

# *Knowledge, attitudes and behaviors of the community about palliative care*

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***Dr. Lumturi MERKURI***

EUROPEAN UNIVERSITY OF TIRANA, ALBANIA

***Dr. Dorina DERVISHI***

EUROPEAN UNIVERSITY OF TIRANA, ALBANIA

## **Abstract**

*Background: Although cancer is the disease for which people need palliative care the most, the number of diseases and conditions requiring palliative care has increased and will continue to grow. Palliative care improves health, reduces unnecessary hospitalization as well as overuse of health services. There are several barriers to palliative care access and the main are those related to the public such as: lack of public awareness on palliative care, on their benefits; cultural and social barriers.*

*Aim: Assess the current level of knowledge, attitudes, and behaviors of the community on palliative care*

*Methodology: This is a descriptive study that collects information from a representative sample of 712 subjects from Lezha, Mirdita and Shkodra districts, through a semi-structured questionnaire. SPSS statistical program was used for data analysis.*

*Results: 77.5% of participants had never heard of palliative care. The majority of respondents, 66.3%, did not know services that provide palliative care in Albania, or in their area of residence. 58.8%, do not recognize any of the rights of palliative care patients. There are incorrect and fatalistic attitudes towards diseases that require palliative care.*

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<sup>1</sup> Corresponding author: Dr. Lumturi Mërkuri is specialist of Public Health with long experience in the field. Lecturer at the European University of Tirana. E-mail: lumturi.merkuri@uet.edu.al

*Most preferred to receive palliative care services in private clinics (42.7%) or abroad (20.1%). Over 2/3 of them, 67.9%, have not seen/heard/read any information on palliative care and only 4.6% mention the medical staff as a source of information.*

*Conclusions: There is a lack of information, misunderstandings and fatalistic attitudes on many issues related to palliative care. The subjects did not have information on the services that provide palliative care in Albania and in their residential areas as well as on the rights of palliative care patients. Medical staff has been a minimal source of information on palliative care issues. The findings of the study were significantly related to the educational level of the subjects in the study and the residence without obvious differences between the districts included in the study.*

**Keywords:** *palliative care, community, attitude, knowledge, misconception*

## **Introduction**

According to the WHO, palliative care is an approach that improves the quality of life of patients facing life-threatening illness-related problems, as well as their families by preventing and alleviating physical, psychosocial, or spiritual suffering [1].

Today's concept of palliative care is much broader than caring only for cancer patients. It is needed for a very wide range of diseases and includes care for patients with other diseases such as end-stage chronic disease, acute trauma, cardiovascular disease, neurological disease, dementia, severe burns, extreme weakness of old age [2]. Evidence shows that the need for palliative care is constantly increasing as the reasons that lead to this - life expectancy (population aging), incidence and prevalence of chronic diseases, as well as people's interest in improving the quality of life - are increasing. [3].

Although cancer is the disease for which people have most need for palliative care, the number of diseases or other conditions that require palliative care has increased. There are over 20 diseases that require palliative care support including HIV, dementia, cerebrovascular disease, congenital malformations, malnutrition, musculoskeletal disorders, etc [4]. Globally, by 2060, deaths with serious health-related suffering will increase in all regions, most rapidly among people aged 70 years or older [5]. Considering that the burden of non-communicable diseases is increasing and as result of the ageing of populations, the global need for palliative care will continue to grow.

The WHO has focused a global response on palliative care and the 2014 World Health Assembly resolution urges all member states to include palliative care as a key part of their health systems. Integrating palliative care at all levels of the health

care system is essential to be accessible to anyone in need of palliative care as well as to achieving the Sustainable Development Goal (3.8: Universal health coverage) [6]. But despite this, currently lack of access to palliative care continues to be a public health problem worldwide. Thus, every year, it is estimated that about 40 million people need palliative care and only about 14% of them currently receive it [2] and 45% of countries do not have access to palliative care [7]. Palliative care improves health by avoiding suffering and thus constituting an indicator of high-quality health systems and generating economic benefits [8]. Early palliative care reduces unnecessary hospitalization as well as overuse of health services [9].

