team appears to be dependent on the needs and availability of appropriate staff in each municipality.

### *Patients*

Chronic care teams target the patient population that requires regular care but is not able to come into the clinic to receive treatment. Many patients receiving care from these teams have age-related degenerative conditions, and the majority of patients in some regions are over the age of 65. Other large patient populations include patients with diabetes, cerebrovascular problems, respiratory problems, or cardiovascular problems. A small minority of patients receiving chronic care have cancer diagnoses. Most patients receiving care from these teams have chronic care needs, not palliative care needs. Many patients who receive home care treatment are of lower socio-economic status, as wealthier patients have better access to transportation to medical centers and are able to travel to regional hospitals or UCCK.

The official referral networks for the chronic care teams are very weak. Few patients are officially referred to home care by their FMC, the NIO, or other doctors. In most cases, appointments are made by family members who contact the FMC or other municipal officials. Some patients are referred from emergency departments, but these cases are relatively rare. In Suhareka, the FMC conducted an outreach campaign to spread information about the chronic care team in order to attract patients. The informal system has been effective in connecting a significant number of patients to the chronic care teams, who are generally working at capacity, but the lack of a formal system likely leaves gaps in patient awareness and access.

### Secondary Care

Some patients receive palliative care, supportive care, and other non-curative care at the secondary level of the health care system in the regional hospitals of Kosovo. There are seven regional hospitals in the seven of the largest municipalities in Kosovo besides Pristina. UCCK acts as both a secondary and tertiary hospital, serving the secondary level needs of citizens of Pristina while also serving patients from around the country for more complex health care needs.

### *Services Offered*

None of the regional hospitals have dedicated palliative care units or even care that is explicitly called palliative care. According to the laws that establish the mandates of different levels of the health care system, regional hospitals are not obligated to provide palliative care. Instead, this kind of care is legally under the jurisdiction of primary care and family medicine at the municipality level. Many doctors, nurses, and other health care administrators pointed to the mandate of regional hospitals as a reason that regional hospitals may not be equipped to provide palliative care.

Most patients who receive palliative services at the secondary level are receiving some form of “supportive care.” Supportive care at the regional level refers to treatments to address symptoms of cancer or other terminal diseases. The treatments included in supportive care ranged from blood transfusions, treatment with vitamins and fluids, talking with family members about how to feed and treat the patient at home, and ordering therapies that have been prescribed for the patient at the Institute of Oncology at UCCK. Some patients receive supportive care that requires longer hospital stays. For example, one regional hospital mentioned caring for a patient with a coma in the hospital at the end of their life. However, this kind of long-term inpatient care is not the norm at the regional hospital level.

While some regional hospital directors demonstrated interest and the capacity to provide palliative care, others expressed that their hospitals were currently overloaded and that they did not have enough trained staff, beds, or general capacity to implement palliative care. Despite these conversations, statistics on hospital bed usage indicate that there is infrastructural capacity at most of the regional hospitals to dedicate beds to palliative care provision. According to 2017 data from the NIPH, bed utilization in the regional hospitals ranges from 39.4 percent in Ferizaj to 79.4 percent in Vushtrri.<sup>34</sup> This value from Vushtrri is an outlier, as the majority of bed utilization rates are under 50 percent and all of the bed utilization rates besides Vushtrri are under 60 percent.<sup>35</sup> Lack of interest or unwillingness to provide palliative care at the regional hospital level likely stems from the lack of palliative care training, different health care priorities at the regional level, issues with financing and procurement, adherence to the legal mandates of the secondary level of health care, and motivation to keep death rates in hospitals low.

### *Providers and Delivery of Care*

As is the case in the rest of Kosovo, there are no palliative care specialists at the regional level. As oncology services are only offered at the one tertiary hospital, UCCK, there are also no oncologists at the regional level. As a result, the delivery model for the supportive care provided at the regional level is not structured in any uniform way. Instead, providers involved in delivering care are chosen based on the disease from which the patient is suffering. For instance, in one regional hospital a patient with terminal lung cancer was treated with

supportive care in the pulmonary department, and a patient with brain cancer needing supportive care would be treated in the neurology clinic.

Because there are no structured delivery systems for palliative care at the regional level, many patients go first to the emergency department and then are referred to the appropriate department for care, usually based on where the cancer or other terminal illness is localized. In general, patients tend to come to the hospital on a daily basis for supportive care treatments, and often return home towards the end of life. Though some patients in need of palliative care may be admitted to the regional hospitals, it is not customary for patients to stay in the hospital for many days at the end of an illness.

### *Patients*

Patients in regional hospitals receive supportive care either in conjunction with curative care or because they no longer have any available curative options. Some cancer patients return to their regional hospital between chemotherapy regimens to receive supportive care. Other patients with terminal stage cancer or other terminal illnesses come to the regional hospital, often via the emergency department, to receive pain and symptom management before returning home. Because palliative care provision occurs on an ad hoc basis in the regional hospital, it is difficult to discern demographic trends among the patient who receive care. In general, patients who receive supportive care at the regional hospitals have either exhausted curative options at UCCK, are awaiting another round of curative care at UCCK, or are only coming into contact with the health care system at the very end stages of life for supportive care.

### Tertiary Care

The only public tertiary care center in Kosovo is UCCK in Pristina. This hospital is the only public health facility in Kosovo where patients can receive cancer therapies, with most services provided inside of the NIO. The NIO has 19 oncologists, 13 specializing in Medical Oncology and six in Radiation Oncology. The vast majority of patients in the NIO receive care in a day clinic, but there are some beds dedicated to inpatient care if a patient cannot travel to and from UCCK.

### *Services Offered*

After consultation with an oncologist, patients receive care in large rooms dedicated to different treatments. In the same room that someone may be receiving cancer treatment, palliative treatments may also be provided. Such treatments cover pain and symptom management needs that arise from cancer and are offered based on the current resources available to the NIO. For example, morphine is a commonly prescribed medication in the NIO, but accessibility to morphine is determined by procurement cycles and varies on a monthly basis. Other analgesics such as Fentanyl patches are generally unavailable in the NIO and must be purchased by patients at a private pharmacy. The NIO sometimes receives pain management medicines from outside donations but relying on donations is not sustainable and does not fully fill gaps in the ability to provide adequate pain management for patients.

### *Providers*

The providers of palliative care at the tertiary level are mainly the oncologists at the NIO at UCCK. In their training, these physicians have been taught how to manage pain caused by cancer and cancer treatments. However, these oncologists have no specialized training in palliative care. Because oncologists have greater experience and comfort in prescribing analgesics to cancer patients, they are often relied on by other physicians as consultants on pain management cases and are asked to prescribe opioids for patients. Other physicians outside of the NIO, especially those dealing with cancer patients, also provide palliative treatments to patients when the need arises. As in the NIO, this type of care is of a lower priority than the curative treatment that is provided in those clinics.



### *Delivery of Care*

Most palliative care delivered on the tertiary level is through the ambulatory clinic at the NIO. In this day clinic, patients receive pain management medication as well as certain intravenous supportive treatments. Certain patients do not receive care at the NIO, including breast and lung cancer patients who receive care in UCKK's thoracic surgery department. These patients, especially those with lung cancer, require more specialized palliative treatments such as providing oxygen or draining fluids from the lungs. Few patients require 24-hour care at the NIO, and there been less than ten deaths since the inpatient service began.

### *Patients*

The patients who receive palliative care at UCKK are those cancer patients whose pain and symptom management needs require extra attention from oncologists. These patients receive care among other patients who are being administered curative and supportive treatments. In the NIO and in other clinics at UCKK, palliative care patients are typically defined as patients for whom curative therapies will no longer be of use. However, based on the internationally recognized definition of palliative care, any patients at the NIO receiving supportive or non-curative treatments can be considered palliative care patients.

### Non-Governmental Organizations

To address the unmet need for palliative care, NGOs have stepped in to provide services. The research team identified three NGOs whose current projects address palliative care needs. The Mother Teresa Society has recently begun an elderly care service in the rural areas of the Prizren municipality. In Gjakova, Smile International provides a palliative home care service to patients at the end of life. Caritas Kosova also provides home care and works in 12 municipalities to treat chronically and terminally ill patients. While these organizations help provide a much-needed service in Kosovo, they still face system-wide challenges such as procuring drugs and open communication with patients near the end of life.

### *Services Offered*

The services provided by each NGO differ based on their individual missions. However, each program serves as a model for how palliative care is implemented and integrated with other services in Kosovo.

The Mother Teresa Society provides a holistic elderly care service which includes palliative care type treatments when required. Nurses in this program provide daily visits to administer treatments and help with nutrition and hygiene. Doctors visit patients monthly to assess the needs of patients and prescribe medications. An important aspect of the Mother Teresa Society program is its focus on the social needs of the elderly patients. Since this service focuses on the abandoned elderly, it emphasizes the important of addressing the social welfare and integration of the people it serves. For this reason, the program employs social workers and facilitates social events for the elderly. This acknowledgement of social needs and their impact on health is a positive step towards more integrated care in Kosovo.

Located in the Gjakova region, Smile International has been working in Kosovo since just after the war and has been providing palliative care services to residents of the greater Gjakova region since 2011. Smile International is currently the only organization in Kosovo that specifically provides palliative care. Smile mostly focuses on pain management and supporting patients and their families at the end of life. Though the care provided used to include more chronic disease management, it is now mostly focused on palliative care for terminally ill patients. Since Smile is not included in the public health system, it often has to purchase drugs for its patients in private pharmacies in Gjakova. Opioid regulations have limited the ability of these pharmacies to carry analgesics such as morphine or fentanyl, therefore patients receiving care from Smile lack access to some of the most important medications for palliative care.

Caritas Kosova provides home care and some palliative care in conjunction with twelve municipalities throughout Kosovo. Caritas has been in Kosovo for 25 years, providing treatment through both home care and ambulatory care in cooperation with the Ministry of Health, Ministry of Labor and Social Welfare, and municipalities around the country. There are three main components to the palliative care provided: pain prevention, treatment of diseases in conjunction with hospitals, and social care. One major challenge for Caritas is coordinating care with the public system. In some cases, such as in-home care provision in Suhareka, the family medicine center and the Caritas team are co-located which helps with care coordination. However, in other cases, it is difficult to coordinate care with regional hospitals so information on patient histories is often lacking. Another challenge Caritas Kosova has faced is the ability to continuously provide care when political priorities in the municipalities shift and disrupt care.

