

# REPORT

# ON THE IMPLEMENTATION BY THE REPUBLIC OF MOLDOVA OF THE PROVISIONS OF THE STRENGTHENING OF PALLIATIVE CARE AS A COMPONENT OF COMPREHENSIVE CARE THROUGHOUT THE LIFE COURSE RESOLUTION,

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#### LIST OF ABBREVIATIONS

WHA – World Health Assembly

MSMPS - Ministry of Health, Labor and Social Protection

MS - Ministry of Health

PAO - People's Advocate Office

PA - People's Advocate

APpDC - Children's Rights Ombudsperson

AMDM - Agency of Medicines and Medical Devices

AOAM - Mandatory Health Insurance

CNAM - National Health Insurance Company

CAPCS – Center for Centralized Health Procurement

FAOAM - Mandatory Health Insurance Fund

IMSP – Public Medical-Sanitary Institutions

IMS – Medical-Sanitary Institutions

AMP – Primary Medical Assistance

CS - Health Center

PC - Palliative Care

PPC - Pediatric Palliative Care

AVC - Stroke

RTI - Resuscitation and Intensive Care

UE – European Union

NGO - non-governmental organization

LPA - Local Public Authority

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#### I. INTRODUCTION

According to the World Health Assembly (WHA), an important function of the health care system is its responsiveness to the expectations and needs of the population which will be addressed in a fair manner in the context of human rights to life and health. Data from the studies<sup>1</sup> conducted by the People's Advocate Office (PAO) in 2016 and, repeatedly, in 2018, shows that the society of the Republic of Moldova wants additional interventions to guarantee the right to health. Moreover, there is an evidence of an increase in the share of respondents who have expressed this opinion (71.6% in 2018 compared to 61% in 2016).

During the last years, petitions have been addressed to the PAO (People's Advocate Office) from the population showing dissatisfaction with certain gaps or deficiencies in the health system. For these reasons, the right to health and access to health services were declared by the People's Advocates as one of the priorities of activity, this subject being included in the institution's 2018-2022 Strategic Development Program<sup>2</sup>.

In the process of analyzing the cases received, by direct address or by self-assessment, PAO (People's Advocate Office) identified gaps in the accessibility, availability and quality of the medical services for different patient groups. A special situation, quite serious, was found in the assistance provided to the terminal patients and the provision of palliative care in the Republic of Moldova. In particular, these gaps were elucidated in 2017 in the case of Niculina Bulat<sup>3</sup>, widely publicized in media sources. The People's Advocate was notified ex officio on this case and developed the Special Report on the results of the investigation carried out through the prism of human rights standards, which has been presented publicly and submitted to the competent authorities for taking concrete actions to improve the situation<sup>4</sup>. This case highlighted several systemic problems: faulty cooperation of structures at community level; lack of intersectoral collaboration in monitoring the patient in the terminal condition; insufficient organization of the services needed to assist such patients, etc.

WHA (World Health Assembly) (2002) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening, illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>5</sup>.

https://www.md.undp.org/content/moldova/ro/home/library/effective\_governance/percep\_ii-asupra-drepturilor-omului-in-republica-moldova.html

<sup>&</sup>lt;sup>1</sup>Perceptions of human rights in the Republic of Moldova. Available at:

<sup>&</sup>lt;sup>2</sup>http://ombudsman.md/sites/default/files/document/attachments/strategieoapr.pdf

<sup>&</sup>lt;sup>3</sup>https://www.zdg.md/stiri/stiri-sociale/avocatul-poporului-despre-cele-zece-zile-in-iad-ale-niculinei-bulat-cinci-urgente-fara-spitalizare-nicio-vizita-a-medicului-si-nicio-responsabilitate

<sup>&</sup>lt;sup>4</sup>www.ombudsman.md

<sup>&</sup>lt;sup>5</sup>Global Atlas of Palliative Care at the End of Life. Connor S.R., PhD, Sepulveda Bermedo M.C. (eds.). World Health Organization, 2014. Available at: <a href="http://www.who.int/nmh/Global\_Atlas\_of\_Palliative\_Care.pdf">http://www.who.int/nmh/Global\_Atlas\_of\_Palliative\_Care.pdf</a>

By signing the General Health Assembly Resolution "Strengthening of palliative care as a component of integrated treatment throughout the life course", approved in 2014, the Republic of Moldova has assumed the responsibility to implement its provisions. In accordance with the Resolution, health systems must ensure access to palliative care as an integral part of the right to continuous medical care. The document lists the measures needed to be mandatorily implemented at country level to strengthen palliative care, from the formulation and implementation of national policies that integrate palliative care services into the continuous flow of healthcare at all levels, focusing on primary, community and on home care, until the development of a cost-effective model of multisectoral approach to the assistance provided. The Resolution imposes to the state the obligation to provide financial and human resources (trained staff) for the development and provision of this service, adequate policies to ensure access to the essential medicines necessary for pain control and other symptoms.

In this context, PAO (People's Advocate Office) has set out to conduct a research on the organization, development, financing, provision and access to palliative care in the Republic of Moldova through the commitments made by the Republic of Moldova.

The main purpose of this study was to assess, at country level, the degree of implementation of the provisions of the General Health Assembly Resolution "Strengthening of palliative care as a component of integrated treatment throughout the life course", approved in 2014, as well as to identify the problems and gaps that prevent the proper development of this service in the Republic of Moldova, for submitting recommendations to the competent authorities, based on the role of the institution and the attributions that reside in the Law 52/2014 on the People's Advocate (Ombudsman).

Thus, there were analyzed the normative acts aimed at palliative care, in order to understand the degree of coverage of this area by the legal and normative framework in force, as well as the remaining gaps. A special aspect was dedicated to the situation regarding the supply of medicines necessary for pain management (opioids).

It was analyzed the insurance of the equitable access to palliative care services for different age groups of the population (children and adults) and types of pathologies (oncological and non-oncological), including access to essential medication for pain control; the existence and degree of the intersectoral approach of the palliative patient; it was analyzed the possibility of providing continuous patient-centered palliative care at all levels of care (primary, secondary and tertiary).

The assessment of the situation was made through the approach based on human rights with emphasis on the following aspects: accessibility (geographical, informational, financial), availability, acceptability for different groups of patients, quality.

#### II. APPLIED METHODOLOGY

The subjects analyzed in this study were based on the provisions of the General Health Assembly Resolution ,, *Strengthening of palliative care as a component of integrated treatment throughout the life course*", approved in 2014.

During the assessment process were analyzed the data available from official sources, including statistical data, public reports, policy documents, etc. At the same time, through official demarches from the People's Advocate, there was requested and collected information from the Ministry of Health, Labor and Social Protection, National Health Insurance Company, State University of Medicine and Pharmacy "Nicolae Testemitanu", Center of Excellence in Medicine and Pharmacy "Raisa Pacalo", National Agency for Social Assistance.

It was carried out the analysis of the legal framework and the normative acts in force aimed at palliative care, regulating the structure, organization and financing of this service at each stage, the patient's route and the provision of medicines and consumables at all stages of medical assistance; the level of assurance of equity and cost-effectiveness of the funds available for this service.

Within this assessment, during May-August 2019, the data were collected by quantitative (statistical data analysis, questionnaire application) and qualitative (analysis of the normative framework in force, individual interviews and group discussions, monitoring visits) in order to measure the size of the phenomenon and understand the causes and impediments that impede the development and functioning of an integrated and continuous palliative care service. Thus, the data were collected with the help of the corresponding research tools, by fields as follows:

# > PRIMARY MEDICAL ASSISTANCE, realized in partnership with the School of Management in Public Health.

**Quantitative study** – It was performed on a sample of 342 family doctors, stratified according to the residence environment, 50% urban (65% municipality vs. 35% district center) and 50% rural. In order to determine the sample volume, it was used the formula for descriptive studies:

$$n = \frac{Nt^2 Pq}{N\Delta x^2 + t^2 Pq}$$
, where

**n** – volume of the representative sample;

t –probability factor, which is 1.96, for a 95% probability;

 ${\bf P}$  and  ${\bf q}$  – probability and counterprobability of occurrence (or non-occurrence) of the investigated phenomenon.

In cases where we have no data on the investigated phenomenon, it is found that " $\mathbf{n}$ " is maximum, when the product " $\mathbf{Pq}$ " is maximum or, taking into account the fact that  $0 \le P \le 1$  and q=1-P, the product is maximum when P=q=0,5.

 $\Delta$  – allowed limit error, the maximum accepted value is 5%, therefore  $\Delta x=0.05$ 

N – the volume of the general collectivity is 1722 family doctors, according to the national statistics data.

After applying the formula, it was obtained the value of 311, to which was added the non-response rate - 10% (31) and thus it was obtained the final figure of 342 family doctors. The doctors were contacted directly in the offices of family doctors, health centers, as well as at the meetings of the professional society.

*Tool applied:* questionnaire developed by the authors, containing open and closed questions (*Annex number 1*).

**Qualitative study** – Hold focus group discussions. There were carried out 10 sessions in focus groups, which included about 200 participants. Three focus groups were created in the urban area (municipalities), in other seven group discussions were invited medical workers from both district centers and adjacent villages. Family doctors and assistants of family doctors participated in the discussions. The sessions were realized, based on the geographical distribution, in 3 regions of the country: north (Balti, Soroca), center (Orhei, Calarasi, Criuleni, Ialoveni, Chisinau), south (Cahul, Ceadar-Lunga, Comrat).

*Tool applied:* interview guide (*Annex number 2*).

# > HOSPITAL MEDICAL ASSISTANCE, carried out in partnership with the School of Management in Public Health.

**Quantitative study** – It was carried out the questioning of 34 managers of district hospitals, with the application of a grid for the assessment of palliative assistance granted within the public medical-sanitary institutions of district level (*Annex number 3*).

**Qualitative study** – conducting in-depth interviews with 7 managers of the hospital public medical-sanitary institutions of the district level.

Monitoring visits – The PAO (People's Advocate Office) team visited hospital Public Medical-Sanitary Institutions of district level – district hospitals (DH) (Orhei, Calarasi, Criuleni, Ialoveni, Cahul, Comrat), as well as of municipal level (Balti Municipal Hospital, Municipal Hospital number 4 Chisinau, Municipal Clinical Children's Hospital number 3 "V. Ignatenco") and of Republican level (Institute of Mother and Child, Oncological Institute, Institute of Phthisiopulmonology "Chiril Draganiuc"). During the monitoring were held discussions with the managers, the staff involved in the provision of palliative care services, were documented the conditions, the infrastructure and the endowment of the sections intended for palliative care.

# > SPECIALIZED PALLIATIVE ASSISTANCE – HOSPICE OFFERED BY NGOs

**Monitoring visits** - The PAO (People's Advocate Office) team made visits to the specialized institutions for the provision of palliative care services – Hospice Gloria; Hospice Zubresti and Hospice Isacova.

During the monitoring were held discussions with the managers, the staff involved in palliative care, were documented the conditions, infrastructure and endowment of the respective institutions for the provision of such care.

#### > SOCIAL ASSISTANCE

**Monitoring visits** - The PAO (People's Advocate Office) team held meetings in the territories with the representatives of the social assistance directorates / departments from the Comrat, Calarasi, Cahul districts.

During the monitoring were conducted discussions to determine the level of involvement of the social assistance staff in palliative care and the achievement of the terminal patient intersectoral approach.

#### **➤ HOME CARE – NON-GOVERNMENTAL ORGANIZATIONS**

**Qualitative study** – Were carried out individual interviews with the representatives of the public associations Angelus Moldova and Hospices of Hope Moldova in order to understand the way of organizing the activity in this field, the ways and possibilities of financing, provision of supplies and medicines, the problems and barriers they face, as well as wishes that would help improve the access and assistance provided to palliative patients in our country.

#### III. GENERAL CONTEXT IN PALLIATIVE CARE

#### 3.1. International framework

WHA (World Health Assembly) estimates that around 20 million people in the world need end-of-life palliative care annually, and an approximately equal number of people would need palliative care in the last year of life, meaning a total of 40 million people. It is estimated that of the total of 20 million people who would need end-of-life palliative care, only 14% of them receive it, about 80% live in underdeveloped or developing countries, 67% are over 60 years old, and 6% - are children 6.7.

The UN Committee on Economic, Social and Cultural Rights, in the General Comment number 14, stresses that "States are under the obligation to respect the right to health by... refraining from denying or limiting equal access for all persons... to preventive, curative and palliative health services". The right to health is recognized as a fundamental human right in the WHA (World Health Assembly) Constitution, as well as in several international instruments, such as: International Covenant on Economic, Social and Cultural Rights; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities. In the case of patients with severe pain, the failure of the state to provide palliative care can also be considered a cruel, inhuman or degrading treatment. Thus, access to palliative care is a legal obligation, as it is recognized by international treaties. In the same context, the European Association for Palliative Care, the International Association for Palliative Care, the International Alliance for Palliative Care and the Observatory of Human Rights are working together to promote access to palliative care as a fundamental human right.

Being a right guaranteed by the Supreme Law<sup>8</sup>, the right to health has found its value in a series of laws and national normative acts on the basis of which was the respect for fundamental human rights and the dignity of the human being in the field of health protection. Thus, during the last years, the right to health in the Republic of Moldova is approached through the prism of international standards, focusing on patient rights<sup>9</sup>, which derives from the fundamental human rights to life and health. These include both social rights: accessibility, fairness and quality in obtaining medical assistance, as well as individual rights that imply respect of the patient as a human being, of his dignity and integrity in the process of providing medical assistance.

In this context, in 2014, within the General Assembly of the WHA (World Health Assembly) was adopted the Resolution "Strengthening of palliative care as a component of integrate integrated

<sup>&</sup>lt;sup>6</sup> World Health Organization (WHO), 10 facts on palliative care [online]. Available at: <a href="https://www.who.int/features/factfiles/palliative-care/en/">https://www.who.int/features/factfiles/palliative-care/en/</a>

<sup>&</sup>lt;sup>7</sup> Global Atlas of Palliative Care at the End of Life. Connor SR, Sepulveda-Bermedo MC (Eds). World Health Organization (2014). Worldwide Palliative Care Alliance: Hospice House, London;

<sup>&</sup>lt;sup>8</sup> Article 36 paragraph (1) of the Constitution of the Republic of Moldova;

<sup>&</sup>lt;sup>9</sup> Article 5 of the Law number 263/27.10.2005 on patient's rights and responsibilities;

treatment throughout the life course" <sup>10</sup>. By signing this Resolution, the Republic of Moldova has made a commitment to ensure the access of the population to palliative care as an integral part of the right to continuous medical assistance.

According to the Resolution, national health systems must include palliative care in the continuous flow of medical assistance. Palliative care should not be considered as an additional option, but must be provided in conjunction with potentially curative treatments and must be tailored to the complex physical, psycho-social and spiritual needs of patients, their families and carers, as the disease evolves.

Palliative care is an interdisciplinary approach and involves providing basic care, that is, meeting the individual needs of the patient, wherever he / she is: at home or in the hospital. This fact implies the creation of a clear mechanism of intersectoral approach, with the assurance of the continuity of the palliative patient's assistance, in a holistic and multi-professional way, in order to ensure the total support and care of the patient and his / her family, according to their specific needs.

According to international recommendations<sup>11</sup> eligible for palliative care, the following groups of patients should be considered:

- people living with chronic diseases and life-threatening injuries, resulting from severe injuries or traumas;
- ➤ children or adults with serious congenital diseases or malformations, which lead to dependence on life-sustaining treatments or long-term care for carrying out normal daily activities;
- > children or adults with intellectual or developmental disabilities who suffer from severe diseases that threaten their life;
- people of any age with severe and life-threatening acute illness (for example: severe trauma, acute leukemia, stroke, etc.), where healing and reversibility is a realistic goal, but where the disease itself or the associated treatments bring with it significant suffering and a low quality of life;
- people living with progressive chronic diseases (peripheral vascular disease, neuromuscular dystrophies, cancer, renal or hepatic impairment, stroke with severe functional deficiency, advanced heart or lung disease, fragility due to old age, neurodegenerative disorders and various forms of dementia);
- patients in the terminal stages of severe diseases such as: dementia, cancer, AIDS, stroke with severe disability, when there is no chance for recovery or stabilization and for which intensive palliative care is the only objective of the assistance offered to them.

http://www.nationalconsensusproject.org/NCP\_Clinical\_Practice\_Guidelines\_3rd\_Edition.pdf

<sup>&</sup>lt;sup>10</sup> Resolution WHA67.19. Strengthening of palliative care as a component of comprehensive care throughout the life course. In: Sixty-seventh World Health Assembly, Geneva, 19–24 May 2014; Available at: <a href="http://www.studiipaliative.ro/wp-content/uploads/2013/09/Rezolutia-OMS-2014">http://www.studiipaliative.ro/wp-content/uploads/2013/09/Rezolutia-OMS-2014</a> RO.pdf

<sup>&</sup>lt;sup>11</sup> Clinical Practice Guidelines for Quality Palliative Care. Third Edition. National Consensus Project for Quality Palliative Care. USA, 2013.

According to the European Association for Palliative Care, there are three levels of granting Palliative Care <sup>12</sup>:

- ➤ Palliative approach that can be provided at the patient's home by the family doctors or by the general practitioners, who carry out their activity in the AMP (Primary Medical Assistance) or in the hospitals wards or residential centers.
- > Specialized support for Palliative Care is provided by volunteer teams, home care teams, mobile hospital teams.
- > Specialized Palliative Care will be provided if necessary, in units with beds, home care teams, day centers.

Access to Palliative care is limited or non-existent in many countries, especially in developing countries. Thus, the overall development of Palliative Care is classified, country by country, and divided into six groups, as follows:

- Group 1 Countries that do not have any known activity of Palliative Care.
- Group 2 Countries with capacity building activity to provide Palliative Care.
- Group 3 (a) Countries that provide isolated palliative care service.
- Group 3 (b) Countries that provide generalized palliative care service.
- Group 4 (a) Countries where Palliative Care services are in the preliminary integration stage in the provision of mass services.
- Group 4 (b) Countries where Palliative Care services are in an advanced stage of integration and mass provision.

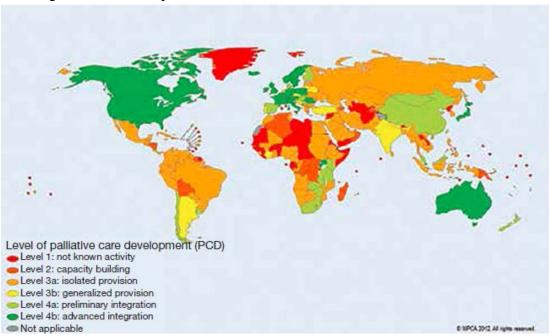


Figure 1. Mapping the levels of palliative care development globally 13

<sup>&</sup>lt;sup>12</sup> Connor S.R., Sepulveda Bermedo M.C., World Health Organization (WHO), Worldwide Palliative Care Alliance WPCA Global Atlas of Palliative Care at the End of Life, 2014. Available at: <a href="http://www.thewhpca.org/images/resources/policy-statements/WPCA%20policy%20defining%20palliative%20care%202011.pdf">http://www.thewhpca.org/images/resources/policy-statements/WPCA%20policy%20defining%20palliative%20care%202011.pdf</a>

According to this classification, the Republic of Moldova is part of group 3(a), the Palliative Care service being provided in an isolated way<sup>14</sup>. Of the approximately 25,000 - 27,500 patients from our country, who have no chance of survival, and who require Palliative Care at the end of their life, according to a study published in 2014, only about 10% benefit from this service<sup>15</sup>.

## 3.2. Palliative care in the Republic of Moldova

Being an integral part of the health system, palliative medicine comes to guarantee the patient's social rights to medical assistance, or *the patient has the right to reducing suffering and alleviating pain, caused by an illness and / or medical intervention, by all the available legal methods and means, determined by the existing level of medical science and by the real possibilities of the health service provider, as well as of terminal care worthy of a human being <sup>16</sup>.* 

In the Republic of Moldova, palliative assistance is organized for the first time in 2000, at the level of non-governmental services, and only much later is offered through the public sector. The first specialized palliative care service in the public sector - the Mobile hospital palliative care team - was created in 2008 within the Oncological Institute, with the support of the Soros Foundation Moldova, being created the specialized palliative care service.