Globally, there are several barriers to insufficient access to palliative care. Among the main barriers to access to palliative care are those related to the public such as: lack of public awareness on palliative care, on the benefits it offers; cultural and social barriers (beliefs about death and dying; misunderstandings) is only for cancer patients, the use of opioid analgesics leads to substance abuse, etc [2]. Low level of awareness can have consequences for palliative care service, leading to negative perceptions resulting in the quality of care provided for palliative care services [10,11]. Palliative care is most effective when considered early in the disease. Early initiation of palliative care improves the quality of life for patients, reduces unnecessary hospitalization and over-use of health care services [2].

In Albania, cancers cause more than 18% of all deaths, ranking second among the causes of death, after cardiovascular disease. It is estimated that cancer rates in Albania will increase in the next decade due to population aging, declining fertility rates and some lifestyle factors. Palliative care in Albania has been established since 1993. Palliative care in the public sector is provided only in one center in Tirana, in-house oncology service (SOB) and in six districts by several non-governmental organizations. The National Cancer Control Committee, the National Cancer Control Program has been set up and the National Cancer Control Strategy, 2011-2020 has been approved. Terminal patients and their families are uninformed and confused about the level of service they need to address their health needs in the terminal stage [12].

**Aim:** Assess the current level of knowledge, attitudes, and behaviors of the community on palliative care

## Methodology

This is a descriptive study that collects information from a representative sample of 712 entities from the community of Lezha, Mirdita and Shkodra districts. The sample size was selected in proportion to the size of the population number. The

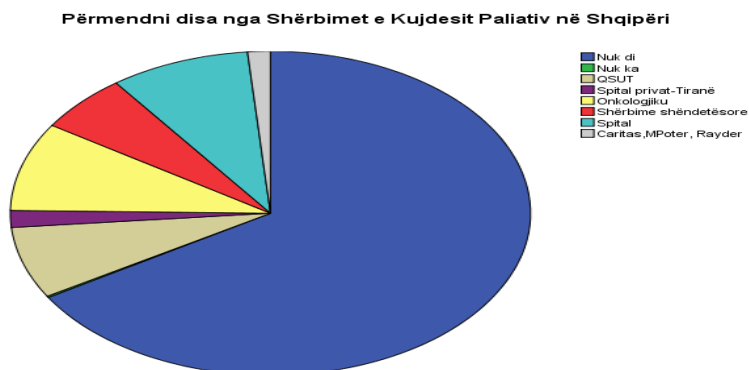
subjects in the study were stratified by districts, then by villages within each district. Within each layer, random selection was strictly observed, simple and proportional to the size of the respective stratum. A semi-structured questionnaire was used for data collection which was tested and then the final version was drafted. The staff who conducted the interviews were trained in advance in the field for the specifics of this study. The subjects selected by sampling were initially explained the purpose of the study, assured of confidentiality, informed oral approval obtained, and encouraged to give the most honest answer possible. All of these were reflected on the first page of the questionnaire. SPSS statistical program was used for data entry and analysis.

## Results and discussion

A total of 712 questionnaires were analyzed: Lezha 172 subjects, Shkodra 404 subjects and Mirdita 136. Out of 712 subjects participating in the study, 57.4% were female and 42.6% male with a wide age range, from 20 to over 65 years old. Of these, 28.7% lived in urban areas and 71.3% lived in rural areas. Data on the education of the respondents showed that 31% of them had higher education, 43.3% had secondary education, 24.9% had 8-year education and 0.8% had primary education.

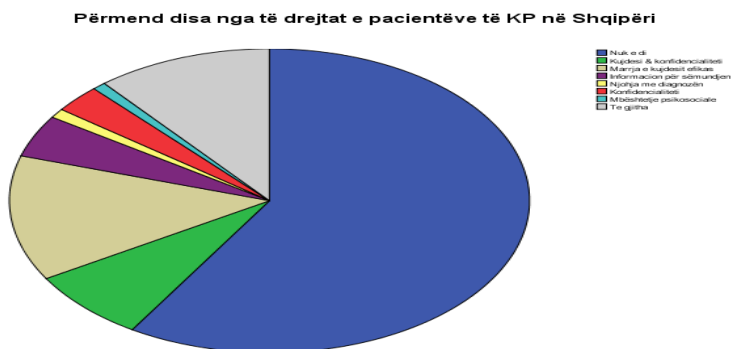
A large number of participants (77.5%) had never heard of palliative care. But even those who claimed to have heard of palliative care when asked the in-depth question “what is palliative care?” defined it as: care for the person with AIDS, care for the person with bed diseases. Most of the respondents (66.3%) did not know services that provide palliative care in Albania, while 67.7% of them do not have information about the existence of these services in their area. Data on knowledge on services providing palliative care in Albania are presented in Chart 1 below.