### *Providers*

The Mother Teresa Society recently began an elder care program that enlists various providers to achieve a more holistic care model for their patients. The main providers are nurses who conduct daily visits to service recipients. These nurses are responsible for the hygiene, nutrition, and health of the elderly patients they serve but do not receive any specific training before entering the program. Family medicine physicians make a monthly visit to patients and are also not trained specifically in geriatrics or palliative care. The program also employs social workers from the Center for Social Welfare on the municipal level that work with the abandoned elderly to improve their access to social support and interaction with other people in the region.

Smile International employs three doctors and two nurses to provide palliative care to its patients, who are also employed by FMCs in Gjakova. These doctors and nurses work half days, doing home visits to provide pain and symptom management and serve as a comforting presence for patients and their families. These providers receive special training from Smile after being accepted to work there. Physicians from England come in to train the Kosovar doctors on best practices in home care and how to manage terminally ill patients. Nurses working for Smile are sent to England to train in hospice centers. The knowledge they gain in this setting is shared with other providers at Smile who are unable to make the trip to England. Social and spiritual care, often provided by chaplains and social workers in larger palliative care clinics, is not provided in the Smile model. This is largely due to patient apprehension to this sort of integrated care which is not entirely medically focused.

Caritas Kosova provides home care which contains some palliative care provision. The teams of nurses and doctors are Caritas employees but work in conjunction with municipalities. Palliative care services are provided by professional doctors and nurses who are licensed by the MoH, the Chamber of Doctors, and the Chamber of Nurses. Doctors and nurses are specifically trained for home care. The first doctors were trained by the German Caritas organization, but now the training has expanded so that Caritas has specific trainers on its professional staff to continuously train doctors and nurses in home care provision. However, leadership at Caritas stressed that training specific to palliative care provision is necessary for the Caritas team to improve care. Caritas has taken steps to providing more multidisciplinary care. Though they do not have multidisciplinary care teams, they are in contact with psychologists and social workers and are able to link patients with these professionals who can assist patients who are alone, depressed, and in need of advanced emotional support. Caritas is currently in the process of trying to license social workers and psychologists to be more fully integrated into care provision.

### *Patients*

There are a range of ways that patients find NGOs and NGOs seek out patients. Many NGOs providing palliative care find their patients via word of mouth, and patients contact the NGOs through this same means. Because palliative care is not specifically institutionalized in the public sector, patients are rarely formally referred to NGOs providing palliative care. Some NGOs, such as Caritas, often work directly with the public sector and serve patients who receive care through the FMCs at the municipality level. Other NGOs work entirely outside of the public sector and treat patients who find the palliative care services through word of mouth. For example, Smile International functions entirely outside of the public sector when it comes to finding patients; they do not

partner with the Gjakova municipality or the Gjakova regional hospital, but instead serve patients who come to the clinic after being referred by other patients or after seeing Smile International promotional literature.

While these NGOs are filling a gap in care, the scope of the services they provide is limited. Smile International serves 35 patients at a time in the Gjakova region and the Mother Teresa Society serves 30 elderly couples in the Prizren region. Limited resources have kept these programs relatively small and gaps remain in access to palliative care. Overall, the palliative care need in Kosovo is not fully met.

## 4. KEY OPPORTUNITIES

There are several areas where Kosovo has scope for improvement with regards to palliative care provision. The research team has identified five key opportunities that would facilitate the development of a national program for palliative care. These five key opportunities are outlined below, including detailed descriptions of main findings and potential policy options for each of the five opportunities.

### 1. IMPROVE CONTINUITY OF CARE FOR PAIN AND SYMPTOM MANAGEMENT

A critical area of improvement within palliative care is the continuity of care for pain and symptom management. Currently, patients are largely unable to receive 24-hour care due to lack of availability and a lack of access to appropriate medicines and medical equipment. Furthermore, due to the informal nature of the palliative care system, patients also experience difficulties accessing care from providers that are best suited to treating them. Addressing these issues will improve continuity of care for patients, thereby greatly increasing their quality of life.

#### Main Findings

- *Palliative care patients require continuous care that is not available in Kosovo in either inpatient or 24-hour service delivery settings.*

A theme mentioned in many interviews was the fact that access to pain and symptom management is often dependent on clinic hours, workforce capacity, or the availability of appropriate medication. Though certain clinics, such as emergency and oncology care, offer some 24-hour services, the majority of services provided to patients in need of pain and symptom management are subject to more restricted hours. Most mobile care programs function only on weekdays during business hours, leaving weekend and evening care for patients at home difficult to obtain. Similarly, day clinics can only offer palliative treatments during their hours of operation. As a result, patients lack access to care during evenings, nights, and weekends.

With regards to medication, a key issue is that oral morphine is unavailable in Kosovo. Because the vast majority of analgesics are delivered in subcutaneous or intravenous forms, most patients are unable to administer them at home without a health care provider present. Without access to slow release or oral forms of drugs, patients have unmanaged pain in between trips to clinics or visits from home care services. IV drip equipment and other associated medical devices also have minimal availability for patients in need of constant pain relief. The use of long-acting pain relief in the form of oral morphine and other medicines would effectively increase the continuity of pain relief for many patients and allow for pain management in the time between visits by medical professionals.

- *An informal and unenforced referral system makes delivering and receiving palliative care harder for providers and patients alike.*

Except for emergency cases, by law patients in Kosovo should make their first contact with the health care system at the primary health care level. At this point, a family medicine practitioner will either treat the patient, or write a referral to a specialist at the regional or tertiary hospital level. In actuality, Kosovar patients and physicians do not follow this prescribed referral pathway. Research on primary care provided in 12 municipalities around Kosovo suggests that the first point of contact with the health system is often at the secondary and tertiary levels.<sup>36</sup> As a consequence of this trend, many ailments that could be easily dealt with at the primary care level are treated by specialty physicians at regional hospitals and UCCK. At these higher levels, physicians will not turn down patients requesting care and the fees for visits without a referral are not high enough to deter patients from bypassing the primary care system.

The lack of an enforced referral system negatively affects patient care and makes it more difficult for providers to deliver optimal treatments. When patients go directly to specialists or higher-level health care centers, they may end up in a clinic that is not appropriate for their needs. This can lead to patients receiving care from doctors who are not the best suited to deal with their conditions. This also wastes the time and resources of clinics that are responsible for treating specialty or emergency cases. In addition, patients who come to a provider without a referral or records leave the provider without information about prior treatments or current medications. This can lead to doctors prescribing the same medicine the patient has already tried without effect and carries the risk of a doctor unknowingly prescribing a medicine that interacts with a drug the patient is currently taking.

Patients requiring pain and symptom management go through this informal referral system, often arriving to a care provider without much help from the formal network. For example, some patients may go directly to hospital emergency clinics as their first point of contact to receive treatment to manage their pain and other symptoms. Others, who are currently being treated at UCCK or those regional hospitals, are not connected to providers at the primary level who may be able to treat them through a home care program. The lack of a formal referral network for palliative care patients leads to the patients moving through the system without direction, missing out on opportunities to receive the care they need.

## Discussion

Without a network of palliative care providers or access to continuous treatment, patients must handle their pain and other symptoms without formal medical support. In these cases, the quality of life for the patient and their family suffers to a great degree. Medical professionals and the health care system at large must be committed to improving access to this care and addressing the systematic discontinuity of care. A formal system that addresses patients' needs on a 24-hour basis is important in ensuring comfort and a high quality of life for all patient receiving palliative care.

## Policy Options

1. *Strengthen the existing referral system to create more formal pathways of care for palliative care patients*

It is crucial to strengthen the existing referral system through policies that make more formal pathways of care work well for providers and patients alike. The MoH should consider using policy levers to increase incentives to visit primary care physicians rather than going directly to secondary or tertiary care centers. These policies could include changes in financial incentives or increases in administrative barriers to receiving care at higher levels without a referral. A working group could be formed to examine specific policy changes that would affect incentives for patients to make first contact with the health care system at the primary care level. It is also important to equip health care providers with information about where palliative care is available to ensure that palliative care patients are referred to clinics where it is provided. For example, if a patient skips the primary level and goes straight to a regional hospital, but the provider believes the patient ought to receive home care, the provider will now be equipped to refer the patient downstream to appropriate services at the primary care level.

## 2. *Expand 24-hour care services for patients*

Gaps in continuous care provision disrupt the potential for quality care. The MoH should consider looking at policy options to provide 24-hour home care services at the family medicine level, as this is the level where most patients receive home care. Another potential policy option would be to focus on giving patients self-administered treatments, such as oral morphine, so pain and symptom management is not reliant on medical professionals. Giving patients self-administered treatments would allow the municipality Director of Health and other relevant actors to spend more time developing a 24-hour service that works well in each municipality. The MoH and other relevant actors should also consider developing a specialized inpatient palliative care center with new infrastructure, though this will take a longer planning process and will come in a later stage of developing a palliative care program, as will be discussed in the Delivery section of the report.

## 3. *Invest in medical equipment and pharmaceuticals that can provide extended pain and symptom relief*

Investing in medical equipment and pharmaceuticals is an important policy option for improving continuity of care. It is crucial to add oral morphine to the ELMK so that patients can administer pain relief without medical professionals present. It is also important to ensure that clinics have basic materials to administer palliative care treatments. It would be prudent to focus on procuring materials that support extended pain and symptom relief that do not depend on the presence of a provider.

## **2. INCREASE ACCESS TO THE ESSENTIAL MEDICINES FOR PALLIATIVE CARE**

Public procurement of medicines and medical equipment in Kosovo occurs through a centralized procurement process and is limited to medicines on the ELMK. This list currently does not contain all essential medicines for palliative care as defined by the *Lancet Commission*, a standard list used for basic palliative care. In addition to the absence of critical medicines from the ELMK, the cyclical nature of the procurement process and issues with contracting with pharmaceutical companies lead to gaps in the availability of medicines and equipment. This negatively impacts care and often forces patients to pay for medicines out-of-pocket. Consequently, increasing access to these essential medicines and equipment is a critical step in improving palliative care in Kosovo.

