

# Social diversity and access to palliative care for minority groups

## Abstract

**Introduction:** Palliative care is an approach in medicine that specifically addresses the needs of a patient with an incurable, progressive and life-limiting disease, as well as his proxies. It does not focus only to end-of-life care but provides possibilities of living a quality life with such a disease. Key demographic characteristics of the population that have been identified as influencing the need for palliative care are age, gender, ethnicity/religion, socioeconomic status and household composition.

**Methods:** Qualitative data were collected, using structured and semi structured interviews. Ten patients and their proxies were included in the study. Major points of palliative care were addressed. Descriptive statistics was used to analyse the collected data.

**Results:** Understanding the scope of palliative care, language barrier, resistance to using morphine and not identified differences at the end-of-life are the major obstacles, identified by all included patients.

**Conclusion:** Access to good palliative care should be made available to all patients having a palliative disease. Home setting, when possible, is a better choice for respecting cultural and ethnical differences.

## 1. Introduction

The increased prevalence of chronic illnesses in ageing population has led to an increasing proportion of people needing palliative care globally.<sup>1</sup> World Health Organisation called to incorporate palliative care

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<sup>1</sup> Simon N. Etkind, Anne E. Bone, Barbara Gomes, Natasha Lovell, Catherine J. Evans, Irene J. Higginson, Fiona M. Murtagh: How many people will need palliative care in 2040? Past trends, future projections and implications for service. In: *BMC Medicine* 15 (2017), pp 102–110.

in the health care system of member countries.<sup>2</sup> Even though access to palliative care is considered a human right in many countries, the percentage of people who actually do receive it, is considerably low, 14 %.<sup>3</sup> Palliative care is an approach that is focused on the patient and his needs, the major end-points being the quality of life and relief of symptoms. Individual needs of the patients constitute a framework in which palliative care is delivered to them. It should cover the physical, psychological, spiritual and social needs. General or basic palliative care is frequently delivered by non-specialists in a primary or secondary setting. Specialist multidisciplinary teams deliver care for more complex needs in a variety of settings and can also provide more straightforward end-of-life care.<sup>4</sup>

Palliative care covers the principle of total body assessment, developed by Dame Cicely Saunders. It also includes the proxies and extends into the phase of bereavement. Due to proper symptom control and good social support it enables good quality of life in spite of the presence of incurable disease.

There have been many factors identified to influence the need for palliative care: age, gender, ethnicity/religion, socioeconomic status and household composition from the patients' perspectives. Therefore, »(...) also healthcare providers sometimes find it challenging to address the palliative care needs of patients from different ethnocultural groups.«<sup>5</sup>

Health access and quality of treatment are not equal for racial and ethnic minorities. Approximately 20 % of older adults belong to racial or ethnic minority. There is growing evidence that disparities exist also in access to palliative care. The rate of usage of the palliative care structures such as hospices, home-care services or inpatients pal-

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<sup>2</sup> World Health Organization: Strengthening of palliative care as a component of comprehensive care throughout the life course. Report by the Secretariat A67/31. World Health Assembly, 67 (4.4.2014). <https://apps.who.int/iris/handle/10665/158962> (accessed 22. 12. 2020).

<sup>3</sup> World Health Organization: Palliative care. Fact sheets (5.8.2020). <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (accessed 1. 12. 2020).

<sup>4</sup> Etkind, Bone, Gomes, Lovell, Evans, Higginson, Murtagh: How many people (Note 1).

<sup>5</sup> David Busolo, Roberta Woodgate: Palliative care experiences of adult cancer patients from ethnocultural groups: a qualitative systematic review protocol. In: JBI Database of Systematic Reviews and Implementation Reports 13 (2015), pp. 99–111.

liative care consultations is consistently reported as lower in comparison to non-minorities.<sup>6</sup>

In Slovenia the Ministry of Health approached towards the organisation of palliative care by providing a national plan of palliative care development. According to the plan palliative care structures should be organised at each level of health system. As for all other healthcare services there is a two-level approach: basic palliative care, provided by non – specialists at all levels and specialized palliative care, provided by specially trained medical staff at secondary and tertiary level. There is possibility of referral at any stage of the disease, whenever the symptom control is more difficult, the social situation more complex or the spiritual and psychological issues more demanding. There is also a possibility to extend the specialized services into the community by mobile palliative care units.