"National Health Policy", approved by the Government Decision number 886 of August 06, 2007, allowed and encouraged the initiation of the development of palliative care services in the Republic of Moldova.

Subsequently there were made joint efforts to develop the appropriate legislative and normative framework, allowing the establishment and implementation of community and social care and home care services, with the elimination of barriers of any character in the way to access to these services.<sup>17</sup>

A study was conducted between December 2005 - June 2006, with the support of the Soros Foundation Moldova, that aimed at assessing the needs of palliative care in the Republic of Moldova<sup>18</sup>.

According to the study:

<sup>&</sup>lt;sup>13</sup> Lynch Th., Connor St., Clark D. Mapping Levels of Palliative Care Development: A Global Update. In: *Journal of Pain and Symptom Management*, June 2013, 45 (6):1094–1106. Available at: https://www.jpsmjournal.com/article/S0885-3924(12)00334-X/fulltext

<sup>&</sup>lt;sup>14</sup> Buta G., Bradu A., Pogonet V., Carafizi N., Ignat R., Curocichin Gh. Palliative care in the Republic of Moldova - reality and perspective. In: *Public Health, Economics and Management in Medicine*, 2018, number 1-2(75-76), pages 24-29.

<sup>&</sup>lt;sup>15</sup> Gherman L., Pogonet V., Soltan V., Isac V. Palliative Care in Moldova. In: *Journal of Pain and Symptom Management*, February 2018, Supplement, 55(2):S55–S58. Available at: <a href="https://www.jpsmjournal.com/article/S0885-3924(17)30396-2/fulltext">https://www.jpsmjournal.com/article/S0885-3924(17)30396-2/fulltext</a>

Article 5 paragraph (1) letters (d), (p) of the Law number 263/27.10.2005 "On patient's rights and responsibilities";

<sup>&</sup>lt;sup>17</sup> Clause 185 from the National Health Policy

Palliative Care Needs Assessment in Republic of Moldova 2005-2006. Available at: http://www.thewhpca.org/resources/item/palliative-care-needs-assessment-in-republic-of-moldova-2005-2006

- 1) 23 567 patients per year is a minimum number to be considered when planning palliative care services at national level, and the figure of 25,000 patients per year would be more realistic.
- 2) Over 50 percent of palliative care needs are concentrated in 2 municipalities and 11 districts. These can be used as starting points for the development of services.
  - 3) Over 60% of the patients with palliative care are in the rural area.

The study described the existing barriers in the development of the palliative care service and offered short-term, medium and long term practical recommendations. Following the launch of the study results, was formed a national working group consisting of palliative care experts, government officials and academic leaders to develop a national plan for palliative care implementation. Thus it was elaborated and approved the "Concept of development of palliative care services and an action plan for the development of palliative care services in the Republic of Moldova", which was approved by the Ministry of Health in June 2008<sup>19</sup>. Later, in 2009, was developed and approved the Regulation for the organization and operation of palliative care services, but due to the political changes in the government and the concurrent competing priorities, the plan was not implemented in full volume.

Through the 2008-2017 Strategy for the development of the health system the state has assumed the positive obligation to promote integrated medical assistance and to ensure the continuity of medical services by increasing the role and authority of primary medical assistance in the national health system, including through the development of community and home care services<sup>20</sup>.

However, the Republic of Moldova has integrated palliative care into the health system since 2010, when, after a long series of debates, was approved the National Standard of Palliative Care<sup>21</sup>. In parallel, the Ministry of Health has approved the revised rules for hospital medical staff and the estimated costs of providing palliative care.

In order to ensure equitable access of the population to palliative care services, to increase the quality and extend the life of the patient, in 2015 the Ministry of Health approved the *Regulation on the organization of palliative care services*<sup>22</sup>, which describes how to organize the services; the rights and responsibilities of palliative care beneficiaries and providers. Thus, palliative care services for eligible patients and their families can be provided in the following structures:

- a) hospice;
- b) wards with palliative care beds within the hospital medical-sanitary institutions;
- c) palliative care services at home;
- d) day centers;
- e) outpatient palliative care consulting rooms;

<sup>&</sup>lt;sup>19</sup> Order of the Ministry of Health number 234 of 09.06.2008 on the development of PC (palliative care) services in the Republic of Moldova (RM).

<sup>&</sup>lt;sup>20</sup> 2008-2017 Strategy for the development of the health system, approved by the Government Decision number 1471/24.12.2007;

<sup>&</sup>lt;sup>21</sup> National Palliative Care Standard, Chisinau 2010. Available at: <a href="http://89.32.227.76/\_files/15098Standardi%2520Na%25C5%25A3ional%2520de%2520%25C3%258Engrijiri%2520Paliative.pdf">http://89.32.227.76/\_files/15098Standardi%2520Na%25C5%25A3ional%2520de%2520%25C3%258Engrijiri%2520Paliative.pdf</a>

Order of the Ministry of Health number 1022 of 30.12.2015 on the organization of palliative care services;

f) specialized mobile palliative care teams within hospital medical-sanitary institutions (interdisciplinary teams).

Palliative care at home is provided by authorized providers, contracted by CNAM (National Health Insurance Company). Palliative care services at home are provided by specialized interdisciplinary teams or by residential structures, for patients with difficult displacement<sup>23</sup>.

Even if these services can be contracted by the medical-sanitary institutions, they do not provide such care. The study found that Palliative care at home is provided at the moment only by the representatives of the nongovernmental sector and only one hospital has a mobile team (IMSP (Public Medical-Sanitary Institution) Cahul), created with the support of an external financing (Hospice of Hope Moldova).

The beneficiaries of palliative care are the patients of all ages, with chronic diseases in advanced stage and other diseases with limited prognosis, who have life expectancy below 12 months, with uncontrolled symptoms, significant psycho-emotional or spiritual suffering and / or have a certain level of dependence<sup>24</sup>.

During the discussions with the primary medical assistance representatives, we determined that many family doctors confuse *medical care at home* with the *palliative care (assistance) service at home*. Basically, in all the districts monitored from the study, it was confirmed that the patients who require palliative care benefit from home care provided by the family doctor team.

According to the Regulation on the organization health care at home <sup>25</sup>, medical care at home involves "any activity of medical care provided at the patient's home by the medical worker with training in the field, which contributes to the improvement of his / her condition; medical care at home includes medical interventions provided in accordance with the National standard of health care at home".

The providers of medical care at home can be the medical-sanitary institutions, regardless of the type of property and the legal form of organization, with the right to provide medical care at home. The basic requirement is that such services will be provided at the recommendation of the family doctor and / or the specialist doctor in the hospital and specialized outpatient wards, including at the direct addressing of the beneficiary to the provider<sup>26</sup>.

Providers offer palliative care at home to people with incurable diseases, in terminal stages, as recommended by the family doctor (referral ticket), including in cases where palliative care at home is recommended by specialized medical professionals"<sup>27</sup>.

During the last 10 years were approved a series of normative acts, guides and protocols in palliative care, to which are made references in this report.

<sup>&</sup>lt;sup>23</sup> Standard 8 of the National Standard in Palliative Care approved by the Order of the Ministry of Health number 884/30.12.2010;

<sup>&</sup>lt;sup>24</sup> Decision of the Government of the Republic of Moldova number 1387 of December 10, 2007 On the approval of the Single Program of mandatory health insurance;

<sup>&</sup>lt;sup>25</sup> Order of the Ministry of Health number 855/29.07.2013 on the organization of medical care at home;

<sup>&</sup>lt;sup>26</sup> Clause 7 of the Order of the Ministry of Health number 855/29.07.2013 on the organization of medical care at home;

<sup>&</sup>lt;sup>27</sup> Clauses 133, 134 of the Order of the Ministry of Health number 596/404 of 21.07.2016 on the approval of the Methodological Norms for the application of the Single Program of Mandatory Health Insurance;

Organization of the Palliative Care Service in the Republic of Moldova, according to the information provided by the MSMPS (Ministry of Health, Labor and Social Protection), is regulated by:

- Order of the Ministry of Health number 884 of 30.12.2010 "On the approval of the National Standard of palliative care";
- o Order of the Ministry of Health number 1022 of 30.12.2015 "On the organization of palliative care services";
- o Order of the Ministry of Health number 219 of 30.03.2016, On the approval of the Guide in palliative care (with particularities in TB, HIV, pediatrics);
- o National Clinical Protocol 133 Palliative care dyspnoea, terminal condition;
- o National Clinical Protocol 134 Palliative care gastrointestinal pathology;
- o National Clinical Protocol 135 Palliative care pain in cancer;
- o National Clinical Protocol 136 Palliative care bedsores;
- o National Clinical Protocol 279 Palliative care in children (year 2017).

At the same time, we would like to mention that these protocols were developed in 2011 and need to be updated, and the pain is targeted only in the case of patients with cancer.

## 3.3. Pain management. Access to opioid analyssics

Pain is a common symptom met among people who are in conditions in need of palliative care. The prevalence of pain is overwhelming, especially in the last months of life, and prompt intervention and appropriate medication ensure the decline of pain and the quality of life of the sufferer. An unhealed pain is an essential factor that erodes the person's dignity. Proper management of pain and symptoms is a basic component of palliative care.

According to WHA (World Health Assembly) estimates, tens of millions of patients suffer from moderate to severe chronic pain each year and ultimately die from lack of access to opioid drugs, including patients with terminal-phase cancer; trauma patients as a result of trauma or violence; patients suffering from chronic diseases.

The key to success in pain management lies in the implementation and observance of three general principles ("WHA (World Health Assembly) triangle"):

- developing national policies for adequate pain management;
- availability and accessibility of opioid analgesics;
- training of patients, doctors and managers<sup>28</sup>.

The legislation regulating the circulation of narcotic, psychotropic substances and its precursors has a noble purpose and, at the same time, a very difficult one: on the one hand, it must protect the individual and society from the impact of drugs, and on the other hand, to allow the use

<sup>&</sup>lt;sup>28</sup> Study "Accessibility and availability of opioid analgesics in the Republic of Moldova: legal and regulatory impediments", Chisinau, 2015;

of opioid analgesics for medical purposes (in particular, for pain relief), ensuring good accessibility of the patient and, at the same time, avoiding their trafficking or abuse.

Opioid analgesics are medicines that require a special regimen of safety, records, prescription and insurance of traceability. These issues are regulated by international conventions and national legislation. This dual mission ensures the principle of "balance". The problem is that the "balance" is often inclined to the detriment of the patient and, in this case, certain changes in the legal framework become indispensable.

The Republic of Moldova is a party to the UN Single Convention on Drugs of 1961<sup>29</sup>, and the provisions stipulated in the treaties concluded are transposed into national normative acts.

Every patient has the legal right to reduce suffering and alleviate pain, caused by illness and / or medical intervention, by all available legal methods and means, determined by the existing level of medical science and by the real possibilities of the health care provider<sup>30</sup>. In this context, having opioid analysics, according to medical indications, is an unquestionable right of the patient.

In the Republic of Moldova, the "drug regime" or the stipulations that can be referred to it are reflected by a series of normative acts, such as:

- Law number 382 of 06.05.1999 on the circulation of narcotic and psychotropic substances and its precursors;
- Decision of the Government of the Republic of Moldova number 1088 of 05.10.2004 "On the approval of the tables and lists of narcotic, psychotropic substances and its precursors, subject to control";
- Decision of the Government of the Republic of Moldova number 79 of 23.01.2006 "On the approval of the List of narcotic, psychotropic substances and of plants containing such substances detected in illicit traffic, as well as their quantities";
- Decision of the Government of the Republic of Moldova number 128 of 06.02.2006 "On the approval of the Technical Requirements regarding the premises and the objectives in which narcotic, psychotropic and / or precursor substances are kept";
- Decision of the Government of the Republic of Moldova number 216 of 27.02.2006 "On the transit through the territory of the Republic of Moldova of narcotic, psychotropic substances and precursors";
- Order of the MS (Ministry of Health) number 71 of 03.03.1999 "On the preservation, recording and release of narcotic, toxic and psychotropic products and substances"<sup>31</sup>;
- Order of the Ministry of Health number 960 of 01.10.2012 "On how to prescribe and deliver medicines";
- Order of the Ministry of Health number 260 of 26.06.2008 "On the approval of the standard "Palliative care of HIV / AIDS patients";
- Order of the Ministry of Health number 187 of 29.02.2012 "On the approval of the instruction regarding the administration of oral morphine".

<sup>&</sup>lt;sup>29</sup> In force for the Republic of Moldova from March 17, 1995;

<sup>&</sup>lt;sup>30</sup> Law on patient's rights and responsibilities, number 263 of October 27, 2005, Article 5, letter e);

<sup>&</sup>lt;sup>31</sup> This order is outdated and obsolete and needs to be abolished, according to studies conducted in the field;

According to the provisions of the Law on the movement of narcotic, psychotropic and precursor substances, only foreign nationals have the right to transport narcotic and psychotropic substances according to the medical prescription, when they transit a foreign territory<sup>32</sup>. We consider that the national framework establishes a potential impediment to the access to opioid medication and the free movement of the citizens of the Republic of Moldova.

With the signing of the Association Agreement of the Republic of Moldova-European Union and the liberalization of the visa regime, the citizens of the Republic of Moldova, when necessary, can travel both for service, rest, but also to treatment or medical consultations in any medical institution abroad. Eventually any person who is prescribed medication with opioid analgesics or psychotropic drugs can benefit from this right. We consider that it is necessary to make changes in the provisions of the Law number 382/1999 on the circulation of narcotic and psychotropic substances and its precursors, to ensure the right of patients from the Republic of Moldova to transport narcotic and psychotropic substances abroad, according to the medical prescription, for personal use.

According to the WHA (World Health Assembly) recommendations, physicians, at all levels of medical assistance, should be allowed to prescribe and apply medicines subject to control under the general license, without the need for any additional authorization.

In the Republic of Moldova, opioids are procured centrally through a national program. The prescription of opioid analgesics is carried out according to the medical indications by any physician from the medical-sanitary institutions, regardless of the subordination and the form of property under which they activate, in accordance with the Order of the MS (Ministry of Health) number 960 of 01.10.2012<sup>33</sup>. Opioid analgesics are prescribed in quantities needed for the duration of treatment up to 30 days. The issuance of a prescription for the same patient before the expiration of the 30-day duration of treatment, but no earlier than the expiry of the validity period of the previous prescription is prohibited<sup>34</sup>.

The physician may issue a new prescription for the same patient, before the expiration of the 30-day duration of treatment, but no earlier than the expiry of the validity period of the previous prescription, in case of the exhaustion of the prescribed quantity, or if during the treatment appear changes in the state of health of the patient, who require a change of dose or medication. The prescription is prescribed directly by the physician, with the application of his / her signature and seal, indicating the number of the patient's medical record. On a prescription form number 2 it is allowed to prescribe only one medicine from these groups. The validity of the prescription for medicines containing narcotic and psychotropic substances, under international control on the territory of the country, is 10 days. The short term of validity of the prescription for this type of medicine implies the delayed presentation of the patient to the pharmacy for the purchase of the

<sup>&</sup>lt;sup>32</sup> Law on the movement of narcotic, psychotropic substances and its precursors, number 382 of 06.10.1999, Article 19 paragraph (1) and (2); <sup>33</sup>Annex number 1 to the Order of the Ministry of Health number 960 of 01.10.2012 "On how to prescribe and deliver

medicines", clause 1;

<sup>&</sup>lt;sup>34</sup> Law on the movement of narcotic and psychotropic substances and its precursors number 382 of May 6, 1999, Article

necessary medicine. These restrictions may also be considered a potential obstacle to patient access to opioid medicines.<sup>35</sup>

Prescribing the amount of opioids required for treatment up to 30 days can be qualified as a potential barrier to access to opioids: patients who are undergoing treatment with controlled medicines for a longer period are required to visit physicians and pharmacies frequently. We believe that these rules do not facilitate the access to opioid analgesics and can be considered as potential barriers.

The decisions concerning the treatments, as well as prescription of medicines, are directly related to the competency and professional skills of the physician, who is driven by the evidence-based clinical guideline data. Thus, the National Clinical Protocol "Palliative care - pain in cancer"<sup>36</sup>, recommend for medication in case of medium or severe pain: NMDA antagonists - Ketamine, pharmaceutical form - pills, or Fentanyl, pharmaceutical form - patch. These two medication products, according to the ATC classification, are anesthetic, but also opioid analgesics. At the same time, it is prohibited the release from pharmacies directly to outpatient and hospital patients of anesthetic drugs<sup>37</sup>.

Therefore, we attest a contradictory norm, which may be a potential barrier in the way to accessibility to opioid analgesics for patients with severe pain. In particular, we mention that the medicines are admitted for use in medical practice only with the authorization of the Agency for Medicines and Medical Devices<sup>38</sup>, the legislation in force does not impose other conditions.

Therefore, we consider it necessary to revise the Order of the Ministry of Health number 960/2012 to ensure the accessibility of patients with medium or severe pain to palliative treatment with anesthetics - opioid analgesics. At the same time, it is necessary to include in the List of Essential Medicines a separate compartment dedicated to medicines specifically used in palliative care.

Prescription of narcotics and psychotropic on special prescription forms do not contravene to the international practice. The procedure for prescribing the controlled substances was revised, the prescription form, according to the Order of the MS (Ministry of Health) number 960/2012 does not contain copies, and has no other degree of protection than the number and series. De facto, the prescription form number 2, of pink color, has 2 copies of green and yellow colors respectively, as well as a hologram. We also attest to the fact that the insurance with prescription forms is the obligation of the head of the medical-sanitary institution, and the normative framework does not establish the insurance procedure with such forms.

NB! During a monitoring visit to a Health Center we were mentioned as a problem that the manager did not distribute pink prescriptions to the family doctors.

Following the assessment of the national normative framework in the context of the practice of the European countries, we can see that the provisions in force regarding the prescription of

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<sup>&</sup>lt;sup>35</sup> Order of the Ministry of Health number 456/2011;

<sup>&</sup>lt;sup>36</sup> Order of the Ministry of Health number 960/2012;

<sup>&</sup>lt;sup>37</sup> Idem;

opioids produce distortions in the activity of the IMSs (Medical-Sanitary Institutions), obstacles in the path of patient access to opioid medication. Thus, the determination of the annual narcotic drugs requirement, according to provisional norms calculated on an "annual bed", not admitting the exceeding of the consumption norms "for a bed" is contrary to the contemporary principles of evidence-based medicine. Moreover, restrictions on the stocks of special prescription forms in medical institutions, the limitation of the right of doctors to dispose of prescriptions, the carrying out of quarterly controls regarding the rationality of prescribing and the use of narcotic drugs, also constitute impediments in ensuring access to opioid medication. In this context, we consider that it is necessary to revise the methodology for determining the need for substances subject to international control as DDD (*Daily Defined Dose*) and, in particular, the revision of the Order of the MS (Ministry of Health) number 71/1999.

The rules<sup>39</sup> governing the size of the stock of special prescription forms, restricted access to prescription forms, the need to request a special prescription form for each patient who requires opioid analgesics, as well as the obligation of an institutional commission to check quarterly the rationality of prescribing and using narcotic drugs – these are outdated rules and constitute significant barriers to patients' access to necessary opioid medication, and, at the same time, contravene to the international good practices.

Under the conditions of mandatory health insurance, decentralization and the transition to the autonomy of the public medical-sanitary institutions, the implementation of the mechanism of assessment and accreditation of the medical-sanitary institutions, these provisions are considered as restrictive norms and need to be revised.

Improving the accessibility and availability of quality, safe, cost-effective medication is a major objective of the health system. In order to achieve the proposed objective and to ensure the accessibility and availability of opioid analgesics, it is necessary to adjust the normative framework to the best European practices, by excluding the legislative and regulatory impediments identified within the revision of the national normative framework.