### Main Findings

- *The ELMK does not contain all essential drugs for palliative care as established by the Lancet Commission.*

A core component of palliative care is pain and symptom management, a type of treatment that is heavily dependent on having the proper medicines readily and continuously available. The *Lancet Commission* identified 19 medicines essential to the provision of palliative care in their 2017 report.<sup>37</sup> This list contains medicines needed to provide basic palliative care and is designed for use in new palliative care systems and in resource constrained settings. Many other medications can be used in palliative care, but access to the medicines on the *Lancet Commission* list allows for basic palliative care provision. Without continuous access to these medicines, the ability to provide palliative care is significantly limited, making their availability a cornerstone of palliative care provision on a national level.

The medicines procured by the MoH and distributed to public health care centers are limited to the ELMK. Medicines not on the ELMK are only available in public sector pharmacies through external donations approved by the MoH. The ELMK contains all medicines used in the public sector, ranging from cancer therapies to vitamins. Clinics and hospitals reference the ELMK when requesting medicines for the coming year. This list was created in 2012 and is now in the process of revision by a group of pharmacists and health care providers with assistance from the WHO.

The ELMK is divided between primary care centers and hospitals, with primary care centers receiving only a subset of the total ELMK. The ELMK does not contain all of the 19 essential medicines for palliative care

established by the *Lancet Commission*.<sup>38</sup> The ELMK for secondary and tertiary centers contains 13 of the 19 medicines in their listed form, two in alternate forms, and does not include four medicines in any form.<sup>39</sup> The ELMK for primary care centers contains ten of the medicines in their listed forms, two in alternate forms, and does not contain seven medicines.

Oral morphine, an important analgesic medicine for palliative care patients, is not available in Kosovo. This medicine provides continuous, long-lasting pain management that does not need to be administered by a medical professional, unlike IV or subcutaneous forms. Access to oral morphine is one of the key recommendations of the *Lancet Commission*. The lack of oral morphine Kosovo is a key issue to address.

**Table 1: Availability of Essential Medicines for Palliative Care**

Medication	On ELMK?
Amitriptyline	Yes
Bisacodyl (Senna)	No
Dexamethasone	Yes
Diphenhydramine (chlorpheniramine, cyclizine, or dimenhydrinate)	No
Diazepam	Yes
Fluconazole	Yes
Fluoxetine (sertraline or citalopram)	Yes
Furosemide	Yes
Hyoscine butylbromide	Yes
Haloperidol	Yes
Ibuprofen (naproxen, diclofenac or meloxicam)	Diclofenac
Lactulose (sorbitol or polyethylene glycol)	Yes
Loperamide	No
Metoclopramide	Yes
Metronidazole	Yes
Morphine (Oral immediate release and injectable)	Yes, injectable only
Naloxone parenteral	Yes
Omeprazole	No
Paracetamol	Yes

- *The annual procurement cycle causes gaps in access to essential medicines and equipment.*

Medicine availability in the public health care system is based on a centralized procurement process, where all medicines and medical equipment are procured by the MoH. For FMCs, medicine and equipment requests are made to the MoH by each central FMC for all clinics within the municipality. Regional hospitals and clinics at UCKK file their requests through the Central Pharmacy in UCKK. These requests are filed annually, requesting the total amount of medicines needed for the full year. At the MoH, procurement cycles occur every three months. These cycles involve contracting with pharmaceutical companies in order to purchase the necessary medicines within the budget allotted. After the medicines and equipment are purchased by the MoH, they are distributed to medical centers throughout Kosovo. Shipments are delivered directly to regional hospitals, while

clinics at UCCK receive their supplies through the Central Pharmacy. Main FMCs receive supplies through the MoH and then supply other clinics in the municipality.

The central procurement process was often cited as a major barrier to providing continuous care and palliative care. The MoH must contract with pharmaceutical companies to get the requested medicines, and in some cases is unable to come to an agreement with a company. This leads to gaps in procurement, where a shipment of medicines arrives later than expected, or a medicine is not purchased in a given cycle. Additionally, because of the cyclical nature of procurement and the length of the cycle, medicine and equipment shortages are often seen in the weeks before a new shipment is expected to arrive, an issue that is compounded by delayed shipments or gaps in procurement. The procurement cycle depends on requests for medications based on estimates of need, which are not always accurate, and the annual requests leave little flexibility in requesting more medicines as needed. The annual requests and budgeting prevent medicines from being procured for multiple years, a practice that can prevent frequent stockouts but relies on more flexible spending. These issues lead to frequent shortages and stockouts of essential medicines in Kosovo, negatively impacting the quality of care provided.

The lack of medicines and equipment in public sector clinics often leads to patients paying for their medicines and equipment out-of-pocket from private pharmacies. This failure of public procurement causes increased spending by patients, impacts the quality of care, and forces patients or their families to exit the public system to get necessary supplies.

- *Though more essential medicines for palliative care are available in the private market, access to essential palliative care medicines remains limited.*

Medicines not on the ELMK can be purchased in privately-owned health care centers and pharmacies. In these settings, medication availability is based on a market structure, with pharmacies purchasing drugs from companies and other providers. These pharmacies can sell any medicine registered for sale in Kosovo with marketing authorization and import licenses from the MoH. Sixteen of the 19 essential medicines from the *Lancet Commission* are registered for sale in Kosovo, two are registered in alternate forms, and one, Naloxone, is not registered for sale.<sup>40</sup> Private pharmacies are permitted to sell narcotics, such as morphine, but this requires additional certification from the MoH, a lockbox for narcotics, and detailed sales logs. This restriction reduces the number of pharmacies choosing to stock opiates. Some areas of Kosovo do not have any private pharmacies registered to sell narcotics.

- *Opioid analgesics are available in some places and in some forms, but there is insufficient use of these drugs in providing pain and symptom management to palliative care patients.*

Pain management is a crucial part of palliative care, and opioid analgesics are often used to relieve pain in patients with late stage cancers and other conditions. These medicines are very effective, but access to opioid analgesics is limited. In Kosovo, intravenous and subcutaneous morphine, fentanyl patches, and tramadol are sparingly available in the public sector. IV morphine is commonly used in the NIO, where oncologists are able to prescribe opioid analgesics and other pain management medicines to patients suffering from side effects of cancer treatments or symptoms of aggressive cancers. In home care settings, morphine is used at the end of life and in emergencies but is used less frequently than at the NIO. Between 2017 and 2018, requests for IV morphine from regional hospitals and clinics at UCCK doubled, indicating increased use of IV morphine in these settings.

Access to opioid analgesics varies, with gaps in the procurement cycle, shortages, and sporadic donations impacting the types of opioids used and the locations in which they are available. For example, a donation of fentanyl patches to the NIO, a medicine not normally available in large quantities, led to increased use of fentanyl for pain management in the clinic while the supply lasted. Doctors returned to using morphine when the donated medicine ran out. Outside of the public health care system or in situations where patients purchase their own opioid medicines, access to morphine and other narcotics depends on proximity to a pharmacy that is licensed to sell narcotics and has the medicines in stock. This varies regionally, and some areas lack any registered

pharmacies. This access issue is separate from the issue of oral morphine, which is completely absent in the Kosovar health care system.

Throughout the public health care system, morphine is used for pain relief and in emergency care. All doctors can prescribe opioids without additional training, however, some doctors refer their patients to oncologists since these specialists have more experience with pain management. Some doctors simply do not feel comfortable prescribing or administering opioids. Doctors throughout the health care system, from family medicine to dentistry, consult with the NIO to prescribe opioids.

### Discussion

Without continuous access to the essential medicines for palliative care, the ability for health care providers to give patients pain relief and symptom management is severely compromised. A lack of flexibility in the highly centralized procurement system leads to gaps in the availability of medicines at all levels of the public health care system. Moreover, public pharmacies are also unable to provide all necessary medications. The lack of oral morphine in the country is another major issue that limits the ability for patients to manage their pain without a medical professional present and prevents continuous pain management for many patients at home. Increasing the availability of the essential medicines for palliative care and providing continuous access to all medicines on the ELMK is an important policy goal that would allow for better care for palliative care patients.

### Policy Options

#### *1. Add all essential medicines for palliative care to the ELMK*

To address the current shortage of the essential medicines for palliative care in Kosovo, all the essential medicines for palliative care as defined by the *Lancet Commission* should be added to the ELMK for both FMCs and hospitals. Inclusion on the ELMK will make these medicines available in public health care centers throughout the country, making them accessible to patients free of charge. The ELMK is currently in the process of revision, providing a valuable opportunity to add the essential medicines for palliative care to the list. Adding oral morphine to the ELMK is a critical part of this revision and should be prioritized. In later stages of palliative care development, all essential medicines from the more comprehensive WHO list of essential medicines for palliative care should be added to the ELMK.<sup>41</sup>

#### *2. Normalize use of opioid analgesics for palliative care patients*

Normalizing and standardizing the use of opioid analgesics and other pain management treatments is central to developing a national palliative care program. Developing national guidelines and protocols for pain and symptom management, including the use of opioids, is an important step in this process. Guidelines created by the PHA and other international groups on pain and symptom management can be referenced in creating these national protocols. In addition to creating national standards for care, doctors should be trained in the use of opioids and other analgesics in order to ensure that they are comfortable and competent in prescribing pain management treatments. These trainings can take place as part of a continuing education program, as part of specialization for doctors who often treat palliative care patients, or as part of the standard medical education for all health care providers.

#### *3. Reform the procurement process*

Ensuring constant access to medicines on the ELMK is crucial for any national health care program. Improvements to the central procurement process can be used to mitigate gaps in availability of essential medicines. Working with NGOs and international groups with experience in medicine procurement and connections with pharmaceutical companies could increase the efficiency of the procurement process and improve contract conditions. For example, NGOs such as UNICEF have long standing relationships with pharmaceutical companies that allow them to receive better rates on essential medicines. These partnerships



could also work to ensure that best practices are being used in all procurement actions. In addition to working with other actors, creating a working group of knowledgeable stakeholders to examine potential reforms to the public procurement process could allow for system-wide improvements. Policy options include allowing greater flexibility in procurement to address shortages and creating longer procurement cycles for medications with longer shelf lives. It is also essential to reform procurement practices for non-medical equipment procurement for hospitals and other clinics to allow for better infrastructure and care delivery.

#### 4. *Increase access to essential palliative care medicines*

In addition to adding medicines to the ELMK, access to pain and symptom management medicines can be increased through partnering with international NGOs to increase donations of analgesics and other key medications. Donations can be further increased by streamlining the medical donation process, allowing for donations to be made more easily and encouraging more donations to the Kosovar system.