After the first Action Plan in 2010–2016 many small steps have been taken but in general the major obstacle, identified by medical workers, which inhibits the proper development of palliative care in Slovenia, is the lack of interest in further education. Although there has been a possibility to expand knowledge by attending the 60 hours' postgraduate course in the skills of palliative care from 2011, only around 600 participants attended the course, with less than 10 % of all the licensed doctors in Slovenia. Ministry of Health therefore approved funds to include the 60 hours' course as a compulsory course in all clinical specialisations.

According to the collected data, there has been some organised palliative care in almost every Slovenian hospital but most of the structures are run, not by whole teams, but by enthusiastic individuals.<sup>7</sup>

In Gorenjska, one region in Slovenia, there has been the only one mobile palliative care unit in Slovenia, operating from 2011. It bridges the gap between hospital and home care. It is well known that the majority of patients prefer to die in their usual place of care. The mobile palliative care unit helps to fulfil such wishes. The num-

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<sup>6</sup> Kimberly S. Johnson: Racial and Ethnic Disparities in Palliative Care. In: *Journal of Palliative Medicine* 16 (2013), pp. 1329–1332.

<sup>7</sup> Državni program razvoja paliativne oskrbe [National Palliative Care Development Program] (2010). <https://www.gov.si/assets/Ministrstva/MZ/DOKUMENTI/pomembni-dokumenti/47cbef2cb3/Drzavni-program-paliativne-oskrbe.pdf> (accessed 29. 9. 2020); Slovensko Združenje Paliativne Medicine: Projekt Metulj [Butterfly Project]. <http://www.paliativnaoskrba.si/o-projektu.html> (accessed 29. 9. 2020).

ber of patients, included, has been steadily on rise; from 110 in 2011 to 650 in 2019.<sup>8</sup>

In Slovenia, immense efforts have been made to bring the idea of good palliative care into practice. Not much research has been done so far. Due to the lack of general understanding of the benefits of palliative care, not much attention could be paid to the ethnic and cultural differences of patients, widening the gap in the perception of palliative care as a useful approach for many patients. In Slovenia, there are around 83 % people of Slovenian nationality, there are more than 1 % of Bosnians, Croats and Serbs, around 8 % of people did not want to declare their ethnical or national origin.<sup>9</sup> Gorenjska is also a region with cultural and ethnical diversity. The longer tradition of delivering palliative care has made it possible to explore the possible differences between the ethnic and cultural groups. The major aspects of good palliative care were addressed and the differences in views noted.

## 2. Methods

Data were collected from patients and their proxies involved in palliative care through the mobile palliative care unit. Structured and semi-structured interviews were used to gain a better understanding of the palliative care experiences of patients and their proxies from different ethnic groups. »Ethnicity has been defined as distinctive shared origins or social backgrounds and traditions of a group of people that are maintained between generations and bring about a sense of identity that may encompass a common language and religion.«<sup>10</sup>

10 participants were included: five patients and five, by them identified, most important proxies: 3 Bosnian, one Croat, one Slovenian. Interviews were conducted at their homes during routine home visit. Three visits were analysed: first visit, second visit after two

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<sup>8</sup> Mateja Lopuh: Mobilna palliativna enota – vidik državne koordinacije [Mobile palliative unit – an aspect of state coordination]. In: 42. Srečanje Timov Družinske Medicine. Zbornik predavanj. Ljubljana 2016.

<sup>9</sup> European Commission: Slovenia: Prebivalstvo, demografsko stanje in jeziki. [Slovenia: Population, Demographic Situation, Languages and Religions]. [https://eacea.europa.eu/national-policies/eurydice/content/population-demographic-situation-languages-and-religions-77\\_sl](https://eacea.europa.eu/national-policies/eurydice/content/population-demographic-situation-languages-and-religions-77_sl) (accessed 29. 9. 2020).

<sup>10</sup> Busolo, Woodgate: Palliative care experiences (Note 5).

weeks and last one before death. There should not be more than a week between the last visit and patient's death.

Some of the questions are regularly asked at scheduled visits: at first visit: the reason for referral to mobile palliative care unit assessment and quality of symptom control, using the Edmonton Symptom Assessments Scale (ESAS), proposed medication plan, special care needs. The consent to be cared at home has to be given at the first visit, possible exceptions have to be listed in the care plan. According to the course of the disease further topics are brought into discussion: preferred place of death, advanced care, funeral arrangements.

The questions were formulated such as: can you tell me, who referred you to mobile palliative care unit, why were you referred, etc. Sub questions could be used to further explain the answers given. Patients were made familiar with the use of ESAS.<sup>11</sup> It was required to fulfil the ESAS at every visit. The answers were noted in the plan of care immediately after the home visit. Plan of care is a part of patient's medical records, therefore no authorised person can access the data. The data were not collected specifically for this study; they are routinely collected by every patient. For this study, data from the included patients in the last month were chosen (May 2020).