# 3.4. Intersectoral approach

The need for palliative care services is constantly rising, due to the increased prevalence of non-communicable diseases and the aging of the population. In the case of non-communicable diseases, the need could be reduced by early detection and adequate control to prevent complications. Increasing demand for palliative care services, coupled with financial constraints, requires a sustainable approach from the public health point of view<sup>40</sup>. This situation requires a reconfiguration of services, in order to integrate palliative care into existing health services and for the involvement of communities in partnership in support of people in need of palliative care.

Order of the Ministry of Health number 71/1999, clauses 8, 9, 10, 11;

<sup>&</sup>lt;sup>40</sup> WHA (World Health Assembly) Resolution "Strengthening of palliative care as a component of integrated treatment throughout the life course", April 4, 2014;

In this context, the WHA (World Health Assembly) recommends to the signatory states the development of the partnership between different sectors for carrying out operational researches in palliative care, including the development of cost-effective models of care. Facilitating the collaborative partnerships between palliative care programs, community hospices and a wide range of other medical service delivery environments is one of the goals of palliative care standards set out in the *White Paper*<sup>41</sup>.

The provision of qualitative palliative care services can only be achieved through intersectoral collaboration, well planned by achieving the partnership between the state, civil society and the community. This implies that all actors, whose activity has a direct or indirect impact on the health of the population, must assume clearly formulated responsibilities, in order to ensure the maximum efficiency of the joint intersectoral efforts for a better health.

The development of palliative care services was included as a priority in the 2016-2018 Program of activity of the Government of the Republic of Moldova<sup>42</sup>. Therefore, in order to implement this priority, there have been established concrete actions in several national policy documents.

Thus, in order to promote the integrated medical assistance and to ensure the continuity of the medical services for solving the population health problems it was planned the development of the *National program for the development of palliative care services still in 2016*<sup>43</sup>.

The development of public-private partnerships for palliative care services is one of the actions provided for in the 2016-2020 National Action Plan on the implementation of the 2012-2020 National Strategy for the prevention and control of non-communicable diseases<sup>44</sup>, having as objective ensuring equitable access to qualitative medical services, with the emphasis on Primary Medical Assistance.

Also in 2016, the Ministry of Health, in collaboration with the local public administration authorities, was going to assess the needs in health care at home, geriatric care and palliative care for the development of an integrated system of providing social assistance, home care and palliative care services, which should more effectively correlate the medical and social services for the elderly<sup>45</sup>.

The 2007-2021 National Health Policy for the years <sup>46</sup> serves as a systemic approach tool of health problems and integration of intersectoral efforts to improve the quality of life and health of the population throughout the life, especially during periods of high risk to health: beginning of life,

<sup>&</sup>lt;sup>41</sup> *The White Paper* was designed to provide guidance and recommendations for service providers, stakeholders and decision-makers. The first draft of the White Paper was presented at an oncology conference in February 2008 during the Slovenian Presidency of the European Union; <a href="http://www.studiipaliative.ro/wp-content/uploads/2013/09/1white-paper-standards.pdf">http://www.studiipaliative.ro/wp-content/uploads/2013/09/1white-paper-standards.pdf</a>

http://www.e-democracy.md/files/parties/program-activitate-guvern-moldova-2016-2018-ro.pdf

<sup>&</sup>lt;sup>43</sup> Decision of the Government of the Republic of Moldova number 1471 of 24.12.2007 "On the approval of the Strategy for the development of the health system during the period 2008-2017";

Decision of the Government of the Republic of Moldova number 403 of 06.04.2016 "For the approval of the 2016-2020 National Action Plan on the implementation of the 2012-2020 National Strategy for prevention and control of non-communicable diseases", action 3.2.3;

<sup>&</sup>lt;sup>45</sup> Decision of the Government of the Republic of Moldova number 406 of 02.06.2014 "On the approval of the Program for the integration of the problems of aging in policies", action 21.1;

<sup>&</sup>lt;sup>46</sup> Decision of the Government of the Republic of Moldova number 886 of 06.08.2007 "On the approval of the National Health Policy";

adolescence period and old age. The document emphasizes that improving and strengthening the population's health parameters can only be achieved through multidisciplinary and intersectoral interventions, being needed the involvement of all social sectors, the policies and programs of which have an impact on public health. The document emphasizes that the achievement of the performances in the health system is determined by the success of exercising the four basic functions: directing, financing, generating resources and providing services.

We appreciate the fact that the action plan of the 2019 Government Activity Program<sup>47</sup> provides the insurance of the modern development of community, geriatric, palliative and rehabilitation services.

### 3.5. Community health care

Community health care is a less known and respectively less developed of the medical system in Moldova. Although, the state policies were oriented to grant "a special attention to the development of the appropriate legislative and normative framework, which will allow the establishment and implementation of the community medical and social services and of home care, with the elimination of barriers of any character in the way of access to these services"<sup>48</sup>, the community health care network is not yet fully popularized. For promoting integrated medical assistance and facilitating population access to health services, especially of vulnerable groups in rural regions, it was considered important the "development of community and home care services"<sup>49</sup> and even "improvement of payment mechanisms for other categories of newly introduced health services: home care, palliative care, etc.."<sup>50</sup>.

Given the fact that the field of palliative care, including at home, comprises a wide range of services (medical, nursing, psychological / emotional spiritual and social) for eligible patients and their families<sup>51</sup>, the provision of these services requires the formation of a specialized interdisciplinary team.

The medical services are provided by a qualified doctor, licensed in general medicine and narrow specialization / improvement in palliative care. These include: decision to take care, initial assessment, establishment of the treatment plan, reassessment and monitoring, medical supervision, transfer, discharge / removal from record, communication and education of patients and family / caregiver, staff training, research.

*Nursing services* are provided by qualified nurses trained in palliative care for at least 6 weeks and supervised for at least 3 months by the coordinating nurse.

<sup>&</sup>lt;sup>47</sup> https://gov.md/sites/default/files/document/attachments/program\_de\_guvernare\_0.pdf

<sup>&</sup>lt;sup>48</sup> Clause 185 from the National Health Policy approved by the Government Decision number 886 of 06.08.2007;

<sup>&</sup>lt;sup>49</sup> Clause 65, letter (f) from the Strategy for the development of the health system during the period 2008-2017, approved by the Government Decision number 1471/24.12.2007;

<sup>&</sup>lt;sup>50</sup> Clause 63 letter (e) from the Strategy for the development of the health system during the period 2008-2017, approved by the Government Decision number 1471/24.12.2007;

<sup>&</sup>lt;sup>51</sup> Standard 7 of the National Standard in Palliative Care, approved by the Order of the Ministry of Health number 884/30.12.2010

These include: observation / assessment of the patient, drawing up and continuous adaptation of the care plan, communication with the patient / family / caregiver and the team, education of the patient and family, control of the activity of orderlies / volunteers, counseling of the family before and after death, education.

**Social services** are provided by qualified social workers with a minimum of 4 weeks training in palliative care and supervision of a minimum of 3 months by the coordinating nurse. These include: psycho-social assessment, participation in the establishment and implementation of the care plan, counseling, relationship with other services, education, defending patient / family rights; participation in the planning of the discharge, support for the organization of funeral services, family support during the mourning period; participation in the selection of volunteers, supervision.

The spiritual / religious support services are provided by clergy (or persons with similar experience and qualifications) trained in palliative care for at least one week. These include: counseling, prayer, specific religious services and rituals, active listening, meditation, participation in funeral services.

**Counseling services and psycho-emotional assistance** are provided by each member of the interdisciplinary team for the individual / family / group, intervention in case of crisis, counselor until and after the patient's death. For complex psychological problems will be ensured access to qualified professionals. They must be trained in palliative care for 4 weeks.

**Volunteer services** include direct work with patients and their families, administrative activities. Volunteers benefit from training and supervision from a coordinator.

Palliative care involves important human resources to ensure accessibility, continuity and quality of medical care. 52

Not less important are the financial guarantees that the State offers at the level of community medical assistance. The payment method for community and home health care is the "per visit" payment<sup>53</sup>, and the number of health care visits is established by the provider, according to the patient's needs, based on his / her permanent assessment. When contracting the provider by CNAM (National Health Insurance Company), the duration of the provision of health care services at home is set out in the contract for their provision"<sup>54</sup>.

The cost of a palliative care visit at home provided by the mobile team in 2012 was set at MDL 69.30<sup>55</sup>, subsequently it was increased reaching in 2016 the amount of MDL 171.0, while the cost of a home visit in the amount of MDL 91.44 was set separately<sup>56</sup>.

We consider it necessary to reassess these costs, taking into account the change in prices and the inflation index.

<sup>&</sup>lt;sup>52</sup> Standard 10 of the National Standard in Palliative Care, approved by the Order of the Ministry of Health number 884/30.12.2010;

<sup>&</sup>lt;sup>53</sup> Clause 55 from the Order of the MS (Ministry of Health) number 1592/594 of 28.12.2018 on the approval of the Criteria for contracting the medical services providers within the system of mandatory health care insurance for 2019;

<sup>&</sup>lt;sup>54</sup> Clause 18 from the Order of the MS (Ministry of Health) number 855/29.07.2013 on the organization of health care at home;

<sup>&</sup>lt;sup>55</sup> Order of the Ministry of Health number 60 of 25.01.2012 "On palliative medical care";

<sup>&</sup>lt;sup>56</sup> Order of the Ministry of Health, number 1000 of 24.12.2015 "On the approval of costs for 2016";

## 3.6. Particularities in the organization of palliative care in children

Children, being a special and very vulnerable category, enjoy special protection from the State, the right to health protection being guaranteed by the Constitution of the Republic of Moldova<sup>57</sup>. At the same time, the state recognizes the right of the child to use the best technologies for treatment and recovery, prophylaxis of diseases<sup>58</sup>.

At the international level, the right of the child to enjoy the best possible condition of health and to benefit from medical and recovery services is guaranteed by the Convention on the Rights of the Child<sup>59</sup>.

When the child gains the status of patient, his / her vulnerability increases, and at the same time appears the vulnerability and despair of his / her family. Therefore, with reference to palliative care for a child, the state is obliged to develop a specific mechanism, through which to provide safe support to the family, or "pediatric palliative care starts from the moment of establishing the diagnosis and continues whether or not the child is receiving curative treatment". 60

Although, there are similar principles on the basis of the palliative care of children and adults, however, there is a difference between the services provided to these two categories of patients. Children may suffer from various complicated diseases that are not encountered in adults. And the diseases that are attested in people of all ages, in children may manifest differently due to the anatomical and physiological particularities. Moreover, the child's body in the growth and development phase can modify the manifestations and the course of the disease. Thus, any specialized medical care, including palliative care, must be adapted, taking into account the needs of infants, children and adolescents<sup>61</sup>.

At the moment, the regulations regarding the pediatric palliative care in the Republic of Moldova are provided only in the National Clinical Protocol PCN -279, approved by the MS (Ministry of Health) in 2017, elaborated with the support of the Soros Foundation Moldova<sup>62</sup> in accordance with current international guides on Pediatric Palliative Care and serves as the basis for the development of institutional protocols. In 2019 this document is to be revised, as provided for the other clinical protocols, which must be revised every 2 years.

At the level of primary medical assistance

The document sets out the stages of the primary medical assistance process for children in palliation. Children with incurable diseases will be put on record as early as possible, so palliative

<sup>&</sup>lt;sup>57</sup> Articles 50, 36 of the Constitution of the Republic of Moldova;

<sup>&</sup>lt;sup>58</sup> Article 4 of the Law on the Rights of the Child number 338/15.12.94;

<sup>&</sup>lt;sup>59</sup> Article 24 of the International Convention on the Rights of the Child number 1989/20.11.1989;

<sup>&</sup>lt;sup>60</sup> WHA (World Health Assembly) publication "Cancer pain relief and palliative care in children", 1998;

<sup>&</sup>lt;sup>61</sup> Guide in palliative care (with particularities in TB, HIV, Pediatrics), Chisinau 2017; file:///C:/Users/ASUS/Downloads/GHID%20in%20ingrijiri%20Paliative\_ro\_final\_IZ.pdf

<sup>&</sup>lt;sup>62</sup> Order of the Ministry of Health number 329 of 28.04.2017 "On the approval of the National Clinical Protocol "Palliative care in children"";

care will begin with the diagnosis of the disease and will continue regardless of whether or not the child is receiving curative treatment.

Assessment will be carried out according to the age and the neuro-cognitive condition and will be followed by the development, in agreement with the patient and the family, of an action plan that will be reviewed periodically, depending on the evolution of the disease and the need. Depending on the disease, the level of control of the symptoms, the severity of the disease at the moment, the need for further investigations or curative therapy, will be appreciated the need for hospitalization of the child and the institution that will provide palliative care. Will be taken into account the wishes of the patient and the family.

In order to mentally, psychologically and spiritually guide the patient and his family, as well as in order to solve social, spiritual, practical problems, the family doctor will use community resources (social worker, psychologist, priest, volunteers, friends, etc.). The family doctor ensures the active supervision of the treatment to support the patient in outpatient conditions, according to the medical indications and recommendations included by the palliative care physician and or the attending physician from the hospital. Also, the family doctor will ensure the communication and continuity of palliative care in the institutional and home care environments, will organize the "respiro" type care in a planned or emergency way.

#### At the level of hospital medical assistance

Palliative care is intended for children with progressive incurable or life-threatening diseases and low life expectancy, as well as their families. Patients will be identified as early as possible to ensure a complex clinical approach. Each patient will be assessed individually and decision taken individually, in order to obtain the best clinical results. Assessment will be carried out according to the child's age and neuro-cognitive condition. Will also be appreciated patient and family expectations regarding the goals of care. The methods of curative treatment will be discussed with the patient and the custodians, and the hospitalization shall be planned or emergency, coordinated with the referring institution.

Palliative treatment in the stationary can be aimed at providing the *respiro* type service to the custodians, management of symptoms difficult to control or uncontrolled under home conditions, permanent supervision, treatment impossible under ambulatory conditions for various reasons, etc. and it will be ensured in the context of respecting the cultural, religious values of the patient and the family. At the same time will be ensured the active, permanent supervision of the patients during their stay in the stationary, with the purpose of preventing and eliminating the suffering. Will be ensured the interaction between the medical staff from different services involved in the care, coordinated the hospitalization and the discharge of the patient, as well as the transfer to another institution. Referred children or those directly addressed will be registered and taken on record with the establishment of the case coordinator and the recommendation of the level of appropriate palliative care. The patient will remain in the care of the usual services (family doctor, etc.) or will be referred to the specialized Pediatric palliative care (PPC) according to the severity of the symptoms, the emotional suffering or the lack of support / social network.

The initial assessment / reassessment and documentation within the palliative care service is an interdisciplinary one, performed in optimal time, depending on age and neuro-cognitive level. Reassessment will be performed at predetermined regular time intervals or as required. Assessment will be documented in the patient record card and followed by the development of the interdisciplinary action plan. The essential element is the communication and inclusion of the patient and the family in the assessment process and decision making. The provision of specialized palliative care services involves the activity of a multi-professional interdisciplinary team.

Children need specialized services provided by specialized pediatric staff. Palliative care services will ensure continuity of care between different levels and throughout the period of illness, terminal condition and mourning period. Continuity of care will help to avoid unnecessary error and suffering of patients affected by an incurable disease. The palliative care team collaborates with professional and knowledgeable caregivers to ensure coordination, communication and continuity of palliative care in institutional care settings and at home. Preventing crises and unnecessary transfers is an important result of palliative care. Effective coordination is best achieved through the case coordinator. The role of interdisciplinary palliative care teams at this level is to provide support for: the development of new services and the increase of the degree of coverage with the need for services in the republic, the education and training of the human resources necessary for the palliative services, the research in order to develop and promote the field of palliative care.

The study carried out by the monitoring of the medical-sanitary institutions and the discussions carried out with their managers, both at primary and hospital level of medical assistance, have led us to conclude that pediatric palliative care in the Republic of Moldova is insufficiently developed, being largely limited only to the assistance provided by the Oncological Institute and a non-governmental organization (Hospice Angelus).

#### IV. PALLIATIVE CARE AT LEVEL OF PRIMARY MEDICAL ASSISTANCE

#### 4.1. Normative framework

WHA (World Health Assembly) resolution of 2014 establishes as success factors in the implementation of palliative care: multidisciplinary and multisectoral approach, adaptation to the cultural, social and economic specificity and integration into existing health systems, with emphasis on primary and community assistance – including on home care. In the areas with limited resources, where the number of people in need of services is high and the number of nurses and physicians is low, the successful approach is by providing services with trained or volunteer community carers, under the guidance of professional medical staff.

According to the WHA (World Health Assembly) guide, it is neither feasible nor necessary for most patients who require palliative care for it to be provided by other physicians than those from the AMP (Primary Medical Assistance) of course, provided that the insurance with these specialists is sufficient<sup>63</sup>. Thus, the family doctor plays an essential role in providing palliative care because she / he is the closest to the community and the most accessible to the patient. In addition, home visits are possible to be made by family doctors compared to other doctors, who are engaged in hospital activity. Family doctors can build a close relationship with the patient and family, as most patients have known their family doctors for years and are aware of the possibilities and history of these patients, know the resources available to them. Therefore, family doctors are able to provide maximum support and care with available resources. Palliative patients should be continuously monitored by family doctors, who can communicate and coordinate with other professionals from the medical field, as well as their family / carers regarding the patient's current situation, including, can participate in solving some of his / her problems. At the same time, the family doctor can make relevant references to other levels of medical assistance and other resources. In this case, family doctors can provide extended care to those who need it, by coordinating with other resources, such as nurses, physiotherapists and social workers.

Primary Medical Assistance constitutes essential medical assistance, which is universally accessible to individuals and families in the community, is granted by methods accepted by them, with their full participation, at a cost that the community and the country can afford<sup>64</sup>. Thus, in line with the Alma-Ata Declaration, following the International Conference on Primary Medical Assistance, the Republic of Moldova has taken several measures to strengthen Primary Medical Assistance. A first step in this regard was the structural and organizational modification of the

<sup>&</sup>lt;sup>63</sup> World Health Organization (WHO), Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers, 2018. Available at:

https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1-

<sup>&</sup>lt;sup>64</sup> Alma-Ata Declaration (Kazakhstan) of 1978 https://www.who.int/publications/almaata\_declaration\_en.pdf

primary medical assistance sector through which was established the function of family doctor and was implemented the principle of free choice of family doctor<sup>65</sup>.

The volume of medical assistance provided under the mandatory health insurance is provided for in the *Single Program of Mandatory Health Insurance*<sup>66</sup>, which includes the list of diseases and conditions that require medical assistance financed from the means of mandatory health insurance.

According to the *Single Program* Primary Medical Assistance provided by the family doctor includes <sup>67</sup>:

- curative medical services, which include the monitoring of the treatment and the evolution of the health status of the chronic patients, including of the persons with disabilities and / or bedridden, according to the recovery plan, and its modification according to the evolution of the clinical-paraclinical parameters, with consultation in case of need of the specialist doctor;
- *health care at home*, including in the case of medical-surgical emergencies granted within the limits of the competence of the family doctor and in accordance with the normative acts in force to children aged 0-5 years under treatment for various diseases, terminally ill patients or with serious diseases that require examination, supervision and treatment.

In order to implement the aforementioned policies and strategies, there were approved the *Rules for organizing primary medical assistance*<sup>68</sup> which establish two types of services:

- 1. **Basic services,** which include, besides many others, the monitoring of chronic diseases, the active medical supervision for the most frequent chronic diseases, the prescription of the treatment and / or the hygienic-dietary regime, the coordination of the periodic assessments carried out by the specialized doctors of profile; prescribing drug treatment and medical devices, including medicines and compensated devices from mandatory health insurance funds; referring patients, by referral ticket, to laboratory and instrumental investigations, to the consultation of doctors other than family medicine, to hospitalization the provision of hospital care.
- 2. **Extended medical services,** which can be provided at the level of primary medical assistance under certain organizational conditions, such as medical-social services: home care, palliative care.