### **3. INCREASE HUMAN RESOURCE CAPACITIES AND COMPETENCIES**

The importance of human resources in palliative care is twofold: first, there must be enough doctors, nurses, and other related health care professionals to effectively deliver palliative care, and second, these health care professionals need to be trained in palliative care provision, which includes training on how to discuss non-curative care options with patients. Training doctors and nurses in specific palliative care provision is crucial to the development of any palliative care program. Currently, there is very little palliative care training in Kosovo. Some health care providers receive no specific palliative care training, even if they are in the position of delivering palliative care.

#### Main Findings

- *There are not enough health care workers in palliative care provision.*

In Kosovo, 2,274 doctors are employed in the public health system, with 1.24 doctors practicing in the public system per 1,000 residents.<sup>42,43,44,45</sup> These doctors are distributed between levels of the health care system. In clinics at UCCK, 743 doctors are employed, and in regional hospitals, 463 doctors are employed, the majority of whom are specialists or in the process of specialization.<sup>46,47</sup> Approximately 1,068 doctors are employed in FMCs to provide primary care to patients in each municipality.<sup>48</sup> Regional hospitals vary greatly in size; the Prizren hospital employs 148 doctors while the Vushtrri hospital employs 18 doctors.<sup>49</sup> Many more nurses are employed at all levels of the health care system, with 3,180 employed in FMCs, 958 employed in regional hospitals, and 1,128 employed in clinics at UCCK.<sup>50,51,52</sup>

In addition to doctors who are publicly employed, there are also many doctors who have private practices. Some providers work in both the public and private sectors. However, exact numbers of private practitioners are not known. Tracking of doctors and nurses through the health care system is not robust, and professional organizations often lack accurate data on the number of practicing doctors and nurses. Current estimates from the Doctors' Chamber indicate that there are between 3,200 and 3,500 doctors in Kosovo. Overall, evidence from the public sector suggests that there are not enough doctors to meet the needs of patients in Kosovo, given that there are fewer physicians per capita than in neighboring countries with more robust health care systems.

Location	Doctors	Nurses
Ferizaj	28	54
Gjakove	46	197
Gjilan	96	142
Mitrovice	40	110
Peja	87	176
Prizren	148	223
Vushtrri	18	56
All Family Medicine Centers	1,068	3,180
All Regional Hospitals	463	958
UCCK	743	1,128

- *Formal palliative care training in Kosovo is very limited, and most doctors lack adequate trainings for providing palliative care.*

Palliative care training for doctors is limited in Kosovo. There are no dedicated units in standard medical training and there is no palliative care specialty. However, while there is no standalone subject for providing palliative care, sections about palliative care are incorporated into other topics such as geriatrics. This practice introduces the discipline and provides basic knowledge on palliative care to doctors trained in Kosovo. Only Family Medicine doctors who are trained in Kosovo receive a palliative care education in their residency program. While these brief modules do expose physicians to palliative care in a basic sense, they generally do not include practical applications and do not prepare the doctors for providing palliative care to their patients. Some specialists receive more specific training in palliative care from schooling and residency outside of Kosovo.

To receive additional training in palliative care, doctors can independently seek out supplemental trainings at conferences held by palliative care organizations in Kosovo or receive training outside the country. These additional trainings are not required by individual clinics or the MoH but are rather a result of individual motivation to receive more training in palliative care. Over the past seven years, an organization in Kosovo called the Professional Health Association has provided pain-management trainings to doctors and nurses from Kosovo and Albania. Smile International, an NGO based in Gjakova, has also held conferences. According to records collected by Smile, they have held conferences in five cities in Kosovo since 2013 and have trained over 3,000 doctors, nurses, and other medical professionals. These conferences are some of the only accredited continuing education programs that teach professionals how to better manage pain and other symptoms and discuss how to speak with patients about a terminal prognosis. However, the group of doctors who receive this training remains self-selecting; not all doctors who are in a position of providing palliative care will choose to attend palliative care specific trainings for their continuing education accreditation.

At UCCK, there are tentative plans to expand palliative care training in the coming years as part of the curriculum review in 2021. However, even with the development of a new module, teaching this material would require training for the instructor which is a complicated undertaking.

- *Palliative care training for nurses is limited.*

Nurses often have more focused training in palliative care and home care than general practitioners, and their role in medicine is more focused on patient care and preferences. Despite this, pain and symptom management practices are not covered in detail for nurses. Many nurses currently providing end-of-life care have not received any additional training in palliative care but have taken on the provision of this care because of a lack of other options. For example, palliative care in Pristina is provided by chronic care nurses who were selected based on need. These nurses did not receive any additional training before taking on the provision of palliative care. Like the doctors described in the previous section, nurses seek out palliative care training independently, usually through internationally organized conferences.

- *Lack of open doctor-patient communication*

The lack of clear, honest, and accurate doctor-patient communication poses many issues for the successful provision of palliative care. When patients do not understand their condition or treatment options, they are unable to make decisions about palliative care, particularly at the end of life. Doctors and nurses alike do not receive comprehensive training on how to speak with patients regarding end-of-life issues. Healthcare professionals must be able to have these conversations in order to provide quality palliative care. Another way to address this issue would be to include psychologists, social workers, and chaplains in palliative care. The possible inclusion of these professionals may lighten the burden on health care workers to have these conversations.

- *Nurses lack sufficient autonomy to adjust care to fit specific palliative cases.*

In many cases, the work of nurses is highly dependent on doctors. Nurses are unable to prescribe medications or carry out independent interventions. Though many nurses do not have autonomy in their roles in providing care, in some cases they are the main point of contact with patients in providing palliative care. One health director described home care programs as very appealing jobs for nurses because they provide an opportunity for nurses to be the agents of health promotion in the community. Because nurses are the main point of contact for patients and families in some cases of palliative care provision, it is important to examine nursing training and autonomy in the context of palliative care.

## Discussion

Workforce availability and training is a crucial pillar of any medical system. Given that Kosovo currently lacks a formal palliative care program, creating and expanding such a program will require an increase in health care providers who are trained to provide care. This need can be addressed through increasing the size of the workforce or through shifting tasks to other health care providers. Both options require training given that many health care providers are not equipped to discuss or provide palliative care. This training can take place at medical schools, in continuing medical education, through the creation of a palliative care specialty, or through other channels, as outlined in the policy options section below.

## Policy Options

1. *Invest in and prioritize palliative care training for doctors and nurses*

To address discomfort in providing palliative care and to improve professional competencies, there must be additional investment in trainings for providers. Specifically, these trainings should address chronic pain management and speaking openly with patients about non-curative treatments. These training initiatives will likely have to begin through continuing medical education programs that help a doctor maintain their medical license. A special focus should be given to providers who are more involved in the palliative care pathway such as family medicine specialists and nurses providing home care. The MoH can work with the Doctors' Chamber to incentivize these programs by assigning them higher point totals toward relicensing or possibly making these trainings mandatory. The MoH can also support NGOs that have experience providing these types of trainings

such as Smile International and the PHA. In time, the Faculty of Medicine at the University of Pristina should include palliative care more formally in medical education, focusing on pain and symptom management as well as open conversations with patients about their care options at the end of life. A working group can be formed in the Faculty to begin drafting a curriculum for the upcoming accreditation in 2021.

## *2. Begin creating a palliative care specialty program*

As palliative care becomes more integrated within the health system, palliative care specialists will be needed to take on the most complex cases. The process of adding a new specialty in Kosovo is a complex undertaking, from formally acknowledging the specialty to creating residency programs in country. Before these programs are available, Kosovo must support a group of physicians to initiate a palliative care specialty. This process can be very similar to the process Kosovo underwent to train the first group of oncologists. The MoH can work with international partners to send young doctors to train with specialists abroad, and subsequently build their own program in Kosovo with international support.

## *3. Consider integration and expansion of provider roles in palliative care*

Palliative care is more multidisciplinary than other specialties due to its emphasis on addressing the social, emotional, and spiritual needs of patients and their families. When developing a comprehensive palliative care program, professionals in these areas will need to be added to care teams. Such professionals include social workers, psychologists, and chaplains. As the awareness of and need for palliative care grows, the number of these professionals needs to increase concomitantly. A greater presence of these professionals in hospital settings is important for more complex cases, but integration in home care should be available dependent on patient need and request. At the regional and tertiary levels, this could be achieved by ensuring a psychologist and social worker are present at each regional hospital and piloting the use of a chaplain at UCCK. Home care teams should be equipped with contact information for local social workers and spiritual leaders. They should also be trained to recognize situations where patients could benefit from this non-medical intervention.

Furthermore, it is important to recognize that nurses are often the main health care providers that patients interact with when receiving palliative care. Consequently, the competencies of these nurses must be considered. Because nurses do not have the ability to prescribe medications or adjust treatment schedules, many patients will receive care that is not flexible enough to meet their needs. This issue could be addressed by supplementing nursing training, modifying legislation regarding nursing competencies, or creating graduate level education that would train Kosovar nurses to provide care at the level of nurse practitioners in the United States.

## **4. IMPROVE HEALTH EDUCATION AND HEALTH CARE LITERACY**

Implementation of a national palliative care policy requires patient awareness of their rights as patients, and their treatment options, curative and non-curative. A lack of comprehensive health education and formal education campaigns has led to a lack of health care literacy amongst many in the population, both in terms of rights to health care and knowledge about palliative care. Palliative care programs can only be successful when all actors involved are aware of the benefits of such a program, and patients and doctors alike are able to make informed decisions about palliative treatments.

### Main Findings

- *Formal education campaigns that focus on late stage care options do not exist in Kosovo.*

The MoH and other actors responsible for health care have never carried out formal health education campaigns on palliative care or on options for care in the last stages of a terminal disease. As conversation and formal planning around palliative care is relatively new in Kosovo, most patients do not know that palliative care is an option and may not know how palliative care is different from curative care.

There is evidence that health information campaigns in Kosovo have been effective in the past. For example, Jeta-Vita, an organization founded in 2006, has launched multiple campaigns to raise awareness about breast cancer and other cancers, and has encouraged women to be screened. Over the years, Jeta-Vita has organized marches and walks to raise awareness about breast cancer, made brochures providing information, and organized workshops with different experts for women in municipalities to learn more about recognizing breast cancer symptoms. Jeta-Vita has also lobbied at institutions, such as the office of the Prime Minister and the Women’s Caucus in the legislative assembly to increase the priority of these issues. The work of the NBCC in increasing knowledge about cancer screening and cancer awareness has also been largely successful. One doctor noted that comfort in discussing cancer has changed enormously over the past five years. The stigma around discussing a cancer diagnosis has decreased and patients more comfortable discussing their care. However, conversations about non-curative options remain uncommon. Similar formal education campaigns on palliative care, either through the MoH or in conjunction with NGOs, may provide opportunities for improved patient health care literacy.