### 3. Results

Among the included were five patients: two were men, three were female. Both men were taken care by their spouses, two females by their sons and by her spouse. All patients were diagnosed with advanced cancer; at the time of referral the disease has advanced to late stage with no specific treatment as an option available any longer. At the first home visit both were present: the patient and the proxy. The consent for home care was given. At that time no participant declared any barriers.

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<sup>11</sup> Cancer Care South East: Edmonton Symptom Assessment System (ESAS). <http://cancercaresoutheast.ca/edmonton-symptom-assessment-system-esas> (accessed 29.9.2020).

### 3.1 *Symptom control*

Patients reported their scores on symptom control scale. Typically, all women proxies scored higher than men. In the sense of symptom medication, all five patients were reluctant to take morphine, but not other opioids. The Bosnians stated that they were afraid to take it because the religion prohibits them to use addictive substances, the other two connected morphine with approaching end of life and were afraid to use, all believed in the possibility that morphine can hasten death. Only after explanation that morphine is the weakest drug of all opioid, they agreed to use it. No other drugs caused disagreement.

From proxies' view morphine was considered as the drug that may cause death. All were afraid that they might be accused of causing death although they understood that in the suggested dosage no such effect can be caused. With advanced symptom control in two of the patients, the subcutaneous pump was suggested to provide continuous infusion of drugs. It was considered a relief for proxies as they were not forced to administer that much medication anymore. In the course of the disease, every decline in patient status such are cognitive impairment or loss of appetite or constipation or vomiting were first attributed to prescribed drugs. Even after explanation that it is the disease not the medication that causes this decline, the Bosnian participants could not accept it. Other participants accepted this information.

»Now you give me morphine, so I am about to die.«

»Is it so far?«

»With morphine I will only sleep.«

»I believe he is like that because of all the medication.«

»I know that he has to die. But do not kill him.«

### 3.2 *Referral to palliative care*

All patients were included by the treating specialist from our Oncology Institute in Ljubljana. They perceived this referral as the end point of their life. The Bosnian patients were very disappointed that the oncologist gave up and two of them sought second opinion. Their proxies included family members from abroad to provide additional

aid. They felt that it was because of their nationality and poor language communication that it was not worth attempting further treatment. No one understood at first what is the aim of palliative care. The Bosnian and the Croat patients identified the language barrier when discussing the treatment option – no interpreter was offered to them and they felt they were missing something. The language barrier was exposed although all people have been living for more than 10 years in Slovenia.

The fear not to understand properly became important when more medication was included and this insecurity was a reason to ask for hospital admission when the disease advanced.

»I am so sad that the doctors gave up on me.«

»I believe they send me home to die.«

»Palliative care is only about dying.«

»Because I am just a worker they gave up. If I were more important, they would still find something.«

»They told me something about you but I could not understand.«

»You can come but leave me alone.«

### 3.3 *Preferred place of care/death*

All participants were willing to be cared for at home, they would often repeat they had enough of hospitals. All proxies were prepared for the care, men more often asked for support in nursing care. Only Slovenian patient considered transfer to a nursing home as a possibility, such transfer was not an option for Bosnian and Croat patients.

Except for Slovenian patient, the other four would like to die in the native land but were afraid to move there because of possible lack of medical support. They considered the level of medical help much more reliable in Slovenia.

The proxies were all reluctant to talk about death at the beginning, they all expressed doubts about their capability of care at the second visit. They were all offered additional help with a certified nurse, which was accepted only by Slovenian patient. Other families considered such help as an additional intrusion.

»I do not want to go to the hospital anymore. I always had to wait for such a long time. There were so many people in the examination room. I could not hear properly.«

»When I called for information, the doctor always spoke so quickly, that I could not understand. I was afraid, I was always missing something.«

»I have a house in Bosnia. I built it with my hands. I shall never see it again.«

»I have good friends here but my real people are in Bosnia. They know me and they will bury me according to our tradition.«

»I do not know if he will listen to me and take the drugs properly. He accuses me of poisoning him.«

»She is my wife; I will not allow any men touch her naked.«

### 3.4 *Advanced care planning*

None of the participants was willing to make an advanced care plan. They only wanted to discuss things in a timely manner. They were all afraid of planning ahead as the situation might change to better and they would lose some possibilities.