Taking into account that the family doctor is the first level of contact of the patient, he / she was assigned the role of coordinator of his / her team in the palliative care process, so that immediately after the diagnosis and assessment of the person, he / she will intervene for the *communication of the diagnosis and evolution of the disease, communication with the family and relatives, clarification of some aspects related to obtaining rights for people with oncological diagnosis, support in making* 

<sup>&</sup>lt;sup>65</sup> Decision of the Government of the Republic of Moldova number 668/17.07.97 "On the approval of the concept of reforming the healthcare system in the Republic of Moldova under new economic conditions for 1997-2003"; Decision of the Government of the Republic of Moldova number 1134/09.12.1997 "On the development of primary health care"; <sup>66</sup> Approved by the Decision of the Government of the Republic of Moldova number 1387 of 10.12.2007;

<sup>&</sup>lt;sup>67</sup> Decision of the Government of the Republic of Moldova number 1387 of 10.12.2007 "On the approval of the Single Program of Mandatory Health Insurance", clause 14 paragraph (2) letter (f) and (j);

<sup>&</sup>lt;sup>68</sup> Decision of the Government of the Republic of Moldova number 988 of 10.10.2018 "On the approval of the Rules for the organization of primary medical assistance", clause 38;

decisions regarding the recommended therapy and treating symptoms caused by disease and treatment<sup>69</sup>.

Family doctors are obliged to inform the patients about the opportunity to provide palliative care services in the medical-sanitary institutions in the administrative territory <sup>70</sup>.

Thus, the financing of palliative care services, according to the National Palliative Care Standard<sup>71</sup> is made from the *Single Program*, managed by the CNAM (National Health Insurance Company), by the National Pay Office of Social Insurance; from the State Budget and administrative-territorial units, as well as from other sources of financing under the conditions of the law (national and international non-repayable loans, donations, grants, sponsorships etc.).

# 4.2. Attitude of family doctors towards the provision of palliative care services

During the focus group discussions with the medical staff and the administration in the sector of the AMP (Primary Medical Assistance), we have determined that most of them are convinced that such type of care does not *de facto* exist in the Republic of Moldova, and the fact that they were placed on the shoulders of family doctors was a wrong step.

Also, many participants in the discussions mentioned that predominantly they have under surveillance oncological patients. In the carried out quantitative study we identified that most family doctors indicated that they have experience in providing palliative care service. In the urban area, seven out of ten doctors had patients who they offered palliative care, and in the rural area almost all the doctors had patients in palliation in their work experience.

Family doctors mentioned that during the last five years, they offered palliative care services, on average, to about 5 patients in the terminal phase. The predominant were the oncological diseases - 90.9% cases, diseases of the central nervous system - 64.3% cases and diseases of the endocrine system - 43.8% cases, predominating the complications of diabetes.

The large volume of attributions in the delivery of primary medical assistance, in the opinion of the family doctors, makes practically impossible the holistic approach of patients in palliation. They consider that palliative patients are a specific category, who, in addition to the treatment of chronic diseases need much more attention and supervision. Family doctors argue that, for the most part, the ministerial documents issued for extended medical services refer to chronic care and treatment, whereas palliation is considered as "... Something more complex, they need daily care, longer care duration, and the treatment for chronic diseases is not relevant to palliation". [FG1].

In several discussions we have been given examples to show that a family doctor's assistant cannot always meet the needs of a palliative patient. A nurse explained to us: "I had a patient who needed bladder catheterization. I will not do something like that! Under house conditions? The relatives did not want to take him to the hospital, because they hadn't transport means to take him

<sup>&</sup>lt;sup>69</sup> Clause 8 of the Order of the Ministry of Health number 1022 of 30.12.2015;

Order of the Ministry of Health number 1570 of 27.12.2013 on the organization of palliative medical assistance.

<sup>&</sup>lt;sup>71</sup> Order of the Ministry of Health number 884 of 30.12.2010 ,,On the approval of the National Standard of Palliative Care"

there... and they were asking me to do it! They didn't understand that I couldn't do such things!" [FG3]

During the quantitative research, more than half of the total respondents (74.3%) consider that the role of the family doctor in palliative care is only to prescribe the necessary medication, without offering other palliative services. This opinion is shared by the majority of respondents from the rural areas and half of the respondents from urban areas. Only one third of the total respondents (34.5%) consider that the family doctor should be the main person to provide complex, active assistance to both the patient and their families (figure 4.1).

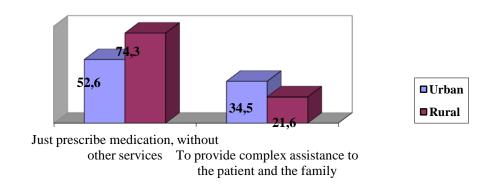


Figure 4.1. Doctors' opinion on their role in the provision of palliative care (%)

The family doctors, included in the study, indicated differently the spectrum of involvement in the assistance of the terminal patient. Most indicated the obligation they have in prescribing antipain treatment and symptom control. From figure 4.2 we notice that the involvement of the family doctor in other aspects of palliative care is much lower.

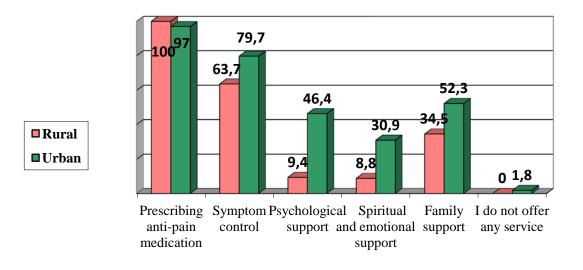


Figure 4.2. The ability to meet the needs of the patient taken in palliative care, (%)

If most of family doctors can provide symptom control to patients in palliation, psychological support, however, is only provided by half of the doctors from urban area, and in the rural area only one doctor in ten can offer this service to the patient in palliation. Only one third of family doctors in urban areas provide spiritual and emotional support to the patient in palliative care, whereas in rural areas only one in ten doctors can meet this need. It is evident the disparity of the capacities in the provision of palliative care service between the family doctors in the urban area, in relation to those in the rural area.

Family doctors who have indicated that they do not offer palliative care have recognized the following causes: "I am not clear about the services I have to offer my family" (33,3%), "I feel that I do not have the necessary skills to assist a patient in palliation" (33,3%) and "I don't have enough time" (66, 6%).

Among the many barriers listed by family doctors is the lack of nurses, including trained in the field of palliation. In many localities we were mentioned that the coverage with nurses is 50-60%, which doubles the work of the existing medical staff. Most have reported that it is very difficult to find people who want to do such care, because usually in this profession there are women and it is "difficult to work with these people, many are lonely, they have no one, they are anxious, sometimes even aggressive". [FG2]

Among patients in palliation are often persons targeted at bed, which requires a huge amount of physical work from the nurse. During a discussion, a recognized doctor: "These patients should be washed, lifted! Nurses have a large workload, fail to provide quality care at home. They are physically and morally exhausted..." [FG4]

A family doctor, on average, spends with a patient in palliative care, from one hour to two hours a week. It is the average time, indicated by most family doctors included in the quantitative research. In the urban area 59.6% of the doctors offer this time, and many more in the rural area -89.5%. A doctor out of ten offers to the patient in palliation only thirty minutes a week. 2-3 hours spent 16.4% of family doctors in urban areas, and only 1.1% in rural areas. More than three hours a week spent with the patients 11.1% of doctors in urban areas, and only 1.2% in rural areas (figure 4.3).

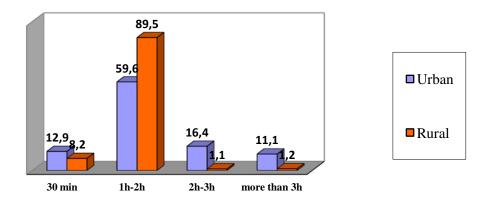


Figure 4.3. The medium weekly time granted to a patient in palliation (%)

Having analyzed the above, we can say that family doctors monitor the patients taken in palliative care, but the time given to a patient during a week is not enough to meet their needs, all the more to cover them all at once. Similarly, there is observed a disparity between the time granted to a patient in the urban area, as opposed to those in the rural area. Only 2.3% of the family doctors in the rural area spent with the patient in palliation more than two hours per week, while in the urban area, the weight is 27.5%.

The provision of palliative care services at home is closely linked to primary medicine, where the family doctor is the coordinator of specialized teams and the promoter of palliative services. However, on the human resources side in the provision of care services at home, there was an acute shortage of nurses, and with regard to the field of palliation, their number is below the standard requirement. There is a shortage of staff among nurses, motivated by the remuneration of work in relation to the work performed - palliative care.

Most of the nurses are women and it is difficult for them to perform nursing / stretcher services, given the ratio between the number of patients at home and the severity of their condition.

## 4.3. Financing of palliative care within the AMP (Primary Medical Assistance)

Both family doctors and nurses who participated in the discussions, in most cases indicated the same fact, that they do home care and not palliative care and that in home care predominate oncology patients.

From the official data presented by the CNAM (National Health Insurance Company) regarding the volume contracted and executed by palliative medical services during the period 2014-2019, it was found that only in 2016 was contracted a single Health Center (IMSP (Public Medical-Sanitary Institution) CS (Health Center) Cimislia) with 200 visits in the amount of MDL 34 200.

The number of home visits in most cases varies, as a rule, they depend on the number contracted by CNAM (National Health Insurance Company) for the provision of care services at home, in some settlements it was even indicated that CNAM (National Health Insurance Company) determines the number of visits. During the discussions it was mentioned ,, per year around 620 home visits are required, but determined by CNAM (National Health Insurance Company) we offer only 415 visits". [FG10]

A family doctor explained to us how things work in the Health Center he / she works: "We have about 108 visits contracted by the Health Center per year by the CNAM (National Health Insurance Company)... CNAM (National Health Insurance Company) pays only for 5 cases / year for palliative care, Thus, these 108 visits should be distributed by us to 5 patients. If more patients are in need, the Health Center cannot cover. Planning is not done, it comes from what offers the CNAM (National Health Insurance Company) ..." [FG8]

With regard to the cost of a visit and consumables for palliative care at home, family doctors consider that they are calculated unfairly and are insufficient. A Health Center manager reproached

us: "Do you think that the cost of **MDL 137** per visit is normal and that is all with the salary of the medical worker and the medication".

With reference to the expenses required for consumables a family doctor acknowledged:" ,.... Patients often want something tangible, such as pampers, ointments or other tangible supplies, which we cannot give..." [FG5]."

With regard to stoma, medical officials have claimed that "oncologists distribute the stomas as they want, often they are of low quality". [FG9]

The insufficiency of consumables (stomas, diapers) was invoked by most of the interlocutors. "It is very problematic to distribute, for example, the 700 stomas given by the Oncological Institute for 35 patients per year, while some patients need 3 per day. Respectively, all expenses are left to the family." [FG10]

The opinion of most people in this regard is that: "The medical insurance system is monopolistic and conditions the provision of medical services, including in palliative care! There should exist alternatives." [FG4]

During the discussions with the staff from the AMP (Primary Medical Assistance) it was claimed that they do not know the costs for palliative care established at national level. It was mentioned the fact that, even if these costs do exist, they need to be reviewed and adjusted to actual spending. "When determining the cost, the age of the patients, the pathology, etc. are not taken into account. And this cost is higher than for treatment of chronic patients" [FG2].

Family doctors told us that they were not satisfied that there is not foreseen special remuneration for the home visits for the palliative patient. These visits are considered from those planned for chronic patients. However, they are convinced that such visits consume much more time and effort. At the same time, they consider that the limit of only 36 visits per patient per year is incorrect and unjustified.

On average, home visits are reduced to 2-3 visits per week, over three months, which in the opinion of those responsible: "It is not correct, because this number of visits is insufficient for a palliative patient, here is needed daily care. You can leave a patient with chronic disease a day without medical supervision, but not a palliative patient, and more consumables are need for this patient".

According to the contract with CNAM (National Health Insurance Company) it is foreseen the remuneration only for the nurse, who makes visits at home and receives an addition to the salary of about MDL 2000, provided for 36 visits, which are obligatory to be done in 3 months. The rest of the months of the year are not covered by the CNAM (National Health Insurance Company) and in order to continue to receive palliative care the patient can only be referred by the family doctor to the hospital or hospice. In this context, a nurse (an assistant) of the family doctor, directly involved in the care of a terminal patient, told us:

"It is very difficult to care for such patients. The family sees you as a rescue and it turns out they were already terrorizing me. It was enough to visit them 2 times and then they started calling me 2-3 times a day, waiting for me to come daily, constantly asking for my help. I could not do my

job; I was very involved only with this patient. But it was even worse when those 36 paid visits were over, but they were still waiting for help. Who to go to? From what money should I buy the consumables? The CNAM (National Health Insurance Company) already does not pay anything! How shall I explain them? Then they complain, they start to make a fuss... And I'm so sorry for them, but you're consuming yourself ... I don't want to take such visits anymore! I don't even need that money!" [FG6]

Another family doctor told us: "If the number of visits contracted by the CNAM (National Health Insurance Company) expires, we voluntarily take care of the patient, at will, but rarely, because we have many more to do. We still have to go to work for the days of rest or extra work and you know, nobody pays us. If we see that the patient will die shortly, we make an agreement with a hospice, we ask them to take it if they have the possibility". [FG3]

During the discussions we identified a problem in providing patients with bags for stomas. Some family doctors acknowledged that they were receiving bags for stomas through humanitarian aid, others confirmed that they receive them centralized from the Institute of Oncology. However, this allocation never corresponds to the real needs that they determine in the territory. Moreover, it is often the case that the bags are of different sizes, which makes it difficult for all patients to use them. In several Health Centers it has been confirmed that the stomas are purchased from their own sources, but it was also mentioned that these expenses are very essential for the budget of the AMP (Primary Medical Assistance). Many family doctors admitted that they did not know the situation regarding the necessity or the provision with stomas, leaving this fact totally on the shoulders of the relatives of the terminal patient. Generally, in this chapter, the team noticed a significant gap, noting a lack of involvement of the AMP (Primary Medical Assistance) in providing with bags for stomas the patient with such needs.

#### **Case study - Good practices**

Cahul Health Center

In the subordinate of the Health Center was opened a center for patients immobilized to bed – Avicena. It is a center developed within a project with external financing, and at the end of the project, it was transmitted to the management of the Cahul CS (Health Center). The center is endowed with washing machines, a room of procedures and equipment for physioprocedures. The center is located next to organizations from the field of social assistance, being in close collaboration in the assistance of serious in-bed patients, in vulnerable situations. Within the Center is employed a nurse, paid from the budget of the CS (Health Center), from the account of home visits. For the reference year the Cahul CS (Health Center) has 857 visits contracted by the CNAM (National Health Insurance Company). However, there is no clear distinction between palliative care offered at home and home medical assistance.

# 4.4. Intersectoral cooperation

• Palliative care team

The patient in palliative care needs a complex approach. And in order to satisfy all the needs that he / she faces it is required a multi-professional approach with an interdisciplinary work style. According to the National Standard of Palliative Care, palliative care services are provided by an interdisciplinary team: "The minimum structure of the interdisciplinary team includes: a doctor, a nurse, a social worker." (chapter IX "Interdisciplinary team", Standard 12)

Unfortunately, we found during the study that palliative care is perceived by Primary Medical Assistance staff more as simple home visits. In the urban area, only two out of ten doctors work in the palliative care team, the share being - 21.1%, while in the rural area, practically, none.

The study elucidated with whom *de facto* family doctors collaborate when they are providing palliative care services and with whom they believe they should collaborate to provide integrated and quality health services. From the data obtained we observe that the desire for intersectoral collaboration in palliative care is much higher than the reality found in the provision of this service.

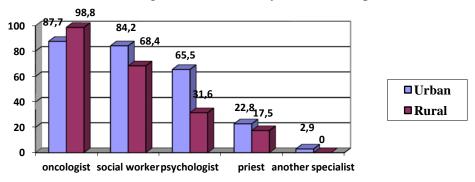


Figure 4.4 Opinion of family doctors with reference to the desire to collaborate in palliative care (%)

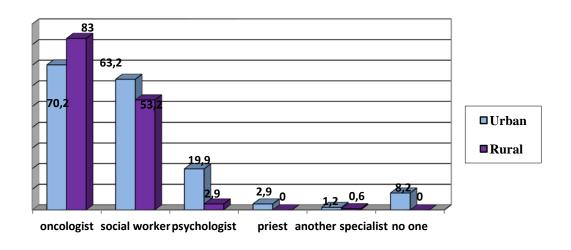


Figure 4.5 Current collaboration of family doctors in palliative care (%)

#### Other specialist doctors

Most family doctors, both from urban (87.7%) and rural (98.8%) areas, consider that they should collaborate with the oncologist. According to the data collected, most family doctors (70.2% in urban areas and 83% in rural areas), indeed indicated the collaboration with the oncologist at a high level.

A very low rate of collaboration was indicated with reference to another specialist, for example, gastrologist, pulmonologist, surgeon or cardiologist (0.9% of the total respondents) and a very small number of doctors indicate the desire or need for such collaboration (2.9%).

#### Social assistance and local authorities

Most family doctors in the urban area - 84.2% and more than half of the family doctors in the rural area - 68.4% consider that they should collaborate with the social worker. Collaboration with this specialist is observed in more than half of the respondents (63.2% in urban and 53.2% in rural areas).

Likewise, during the discussions it was mentioned frequently the bad cooperation with the social workers. On the one hand, it is a problem related to the human factor, the lack of staff, but on the other hand, there is a serious gap in the content of the documents developed at the ministry level. During a discussion with the family doctors we were told: "The orders and indications that come hierarchically superior authorities, knock head to head, there is not a clear delimitation of the duties of social workers in the palliative care process, and it is always a ping-pong who and what to do". [FG5]

During the monitoring visits it was found an essential difference in the degree of collaboration between the family medicine and the local social assistance service. If in some districts was confirmed a good collaboration, in others the subject of the collaboration was reduced only to informing the social worker about the existence of a patient, without jointly coordinated activities.

Most nurses have argued that the social workers do not cooperate. A nurse (assistant) from a family doctor's office recognized us: "Social workers do not even want to hear about us when we try to tell them that they already have to do certain actions, motivating that they have a lot of work to do." [FG6].

"I think you are referring to the interdisciplinary teams that should deal with these patients, they are not, I have not heard that they are somewhere. I do not know if the social workers are trained, but You should know that this would help us a lot, we have no community assistants, I think in the villages they are. And we are very busy, in these patients we only write painkillers and that's about them..." [FG7].

There are settlements where social workers only get involved if they are well-disposed or in friendly relationships with the nurses, and these ones ask them to help.

During the monitoring process there were also held discussions with representatives from social services in territorial localities. We found that most of them are not informed about the essence of palliative care. A social worker told us: " I found out about palliation through Internet

after you called me ... before we met with you. But we do not have such persons and our duties are related to social assistance, that is to bring them their pension, help them with coal, etc." [FG3]

This inhomogeneity in establishing a collaboration between these two important sectors in organizing palliative care raises concerns about the quality and continuity of the care provided.

#### The psychologist and the priest

Only two out of ten family doctors from the urban area collaborate with the psychologist - 19.9%, and in the rural area only 2.9% of the respondents. At the same time, the desire for collaboration from family doctors is much higher (65.5% in urban area and 31.6% - in rural).

In this regard, the doctors told us: "I also recommend to the patients the consultation of the psychologist, in the district there is a community center of mental health, but the patient and his relatives do not want to go, considering that I make him crazy, and after that the relations between us are broken…" [FG1].

"I know that the social worker goes to such patients, I give them the form 027 for home care, but I do not work with the psychologist, we do not have a psychologist, I give them pills if they need to…" [FG7].

"The patient refuses, or his / her relatives refuse the consultation of the psychologist, we have a community mental health center, and often I make referrals there. We work with the social worker, but when we fill out the patient's home care sheet we do not go together at him / her, each of us when we have time...." [FG4].

Only 2.9% of family doctors in the urban area and none in the rural area collaborate with the priest, although practically two out of ten doctors (22.8% of the doctors in the urban area and 17.5% of the doctors in rural area) indicated a willingness to work with this specialist.

Of the total respondents included in the study, only - 1.2%, indicated the collaboration with all the actors mentioned above and only 18.7% mentioned that they would collaborate with all the actors listed above, to provide palliative service to the eligible patient.