- *Patients are unaware of their rights, particularly their right to palliative care and its benefits.*

Most patients do not know about palliative care and do not discuss non-curative options with their doctors or families. There have been no studies on the knowledge of palliative care among patients, but studies on knowledge of health care rights reveal gaps in knowledge that affect access to quality care.

According to survey responses reported in a 2016 study, most patients lack basic knowledge about their health care rights and particularly the right to pain and symptom management. Approximately 47.1 percent of respondents replied “no” when asked the question, “Have you ever heard of rights of patients in Kosovo?”<sup>53</sup> Only 20 percent of respondents said that they believed that they as a patient are entitled to the “right to avoidance [of] suffering and pain.”<sup>54</sup> In general, rates of responding positively to knowing about different patients’ rights are low, with the highest positive response rate around 50 percent. Nonetheless, over 50 percent of respondents said that they do feel they are entitled to the “right of access to health care services.”<sup>55</sup> As knowledge about patients’ right to health care rises, it is crucial to educate the population on their rights to all kinds of care—including palliative care. Lack of knowledge about non-curative options may bias people towards wanting more intensive and costly health care services that do not meet their needs. More research must be conducted on these trends to make definitive claims.

- *Patients are often unaware of all treatment options and are even sometimes unaware of their diagnosis.*

A lack of clear and honest communication between doctors and patients, which is perpetuated on both the patient and doctor side, leads to patients lacking knowledge of treatment options and being unable to make informed decisions about palliative care. Nearly all health care practitioners explained that it goes against cultural customs to give patients an unfavorable diagnosis without consulting with the family first. In most cases, patients do not ever receive a terminal diagnosis from their doctor. As one doctor explained, “when a family member is ill, then the whole family is ill.” While the family provides an important source of support throughout an illness and particularly in end stages of an illness, families often ask doctors to withhold information from the patient regarding the seriousness of the illness or even the diagnosis itself. Many doctors also expressed discomfort with using open and honest communication when speaking with patients, with some expressing that they did not feel comfortable telling patients their diagnoses. All doctors noted the necessity of respecting the wishes of the family in how much information to share with the patient.

## Discussion

Public education and awareness are crucial to the successful functioning of palliative care systems. Palliative care does not fall under the umbrella of traditional curative care, and therefore may be unknown or misinterpreted by the public. Educating people about what palliative care is and what it aims to accomplish, as well as what palliative care is *not* is crucial to promoting its use when appropriate. It is also vital to educate patients on their rights regarding all forms of health care so that patients and their families can make informed decisions. Health

education campaigns in the past have been successful. A developing palliative care system would likely benefit from similar campaigns.

### Policy Options

#### *1. Invest in patient education regarding palliative care options*

When patients do not know about palliative care options, they are less likely to ask for palliative care and may be resistant to receiving this kind of care. Investing in patient education is an important element of ensuring that palliative care reaches all patients in need. There are many different methods for educational outreach, and a combination of different methods could be utilized to reach different kinds of patients. To best reach as many patients as possible, it is important to have information about palliative care in all locations where a patient might go to receive care or information on care.

One way to improve education is to work with NGOs and other groups who already provide education on palliative care. The MoH should consider supporting the work of these NGOs and contracting with them to run specific programs. The MoH can also consider working with NIPH Center on Aging to include palliative care in their outreach literature. Currently the NIPH Center on Aging provides patients and their families with literature on NCDs such as diabetes and hypertension, as well as healthy lifestyle advice. The NIPH would likely be able to reach much of the Kosovar population in need of palliative care since they already focus on aging issues. For example, an informative pamphlet on palliative care could successfully improve education without adding much cost.

The MoH should also encourage all health care providers to educate their patients about palliative care, and provider training should include equipping providers with the best information about how to refer patients for palliative care services, and the existence of palliative care programs in the country. One way to help providers in educating their patients would be to create an information sheet about palliative care to be displayed at health care centers, which providers could also hand out to their patients.

Lastly, the policy option that may be able to reach the greatest number of patients and families in need of palliative care is a website that consolidates all the information about access to palliative care in Kosovo in one place. A website or online portal with information about palliative care, end-of-life options, and commonly asked questions can reach a large number of patients and families in need at a relatively low cost. The Butterfly Project in Slovenia may serve as a useful model in creating such a website.<sup>56</sup>

#### *2. Promote communication about palliative care issues to reduce stigma for patients and their families*

Conversations about end-of-life issues as they pertain to palliative care are very difficult to approach, and often more difficult to approach when there are not appropriate spaces to have these conversations. In the stages of palliative care development where there are standalone inpatient palliative care centers, it will be important to create spaces for families to discuss common palliative care issues and spend time together in a comfortable setting. Though Smile International does not currently use their facility infrastructure for inpatient space, the model of bedrooms for care and lounges and other areas for people to spend time could work as a successful model for other inpatient palliative care centers.

## **5. INTEGRATE SOCIAL, EMOTIONAL, AND SPIRITUAL CARE**

The health infrastructure in Kosovo supports formal medical treatments for patients but is not directly involved in the types of social, emotional, and spiritual support that are integral to palliative care. When patients are receiving palliative care due to SHS, they are often in a great deal of distress. Providing social, emotional, and spiritual support for this distress can offer a great deal of comfort as well as allow patients to express their needs and priorities clearly.

Many palliative care programs globally include activities to address the concerns and priorities of a patient, as well as their spiritual needs. In some systems, emotional and spiritual support is provided largely through community and spiritual leaders outside of the palliative care setting, while in other systems this support is fully integrated into various components of care. Programs can also provide social and bereavement support by connecting the family to local resources to help ease the grieving process.

### Main Findings

- *Patients and providers express apprehension to institutionalized spirituality.*

After years under communist Yugoslav rule, the role of spirituality and religion has been minimized in public settings. Since health care has continued to be organized through the public sector, there is little to no presence of religious or spiritual leaders in hospitals. Interviews and conversations have suggested that patients may not include spiritual care along with medical treatments for a multitude of reasons. Primarily, many patients are unaware of their spiritual needs. In many palliative care or end-of-life situations, the physiological needs of the patients take priority. Without a model of integrating spiritual care, patients and their families are responsible for bringing in religious and spiritual leaders to guide them.

Another important issue for patients and their families is the idea that the integration of a spiritual or emotional support implies the impending death of a patient. As a theme that has come up throughout this section of the report, many patients are unaware of their current diagnosis and prognosis. This means that the integration of non-medical professionals such as chaplains or social workers could be confusing if not unwelcome by a patient who is under the assumption that they are receiving curative therapies.

- *Care at the end of life is not integrated with other actors outside of the health care workforce and is rarely delivered by a multidisciplinary team.*

Currently there is no model for integrated or multidisciplinary care in Kosovo. Most care pathways will only include care provided by doctors and nurses in traditional roles. Many providers are not aware of the benefits of multidisciplinary care for patients. While inter-professional education is included for some nurses in their educations, there is no complementary program for doctors in the Faculty of Medicine at the University of Pristina. There have been important discussions to add this type of training into the medical curriculum upon the next accreditation cycle for the Faculty of Medicine.

With the help of Accessible Quality Healthcare (AQH), an integrated care program is about to be piloted in the Fushe-Kosova municipality.<sup>57</sup> In this model, social workers employed by the municipality will accompany health care providers to visit elderly patients with diabetes and hypertension. The social workers will assess the socioeconomic needs of these patients to better connect them to resources that can support them along with their medical treatment. As the number of elderly patients with chronic and terminal illnesses increases, it will be important to monitor these initiatives and expand them if they are successful. Overall, the needs of patients go beyond medical treatments and a formalized integration of social and emotional care will be important for Kosovo in the future.

- *There are very few social workers and psychologists in health institutions.*

Because of the minimal focus on multidisciplinary care throughout the health care system, professionals trained to provide social, emotional, and spiritual care are sparse throughout the health system. According to facility level data from the NIPH, there are no psychologists and there is only one social worker employed at the regional hospital level. This is slightly supplemented by two psychologists and ten social workers at UCCK.<sup>58,59</sup> Without professionals competent in providing social and emotional support, integration of this type of care will be impossible.

The research team was unable to uncover the number of psychologists present at the family medicine level of care. Despite this, in conversations with certain FMCs, the research team can anecdotally project an increased need for mental health services. As the stigma surrounding mental health issues declines and palliative care becomes more integrated with other forms of medical care, psychologists will become increasingly important members of medical care teams.

### Discussion

Palliative care patients have needs that span far beyond medical treatments. Though pain and symptom management are top priorities, they must be complemented with emotional and social support for the patient and their family. In addition, the SHS of patients can leave them unable to perform their daily tasks in the way they could before their illness. Many can no longer work, or even leave their homes. In this case, family members must also forego their work opportunities to care for their loved ones. In a comprehensive palliative care program, these burdens can be alleviated by respite services and by social workers who offer connections to community resources.

Patients and family members may also experience grief in relation to receiving the diagnosis and prognosis of an illness. Without the inclusion of emotional or spiritual care, patients and their families may find it difficult to cope and may not be able to make the best possible decisions about medical treatments. The inclusion of psychologists or spiritual leaders in care would afford patients and their families the ability to regain autonomy in their decision making despite dealing with a terminal disease.

### Policy Options

#### *1. Develop integrated care guidelines for providers when dealing with palliative care patients*

Integrated care is an important part of any palliative care system, but providers who are accustomed to more traditional care models must be given the resources to learn when to employ integrated care practices. In addition, these providers would benefit from specific training programs that educate them on value of integrating social and emotional care with clinical care. Using the findings from the integrated care pilot in Fushe-Kosova, the MoH can examine the utility of including social workers in care, and determine which patients benefit most from this inclusion. The MoH could also developing guidelines for providers outlining the situations in which integrating social and emotional services would improve patient care. These guidelines would help providers holistically care for patients with multiple needs.