»If I plan ahead and decide I do not want CPR and then I get hit by the car, would they not do it?«

### 3.5 *Care of the body after death, funeral arrangements*

Patients and their proxies were routinely asked about their wishes for funeral arrangements. Bosnian patients were afraid that autopsies would be performed. Very often it was mentioned that no respect was given to their traditional values at the hospital: undressing, toilet arrangements, praying possibilities. They were happy to be at home, so that they could follow their cultural aspects.

Spiritual part was poorly addressed. Although our service has no language barrier, it still lacks the knowledge about differences in perceiving death. It was suggested to include support from their own spiritual groups.



- »Do you have to perform an autopsy? That will kill the soul.«
- »Nobody ever asked me about myself. I could tell them what kind of person I was.«
- »She wants to be buried in our way, dressed in a long dress.«
- »Will you take away all the needles, so that she be again normal?«

#### 4. Discussion

In Slovenia a lot of efforts have been put in the last 10 years in introducing the palliative care in the health system. Some of the options that such care enables: being at home, home visits by mobile palliative care unit, patient-centred care, including proxies, respecting values, dignity are so completely different and so new that more time is needed to make them acceptable and recognized by all stakeholders. With this struggle to make palliative care properly set in the health system, the needs of minorities tend to be overlooked.

Our study is a very small study but one of the first to expose the problem of cultural and ethnical diversity in Slovenia in palliative care. In Gorenjska region there is a big social diversity that will enable future research work in this field.

Although it is well documented that palliative care brings benefits in quality of life, there are still many obstacles to its utilisation. As McAteer and Wellbery state, there is still a confusion about terminology, misperception about the intent and scope (only for terminal stage), that it can be administered only in centres or hospices rather than at home, fear that palliative care will deny the patient's life prolonging therapy. Many physicians are unfamiliar with disease development, prognostic indicator tools, and symptom control guidelines.<sup>12</sup> It is assumed that the concept of palliative care can be interpreted as desired. It has been suggested that palliative care should be incorporated into standard of care. The following strategies have been proposed: stating the prognosis at the first visit, appointing someone to ensure that advance directives are discussed, offering to discuss prognosis, coping strategies and goals of care at each transition.<sup>13</sup>

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<sup>12</sup> Rebecca McAteer, Caroline Wellbery: Palliative Care: Benefits, Barriers, and Best Practices. In: American Family Physician 88 (2013), pp. 807–813.

<sup>13</sup> McAteer, Wellbery: Palliative Care (Note 3).

In pursuing such a model, one should always keep in mind that the model is suitable for the majority but can have a great negative impact on minorities. Therefore, efforts must be made to conduct more studies on the topic and to encourage minorities to participate in such studies. Proper education of all stakeholders will promote the benefits of palliative care. Home based palliative care is a concept that follows the patients' wishes to be cared for and to die at home. Such care is associated with improved patients and family outcome, reduction in symptom burden and a more positive, satisfying experience.<sup>14</sup>

Special attention should be paid to the last days of life. The term end-of-life (EoL) does not have a proper definition yet. It may be referred to the very last days (one week to 10 days) before death or it can be understood even broader than palliative care itself.<sup>15</sup>

The study, published by Lan Fang et al., supports the findings in our study, considering the culturally and spiritually diverse groups. They performed a scoping interview and thematic analysis of article contents in 14 electronic databases. The search identified eight themes that need to be addressed: need for culturally and spiritually sensitive palliative care, impact of spiritual support on quality of life of terminally ill people, role of families in EoL decision making, EoL preferences by ethnicity and gender, diverse needs of hospitalized patients and applications for clinical practice, cultural competence and providers' values impacting healthcare decision making, interventions to inform and facilitate culturally sensitive EoL care.<sup>16</sup>

The influence of religious values and principles is found on both sides: health care providers and individuals approaching EoL. In our study, two spiritually different groups are included: Muslims and Catholics. Catholic is the main religion in Slovenia. Muslims are well connected in Jesenice and have good support among them, but

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<sup>14</sup> Barbara Gomes, Natalia Calanzani, Vito Curiale, Paul McCrone, Irene J. Higginson: Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. In: *The Cochrane Database of Systematic Reviews* 6 (2013), pp. 1–279.

<sup>15</sup> David Hui, Zohra Nooruddin, Neha Didwaniya, Rony Dev, Maxine De La Cruz, Sun Hyun Kim, Jung Hye Kwon, Christiana Liem, Eduardo Bruera: Concepts and Definitions for »Actively Dying«, »End of Life«, »Terminally Ill«, »Terminal Care«, and »Transition of Care«: A Systematic Review. In: *Journal of Pain Symptom Management* 47 (2014), pp. 77–89.