Analyzing the collected data, we observe that family doctors in the urban environment have a better cooperation with other professionals in order to provide the palliative service, as compared to those in the rural area. And this is evidenced by the fact that the share of doctors who mentioned that they work in the palliative care team are mostly those in the urban area.

## Community involvement

Another problematic aspect highlighted in the discussions with the medical staff from the visited Health Centers concerns the insufficient involvement of the community, the relatives do not always want or have the possibility to take care of these people. From the words of the respondents "at first, when were planned these types of care it was intended to create a collaboration, it was expected to be community nurses, but it didn't work, there is no such thing at the moment, we have to do all the work.". [FG3].

During the visits we found that even the local public administration is not involved in this area. According to the respondents "they raise their hands up and tell us that they have nothing to help us with, they can only help when the person has died and there is no one to bury him / her".

According to all those responsible at community level, palliative services should be redirected apart to hospices or specialized services. The community approach of this subject is not understood and accepted.

#### • Collaboration with hospital institutions

A special topic of the research was the referral of patients to the hospital medical-sanitary institutions.

Some doctors mentioned that patients refuse hospitalization, others acknowledged that "*They can send the patient to hospital only in case of cancer diagnosis*". [FG7]

We were surprised to find that many family doctors do not know that in the same district hospital there are provided beds for palliative care. Some family doctors have mentioned that they refer patients to the hospital for palliative care, but there exists a waiting line. Sometimes, in case of need, they also sent the patients to the IMSP (Public Medical-Sanitary Institution) number 4 from Chisinau.

About 78% of family doctors included in the research send patients to palliative care units, according to some indications (figure 4.6). Most often, family doctors make a referral ticket to the patients in the palliative care ward when their general condition worsens. One-third of family doctors indicate hospitalization of patients for correction of treatment and of opioid doses. Only two out of ten family doctors send the patients for hospitalization in the palliative care wards, to leave the family's "place of respiro". And also two out of ten family doctors send the patient to the ward for symptomatic treatment.

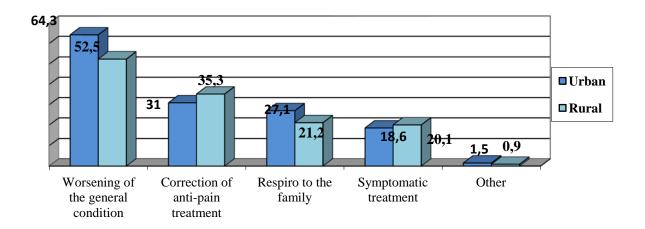


Figure 4.6. AMP (Primary Medical Assistance) collaboration with the hospital palliative care wards, (%)

It is important to mention the situation detected in a district included in the study, where we were told that in the palliative care ward are admitted patients with only 4 serious conditions: cancer intoxication, acute dyspnea, severe pain and bedsores. The patients who are in palliation but do not have one of these conditions are not accepted for hospitalization.

We were also told other cases of groundless refusal for hospitalization received by the family doctor from the hospital institutions.

#### Case study identified during the visits to the territory

A young woman with severe disability, infected with HIV, dependent on a wheelchair, eligible for palliative care was cared for by her father. In order to provide the "respiro" to the caregiver and to assure the patient with the respect for her human dignity and the increase of the quality of her life, the family doctor addressed to the hospital, in the chronic diseases ward, where are provided beds for palliative care. The hospital refused hospitalization due to HIV status, the person being directed to the infectious diseases ward. In that ward, however, she was informed that they have no available places, but neither have beds provided for palliation.

Eventually the person was referred to a psychiatrist, then hospitalized to a Psychiatric Hospital.

At the same time, about a quarter of the respondents (24.6%) admitted that they never sent patients to the palliative care ward, invoking the following reasons: most often, the patients or relatives' refusal to hospitalization; own opinion that the palliative care service is more efficient at home, the lack of transport to transfer the patient to the palliative care ward, especially in the rural areas etc. (figure 4.7).

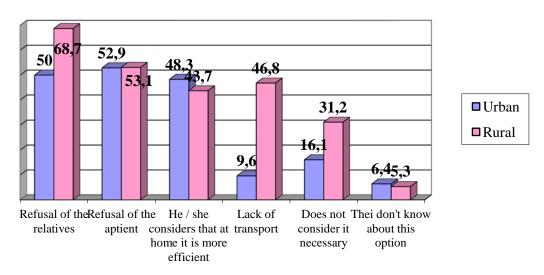


Figure 4.7. Causes of not sending the patient to the stationary (%)

Family doctors who participated in the research were asked to rate the activity of palliative care units. More than half of the respondents - 62%, indicated that it is "a ward with qualified specialists, offers quality services". About one fourth of all doctors - 26.3%, indicated that

"assistance in this ward leaves something to be desired", and, in practice, one doctor in ten (11.7%) mentioned that he did not know anything about the activity of these wards.

Thus, we can conclude that the study resulted in insufficient collaboration between the AMP (Primary Medical Assistance) sector and the hospital one, with a low degree of intersectoral communication and lack of exchange of information.

Specialized palliative care services

Many representatives of primary care institutions believe that it is necessary to reconfigure the palliative care system, creating more day centers and hospices specialized in palliative care. Especially the doctors from the northern districts mentioned that there is no hospice in the region where patients could be referred.

Some family doctors believe that the concept of palliative care is not promoted in hospices, the difference is only that more consumables are offered.

At the same time, very few family doctors have been able to confirm that they know any contact details of a Hospice, in order to recommend it to patients in palliation.

# 4.5. Pain management in the practice of family doctors

Proper management of pain and symptoms is the basic component in providing palliative care service, and is provided, including by the family doctor.

According to the data collected, only two out of ten doctors, out of the total included in the research, perform pain assessment in patients taken into palliative care (figure 4.8). Most often, for the assessment of pain the family doctor uses the scale from 1 to 10.

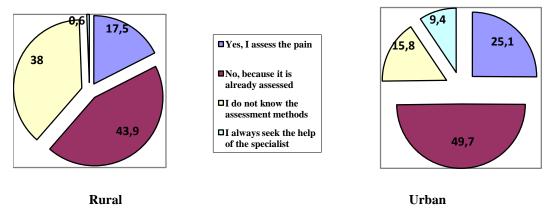


Figure 4.8. Pain assessment by family doctors, (%)

About half of family doctors do not assess pain in patients whom they have in palliative care, because the patient already comes with anti-pain treatment indicated by an oncologist. And during the course, the correction of the treatment is done by increasing the doses of anti-pain medicines, without repeatedly assessing the pain threshold. One in ten doctors from urban area (15.8%) and

more than one third of family doctors in rural areas (38%) do not know the methods used to assess pain.

If in the urban area 9.4% of the respondents mentioned that they request the help of the specialist, in order to assess the pain of the patient in palliation, in the rural area only 0.6% of the doctors resort to this option.

Only two out of ten doctors specified that they were the first to indicate opioid treatment to the patient in palliative care. The rest of the family doctors consider that the only specialist empowered to initiate treatment in these patients, is only the oncologist (figure 4.9). Respondents who gave another answer said that they initiate treatment by consulting with their oncologist or other specialist.

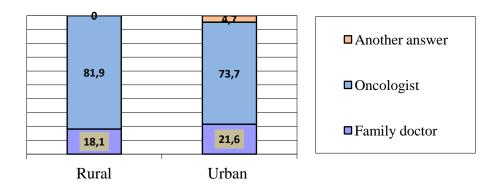


Figure 4.9. Initiation of treatment with opioids, (%)

Of the physicians who refuse to initiate treatment with opioids, the majority considers that this right is assigned only to the oncologist (urban area - 84.3%, in the rural area - 58.5%). Another cause invoked by physicians is the fear of adverse reactions and lack of training in this area. If in the urban area, two out of ten physicians have such fears, then in the rural area, about half of the doctors indicated them (figure 4.10). Approximately one family doctor in ten perceives as a barrier in prescribing anti-pain medication the probability that the patient will not administer the treatment correctly, and this fact was also reflected at the time of the exposure of the respondents, regarding

the fear of adverse reactions to opioids, by their incorrect administration, or overdose.

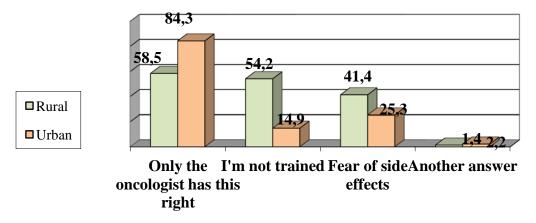


Figure 4.10. Causes of not accepting the initiation of the treatment with opioids, (%)

It is worth mentioning that, the basis for the indications of opioid treatment are the provisions of the Order of the MSMPS (Ministry of Health, Labor and Social Protection) of the Republic of Moldova number 960 of 01.10.2012 on how to prescribe and deliver medicines<sup>72</sup>, which expressly provides for the right to prescribe opioids, and this is not just limited to the oncologist. Thus, the ones described above show us that family doctors are misinterpreting their functions in this regard, or the family doctor should initiate the treatment with opioids and correct it whenever necessary. At the same time, we can suppose that one of the reasons for the poor information of the doctors on this subject and the reduced or even impossible access to the necessary documents on the official web page of the MSMPS (Ministry of Health, Labor and Social Protection).

During focus group discussions, even though some family doctors believe they do not see a problem prescribing opioids, they say that they have been sufficiently trained, at the same time, most have shown reluctance and avoidance to prescribe opioids. Many family doctors have acknowledged that they do not prescribe opioids, although they know they have the right to prescribe, because they do not want to take responsibility, both for the patient and his / her relatives, as well as "they are afraid of the law enforcement bodies".

A family doctor explained to us: "...I just can't predict when the incurable patient will die. If he / she lives far away, I prescribe opioid medicines even for 2-3 weeks... So ask his / her relatives! Not to come tens of kilometers every 2 days. But he / she may die the next day! Thus, they remain with many unused medicines, and that's really a problem! I don't know how to do it right... That's why we avoid it..." [FG10, doctor from the urban area, 47 years].

At the same time, some family doctors have acknowledged that the patients have problems with access to opioids, especially when the oncologist is missing in the district or when this specialist is away or is on vacation (leave).

We can find that family doctors do not perceive professional safety in prescribing opioids, which leads to omitting or avoiding prescribing them.

<sup>&</sup>lt;sup>72</sup> Modified by the Order number 265 of 31.03.2017, published on 21.04.2017 in the Official Gazette;

We noticed that doctors are influenced by "myths about morphine treatment". Many have told us the following:

"...I am afraid of the adverse reactions that may occur in the patient after the first dose of morphine, after that the patient refuses to use it, and I have nothing to replace it with, and I find it very difficult to convince him / her that he / she should use opioids, they believe that after that they will die soon..." [FG3, doctor from rural area, 57 years].

"...I start prescribing morphine later, because it shortens the patient's life and inhibits breathing center, and they often die in sleep..." [FG4, doctor from rural area, 63 years].

"...I'm afraid to prescribe high doses of opioids, I do not have the necessary training..." [FG8, doctor from the urban area, 41 years].

"...If I start prescribing morphine from the beginning, in time I will have to increase the dose, because the body becomes accustomed and does not react, and I as a doctor I will not have anything to work to reduce the pain..." [FG1, doctor from rural area, 55 years].

From the foregoing, we can deduce that the fears of family doctors, regarding the reducing of pain syndrome, are most often related to morphine administration and morphine myths. One aspect of this problem is the fact that doctors do not have the training, the necessary competence in the field of reducing the pain syndrome. They believe that they should start the treatment as early as possible after the onset of the disease, which is mandatory with the morphine injectable form, because patients will develop quickly habituation and will require high doses of preparation. They fear that patients will die from respiratory arrest, caused by inhibition of the respiratory center, by morphine.

The exposed ones are errors in the interpretation of the pain syndrome reducing with the opioids by the family doctors, which is the most important barrier in pain management when providing the palliative care service. The lack of oncologist specialist, which could help family doctors in dose adjustment is another important aspect to consider.

A very important topic to consider is also the insufficient approach by the doctors of the non-oncological pain, for which there are no algorithms and no national clinical protocol.

In most of the discussions held with family doctors, we have noticed that at the level of primary medical assistance, no adequate estimates of the needs in opioids are made.

# 4.6. Providing palliative care to children by the family doctor

With regard to pediatric palliative care, most family doctors noted that they did not have children under palliative care or if there existed such cases, they did not have any involvement anyway: "There the parents think about this, we don't really get involved". [FG7].

From the discussions with family doctors, palliative care at home for children is not performed: "We don't even have children in palliation, maybe at the Oncological Institute there are children, but we don't have... Parents ask us where they can go and we tell them to go to the hospice directly". [FG3]

However, being asked if they know where minor patients could refer to palliative care, most family doctors responded that they do not have such information, except for those from Orhei district who mentioned the institution in Isacova village, Orhei district (Hospice Angelus), still very vague, without knowing contact details or referral procedure.

# Case study

Patient - 3-year-old child diagnosed with cancer, receives about 40 weekly opioid injections. Primary Medical Assistance does not manage the case, the patient being totally in the care of family members."

#### V. PALLIATIVE CARE PROVIDED AT THE HOSPITAL LEVEL

#### **5.1 Normative framework**

Within the health system, hospitals have a special place, being the largest consumers of resources, being best endowment with medical equipment and technologies, having the potential to provide high quality and complex health care. In general terms, any hospital has the mission to provide the necessary medical services to solve patients' health problems.

Single Program of Mandatory Health Insurance formulates the hospital assistance as "the solved case which includes, usually and in accordance with the normative acts in force, consultations and investigations for the establishment of the diagnosis, medical or surgical treatment, care, medicines, consumables, sanitary materials, accommodation and food, granted in the cases justified from the medical and epidemiological point of view and in cases where the patient requires palliative care services provided under hospice conditions or palliative care wards and mobile teams specialized in palliative care within hospital medical-sanitary institutions"<sup>73</sup>.

According to the same normative act "palliative care provided to the patient is offered when the primary clinical objective or the purpose of the treatment is to optimize the quality of life of the patient with an active and advanced pathology that limits his / her life"<sup>74</sup>.

By the Order of the MS (Ministry of Health) number 1570 of 27.12.2013 on the organization of palliative medical care, the leaders of the district public medical-sanitary institutions, starting with 01.01.2014 were obliged to carry out palliative care beds, based on the number of the population served, with the assurance of the necessary conditions for the provision of palliative care services.

In 2015 was approved a new *Nomenclature of hospital medical-sanitary institutions*<sup>75</sup>. According to this, 30 beds of palliative care are provided in the Municipal Clinical Hospital number 4 from Chisinau (hospital specialized in palliative care) and 30 beds in the Psychiatric Hospital from Balti municipality. The other hospital Medical-Sanitary Institutions have beds provided for chronic and acute care.

Assessment and accreditation standards for palliative care providers were established by the National Accreditation Council in 2015<sup>76</sup>.

The basic requirements intended to ensure the provision of quality palliative care services which are mandatory for the providers of such services are set out in the National Standard in Palliative Care (2010). According to the Standard, the admission / hospitalization of beneficiaries for palliative care is based on the referral ticket, issued by the family doctor. Specialized palliative care services for eligible patients and their families are provided in units with palliative care beds where

<sup>75</sup> Order of the Ministry of Health number 466/11.06.2015 "On the approval of the Nomenclature of the hospital medical-sanitary institutions";

http://old2.ms.gov.md/sites/default/files/activitate\_evaluare\_acreditare/ingrij\_paliative1.pdf

<sup>&</sup>lt;sup>73</sup> Decision of the Government of the Republic of Moldova number 1387/1012.2007 "On the approval of the Single Program of Mandatory Health Insurance";

<sup>&#</sup>x27; Idem;

"assistance is provided in hospitalization regime, for eligible patients, including offers services of "respiro" type (temporary placement)"<sup>77</sup>.

When planning the services by hospital institutions, the norm of 8 beds per 100,000 inhabitants will be taken into consideration, with a minimum of 5 beds per ward. The average number of days per year per patient is provided for 30 days.

The standard describes the mandatory requirements regarding the structure and endowment of the palliative care ward, namely: isolation of the respective ward from the other stationary wards, due to the specifics of the palliative care; the access of the caregivers should be allowed and possible, without going through the active treatment wards; the ward must have its own sanitary group; the ward should be tailored to the needs of patients, allowing them easy access to toilets, salons, etc., including for patients in wheelchairs.

In all areas where patients have access must be installed sound and visual alert systems to allow staff to be called in by patients. Also the ward must include sanitary group for staff, treatment room, storage space for medical materials and devices and medical equipment, room for food, for storage of clean and dirty linen, for storage of household waste and of contaminated / hazardous waste, space for recreation, counseling and meeting with visitors.

At the same time, it is compulsory to have a room with safe box connected to the centralized signaling for the storage of opioids, psychotropes and a specially designed refrigerating room for the temporary storage of the bodies.

The salon for patients in palliation must have a surface of at least 6 m<sup>2</sup> and be equipped with adjustable beds with accessories (preferably with 3-piece bed base, with hydraulic mechanism and electric control). It is important that the beds have mattresses that prevent the emergence of bedsores, with washable surface, dividing partitions, bedside table for each bed, movable table for each bed, washable medicine chair, cabinets for patients' personal items, sink. The sanitary group (toilet - WC) for patients must include toilet adapted to the needs, adaptable showers with accessories for the disabled persons, elevator for the mobilization of patients, as well as space for washing, disinfection, drying and storage of urinals.

# 5.2. Financing of palliative care at the hospital level

One of the main factors that determines the sustainable functioning of the health system and creates favorable conditions to meet the needs and demand of the population in quality medical services and the adequate volume is the financing.<sup>78</sup>

For 2019, the contracting of the hospital medical assistance provides the amount of MDL 376 222.0 thousand <sup>79</sup>.

<sup>78</sup> Decision of the Government of the Republic of Moldova number 1471 of 24.12.2007 "On the approval of the Strategy for the development of the health system during the period 2008-2017";

<sup>&</sup>lt;sup>77</sup> Standard 8 of the National Standard in Palliative Care;

Order of the Ministry of Health number 1592-A of 28.10.2018 "On the approval of the Criteria for contracting the medical services providers within the mandatory health system of medical assistance for the years 2019 -2026";

The unit of measure of the short-term hospital activity is the *treated case*. The treated chronic cases are the cases provided by the profiles: geriatrics, rehabilitation and palliative care. One of the mandatory criteria for contracting by CNAM (National Health Insurance Company) in the chronic care program is the separate physical location delimited by the chronic care ward with the hiring / training of the rehabilitation doctor / specialist with training in palliative care, specifying the daily tariff for palliative care activity in hospital / hospice conditions.

For  $2011^{80}$  the cost of one day / bed was – MDL 93.0, in  $2012^{81}$  the established cost of one day / bed was MDL 214.40.

From the information presented by the CNAM (National Health Insurance Company) regarding the hospital institutions contracted for palliative care services, including the number of bed-days provided during the years 2014-2019, there is a decrease in the cost per day / bed, after 2016, and this under the conditions where every year there is an increase in prices and tariffs for consumer goods <sup>82</sup>.

Table 5.1. Number of the IMSPs (Public Medical-Sanitary Institutions) and the type of services contracted to provide palliative care from the FAOAM (Mandatory Health Insurance Fund)

Year	Number of hospital institutions contracted by the CNAM (National Health Insurance Company) for palliative care	The cost of one day / bed, MDL	Total number of days / bed provided	Total expenditure from the FAOAM (Mandatory Health Insurance Fund), MDL
2014	33	242,00	23 970	5 800 740,00
2015	35	302,10	34 018	10 276 837,80
2016	41	351,00	47183	16 561 233,00
2017	40	331,00	50 422	16 689 682,00
2018	41	343,25	49 037	16 801 057,75
2019		343,25		

With reference to the Balti Psychiatric Hospital, it was found that it was contracted by CNAM (National Health Insurance Company) for palliative care only in 2014 and 2015, although according to the Order of the MS (Ministry of Health) number 466/11.06.2015 for these services are provided 30 beds. The hospital administration confirmed that the palliative care unit was liquidated in 2016 due to the non-compliance of the conditions with the provisions of the Standard. Respectively, the provision of palliative care in this institution was stopped.