#### *2. Incorporate spiritual care into palliative care*

Spiritual care is an important part of palliative care at the end of life that is not currently incorporated into health care provision in Kosovo. This care can be integrated into formal health care provision gradually, accounting for patient preferences and provider competencies. This process can begin by connecting health care providers with spiritual leaders in their communities, building the formal groundwork that would allow connections between patients and spiritual leaders through health care providers. This process can be supplemented by educating health care providers on the importance of discussing and meeting the spiritual needs of their patients. In the future, chaplains and other non-denominational spiritual leaders can be formally employed by health care centers, allowing patients convenient and institutionalized access to spiritual leaders. To sensitively and effectively provide spiritual care to patients throughout Kosovo, accurate information is needed about patient preferences and views towards spiritual care in a medical setting. Collecting this information through formal surveys or other methods is a key step towards developing a suitable plan for integration of spiritual care.

#### *3. Educate all health care providers on multidisciplinary care at university level*

Currently there is a module on multidisciplinary care in the nursing school at the University of Pristina, but a multidisciplinary program will only be successful if it includes curriculum from and involves cooperation



between different departments. The Faculty of Medicine at the University of Pristina should foster the creation of an inter-departmental task force at UCK to develop a multidisciplinary care curriculum for all health care providers. This kind of curriculum should include information on why multidisciplinary care is important for patient-centered health care, as well as practical experience working in multidisciplinary teams to provide care, such as learning from a palliative care team that includes doctors, nurses, social workers, psychologists, and spiritual leaders.

## 5. DELIVERY FRAMEWORK

In order to create a comprehensive palliative care system, Kosovo must build capacity across each level of the health care system and make system-wide changes over time. In this section of the report, the research team outlines three stages of development. The first stage is defined by reallocating current resources and making crucial, system-wide changes to formalize palliative care provision across all levels of the health care system. The second stage is defined by capacity building activities, particularly focused on human resources and the beginning steps of integration of social and emotional care. The third stage is defined by implementing comprehensive, multidisciplinary care that reaches full need through the introduction of standalone inpatient centers in addition to further improvements at the other sites of care developed in stages 1 and 2. Overall, this framework provides a timeline for creating a palliative care system, with the ultimate goal of developing multidisciplinary, integrated, comprehensive care.

### **STAGE 1**

**Table 3: Stage 1 Development Goals**

Health System Level	Defining Characteristics
System-wide	<ol style="list-style-type: none"> <li>1 Electronic health record system tracks patient care across all levels of the health care system</li> <li>2 Population-level data is collected to properly assess the need for palliative care</li> <li>3 Palliative care responsibilities are formalized at all levels of the system</li> <li>4 Increased awareness of palliative care programs</li> <li>5 Basic pain management trainings for palliative care providers</li> <li>6 Revised ELMK that includes essential medicines for palliative care as defined by the Lancet Commission</li> <li>7 Increased access to essential medications for palliative care, specifically oral morphine</li> <li>8 Palliative care curriculum in working group at Faculty of Medicine</li> <li>9 Encourage patient consultation with spiritual leaders</li> <li>10 Pain management protocols for providers</li> </ol>
Primary Care	<ol style="list-style-type: none"> <li>1 Expanded home care services, still not 24-hour services</li> <li>2 Expanded training for family medicine specialists and nurses</li> <li>3 Connection of primary care providers with social and emotional care resources.</li> </ol>
Secondary Care	<ol style="list-style-type: none"> <li>1 Existing inpatient space repurposed as palliative care wards</li> <li>2 One doctor serves as Head of Palliative Care at each Regional Hospital</li> </ol>
Tertiary Care	<ol style="list-style-type: none"> <li>1 Strengthened downstream referral networks to palliative care providers and home care</li> <li>2 Stronger connection between palliative care providers and social workers</li> </ol>

In a Stage 1 palliative care system for Kosovo, existing infrastructure will be reallocated and existing health care providers will take on greater roles in order to expand palliative care services. Palliative care provision will be centered in home care teams based in FMCs and in dedicated sections of regional hospitals. There will be limited provision of palliative care at UCK in line with the current framework and capacities. Stage 1 is also characterized by system-wide improvements that will allow for the expansion of palliative care provision.

### Health System

At the system-wide level, a combination of minor adjustments to current policies and major investments in system-wide infrastructure will be needed to lay the groundwork for a high quality, efficient palliative care system. The largest investment in system-wide infrastructure will be the introduction of an electronic health record system. Though this improvement is not specific to the palliative care program, it would greatly support its development. For example, an EHR system would allow for detailed and accurate collection of death data, laying the groundwork for data collection to improve the palliative care system in Stage 2 and Stage 3. This is perhaps the largest undertaking in terms of the cost and time requirement, as the system needs to work well across levels, and providers need to be trained to properly utilize the system.

In terms of smaller policy adjustments at this stage, the MoH and other relevant stakeholders should work towards formalizing care responsibilities, improving access to essential medicines, and improving provider training. The MoH should begin by formalizing palliative care responsibilities at all levels of the health care system. Palliative care is currently legally the jurisdiction of primary care. However, it is also important to include palliative care provision as a legal responsibility of the secondary and tertiary levels. At this stage, the MoH should also prioritize adding all the essential medicines for palliative care as defined by the *Lancet Commission* to the ELMK. It is crucial for this to happen at Stage 1 because access to pain management is the most basic and perhaps most essential element of palliative care. If not all the essential medicines for palliative care can be added to the ELMK simultaneously, the MoH should place the highest priority on oral morphine for the reasons outlined in the “Key Opportunities” section of this report. The rest of the essential medicines can then be introduced in later phases. As these new medicines are added to the ELMK, the MoH will also need to consider which providers will have access to and be able to prescribe these medications. This decision-making process may require legislative changes.

Furthermore, providers should be trained in basic pain and symptom management through the continuing education programs affiliated with the accreditation process. The MoH should prioritize developing pain management protocols for providers to follow at all levels of the health care system. Along this same vein of improving provider training, the Faculty of Medicine should begin working on plans for a palliative care training program by creating a working group to begin crafting an education program. At this stage, though care may not yet be fully multidisciplinary, providers will be better trained in pain and symptom management and will be able to encourage their patients to consult with social workers, psychologists, and spiritual leaders, even if these personnel are not fully incorporated into palliative care teams. Though the system-wide policy changes outlined in this section may seem extensive, these are crucial steps the MoH should take to lay the groundwork for successful palliative care provision at all levels of the health care system.

### Primary Care

In Stage 1, palliative care provision at the primary level will be characterized by expanded care, though this care will still not be provided on a 24-hour basis. Patients will continue to receive home care services from home care teams that are based in the FMCs. Currently only Ferizaj and Štimlje have palliative-care-specific home care teams. While other municipalities have elements of palliative care included in home care for chronic diseases, all municipalities should be including some pain and symptom management services for patients receiving home care. Therefore, home care providers throughout Kosovo will need to have extended training in basic pain and symptom management. Additionally, these providers will need contact information for social workers, psychologists and religious leaders on hand, allowing them to informally connect palliative care patients with resources to address non-medical needs.

Patients in need of palliative care at this stage of development can seek care at FMCs and receive care at home for as long as necessary. This care available based on clinic hours, not around the clock. However, care will be delivered by a home care team that provides both palliative care and chronic care. These providers will have formalized knowledge of pain and symptom management and will be able to provide medicines for continuous pain management. Patients in need of social assistance, emotional support, or spiritual guidance will be connected to the appropriate resources.

### Secondary Care

In Stage 1 at the secondary level, all regional hospitals will dedicate beds to inpatient palliative care provision. Because of the new formalized palliative care provision mandates, regional hospitals will now be legally authorized to provide palliative care. The data on bed usage indicates that dedicating some beds to palliative care provision will not be overly burdensome for regional hospitals in this stage. At each regional hospital, one doctor will serve as Head of Palliative Care to coordinate doctors and nurses in providing palliative services. This doctor will likely be an internal medicine specialist who would shift his or her responsibilities to take on palliative care coordination as their main role.

Patients with more complex palliative care needs who cannot be treated exclusively at home will be referred to secondary care centers by family medicine providers when necessary. These secondary care centers will also treat patients who are referred from UCCK following treatment at the NIO or other clinic. These patients will receive their care from internal medicine doctors and nurses and receive a range of palliative care treatments, including more complex treatments such as fluid drains that are not available at the primary care level. These patients will be able to stay in the palliative care clinic in the regional hospital for as long as needed or will have the option to receive treatment and return home.

### Tertiary Care

In Stage 1, care at the tertiary level will not see any major changes in care provision or infrastructure. Patients will continue to go to UCCK for cancer treatments and may receive basic palliative care or palliative care consultation in the end stages of an illness. Tertiary level doctors will be trained in referring patients down to secondary and primary care levels for inpatient or home-based palliative care provision. These doctors will also receive training in having conversations with patients experiencing SHS and providing patients with non-curative care options.

Patients in need of palliative care at UCCK during Stage 1 will have a similar experience to current palliative care patients at the clinics but with increased emphasis on referral to secondary and primary care centers for patients who can be moved. For patients who are unable to return home or receive care in another setting, basic palliative care treatments and consulting services will be offered in available inpatient space. These patients will be able to receive a range of pain and symptom management treatments. Increased provider focus on conversations about end of life care will allow for more patient involvement in end of life care options.

## **STAGE 2**

**Table 4: Stage 2 Development Goals**

Health System Level	Defining Characteristics
System-Wide	<ol style="list-style-type: none"> <li>1 Increased palliative care trainings</li> <li>2 Public education campaign on palliative care</li> <li>3 Continuous access to essential medications</li> <li>4 Formalized palliative care pathways</li> <li>5 MoH starts initial plans for dedicated palliative care center</li> <li>6 Investment in palliative care specialty</li> </ol>
Primary Care	<ol style="list-style-type: none"> <li>1 Dedicated home care services expanded to provide 24-hour care</li> <li>2 Psychologists and social workers integrated into care</li> <li>3 Increased medical staff to provide continuous home care</li> </ol>
Secondary Care	<ol style="list-style-type: none"> <li>1 Psychologists and social workers employed and integrated into care</li> <li>2 Expanded dedicated inpatient palliative care space dependent on increased need</li> </ol>
Tertiary Care	<ol style="list-style-type: none"> <li>1 Psychologists and social workers employed and integrated into care</li> <li>2 Dedicated inpatient space to palliative care</li> <li>3 Chaplains employed at UCCK</li> </ol>

Stage 2 of development of a national palliative care program is characterized by capacity building, with increased infrastructure dedicated to palliative care, the beginning of multidisciplinary care, and increased training for palliative care providers. Palliative care in this stage is largely provided by 24-hour home care teams, dedicated palliative care units in regional hospitals, and the inpatient palliative care unit at UCCK. This stage involves investments in expanding palliative care infrastructure, hiring of new providers, and increased trainings that will lay the groundwork for future specialized care provision.