<sup>16</sup> Mei Lan Fang, Sixsmith Judith, Sinclair Shane, Horst Glen: A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping interview. In: *BMC Geriatrics* 16 (2016), <https://doi.org/10.1186/s12877-016-0282-6>.

somehow they do not trust or open up to people who do not belong to their religion.

This was also confirmed in a study by Gustafson and Lazeby. Many needs at the Eol of Muslim people are not properly addressed and remain unmet.<sup>17</sup> It is feared by some patients that the symptoms of advanced disease cannot be properly controlled. In the literature there is no such evidence. Having in mind patients' desire to be informed about the medication, the dosing schedule, the anticipated side effects, this allows the patient and his proxy to control the symptom in the most personal way: by the clock and on demand. One has to have in mind that proxies need to learn a lot about the drugs and the dosing intervals and the expected effects in a short period of time. Therefore, it is good to have some written material available. The proxy also takes the responsibility for administering the drugs.<sup>18</sup> In Slovenia there is no such authorisation for the proxies yet. It would though be good to have a document with which the proxies would be authorised to administer drugs by doctors' orders. Proxies play an important role in the care of the patient. They often are too protective, their stories intensify the symptoms, as seen in our Bosnian patients, or diminish them in order to present the patient in a better way.

Many physicians are reluctant to talk about the end of life. They fear that such conversations might deprive the patient of hope.<sup>19</sup> It is often considered one of the goals to discuss with the patient the end of life. One has to have in mind that the patient might not be willing to participate in such conversations. It is surprising that the conversation about funeral arrangement might be better accepted than the one about the end of life.

Providers of palliative care should have some insight in the ethno cultural specifics of their patients. Language barriers should not exist, interpreters should be used more often, especially when important topics are discussed. »When ethnocultural knowledge is lacking,

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<sup>17</sup> Carolina Gustafson, Mark Lazenby: Assessing the Unique Experiences and Needs of Muslim Oncology Patients Receiving Palliative and End-of-Life Care: An Integrative Review. In: *Journal of Palliative Care* 34 (2019), pp. 52–61.

<sup>18</sup> Eleanor Wilsonß\_bau4\_bß, Glenys Caswell, Nicola Turner, Kristian Pollock: Managing Medicines for Patients Dying at Home: A Review of Family Caregivers' Experiences. In: *Journal of Pain Symptoms Management* 56 (2018), pp. 962–974.

<sup>19</sup> Sarah Brown: Why many doctors still find it difficult to talk about dying with patients. In: *Canadian Medical Association Journal* 191 (2019), <https://doi.org/10.1503/cmaj.109-5691>.

healthcare providers, especially those with minimal training on ethnocultural issues, may provide unsatisfactory palliative care.«<sup>20</sup>

In Gorenjska, there are strong ethnical society which advocate differences in needs. Sometimes their representatives are summoned to help with difficult issues. Several meetings have already been organised to help them understand the principles and the scope of palliative care.

As stated above our study is far too small to provide any concluding evidence. It is an observation of difference between ethnic groups that could have an impact on providing palliative care if not taken into consideration. A bigger study in all parts of Slovenia should be performed in the future.

## 5. Conclusion

Access to good palliative care should be made available to all patients with fatal illness. Communities and health care workers should be well informed about the benefits of such care. The main barrier to access to palliative care in our region is still the lack of understanding of its benefits, so that most palliative care is reduced to symptom control. Since there are no guidelines about respecting different cultural and ethnicity backgrounds, differences in needs are hardly taken into consideration. Home setting, when possible, is a better choice for respecting cultural and ethnical differences. The identified barriers in our study are similar with the ones that exist in the literature. Very important are considered the cultural differences between health care providers and persons, approaching EoL and their family members, language barriers, lack of awareness of cultural and spiritual diversity issues and lack of suitable information on EoL. It is necessary to learn about priorities in other cultures and to gain confidence. Therefore, the need for palliative care should be recognized early in the course of the disease and first contacts established before the symptom burden is too high. When poor understanding of the disease trajectory due to insufficient language command is an issue, an interpreter should be sought.

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<sup>20</sup> David Busolo, Roberta Woodgate: Palliative care experiences of adult cancer patients from ethnocultural groups: a qualitative systematic review protocol. In: JBI Database of Systematic Reviews and Implementation Reports 2015, pp. 99–111.