82 www.statistica.gov.md;

47

<sup>&</sup>lt;sup>80</sup> Order of the Ministry of Health number 875/27.12.10 "On the approval of the cost of an assisted case of palliative medical care provided in stationary / hospice conditions";

<sup>81</sup> Order of the Ministry of Health number 60/25.01.2012 "On medical palliative care";

From the results of the quantitative study we observe that most hospitals (97%) are provided with medicines and consumables necessary for the provision of palliative care services from the means of compulsory health insurance funds intended for this purpose, 6% of hospitals report other sources - charitable donations, non-governmental organizations, etc., and in 1 (3%) hospital it confirmed that it uses the means of mandatory health insurance funds with another destination.

When asked whether there is funding from the National Social Insurance Fund for such services, the answer was unanimous: "No, we do not have any support from the CNAS (National Pay office of Social Insurance) fund, if we are lucky, the NGOs help us with humanitarian aid".

During the discussions with the hospital managers we were told that one of the barriers to the development of this area is the fact that there are contracted few cases of chronic care, including palliative care, the wards are not profitable and the medical staff is not motivated to re-qualify.

Like those responsible for primary medicine, those in the hospital one indicate that the founder, who is usually the local public authority, does not contribute in any way to the development of palliative care services.

# 5.3. Assessment of palliative care provided in district hospitals

In order to relate as much as possible, the situation on the palliative assistance organized at the level of hospital institutions, there have been applied two data collection tools: filling in a questionnaire grid by the managers of all the district hospital institutions and direct observation through random visits in the territory with individual interviews with some hospital managers.

#### Availability of palliative care at the district level

Following the visits made in about 8 district hospital institutions in the country, no separate palliative care unit was identified. The form of organization of palliative care services in the district hospitals is the placement of palliative care beds within the departments of chronic diseases, palliative care and geriatrics, from 1 to 10 beds. In 3 district hospitals, these beds are placed parallel to other wards, and one hospital reported to us that it has such beds only in other wards.

In a hospital institution we observed 2 salons with the inscriptions "Palliative care", which is a stigmatizing practice and a violation of patient confidentiality.

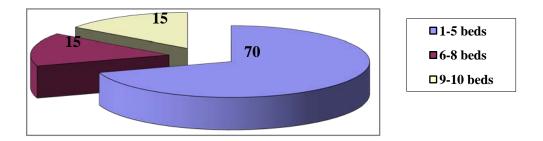


Figure 5.1 The way of organization of palliative care services at the level of district hospitals, distribution within chronic disease wards, (%)

The separation of the patients-beneficiaries of palliative care from the chronic patients is done by granting free salons. A doctor in the ward explained it to us: "We strive, humanely, to put the patient in a separate salon".

In some medical institutions the officials have invoked that they do not need many beds, because the patients do not want to be hospitalized and prefer the care at home, next to relatives and family. In an institution the manager announced that they had reduced the number of beds for palliative care from 10 to 3, because there were no requests. Other managers claimed that family doctors are reluctant to refer patients to the hospital. At the same time, in some institutions it was noted the over-demand for palliative care services. In such cases, according to the words of a ward head: " if there is a line in the chronic patients, then the palliative patients have priority in hospitalization".

With regard to the placement of palliative care beds together with the beds for chronic patients and geriatrics, the opinions of the managers involved in the study were divided. Some managers believe that "7-8 beds are sufficient for palliative care located in the chronic care wards" and that the "Specialists in the care of chronic patients are sufficient to provide care to the patient in palliation". At the same time, many managers believe that: "It is necessary to open a specialized palliative care ward"; "Patients in palliative care are dying, they often require special care, and the combination with chronic patients leads to depression"; "In a specialized section the service would be much more qualitative".

The data gathered from the applied grid showed us that the use of palliative care beds in the district hospital institutions was estimated by the managers as follows: they are overloaded, being a long waiting list (24%); insufficiently requested (50%) and sufficiently used (26%).

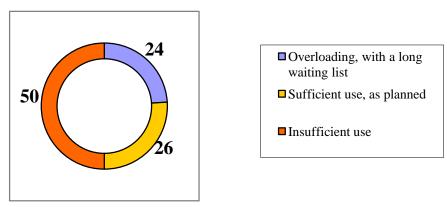


Figure 5.2 Appreciation of the degree of use of palliative care beds at the level of district hospitals (%)

The salons provided for palliative care are usually small and are not adapted to the specific of the care of a terminal patient. The number of beds in a "palliative salon" varies in average between 2-4 beds.

From the data collected by the applied grid we found the area offered for a palliative bed. Thus, the declared area for a palliative bed in the institution is:  $4 \text{ m}^2 - \text{in } 14 \text{ hospitals } (41\%)$ ;  $5 \text{ m}^2 - \text{in } 2 \text{ hospitals } (6\%)$ ;  $6 \text{ m}^2 - \text{in } 9 \text{ hospitals } (26\%)$ ;  $7 \text{ m}^2 - \text{in } 3 \text{ hospitals } (9\%)$ ;  $8 \text{ m}^2 - \text{in } 5 \text{ hospitals } (15\%)$ ;  $9 \text{ m}^2 - \text{in } 1 \text{ hospital } (3\%)$ .

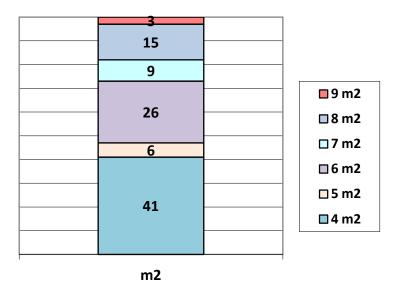


Figure 5.3 The surface granted for a palliative bed at the level of district hospitals (%)

Generally, the wards are not equipped with functional / adjustable beds according to the standard with the provided accessories (3-piece mattress, hydraulic mechanism and electrical control). Moreover, the beds do not have mattresses that prevent the appearance of bedsores, with washable surface.

In most of the visited salons there were no dividing partitions, bedside tables for each bed, mobile tables for each bed, washable medicine armchairs, cabinets for patients' personal items, sinks.

Most of the visited wards are not equipped with their own sanitary group and are not adapted to the needs of patients so as to allow them easy access to the sanitary groups, including for patients in wheelchairs. In no visited medical institution there were observed sound and visual alert systems installed in the salons to allow the staff to be called by the patients.

Also, not all wards are endowed with medical equipment relevant to palliative care (for example: infusomats).

Patient sanitary groups usually include toilets (WC) and showers, which are not suitable for this category of patients. There were not identified elevators for the mobilization of patients, as well as separate space for washing, disinfection, drying and storage of urinals, all medical accessories being kept in the rooms where are located the sanitary groups. Most of the visited hospital medical institutions do not have refrigerated rooms specially arranged for the temporary storage of the bodies.

Only in a public medical-sanitary institution at district level there is a mobile team specialized in palliative care (Cahul), which is made up of its own staff. It is organized and financed at the moment from the sources of the NGO Hospice of Hope, with the intention of subsequently passing to contracting from the CNAM (National Health Insurance Company).

Regarding the existence of an ambulatory of palliative care within the district hospital, none of them has it as a structure with endowment, according to the National Standard of Palliative Care.

From the discussions conducted with the hospital managers we observed a resistance to the idea of organizing outpatient palliative services and of the mobile team. Many managers believe that such services are not required at the district level: "At the moment, the organization of palliative care service does not require the organization of an ambulatory."; "There is no need in such an ambulatory."; "Mobile teams cannot cover the most extreme situations of palliative help".

Most are of the opinion that these services should be geared towards primary medical assistance responsibility: "Such an ambulatory would be of real use in primary medicine."; "In outpatient conditions, palliative assistance must be provided by the family doctor.", "I believe that specialized mobile teams would be needed in primary medicine".

Most managers recognize shortcomings in the possibilities of organizing these services at an appropriate level because of the "Lack of space, lack of specialists trained for palliative care.", "The payment of services - specialized mobile teams - does not cover the costs - gasoline, car, driver; must have well-trained teams, ready 24/24 to provide assistance".

This negative attitude from the part of the managers with regard to the organization of assistance / palliative care services indicates deficiencies in the proper perception of the organization of this service, of the role of each actor, as well as serious gaps in the training and information of the managers in the field of palliative care management according to the international and national recommendations.

The attitude towards the way of organizing an ambulatory of palliative care within the hospital and its impact on the coverage with palliative care services at district level is a pro in

minority, the arguments being: "I agree, in case the institution has spaces and specialists", "it is necessary to organize, it will decrease the number of hospitalized patients - respectively the expenses will be reduced", "it must be organized in all hospitals, besides the chronic care units", the majority being against, coming with the following counterarguments: "in ambulatory conditions palliative care should be provided only by the family doctor", "there is no need in such an ambulatory", "lack of adequate space, lack of specialists trained for palliative care".

#### Accessibility of palliative care provided in the hospital wards

The hospitalization of patients is usually done through the referral ticket from the family doctor. From the information presented in the questionnaire - grid, it turns out that the patients arrive in the hospital on a palliative bed at the referral of the family doctor (100%), of the oncologist (85%), of the treating physician (35%), at the request of relatives (41%) and through the emergency medical assistance service (6%).

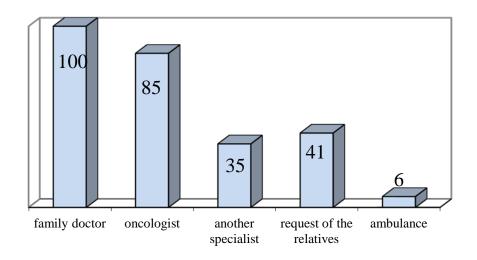


Figure 5.4 The way of hospitalization of patients for palliative care (%)

However, some officials of the hospital institutions have invoked the tendency of family doctors to hesitate to refer to hospital institutions, to avoid conducting basic medical investigations of the patients, and to guide them to receive urgent medical assistance for hospitalization. Respectively, all the expenses for medical investigations are borne by the hospital medical institutions.

At the same time, it was invoked that the family doctors do not indicate in the referral tickets that the patient needs certain palliative care. A doctor explained to us " they write in the recommendations section, simply for "treatment of chronic diseases"".

From the grids completed by the hospital managers we observe that some of them consider that there is a permanent connection with the level of primary medical assistance by creating a waiting list based on the requests of the family doctor (79%), while others say that there is no cooperation, the family doctor makes the referral and the patient goes directly to the hospital for palliative care (21%).

Patients with pain in cancer are sent by referral ticket from the territorial localities from the doctor of profile, who is usually the oncologist.

When asked if the district population knows about the access to palliative care services, a large part of the managers said that the population knows, as evidenced by the frequent addresses from relatives of serious and incurable patients (70%), who go independently to the family doctor and ask for a referral ticket. However, every fifth manager (21%) considers that the population does not know about the available palliative care services, and one in ten managers is convinced that the population knows, but does not use this service.

According to hospital managers' affirmations, on average, the number of hospitalizations per year of patients in palliative care reaches 500-600 patients. Based on the data provided in the applied grids, we observe the tendency of increase of the number of patients who have benefited from palliative care at the level of district hospitals during the last years.

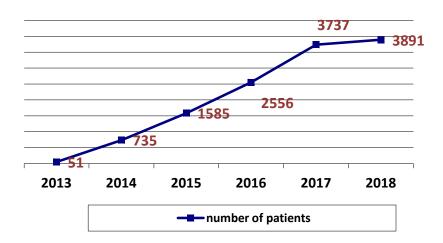


Figure 5.5 Number of patients who have benefited from palliative care at the district hospitals level (abs.)

Primarily people with oncological diseases are hospitalized for palliation, because, according to some respondents, " even those from the CNAM (National Health Insurance Company) gave unofficial indications that **only** oncological persons should be admitted for palliative services".

Thus, from the grid we observe that the oncological patients are accepted by all hospital institutions (100%), whereas only 70% of the institutions accept incurable non-oncological patients, usually those transferred from other wards of the hospital.

The term of hospitalization for palliative patients is 30 days per year, which, in the opinion of the medical workers, is "a nonsense". An example is the case of a patient eligible for palliative care who has been hospitalized for 40 days, as required. CNAM (National Health Insurance Company) paid only 30 days, the expenses for the next 10 days were incurred by transferring the given person

to the category of "chronic patient". A ward chief acknowledged: "Pure humanely, we can't let them go, let them out if we see them suffering and transfer them to bed for geriatrics or chronic diseases".

Therefore, in case of urgent need, when this deadline is exceeded (30 days), the service providers are required to identify solutions to cover the expenses for the next days, trying to avoid by itself the barriers imposed by the system.

#### Case study:

Patient / homeless person, without insurance policy, was urgently hospitalized during the winter on a chronic bed, although he needed palliative care. This person benefited from treatment as a patient with chronic disease, until his condition of health stabilized, on behalf of the hospital.

The manager of the institution told us: "Usually, the socially vulnerable people are not very closely monitored and visited by the family doctors, and because of this they arrive in serious / decompensated condition in hospitals, already for palliative care. Primary medicine does not help prevent these situations ... we have to solve all the complications, while there must be work done on prevention..."

In some hospitals we have identified cases when there is a narrow spectrum of conditions that are admitted for the hospitalization of the patient in palliation, namely: bedsores, dyspnea, painful syndrome and cancer intoxication. The medical staff recognizes that the spectrum is very small and needs to be expanded. This finding indicates that the medical staff does not know and thus does not respect the normative acts in force.

With regard to the multidisciplinary teams that, according to the Standard, must exist in the hospital medical-sanitary institutions where there is no separate ward for palliative care, it was found that they are missing. Most managers invoke staff shortages, in general: "The staff we have in these wards refer more to chronic care, not palliative care, not to mention the impossibility of hiring a psychologist or kinetotherapist!";

Another manager told us about this topic: "We have a large deficit of nurses, about 27 vacant positions. At the moment we do not have doctors trained in palliation, because the one who was trained is on child care leave".

In another institution we determined that out of 22 needed nurses only 10 are active. For this reason, the new ward provided for chronic / palliative care, already renovated for a year, cannot be opened.

Another problem raised is the lack of means of transport for mobile teams "if we have a car for all the hospital, how can we go?".

A good example in this regard can serve the experience of Cahul District Hospital, which with the external financial support (Hospice of Hope Foundation) created such a team. We found that only in this institution is employed a social worker and is made an interdisciplinary approach of the palliative patient. The project equipped the team with a car, which significantly facilitates access to patients.

# Ensuring the quality of palliative care in district hospitals

Being asked to give an assessment of the quality of the palliative care service within the hospital managed, 22 managers (60%) stated that it corresponds to the needs and is in accordance with the standards in force; does not correspond to population standards and needs - consider 12 respondents (40%), of which 3 persons (8%) had also other opinions (does not correspond to the contracted financing).

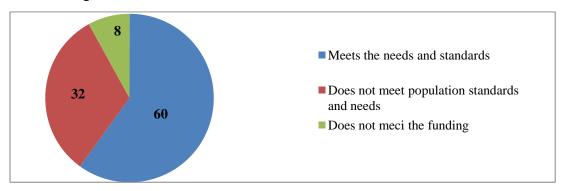


Figure 5.6 Appreciation of the quality of palliative care offered at the level of district hospitals (%)

During the discussions with the managers and the staff of the wards where palliative care is provided, we addressed the issue of the level of compliance with the National Standard of Palliative Care. Although the rate of those who reported a consistent quality of services is high - (60%), only in a few cases, during the discussions, it was stated that "The National Standard for Palliative Care is fully implemented in the hospital" and "The patients benefit from these services and are mostly satisfied". In most cases, however, we have been told that "The standard is partially implemented, must be modified, adjusted to current realities"; "There are no sufficiently trained specialists, both doctors and nurses"; "The current national clinical protocols and the National Standard of Palliative Care, in some positions are not in agreement".

This divergence in opinions is also observed in the answers to other questions in the quantitative study. Half of the managers of the hospital institutions (50%) consider that the standards are implemented. Practically every fourth (24%) of the respondents consider that they are implemented partially or in combination with other protocols, and 26% of managers acknowledged that the standards are not implemented in their institutions.

One of the basic principles of palliative care is the holistic approach of the patient. Thus, psychological counseling, spiritual support, are essential moments in the specific care of these patients. we have identified from the study that in more than half (59%) of the district hospital medical institutions, the psychologist is missing; practically, in one third of the institutions (35%) there is a psychologist employed, but who does not have training in palliative care; and only in 2 institutions (6%) activates a psychologist with special training in palliative care, who offers immediate counseling to the patient and his / her family.

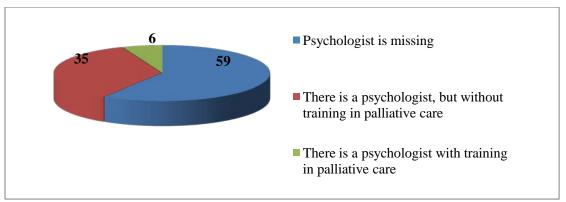


Figure 5.7 Existence of the psychological counseling service of patients in palliative care at the level of district hospitals (%)

With regard to the degree of coverage with medicines and consumables required for the provision of palliative care services, we determined satisfactory coverage in 74% of cases, while in 26% cases there is a partial coverage with medicines and consumables (9 institutions).

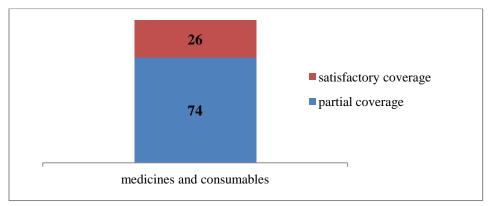


Figure 5.8 Degree of coverage with medicines and consumables for the provision of palliative care services at the level of district hospitals (%)

The staff in the wards with palliative beds confirmed to us that there is sufficient insurance with opioids. However, we could not identify any district-level hospital with opioids in the form of pills. Doctors work only with the injectable form of opioids. At our question regarding the refusal to work with the pill form, we could not receive any clear explanations, the reason being invoked that "That's how they learned..." or that "They do not know that they may also have pill forms of opioids".

The need for opioid analysesics for the following year is estimated annually in the first semester by the head of the palliative care service, according to the *Methodological recommendations*, *Estimating the need in opioids used in palliative care*".

The annual demand is sent by the medical institution until May 1 of the management year to the address of the MSMPS (Ministry of Health, Labor and Social Protection), which transmits the necessary to the subdivisions responsible for planning and organizing the centralized procurement procedures.

The administrative staff of the hospitals through the questionnaire grids were asked to identify the barriers that they notice at the moment for the provision of qualitative services in the field of palliative assistance. From the received answers were highlighted the following barriers in the organization of palliative care services within the institution: lack of qualified palliative care staff (62%); lack of space to meet the standards in force (50%); lack of funds, of adequate funding (32%); lack of collaboration with the Primary Medical Assistance (18%); lack of medicines and consumables (18%), other (9%), where the financing per case limited to only 30 days / year is listed, when the patient's and relatives' requests are for longer periods; few cases are contracted by the CNAM (National Health Insurance Company); medical staff are not motivated to re-qualify; lack of support from the society, volunteering in this area is not developed etc.

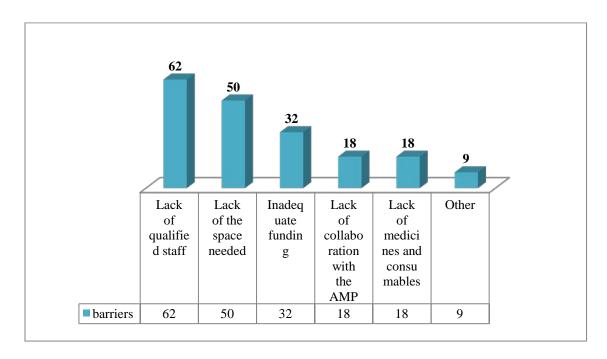


Figure. 5.9 Barriers in the organization of palliative care service at the level of district hospitals (%)

It should be mentioned that these barriers were also listed to us in the discussions with the managers or the staff of the wards where palliative care is offered. A doctor told us with regret that: "At the present moment, there is no adequate cooperation at district level to ensure the continuity of the provision of qualitative palliative care services for patients in the territory and those discharged from the hospital, which seriously influences the quality of the assistance of these patients."