### Health System

At the system-wide level, the Stage 2 involves investment in provider trainings, public education, continuous access to medications, and formalized palliative care pathways, a dedicated palliative care center, and a palliative care specialty.

Increasing palliative care trainings for providers through continuing education opportunities supported by the MoH will arm providers with the necessary information to properly identify and treat palliative care patients. Provider education will be mirrored by public education so that patients and their families better understand palliative care and its benefits. This education campaign could take the form of an online portal, education materials at health care clinics, or encouraging health care providers to discuss palliative care options with their patients.

In this stage, MoH dedication to continuous access to the essential medicines is vital. This goal can be addressed through the creation of a working group to evaluate ways to improve the central procurement system and partnerships with NGOs. Formalized palliative care pathways, and provider education on these pathways, is another important characteristic of Stage 2 development. The creation of dedicated palliative care centers and pathways through which palliative care patients can reach them ensures patients have a place to go in the public health care system and are not passed on without care.

This stage is also characterized by investment in the future development of palliative care programs. Specifically, investment and initial planning for a dedicated palliative care center is a key component of this stage because the creation of a dedicated center requires an extended planning and funding period. This initial stage of planning will involve scouting possible locations for the dedicated clinic, as well as plans for staffing and funding the clinic in the long term. This stage also includes investment in a palliative care specialty, a complex development that takes years to achieve. Lastly, this stage will involve initial curriculum development for the specialty by connecting with palliative care providers in nearby countries and working with international groups to ensure the program will be accredited.

### Primary Care

At the primary care level, Stage 2 development of palliative care is characterized by the expansion of home care services to provide 24-hour care and the integration of social and emotional care.

The creation of 24-hour home care teams focused on palliative care will allow patients seeking palliative care at the primary level to receive comprehensive care around the clock at home. These teams will be staffed by doctors and nurses who operate outside of traditional clinic hours to deliver around-the-clock care to patients. This expansion will call for increased medical staff and greater investment in long acting, self-administered treatments for more continuous pain and symptom management.

Incorporation of social and emotional care at this level will involve the integration of existing social workers and psychologists into the home care teams as in system piloted in Fushe-Kosova. These social workers and psychologists do not need to be hired directly by FMCs for this service, but a formal partnership between social workers, psychologists, and the FMC is expected at this stage. Consequently, will be able to formally refer

patients to social workers, psychologists, and religious leaders who work with the FMC. As a result, patients and their families will no longer bear the burden of seeking additional support services.

### Secondary Care

In regional hospitals, Stage 2 development involves the expansion of existing services and integration of social and emotional care. Regional hospitals will expand their dedicated space for palliative care as needed based on utilization data. This expansion may require a concomitant increase in providers dedicated specifically to palliative care. With regards to the integration of social and emotional care, all regional hospitals will employ social workers and psychologists who will assist in palliative cases as necessary. It is important to note that the integration of these providers requires that they be involved in the entire course of treatment, not only a single evaluation.

Patients receiving palliative care in regional hospitals at this stage of development will receive care like that given to patients in Stage 1. They will receive care from internal medicine doctors in dedicated palliative care wards with more advanced pain and symptom management treatments than are available in primary care home visits. One important improvement to this care is the hiring of psychologists and social workers by regional hospitals that will allow for the formal integration of social and emotional care into palliative care in the inpatient clinics.

### Tertiary Care

At the tertiary level, Stage 2 development calls for the creation of a dedicated inpatient palliative care unit using current infrastructure, the integration of social and emotional care, and the employment of a chaplain. Rather than investing in new infrastructure, this step involves the repurposing of existing space to create a separate unit dedicated solely to inpatient palliative care. This inpatient unit will be staffed with internal medicine doctors and nurses with general experience in palliative care. Additional providers may need to be hired to prevent overburdening of existing providers at UCCK. The integration of social and emotional care can be achieved through hiring new social workers and psychologists or re-assigning existing social workers and psychologists to the palliative care unit. Finally, this stage calls for the employment of chaplains at UCCK. These chaplains should be able to provide non-denominational spiritual care to patients of all religions. The employment of chaplains at UCCK can serve as a pilot program for the institutionalization of spiritual care throughout the health care system in Kosovo.

Palliative care patients at UCCK will receive significantly improved care in the second stage of development. These patients will be cared for in a dedicated clinic and receive true multidisciplinary care with the integration of social workers and psychologists. Treatments in these clinics will be similar to the care offered in regional hospitals. All essential medicines for palliative care will be made available and patients will be able to receive more advanced pain and symptom management therapies than at the primary care level. The integration of religious care at UCCK will make this the first palliative care clinic in Kosovo where patients can receive integrated spiritual care, an important component in an advanced palliative care system.

## STAGE 3

**Table 5: Stage 3 Development Goals**

Health System Level	Defining Characteristics
System-Wide	<ol style="list-style-type: none"> <li>1 Creation of a palliative care specialty</li> <li>2 Adding medicines on the WHO Essential Medicines for Palliative Care List to the ELMK</li> <li>3 Incorporation of palliative care into the curriculum at the Faculty of Medicine</li> <li>4 Consideration of building hospice centers</li> <li>5 Official inclusion of social workers in palliative care teams</li> </ol>
Primary Care	<ol style="list-style-type: none"> <li>1 Home care teams providing 24-hour, multidisciplinary palliative care</li> <li>2 Inclusion of respite services for family members</li> </ol>
Secondary Care	<ol style="list-style-type: none"> <li>1 Creation of a palliative care department</li> <li>2 Dedicated palliative care team providing multidisciplinary care</li> </ol>
Tertiary Care	<ol style="list-style-type: none"> <li>1 Specialty palliative care center which provides pain and symptom management for complex cases</li> </ol>

Palliative care in Stage 3 can be described as a comprehensive palliative care program. In this stage, the health care system is well equipped to meet the palliative care needs of the country, and patients and providers are able to efficiently navigate the network of palliative care provision to determine the most appropriate location for care. For most patients, palliative care will be available in a 24-hour capacity with a multidisciplinary care team regarded as the norm in palliative care provision. Palliative care will also include specialist care for patients that require complex pain and symptom management.

### Health System

At the system-wide level, palliative care will be established as a specialty. Physicians will be able to train as palliative care specialists in an accredited program. In addition, palliative care will be incorporated into the standard medical education at the Faculty of Medicine as a standalone module with practical applications. Social workers and psychologists will have solidified, formalized roles on palliative care teams at all levels of the health system so that palliative care will be multidisciplinary nationwide. Drug access for patients will extend to all the essential medicines for palliative care defined by the WHO, but in cases where more specialized treatment is required, patients will have access to pain and symptom management treatments not included on the essential list of medicines for palliative care.

### Primary Care

In stage 3, palliative care at the primary level will still be carried out by a home care team, but this team will be equipped to meet the holistic needs of palliative care patients. There will be formal inclusion of psychologists and social workers on the mobile teams. Each municipality in this program will offer 24-hour mobile care with a complete assortment of the essential medicines for palliative care as defined by the *Lancet Commission*. An important addition to the home care services provided in Stage 3 is the inclusion of respite services for the caregivers of patients. In this kind of service, a health care provider will care for a patient for a given period,

allowing the caretakers to leave the home without worrying about the patient. Without the integration of services such as nursing homes, respite services will be very important in a Stage 3 program.

At the family medicine level, patients will continue to receive palliative care from dedicated teams, with an expanded range of treatment options as the national availability of pain and symptom management medications increases. Patients and their families will also be able to request respite services from FMCs, allowing the patient to be cared for by professionals while the family rests and takes time for themselves.

### Secondary Care

Secondary care in Stage 3 will see more specialization in the inpatient space already dedicated to palliative care delivery. There will be a palliative care specialist at every regional hospital along with a dedicated multidisciplinary palliative care team. The team will provide all aspects of palliative care in their clinic as well as consult with other patients in the hospital. The palliative care department will be increasingly formalized at the secondary care level and will recruit and train physicians just as regional hospitals do for other specialties.

Patients receiving palliative care at regional hospitals at this stage of development will be cared for by a dedicated team with specialized training, allowing for specific and advanced treatments that are outside of the basic essential package for palliative care. These patients will have easy access to social and emotional care, as social workers and psychologists will be part of the palliative care team. Palliative care will also be made available to other patients in the hospital who may still be receiving curative care or who do not have needs complex enough to warrant inpatient care.

### Tertiary Care

The tertiary level for palliative care at this stage will include dedicated infrastructure aimed at delivering holistic palliative care. This space will be dedicated to the most complex palliative care cases and will also address the social, emotional, and spiritual needs of patients and their families. These spaces should be designed in such a way that patients and their families can socialize without the feeling of being in a health institution.

Patients seeking palliative care at the tertiary care level in the final stage of development will receive high level palliative care from specialists and multidisciplinary teams in a standalone facility designed for palliative care delivery. These patients will have access to a range of treatments, and their care will incorporate social, emotional, and spiritual health in addition to physical needs. Spaces for families to discuss their needs and experiences will also be provided in this stage, allowing for open discussion of palliative care issues.

## 6. CONCLUSION

While spending ten weeks researching palliative care at Dartmouth and ten weeks conducting field research in Kosovo, the Dartmouth team examined palliative care delivery at each level of the health care system in Kosovo and identified opportunities for improvement. Six primary areas of focus emerged from this research: system-wide opportunities; continuity of care for pain and symptom management; access to the essential medicines for palliative care; human resource capacities and competencies; health education and health literacy; and the integration of social, emotional, and spiritual care. To address these six areas of focus, the team developed policy recommendations and a three-stage, conceptual service delivery framework for a national palliative care program. With the support of key stakeholders such as the NBCC, Kosovo has the opportunity to create a national palliative care program in the coming years based on the recommendations and framework outlined in this report.