**GRAPH 1.** Knowledge of palliative care services in Albania



More than half of the respondents (58.8%) did not recognize any of the rights of palliative care patients and only a small number (11.0%) knew more than one of these rights. Specifically, receiving efficient care was recognized by 13.3% of participants, receiving palliative care and confidentiality, recognized by 7.6%, receiving information on the disease by 4.5%, maintaining confidentiality by 2.9%, getting acquainted with the diagnosis by 1.0 % and psychosocial support from 0.8% of respondents. Data on the knowledge of the subjects in the study, on the rights of palliative care patients in Albania, are presented in Graph 2.

**GRAPH 2.** Knowledge on the rights of palliative care patients in Albania

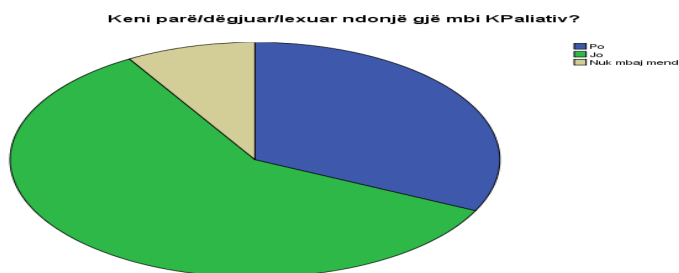


There are incorrect attitudes on many of the issues related to palliative care. Incorrect attitudes about continuing care for a patient until the end of life were identified in 4.9% of respondents. They think that if the patient is at the end of life, care for him should be stopped. Data analysis also showed that issues related to palliative care continue to remain taboo and there are still fatalistic attitudes towards diseases requiring palliative care. Thus, 14.2% of the respondents would not want to discuss their problems with anyone, if they were palliative care patients, while 15.6% of them would not want to provide services to palliative care patients.

The analysis of the data shows a preference for the use of private sector services, which indicates a lack of trust in public health services. Thus, when asked “where would you prefer to receive services if you needed palliative care?”, Only 31.6% of them refer to a doctor at a health center. The rest answered that they would prefer clinics and a private doctor, 42.7%, in clinics abroad 13.1%, and to the best service without defining 7%. An issue of interest due to its importance was the information on the deposit of opioid / analgesic drugs that remain in cases where the patient loses his life. More than 2/3 of the subjects, 69.2% of them, did not know how to deal with them in these situations. About 13.6% of them reported that they should be thrown in the trash, 9.3% answered that they are buried and only 5.4% of them answered that they should be handed over.

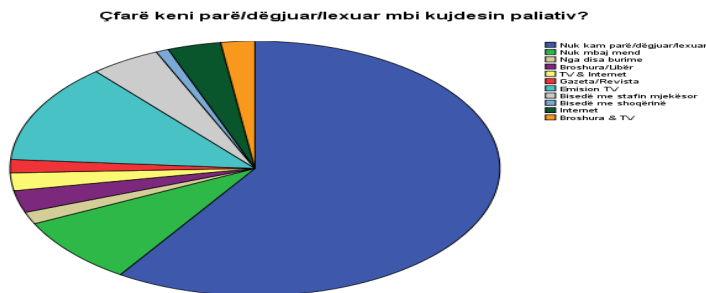
A variety of answers were taken from the question “what do you think are the problems / needs of palliative care patients”, where two of the most mentioned needs were economic and psychological. Other problems that were identified were: lack of medicines, expensive medicines, lack of 24-hour service, delay in receiving services, lack of palliative care services, lack of palliative care center in their areas, lack of psychosocial staff, lack of confidentiality, lack of necessary equipment for this patients, etc. The subjects in the study were asked the question “have you seen / heard / read any information related to palliative care”?, only about 1/3 of the subjects (32.2%) reported that they have seen / heard or read information related to palliative care. Others, 59.3% have not seen / heard / read any information and 8.6% do not remember this. Data on the information on the palliative care, are presented in graph 3.