In the part regarding the consent of the persons without discernment for the treatment, all the managers indicated that it is offered by relatives. When asked how to proceed when the patient has no relatives, it was mentioned that: "If there are not relatives, we treat them without consent, they sign for data protection and that's all'.

# 5.4. Palliative Care in the Municipal Clinical Hospital number 4 from Chisinau

This hospital is the only hospital medical-sanitary institution in the country which has a separate ward for palliative care.

The PAO (People's Advocate Office) team made a visit to this institution, in which it was found that the institution's building is very old and is considered *"historical monument*". The hospital infrastructure does not meet the current standards for organizing a hospital institution for people with special needs, such as those who need palliative care.

The conditions in the ward are completely unadapted for patients in palliative care. The palliative care ward is located in a separate two-storey block, but it does not have an elevator for mobilizing patients and is not adapted to their mobility needs, which hinders the activity of medical staff. Although there is a bathroom and a chair adaptable for patients, from the on-site observations we have concluded that it is not used according to the destination or is rarely used. According to the staff statements of the institution during summer time for the patient's hygiene, as a rule, there are used single-use wet wipes.

There is also a lack of space for washing, disinfecting, drying and storing urinals. The WC also does not meet the needs of these categories of patients. The rooms do not have a ventilation system and inside, there is a smell that is hard to bear.

The ward has the capacity of 30 beds, which according to the officials "are always busy". At the time of the visit, 32 patients were hospitalized. The annual flow is about 600 patients.

The number of beds in salons varies between 4-7 beds. The partitions between the beds are missing. The patients in terminal conditions, being in delicate or embarrassing situations, are exposed to humiliating situations, without having elementary conditions of respect for the dignity and intimacy of the person.

Due to overcrowding of the salons, patients have to endure the cries / groans of pain of other patients in the same salon.

Most beds do not meet the standards, only a few of them have electric mobility mechanisms. But these are also not connected to electricity, due to insufficient sockets in the salon. Special mattresses are missing to prevent the appearance of bedsores. There is no infusomats per bed / patient, as well as oxygen supply systems at each bed.

According to the manager of the institution, to the ward are hospitalized patients with chronic diseases (cancer, heart failure, fractures of the bone system, etc.). Beneficiaries of the hospital are patients from all over the country, referred by the medical specialist from the place of life.

Usually, there is a waiting list for hospitalization, which depends largely on the discharge of patients. Palliative care is only granted for 30 days per patient per year at the cost contracted by the CNAM (National Health Insurance Company).

At the expiration of the term of 30 days, if the person still needs palliative care, according to the manager, assistance is offered against payment, in the amount of MDL 343 day / bed".

If the person does not have relatives, sometimes the local public authority pays for him / her. "For the cold period of the year we have the indication, by demarche, to grant assistance to the people without a place of living, but it is a general thing, without specifying in palliative care", explained the manager of the institution.

Within the palliative care ward activate 3 doctors with work experience, but without specialization in palliation. Only one doctor had training in a specialized program. Out of the required number of five nurses, only three are active and three orderlies. The nurses received training in palliative care in Brasov, Romania. The institution lacks psychologist and stretchers.

Pain management is done by the doctor from the institution of reanimatologist-anesthesiologist profile. Opioids only have injectable form, the explanation being that "doctors are used to work only with injections". There are no requests for opioids in pills. Purchases are made through the CAPCS (Center for Centralized Health Procurement). According to the statements, the hospital chooses the forms of opioids from the list proposed by the CAPCS (Center for Centralized Health Procurement).

It is attested the acute insufficiency of consumables / stomas. "We beg them from Hospice of Hope. Those offered by the Oncological Institute are insufficient or do not correspond", told us a doctor from the ward.

The planning of consumables and devices is presented to the CAPCS (Center for Centralized Health Procurement), which procures them centrally. The medical devices are insufficient, and the existing ones are not adapted to the requirements in palliative care. The manager explained the situation to us: "The ultrasonography device dates from 2005, and a Roentgen device is missing, the service being outsourced".

Also, there is no special refrigerated room arranged for the temporary storage of the bodies. Moreover, the deceased are taken out through the central door of the hospital in the eyes of patients and their relatives / visitors.

The team found the lack of a patient database, disaggregated by disease categories, their evolution at each treatment stage, including of age and sex.

According to the Hospital administration, the institution was subjected to the accreditation procedure in 2018, which was conditioned due to certain non-conformities.



# 5.5. Pediatric palliative care at the level of hospital institutions

Although in the informative note of the MSMPS (Ministry of Health, Labor and Social Protection) it is mentioned that the district hospitals hospitalize patients with care problems in the pediatric wards in the district, if necessary, in the study we have determined that within the district hospital medical-sanitary institutions there is no palliative care service for children. The managers of the institutions mentioned to us that there is no separate funding for children in palliative care, and the CNAM (National Health Insurance Company) contract the services for palliative care without a delimitation between the elderly and children. Thus, there is no way to calculate the needs and consumables for children in palliation. At the same time was invoked the situation of lack of the interdisciplinary team specially created and trained for palliative care in children, with only the assistance offered within the Oncological Institute. We also found that no hospital institution employs a psychologist specialized in pediatric palliation.

#### IMSP (Public Medical-Sanitary Institution) Institute of Mother and Child

From the information presented by the CNAM (National Health Insurance Company)<sup>83</sup>, it turns out that the IMSP (Public Medical-Sanitary Institution) Institute of Mother and Child has been contracted for pediatric chronic diseases, starting with 2016, according to the table:

Table 5.1. Days / bed contracted by the CNAM (National Health Insurance Company) at the IMSP (Public Medical-Sanitary Institution) Institute of Mother and Child

Year	2016	2017	2018
Days / bed	209	2091	699

During the visit to this institution it was found that there are no special beds for palliative care. The administration of the institution mentioned that at the moment in our country there is no clear regulation of the concept of pediatric palliative care. Also, there is no clear definition and delimitation of children eligible for palliative care and those in intensive care.

"There are children who only need maintenance, connection to an artificial ventilation apparatus. Respectively, they are hospitalized to intensive care, while they are for palliative care", told us a representative of the administration of the institution.

At the same time, it was mentioned the annual increase in the number of children requiring palliative care, being with both oncological and non-oncological diseases.

<sup>&</sup>lt;sup>83</sup> Informative note provided by the CNAM (National Health Insurance Company) on the hospital institutions contracted for pediatric palliative care services, including the number of bed-days provided during the years 2014-2019;

At the time of the visit, four incurable children were in palliative care, being hospitalized to the Resuscitation and Intensive Care section, connected to pulmonary ventilation devices. Doctors in the ward confirmed that these children are cared for months, about a year and more each. This state of affairs creates many problems in the activity of the ward, which is intended to assist children in acute conditions, with life-threatening conditions. Permanent connection of four artificial ventilation devices to children in incurable conditions creates serious impediments in providing such equipment when more children are brought in serious conditions, which require connection to devices for maintaining vital functions.

A doctor from the Intensive Care ward explained to us: "These children stay for years connected to the devices, as patients for palliative care, but they have the specific of intensive care. Thus, if another patient urgently needs to be connected to such a device, the hospital cannot cope".

The cost of a case in palliation contracted by the CNAM (National Health Insurance Company) is MDL 343, but considering that such children are usually hospitalized to the intensive care unit, the expenses for the case far exceed this amount.

The representatives of the institution emphasized about the bad collaboration with other hospital medical institutions in the cases of incurable children: "It would be good to be transferred after a period to a children's hospice, but there is no such possibility at the moment. The parents refuse what is possible at the moment, because they consider that they will be better cared for here in the hospital. But we are level 3 hospital, we have another level of medical assistance...",

The administration of the institution provided us with details regarding the serious state of affairs concerning the financing for the assistance of these children. As there are no mechanisms for contracting and financing palliative cases, the institution has lodged a demarche to the CNAM (National Health Insurance Company) to consider the cases as chronic patients. The CNAM (National Health Insurance Company) but it refused to pay, considering them invalid, because a chronic case can be hospitalized for a maximum of 30 days, after which must follow the discharge and, only after a certain period, the repeated hospitalization. Of course, the doctors from the IMC (Institute of Mother and Child) cannot discharge the child connected to the device for maintaining vital functions. On the one hand, there is no medical institution where these children could be transferred, on the other hand, discharging the child would mean disconnecting him / her from the device, which means euthanasia - an action prohibited by the law in force. Respectively, these children remain connected for months in the Intensive Care wards of the hospital, all expenses being covered by the hospital, the day / bed being considered at the price of MDL 982. However, these expenses are reflected in considerable amounts as a deficit in the budget of the institution, which has no other additional sources than the payment of the case treated from the CNAM (National Health Insurance Company). The hospital administration gave us concrete figures regarding the situation for the hospitalization of 10 children with necessary palliative care conditions (for example: spinal amyotrophy, medullary cyst, vegetative state, pneumofibrosis, respiratory system development abnormalities, etc.), with age between 3 months and 13 years, which were hospitalized for several months to 1 year and a half. The expenses for these 10 cases reach the amount of about MDL 127

thousand, which are not validated, at the moment, by the CNAM (National Health Insurance Company) for the reason mentioned above.

Thus, due to the lack of clear regulations or a mechanism for contracting and financing pediatric palliation cases by the CNAM (National Health Insurance Company), it is seriously affected the budget and the entire activity of a very important institution in the pediatric health system in the country.

However, the administration of the institution assured us that they are very interested to open a separate ward for palliative care, with separate staff, well trained in the field, with clear funding and contracting mechanisms from the part of the CNAM (National Health Insurance Company), which would bring to normal the activity of the hospital as a whole.

# IMSP (Public Medical-Sanitary Institution) Chisinau Municipal Children's Hospital "V. Ignatenco"

Although this institution was accredited on November 30, 2018 for the provision of palliative services (2 beds), they were not included in the contracting by the CNAM (National Health Insurance Company). And in this institution, as in the case of the IMC (Institute of Mother and Child), such services are provided, the children being hospitalized under different "umbrellas" - either in the Chronic Diseases ward or in Resuscitation and Intensive Care (RTI).

The administration of the institution shared with us the serious problems it is facing in reporting these cases. Even if from 2017 the palliative beds of this institution were included in the nomenclature and such services were provided to a specific number of patients, the CNAM (National Health Insurance Company) refused their validation. As a proof, we were presented the institution's demarche of 01.08.2018 to the CNAM (National Health Insurance Company) to be validated and paid the amount of MDL 200 thousand for chronic cases (which also included children in palliative care). The administration requests the payment of this additional amount to the original contract, because the chronic cases were not included in the contract, but the institution had to hospitalize and provide assistance to these children. With regret, from the CNAM (National Health Insurance Company) was received a vague answer, which denies the reimbursement of this money, for lack of financial means. Such situations create serious financial problems for the institution, which has to pay these expenses on behalf of other budget lines, affecting the proper activity of the hospital.

The most serious problem in the interpretation of the representatives of the management of the institution, is that so far there is no mechanism for reporting / financing chronic cases / palliation developed by the CNAM (National Health Insurance Company). If the reporting of severe (acute) cases is reported through the DRG system and, respectively, validated and funded, then things are much worse in terms of chronic diseases and palliation.

The institution is open and wants to provide palliative care services, but under the conditions that CNAM (National Health Insurance Company) will clearly indicate in the contract for 2020 how to report and finance these cases.

At the time of the visit in the RTI (Resuscitation and Intensive Care) ward were 3 patients in palliative treatment. Likewise, in this institution, we also found the frequent use of artificial ventilation devices in the RTI (Resuscitation and Intensive Care) ward for children in palliative care. The hospital is equipped with 2 artificial ventilation devices. At that time, a child eligible for palliative care was connected to one of these devices (only for artificial respiration). A doctor in the ward confessed to us: "In such a situation, an emergency hospitalized child, with chances of survival, cannot be connected to the respective device, which is not correct. There were cases when 3 children were connected to 2 devices, 2 children being connected for a month".

For this reason, the aim of the specialists is for patients eligible for palliative care to be hospitalized and maintained either in a separate ward or in a specialized center. The lack at national level of a specialized institution to ensure the provision of pediatric palliative care is a major problem in the vision of the medical staff involved in the discussions.

The administration of the institution explained the inequitable situation in which it is: "The cost for the treated case is set by the CNAM (National Health Insurance Company). Of all the children's hospitals, this hospital receives least payment. We don't know what the reasons are! The expenses being the same, the CNAM (National Health Insurance Company) pays differently! Respectively, such cases of children in palliative treatment represent a financial burden for the institution. Moreover, the long duration of the patient's hospitalization influences the performance indicators of the institution. The standard indicator that should be reached is 6.5 days. Having children for long periods, we must write explanations to the ministry for outdated indicators... But what to do? Throw them out of the hospital? Another indicator of the hospital is mortality. Of course, incurable children hospitalized here, stay here till the end... This significantly influences our statistics, but also the image of the institution. Nobody takes into account that we provide palliative care".

The concern of the hospital managers is determined by the fact that the medical staff of the institution involved in the care of the incurable children is overloaded, without training in the field of palliative care.

#### IMSP (Public Medical-Sanitary Institution) Oncological Institute

According to the CNAM (National Health Insurance Company) the Oncological Institute has been contracted for the provision of palliative care services starting with 2016.

Table 5.2. Days / bed contracted by the CNAM (National Health Insurance Company) at the IMSP (Public Medical-Sanitary Institution) Oncological Institute

Year	2016	2017	2018
Days / bed	261	510	695

Children with cancer are hospitalized for palliative care within the pediatric ward. The head of the respective ward has training in palliation.

#### VI. PALLIATIVE CARE OFFERED BY NON-GOVERNMENTAL ORGANIZATIONS

#### **6.1.** Hospice-type institutions

# PA (Public Association) "Gloria", Ceadar-Lunga

The hospice was opened in 2013 with the financial support of the "Wort und Tat" Association from Germany and has a capacity of 19 beds, which are permanently occupied. At the time of the visit, 21 beneficiaries were accommodated. Patients are accommodated 2-3 in the salon.

The human resources that ensure the activity of the hospice constitute on average 24 persons, of which 6 nurses, 6 orderlies and 1 doctor with therapeutic profile.

The medical staff is permanently trained by their "curator from Germany".

With its opening, they carried out active promotion activities among the Health Centers and IMSPs (Public Medical-Sanitary Institutions) from the whole territory of the Republic of Moldova. They announced about their lunch the MF (Ministry of Finance), the hospitalization units in hospitals and the Oncological Institute.

From those reported by the hospice representative there predominate oncology patients ,, because the greatest suffering is oncological pain". The other categories of patients make up about 3-4%.

Pain management is performed by the therapist of the hospice.

The period of hospitalization in the hospice is decided individually for each patient, according to his / her needs. For example, a patient has been in hospice for 6 months.

"There are patients who feel better for a while and are asked to be discharged, where they stay a little with the family, then return", told us a doctor from the institution.

According to the representatives of the institution, the expenses for ensuring the activity are borne by the founder from Germany and only for a small part (home visits) from the FAOAM (Mandatory Health Insurance Fund). According to official data, submitted by the CNAM (National Health Insurance Company), contracting this hospice began in 2015 for palliative care provided by the mobile team and for services under stationary conditions, the total expenses constituting:

Table 6.1. Services contracted by the CNAM (National Health Insurance Company) at the Hospice "Gloria", Ceadar-Lunga

Year	2015	2016	2017	2018	2019
MDL	MDL	MDL	MDL	MDL 431	MDL 431
	419 235,30	422 694	414 103,60	312,65	312,65

#### Hospice Zubresti, Zubresti village, Straseni district

The Public Association "Prosperare" Zubresti began its activity in 2006 with the financial support of the US state of North Carolina. The hospice provides home care and care services in units with beds, with the capacity of 15 beds.

Within the institution there are 5 nurses and 2 doctors. According to the employees of the institution, the oncological patients predominate, but they also have beneficiaries with stroke and cirrhosis.

At the moment, most of the expenses for the services provided by the institution, including the remuneration of the staff are covered by the contracting with the CNAM (National Health Insurance Company).

According to those reported in the discussions, the CNAM (National Health Insurance Company) contracts the hospice for the provision of palliative medical care services under stationary conditions with number of days-bed, for example, in 2018 constituting about 4400 days / bed, for 329 patients. The limit per patient constitutes 30 days per year, and the cost of a day-bed constituted MDL 331.

We were informed that pain management is not done within the institution. The dose of opioids is only set by the oncologist and the patient is already hospitalized with this set dose. A doctor explained to us: "If in the meantime the dose needs to be increased, the hospice doctor coordinates this step with the oncologist. Relatives come with morphine vials, already released by the family doctor, at the oncologist's prescription. Medical staff only administers the opioids".

#### Hospice Isacova, Isacovca village, Orhei district

Angelus house, represents the first Pediatric Palliative Care Center, opened in the summer of 2017, in the Isacova village, Orhei district, by the Hospice Angelus Moldova. The mission of the Angelus House Center is to provide medical-social assistance, for a period of at least 14 days, to children with progressive and advanced incurable diseases, with the possibility of reintegration.

Angelus House has the capacity to hospitalize up to 15 children, in case of necessity, together with a caretaker. The services offered by the Angelus House Center are completely free, intended for children throughout the republic. They started the activity with 3 children, taking care from home in Chisinau.

Within the institution activates a doctor with 0.5 function; 0.5 psychologist-pedagogue; 0.5 kinetic therapist; 5 nurses and 5 orderlies. The medical staff benefited from training of specialists from Romania and Germany.

In 2018, 110 patients benefited from the services of the institution.

Patients with cerebral palsy and Rett syndrome predominate. The manager of the institution explained to us: "Children with mental health problems cannot be placed in Hospice, because doctors do not deal with such patients. This type of patients' needs more specific care and a palliative ward would be needed in the psychiatric profile hospital".

Children are placed in salons including with their parents. The age of the patients varies from 1-22 years. The youngest patient was 1.8 months old, with brain tumor, who died in the hospice.

According to hospice representatives: "Family doctors do not know how to refer to Hospice or the specifics of palliative care".

At the same time, because family doctors do not correctly disclose hospice information, parents often confuse services and have exaggerated expectations from the hospice. Upon

hospitalization, the Center notifies the parents by agreement that they do not provide resuscitation or ventilation services. And parents need a psychologist to deal with the situation.

During the discussion with the doctor we were told: "Since the onset of the disease, parents need to be well informed about the child's real condition and chances of survival. Better communication with primary medicine is required."

There is no pain management within the institution: The PAO (People's Advocate Office) team received the following explanation: "We do not have opioids, we do not prescribe and we do not manage pain. Patients come with their medication"

The CNAM (National Health Insurance Company) finances 90 days / year / patient, 30 days at a time. There are cases when the patient needed care for more than 90 days, sponsor funding being used.

The staff of the institution mentioned that the amount offered by the CNAM (National Health Insurance Company) (MDL **343** day-bed) is insufficient, it would be desirable to be allocated at least **MDL 600** for the day / bed.

The staff is always stressed, it is a job with a very strong emotional load, but the pay is small to motivate the employees to stay. Even if the working conditions are good, with the money offered from the CNAM (National Health Insurance Company), it is impossible to provide adequate staff remuneration. From the money offered from the CNAM (National Health Insurance Company) for the day / bed, are paid the maintenance of the building, the feeding of the accommodated children and other necessities.

If very serious children are hospitalized, the center accepts fewer children, in order for the staff to be able to provide quality services. Thus, the day / bed remuneration is insufficient and has been suggested the idea of identifying a payment mechanism per service / case. Poor remuneration induces the risk that staff will generally give up and then the institution will no longer be able to provide the respective services.