# APPENDICES

## APPENDIX A: CASE STUDIES OF PALLIATIVE CARE IN THE BALKANS

### Albania

#### *Current Delivery of Palliative Care*

Palliative care in Albania is currently provided by a mix of public providers and NGOs such as Caritas Albania and Ryder Association Albania. In the public health care system, palliative care is provided through dedicated centers at regional hospitals. Teams of palliative care doctors based at these hospitals provide home visits to patients in the surrounding areas.<sup>60</sup> These teams are composed of two full time nurses, one part time physician, and one part time social worker.<sup>61</sup> In hospitals, the palliative care clinics provide day services to patients. In Albania, 80 percent of essential medicines for palliative care as defined by the WHO are available, and 50 percent are paid for by the public health care system.<sup>62</sup> Palliative care providers are primarily trained by NGOs, including Mary Potter and Ryder Association Albania, but international training modules have been translated into Albanian and are available throughout the country.<sup>63</sup> Palliative care modules have been integrated into the standard medical education for both doctors and nurses, but residencies still do not incorporate palliative care trainings. The development of a palliative care specialty is currently taking place but has not yet been implemented. Albania has effectively expanded and improved palliative care in the country in the past five years, and expanded trainings and clinics will continue to improve access and quality of care in the country.

#### *History of Palliative Care*

Palliative care in Albania began in 1993 with the introduction of a team of two palliative care doctors and one nurse by Ryder Association Albania.<sup>64</sup> In the following years, other NGOs, including Mary Potter and Caritas Albania, became involved in the country as well. Government involvement with palliative care delivery in Albania has been primarily driven by the burden of cancer in the country, particularly the high mortality rates of many cancers. This led to the first public palliative care program in 2001 where a small home care team linked to the national oncology institute served patients with terminal cancers around Tirana.<sup>65</sup> The creation of a national palliative care system became part of the national health strategy in 2011 with the signing of the National Cancer Control Plan proposed by the National Committee for Cancer Control. This comprehensive plan included a national palliative care program in order to treat patients without curative options.<sup>66</sup> In 2014, the national law on palliative care was signed which states that palliative care is a basic human right and seeks to expand access to palliative care throughout the country.<sup>67</sup> Public provision of palliative care is delivered through hospital-based home care teams, with funding from the national health care system to expand to all regional hospitals in the country.

### Croatia

#### *Current Delivery of Palliative Care*

Until 2010, all palliative care in Croatia was provided by NGOs. Upon creation of the Strategic Plan for Palliative Care, the formal palliative care pathway was defined. This meant more outlets of palliative care were created at every level of the health system. At the primary level, ten of Croatia's 21 counties have palliative home care teams. Home care is provided by family medicine physicians and community nurses. Increased home care was accompanied by extended non-medical palliative care provided by social services, NGOs and religious communities. Hospitals also increased their palliative care provision such that roughly 1 percent of beds were repurposed for palliative care. Thirty-one hospital-based clinics have been established in 19 counties containing a total of 206 beds. There is one standalone hospice center in Rijeka with 14 inpatient beds. The pathway of a patient receiving palliative care has become much more streamlined because of investment in care coordination. When a patient presents at a hospital or at the primary care level with palliative care needs, the patient will be

directed to the county coordination center for palliative care. As of 2016, only five counties in Croatia have these centers. The goal of these centers is to send patients to all three levels of the health care system based on their current needs.<sup>68</sup>

### *History of Palliative Care*

Palliative care delivery in Croatia was initiated in 1994 with the Croatian Society for Hospice. This program began a trend of palliative care provision through NGOs in Croatia. This system of “islands” of palliative care provided by NGOs was continued until 2010, when public action was taken and the Center for Palliative Medicine, Medical Ethics, and Communication Skills (CEPAMET) was founded. CEPAMET is centered in the School of Medicine at the University in Zagreb and it leads research and education in palliative care in Croatia.<sup>69</sup> In 2012, the Croatian Ministry of Health formed the National Committee for Palliative Care. The following year, the government adopted a Strategic Plan for Palliative Medicine for 2014-2016. This plan drew upon the palliative care systems of Poland and Bosnia and Herzegovina as well as standards based on UK practices.<sup>70</sup> It is important to note that Croatia modeled its palliative care system on Poland’s due to their shared Catholic heritages. Since then, pilot palliative care projects have been implemented throughout Croatia, including mobile care teams, a hospice unit, and the creation of palliative care wards in several hospitals. Education campaigns through CEPAMET are accompanying this expansion to ensure provider competencies meet the need of palliative care patients.<sup>71</sup>

## Slovenia

### *Current Delivery of Palliative Care*

The Slovenian palliative care system is relatively advanced compared to other Balkan countries, with palliative care integrated through all levels of the health care system. There are dedicated units in tertiary hospitals, consultation units in regional hospitals, and a primary care palliative care network in progress.

Some sites of care are more advanced than others. For example, the palliative care offered at palliative care departments in oncology centers, such as the one in Ljubljana, are known to offer the most advanced palliative care, which is consistent with the fact that 99 percent of patients receiving palliative care services in Slovenia were cancer patients as of 2005.<sup>72</sup> Though palliative care has expanded to patients with other terminal illnesses, cancer patients remain the majority of palliative care patients.

Slovenia has palliative care training opportunities for students at two medical schools, as well as a 60-hour course in palliative care.<sup>73</sup> In a more recent development, students can now study palliative care at the National Society for Palliative Care, but because comprehensive training in country is such a recent development, many of the providers currently involved with palliative care provision received their training outside of Slovenia. Slovenia has a relatively large capacity for palliative care research in country, with multiple research centers dedicated to examining aging and end of life care provision.<sup>74</sup> The Slovenian palliative care system is also relatively advanced in access to the essential medicines, with no major issues in access to all the essential palliative care medicines. Slovenia has benefitted from public awareness campaigns that have increased patient knowledge about palliative care options and made patients and their families more likely to request palliative care services. In 2014, “The Butterfly Project” published a website that provides patients and their families with information about palliative care in their national language, Slovene.<sup>75</sup>

### *History of Palliative Care*

This system, like many others, emerged through a hospice movement with government support and involvement beginning in 1998. The Slovenian palliative care system has developed through the work of both NGOs and the Ministry of Health, though the work of NGOs was crucial in making palliative care provision a national policy priority.<sup>76</sup> In 1995, an NGO called the Slovenian Hospice Association began providing some hospice care and some palliative care education and started spreading awareness about the importance of palliative care in

Slovenia through this education for patients and their families.<sup>77</sup> The Slovenian government formally recognized the work of this NGO in 1998 and officially became involved in care in 1999 when it published national guidelines for pain management and facilitated the translation of relevant WHO documents on palliative care and pain management into Slovene.<sup>78</sup> Another NGO, the Palliative Care Development Institute, was also crucial in continuing the development of education and research and higher level policy planning in conjunction with the Ministry of Health of Slovenia.<sup>79</sup> This NGO support of palliative care was an essential part of bringing palliative care to the forefront of policy goals in Slovenia. In 2004, the first hospital palliative care ward opened at the general hospital in Golnik, with four beds dedicated to palliative care, and the capacity for palliative care provision has grown ever since. Slovenia's current National Palliative Care Program was confirmed by parliament in 2016 and lays the groundwork for an integrated and comprehensive national system.<sup>80</sup>

**APPENDIX B: TABLE OF THE DEVELOPMENT OF COMPONENT PARTS FOR PALLIATIVE CARE PROVISION**

<b>Degree of Development</b>	<b>Low</b>	<b>Mid</b>	<b>High</b>
Pain Relief	Very restricted opioid pain relief, basic symptom management. Medication based treatments, with access to opioid pain relief restricted to inpatient settings and IV forms, provided at the community level. <sup>81</sup>	Limited opioid pain relief, some symptom management, larger range of available medications, with increased access to opioids. More access to symptom limiting equipment. Provision through regional centers and specifically trained doctors. <sup>82</sup> A range of medications and treatments are provided through community-based centers, with an emphasis on community health volunteers. Opioid analgesics are available but restricted and are prescribed by trained doctors. <sup>83</sup>	Opioid and non-opioid pain relief, full range of symptom management, all medication options are available, including restricted opioids. Symptom management is fully available in an inpatient setting with trained doctors and nurses. Medications and treatment are provided by a dedicated team.
Emotional and Spiritual Support	Little formal support. Doctors and nurses have little professional training to address emotional and spiritual issues, and these are largely addressed at the community level. <sup>84</sup> .	Some professional support. Referral to outside spiritual leaders. Doctors and nurses have formal training to discuss emotional and spiritual issues. They are able to refer patients to outside resources unconnected to the palliative care setting.	Professional emotional support, dedicated and varied spiritual support. Doctors and nurses are trained to have discussions about the end of life, and palliative care teams contain an interfaith chaplain to discuss spiritual concerns, with specific spiritual leaders brought in when needed.
Social and Bereavement Support	Limited or no social support. Emotional support is limited and provided largely by the community.	Some social and bereavement support, but not necessarily integrated with other components of palliative care. Little use of individual case management or holistic palliative care teams.	Individual case management. High level of bereavement support. Dedicated social workers on palliative care teams take on each case and connect families to all available resources. <sup>85</sup> Bereavement support is provided in a graded model based on need, with individuals experiencing more grief given more care at higher levels in the health care system. <sup>86,87</sup>

## APPENDIX C: HOSPITAL LEVEL DATA

Hospital Capacity and Staff Data							
Facility	Beds	Total Doctors	Total Nurses	Psychologists	Social Workers	Patient Admissions	Bed Utilization (%)
Ferizaj	78	25	55	0	0	3,281	39.4
Gjakove	426	49	221	0	1	15,771	47.7
Gjilan	374	93	154	0	0	12,287	46.8
Mitrovice	148	41	127	0	0	6,224	45.3
Peja	396	64	131	0	0	15,538	56.2
Prizren	509	115	164	0	0	23,383	57.9
Vushtrri	57	18	56	0	0	4,111	79.4
UCCK	1864	703	1119	2	10	97,171	53
Total	3852	1108	2027	2	11	177,766	74.4

## APPENDIX D: LINKS FOR FURTHER INFORMATION

- PHA Guidelines for Pain and Symptom Management
- Slovenia Butterfly Project: <http://www.paliativnaoskrba.si/>
- Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: The Lancet Commission report. [https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)32513-8.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)32513-8.pdf)
- Essential Medicines in Palliative Care - World Health Organization: [http://www.who.int/selection\\_medicines/committees/expert/19/applications/PalliativeCare\\_8\\_A\\_R.pdf](http://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf)

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