**GRAPH 3.** Have you seen / heard / read any information on palliative care



Regarding the source of information on palliative care issues, television is mentioned the most by 12.6% of respondents. The Internet was mentioned by 3.5% of respondents, followed by brochures and books, 2.8%, newspapers and magazines 1.7%, society by 0.8% and 1.5% claimed to have received information from several sources. Medical staff is mentioned as a source of information by only 4.6% of the subjects in the study. Data on the source of information on palliative care are presented in graph. 4 below.

**GRAPH 4.** Data on the source of information on palliative care



One of the main goals of the study was to identify communication channels for the delivery of health messages, as part of the assessment, before initiating a communication intervention to change behaviors. Based on this, participants were asked about their preferences for receiving information on palliative care. Primary preference for receiving information on palliative care was health staff, reported by 36.1% of respondents, television by 7.3%, internet by 16.2%, brochures/magazines/books by 7.0%, and 18.1% of respondents considered all sources of information listed in the questionnaire

## Conclusions

There is a lack of information, limited information and misunderstandings on many of the issues related to palliative care by the community. The subjects did not have information on the services that provide palliative care in Albania and in their residential areas. There is also a lack of information on the rights of patients in need of palliative care. Issues related to palliative care and terminal diseases in particular, continue to remain taboo and there are fatalistic attitudes towards diseases that require palliative care. Respondents reported a number of problems related to palliative care such as lack of 24-hour service, lack of a palliative care center in their areas, lack of psychosocial staff, lack of confidentiality, lack of necessary equipment, etc. Our study also found that health staff has been a very minimal source of information on PC issues. Television and radio have been reported as among the main sources of information on palliative care. Almost all the findings of our study were significantly related to the educational level of the subjects in the study, and residency. Subjects residing in urban areas and with a higher level of education demonstrated better knowledge than their counterparts residing in rural areas and with a lower level of education. There were no obvious differences in the knowledge, attitudes or behaviors of the subjects when compared between the districts included in the study.

## References

1. World Health Organization (WHO): Palliative care. Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
2. World Health Organization (WHO): Palliative care. Available from: <https://www.who.int/health-topics/palliative-care> (accessed March 18, 2022)
3. Chan KS. Palliative care: the need of the modern era. *Hong Kong Med J.* 2018; 24 (4): 391–9.
4. The Worldwide Hospice Palliative Care Alliance. *Global atlas of palliative care*, 2nd edition: World Health Organization and The Worldwide Hospice Palliative Care Alliance, 2020 <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>

5. Sleeman K E, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health*. 2019; 7(7):883–892. [https://doi.org/10.1016/S2214-109X\(19\)30172-X](https://doi.org/10.1016/S2214-109X(19)30172-X) PMID: 31129125
6. Strengthening of palliative care as a component of comprehensive care throughout the life course. Geneva: World Health Organization, 2014. [http://apps.who.int/gb/ebwha/pdf\\_files/wha67/a67\\_r19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/wha67/a67_r19-en.pdf) (accessed Dec 18, 2018)
7. The Worldwide Hospice Palliative Care Alliance. Global atlas of palliative care at the end of life. Geneva: World Health Organization and The Worldwide Hospice Palliative Care Alliance, 2014 [https://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)
8. Kruk ME, Gage AD, Arsenault C, et al. High-quality health systems in the Sustainable Development Goals era: time for a revolution. *Lancet Glob Health* 2018; 6: e1196–252
9. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. Geneva: World Health Organization; 2018. Available <https://apps.who.int/iris/handle/10665/274559>
10. Lynch T, Clark D, Centeno C, Rocafort J, de Lima L, Filbet M, Hegedus K, Belle O, Giordano A, Guillén F, Wright M: Barriers to the development of palliative care in Western Europe. *Palliat Med*. 2010, 24 (8): 812-9
11. Seymour J, French J, Richardson E: Dying matters: let's talk about it. *BMJH*. 2010, 341 (c4860): 646-648.
12. Palliative Care Needs Assessment for Albania, by Stephen Connor, Kristo Huta [https://www.osfa.al/sites/default/files/vleresimi\\_i\\_nevojave\\_per\\_kujdes\\_paliativ\\_ne\\_rang\\_kombetar.pdf](https://www.osfa.al/sites/default/files/vleresimi_i_nevojave_per_kujdes_paliativ_ne_rang_kombetar.pdf)