#### **6.2.** Palliative care at home

NGOs contracting by the CNAM (National Health Insurance Company) for the provision of palliative care services during the years 2014-2019 is described in the following table:

Table number 6.2. Contracting NGOs for the provision of palliative care services from the FAOAM (Mandatory Health Insurance Fund)

Year	Number of	NGOs	Total number of	Expenses for the provision of palliative care services, MDL			
	contracted to	provide	days-bed				
	palliative care se	rvices	provided (hospice)	including at:	total, MDL		
				the mobile team	units with beds	1	
	mobile team at	units		at home, MDL	(hospice), MDL		
	home	with beds					
		(hospice)					

2014	8	1	4 270	1 199 800,56	1 033 340,00	2 233 140,56
2015	10	2	5 163	1 965 865,00	1 559 742,30	3 525 607,30
2016	9	2	4 555	2 273 103,00	1 598 805,00	3 871 908,00
2017	8	3	5 977	2 699 594,80	1 978 387,00	4 677 981,80
2018	8	3	10 429	3 252 139,20	3579754,25	6 831 893,45
2019	9	3	10 429			

Note: The cost contracted from the FAOAM (Mandatory Health Insurance Fund) for PI (Palliative institution) services it is unique for all service providers

(IMSP (Public Medical-Sanitary Institution), CS (Health Center), NGOs and hospices), according to the table number 1

The PAO (People's Advocate Office) team held discussions with the representatives of non-governmental organizations on the conditions and barriers they perceive in providing palliative services.

#### Hospice Angelus Moldova Foundation

The motto of the organization is that "Man has the right to live his life and to die in decent conditions". Palliative care services at home are provided in Chisinau and within 50 km of the capital.

The administration of the organization considers that the health system in the Republic of Moldova is practically not participating enough to provide adequate palliative care in the country.

Among the most important problems faced by the NGOs working in the field of palliative care was mentioned, first of all, the inadequate financing from the CNAM (National Health Insurance Company), who purchase these services, for both home visits and days / bed.

The belief was expressed that NGOs have great potential to provide more services, visits, but these are limited in contracts with the CNAM (National Health Insurance Company). For example: Hospice Angelus for 2018 requested from the CNAM (National Health Insurance Company) 11.000 visits, being able to make these visits at that time, having enough staff, but the CNAM (National Health Insurance Company) has contracted only 6,000 visits. For the 2019 the CNAM (National Health Insurance Company) contracted the same number of visits - 6,000 visits, as in 2018.

From the money offered by the CNAM (National Health Insurance Company), the service provider cannot afford to remunerate the staff employed, send them to trainings abroad, or procure certain necessary equipment. As a result, the Angelus Hospice Foundation lost its qualified staff due to lack of remuneration. Of course, first of all, the patients who need these visits had to suffer.

The Foundation can also cover these services only due to the charity events organized, in addition to the sources from the CNAM (National Health Insurance Company). The money paid by the CNAM (National Health Insurance Company) constitutes about ¼ of the required budget.

We have been offered the example of Norway, where the amount is allocated for the needs of the patient in the palliation, with no fixed amount.

Another serious problem mentioned is the provision of consumables. Each NGO finds financial sources to buy these consumables, or receive humanitarian aid. In the last period, however,

it is unclear how the humanitarian aid reaches the Republic of Moldova, to whom and how they are distributed.

For example: Angelus House (Iscova village) requires many diapers for serious children, about 5-6 per child / day. From the money allocated by the CNAM (National Health Insurance Company), they are not fully insured, they also get them from the donated money. Other consumables such as: wheelchair, functional beds, WC chairs, crutches / sticks, cannot be purchased for the money from the CNAM (National Health Insurance Company).

With regard to stomas, the Oncological Institute only once procured centralized stomas from the money allocated by the state, a few years ago, then another planning was made, the stomas being distributed through primary medicine. But the opinion of the specialists in the field of stoma-therapy was not taken into account and the sizes of the bags purchased do not always correspond.

Previously, all stoma bags were distributed directly to Hospice Angelus, who served and distributed them to patients, being the only NGO with a specialist in stoma therapy. There was even opened a stoma-therapy office, with a doctor trained abroad and a trained nurse. Hospice Angelus served patients throughout the Republic of Moldova. The stomas were distributed according to an established weekly chart, being released directly to the patient, relatives or during the home visit.

About 2 years ago, this mechanism was changed, the stomas being distributed to the patients by the family doctors, by prescription, released from the pharmacy of the Health Center, with the purpose of ensuring faster access to them. But for a patient with a stoma, it is sometimes difficult to go for a prescription to the family doctor, and the family doctor does not release this prescription to someone else. Finally, the bags prove to be inappropriate. Hospice Angelus provided the patient with the right bag, even to the home. This problem requires an urgent solution, because for a patient with a stoma, the bag is a vital necessity.

With regard to collaboration with the public institutions, the administration of the organization considers that there are some reservations here and it is possible to collaborate much better.

There has been seen a great reluctance from the part of family doctors to get involved in palliative care. Moreover, it is considered that some family doctors do not deliberately refer patients to Hospice, or even denigrate its image.

The situation has been confirmed once again that many family doctors refuse to prescribe opioids, which can be considered an act of torture by doctors. Instead of morphine, family doctors prescribe 4 other drugs (non-steroidal anti-inflammatory drugs) that do not help. Drugs are prescribed uncontrollably, without taking into account that an opioid should be prescribed and that they have the right to do so, compared to an NGO.

The reasons for the reluctance / unwillingness to prescribe opioids may be more (indifference, ignorance, etc.), but the opinion was expressed that some measures should be developed to penalize the doctor for such situations, when they do not fulfill their obligations.

We were presented with clear arguments regarding the very bad collaboration with the hospitals in Chisinau, in particular the belief that the Municipal Hospital number 4 must be closed, because it does not meet any standard. Hospital does not send patients to this hospital

because they had conflicts with relatives or patients who were outraged that they referred them to this hospital with disastrous conditions.

An identified problem is also the fact that so far in the country there is no Hospice according to international standards. In the last 20 years, only good normative acts have been developed in the Republic of Moldova in the field of palliative care, with the contribution including of the National Association of Palliative Treatment and Hospice Angelus, in collaboration with the MSMPS (Ministry of Health, Labor and Social Protection), however, institutions that comply with these provisions are not created.

The total disapproval of the current situation in the district hospitals was exposed, in which the palliation is together with the chronic beds and the rehabilitation. It is also an ethical issue. Palliative care means a patient with a prognosis of life up to 12 months, while chronic patients are patients with a longer prognosis. In rehabilitation are patients after a heart attack, stroke, fracture, who, after rehabilitation, return home to daily life. How can the patient from the rehabilitation with the one from the palliation hospital, who dies, be hospitalized under the same conditions? Palliative care cannot be compared for a dying patient and for a rehabilitated patient. Enormous emotional involvement persists.

A negative assessment was given to the process of co-operation between hospitals and family medicine at district level, because family doctors do not want to refer patients to the hospital, considering that the CNAM (National Health Insurance Company) will not pay the case and they will lose money from that patient, which indicates a lack of knowledge of this service.

Another problem of the non-governmental organizations involved in palliative care is the prescription of compensated drugs for patients. The prescription of compensated drugs in the Republic of Moldova is done only by the family doctor. Thus, the NGO sends the palliative patient to the family doctor to prescribe the recommended preparation. There the patient faces the family doctor's upset, which arises because of the bad collaboration with this doctor, who does not recognize the NGO and its recommendations and even denigrates the activity of the organization.

Recommendations and complaints expressed:

- 1. It is necessary to notify authorities at all levels, Parliament, Government, ministries, CNAM (National Health Insurance Company) regarding the serious state of affairs in the field of palliative care. We need a national plan / program with adequate funding that also involves the creation of the palliative care service.
- 2. The authorities consider that the involvement of family medicine in providing palliative care is sufficient, but we have solid evidence that these specialists cannot cope with the real situation. It is necessary to create a well-organized service at the district level, with a trained team, that has a transport to go to the patient's home, to carry out the activity jointly with the family doctor, the hospital, the social assistance etc.
- 3. The specialist in palliation needs a very specific training, this is a profession and must be recognized in our country as a special specialty, at the level of residency training program. We have today a very small number of people trained in this field, and the

assistance that is given today to patients in the terminal stages, in our country, is far from the true concept of palliative care.

# Hospice of Hope Moldova

Hospices of Hope Moldova (representative of the international organization Hospices of Hope in the United Kingdom) is a charity organization that supports the development of palliative care services in the Republic of Moldova since 2008. Starting with 2017 Hospices of Hope Moldova initiated the development of a National Network of Palliative Care Services to provide free medical-social assistance services to people suffering from incurable diseases.

The mobile teams from 4 non-governmental organizations are currently supported (Ocnita, Taraclia, PA (Public Association) "Aripile Sperantei", Orhei, PA (Public Association) "Angelus Soroca") and a mobile team within one Public Medical-Sanitary Institutions (Cahul District Hospital). The mobile team, made up of doctors, nurses, social workers and psychologists, offers medical, social and psycho-emotional assistance services to patients, who are in the last stage of an incurable disease. The project ensures the mobile team benefits from full financial support, medicines, consumables, including stoma bags. Each team received a car, intended for home visits. The project organized the training of the staff involved in the mobile teams.

Of the problems for carrying out the activity, many were mentioned in the discussion with the representatives of the Angelus Foundation. It was also mentioned underfunding and refusal of the CNAM (National Health Insurance Company) to contract the number of visits required. For example, the PA (Public Association) "Angelus Soroca", for the year 2018 requested 1020 visits, while the CNAM (National Health Insurance Company) accepted only 937 visits, without explanation. Also, the PA (Public Association) "Aripile Sperantei", Orhei for the year 2019 requested the contracting of 5000 visits, but only 1382 visits were contracted by the mobile team and 1088 medical visits.

It was also confirmed that without additional funding, only on the money provided by the CNAM (National Health Insurance Company), these organizations could not survive. For example, for the activity carried out by the PA (Public Association) "Angelus Soroca" MDL 427 913,25 come from the CNAM (National Health Insurance Company) and MDL 470 500 from the Hospice of Hope Foundation (with 52.4% of the total budget of the organization). For the PA (Public Association) "Aripile Sperantei", Orhei things get even worse. The expenses incurred for the provision of palliative care services were covered by the contract amount of the CNAM (National Health Insurance Company) for both types of visits – MDL 400022 and the support provided by Hospice of Hope – MDL 670000

Representatives of the NGOs involved acknowledged that the amounts provided by the CNAM (National Health Insurance Company) do not at all meet the existing needs in the provision of services. The cost of a palliative visit at home (mobile team) – **MDL 181.40**, the cost of a medical visit at home – **MDL 137.25**. The cost of the visit is divided respectively: for the procurement of medicines - 11%; salary - 55%; other expenses - 34%. At the same time, for the year 2018 the PA (Public Association) "Angelus Soroca" paid the rent of the premises in the amount of about MDL

3000 / month, and the PA (Public Association) "Aripile Sperantei", Orhei paid for rent MDL 6000 per month plus communal services. The involvement of local authorities is missing.

The conviction was expressed that without the support from outside, the activity would be very difficult, only on the money contracted with the CNAM (National Health Insurance Company).

#### VII. HUMAN RESOURCES IN PALLIATIVE CARE

#### 7.1 General framework

In order for the access to palliative care to be reliable and to have continuity, it is important for the state to develop its health policies so that vocational training in palliative care remains an obligation, which guarantees the quality and professionalism of the actors involved in providing palliative services, or *ensuring education in palliative care (including ethical issues) at the level of basic training of physicians and nurses and healthcare staff at all levels must be consistent with the roles and responsibilities within the services, as well as part of human resource development.* <sup>84</sup>

It is important for the state to provide the staff of the health system with vocational training in palliative care and pain control in the basic and post-basic training through: adopting the necessary changes in the education curriculum for the health professions (medicine, nursing, pharmacy, psychology, etc.) and social assistance, to ensure that all health professionals acquire basic knowledge about palliative care and are able to provide it, no matter what level they work in the sanitary system; supporting the implementation and development of post-university educational programs and specialization in palliative care, so that patients with complex situations can receive adequate care, as well as by ensuring the availability of continuous training courses in palliative care for health personnel.<sup>85</sup>

In accordance with the provisions of the National Health Policy, the training programs of the health, education and social assistance staff will necessarily include aspects of the care of persons with special needs<sup>86</sup>.

We have not identified normative acts that provide for the training in the field of palliation of specialists other than the medical ones.

According to the National Standard of Palliative Care<sup>87</sup>, training is an integral part of palliative care and will be provided at an appropriate level for professionals, volunteers, patients,

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<sup>&</sup>lt;sup>84</sup> Strengthening palliative care as a component of integrated treatments throughout life course, Report of the WHA (World Health Assembly) Secretariat; EXECUTIVE COMMITTEE EB134/28 Session 134 December 20, 2013 Provisional agenda, chapter 15.5;

<sup>&</sup>lt;sup>85</sup> The Prague Charter: Governments are urged to alleviate suffering and recognize palliative care as a human right European Association for Palliative Care (EAPC), International Association for Palliative Care (IAHPC), International Palliative Care Alliance (WPCA) and the Human Rights Watch (Human Rights Watch - HRW) collaborates to promote access to palliative care as a human right;

<sup>&</sup>lt;sup>86</sup> Decision of the Government of the Republic of Moldova number 886/06.08.2007 "On the approval of the National Health Policy", clause 185;

<sup>&</sup>lt;sup>87</sup> Chapter VIII, Human Resources and Training, Standard 11

families, carers and the public. The providers of palliative care services need training, which will cover the specific topic.

With the development of the field of palliative care in the Republic of Moldova, clear indications have been provided to ensure the training of family doctors, community nurses / family nurses in the field of palliative care, in order to obtain the competences in the field of palliative care and the provision of palliative care services in the Republic of Moldova in accordance with the standards in force <sup>88</sup>.

## 7.2 University training

Starting with the study year 2016 - 2017 in the curricula of the State University of Medicine and Pharmacy "Nicolae Testemitanu" was included the discipline - Palliative Medicine. This fact was achieved within the project "Strengthening human resources in the field of Palliative Care in the Republic of Moldova", supported by the Soros Foundation Moldova. The implementation and coordination of this discipline, the university stage was assigned to the University Center for Simulation in Medical Training. The purpose of the course is to familiarize students with the basic principles of palliative care; management of acute and chronic pain in palliation; symptom management in palliative medicine; management of the multidisciplinary team in palliative assistance; psycho-social aspects, culture, religion and spirituality in palliative care and applied ethics or communication in palliative assistance.

The discipline represents a combination of theoretical and practical courses, applying medical training through simulation. <sup>89</sup> It is welcomed that the 40-hour training module in palliative medicine has become a compulsory one in the university program for the 5th year students from the medical faculties 1 and 2.

Analyzing the data obtained during the quantitative study conducted with the family doctors, we observe that of the participants in the research, received training in the field of palliative care less than half of the family doctors in the urban area (41.5%) and, practically, only a doctor in ten (12.9%) of the rural area was trained in the field of palliation.

<sup>&</sup>lt;sup>88</sup> Order of the MSMPS (Ministry of Health, Labor and Social Protection) number 1022 of 30.12.2015, clause 2, subclause 2;

<sup>89</sup> http://www.cusim.md/news/67-medicina-paliativ-o-nou-disciplin-n-aria-curicular

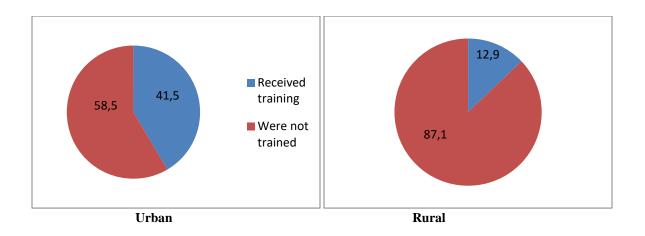


Figure 7.1. Rate of trained family doctors, (%).

Of the people who stated that they received training in palliative care, *from the urban area*, 21.1% were trained in the university curriculum, 19.7% were trained in the residency and 84.5% - in the courses of continuing medical education. *In the rural area*, only 4.5% were trained in the university curriculum, 18.1% were trained in the residency and 77.2% in the continuous medical education courses. Up to the time of the study, more than half (58.5%) of the family doctors in the urban area and almost all the family doctors in the rural area (87.1%) remained without training.

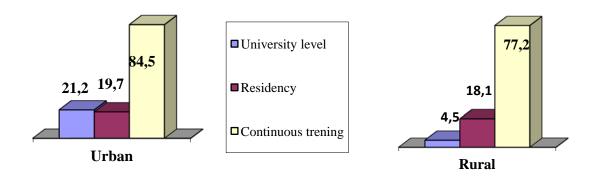


Figure 7.2. Source of palliative training of family doctors, (%).

From the data gathered from other universities in the Republic of Moldova, such as the Pedagogical University "I. Creanga" (Faculty of Psychology), the State University of Moldova (Faculty of Social Assistance) we could not identify courses in the field of palliative patient care and the holistic approach to this by non-medical specialists.

# 7.3 Training of specialists with secondary education

Information on the training of medical professionals with secondary education in the field of palliative care was requested from the Center of Excellence in Medicine and Pharmacy "Raisa Pacalo".

From those presented by the institution concerned, it was found that the training of medical specialists with non-post-secondary and post-secondary studies based on the 2016 curricula, provided for the training of professional competences in the field of palliative care by studying the discipline "Palliative care" in the "Medicine" training program, nurse qualification - 60 hours; and at the vocational training program, caring for the sick, qualifying as a Medical assistant (nurse) - 90 hours.

At the same time, it was mentioned that annually the training of the professional competences in the field of palliative care is provided by the teachers with specializations in the respective field to about 300 students (in the year 2 and 5 of studies).

Theoretical training within the "*Palliative Care*" discipline is carried out within the institution, and the practical training is carried out within the University Center for Simulation in Medical Training and at the patient's bed, in partnership with the economic agent: IMSP (Public Medical-Sanitary Institution) Oncological Institute and the IMSP (Public Medical-Sanitary Institution) Municipal Clinical Hospital number 4.

At the moment there are teams of volunteers within the mentioned institution, which in partnership with the IMSP (Public Medical-Sanitary Institution) Municipal Clinical Hospital number 4 and the IMSP (Public Medical-Sanitary Institution) Oncological Institute, provide palliative care outside of course hours (medical care, communication with patients, extracurricular activities on the occasion of world days, etc.)

We mention that the Curriculum at the Center of Excellence in Medicine and Pharmacy "Raisa Pacalo" was developed with the support of the Soros Foundation Moldova, piloted 1 year, and then introduced in all medical colleges in the country.

# 7.4 Continuous training

Continuous training in the medical and pharmaceutical field is compulsory throughout the entire professional activity and is organized under various forms of training regulated by the MSMPS (Ministry of Health, Labor and Social Protection). <sup>90</sup>

In the Republic of Moldova, training in the field of palliation has been initiated, in particular, starting with 2013, being organized from donor sources, but being sporadic. The courses were offered to both family doctors and oncologists and nurses. In the period 2015-2016, with the support of the Soros Moldova Foundation, a project to strengthen the training capacities of the USMF (State University of Medicine and Pharmacy) "Nicolae Testemiţanu". There have been developed curricula at university level (year 5 of studies), residency Family Medicine and continuous training course for family doctors.

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 $<sup>^{90}</sup>$  Article 121, paragraph (10) of the Education Code of the Republic of Moldova;

During the period 2013 - 2017, 2054 people were trained, of which 1851 (90.1%) doctors and 205 (9.9%) nurses. The assessment of the structure of the doctors according to specialty attests that 92% of the trained are family doctors, 5% - oncologists, 3% - internists or other specialties, 1.5% head doctors and managers, 0.5% - doctors in palliative care. At the territorial level were included the medical-sanitary institutions from all territorial administrative units. The trained people work at the level of CS (Health Center) (91%), at district hospital level (8%) and at other levels of health care delivery (1%).<sup>91</sup>

At the same time, consider that would need special training in the field of palliative care more than half - 69% of the respondents in the urban area and almost all those in the rural area -94.2%. Or, an important factor in the provision of any service is knowledge, in order to be able to provide this service in accordance with the standards in force.

For 2019, the plan for the continuous training of doctors and pharmacists includes 37 new courses, including the palliative care course in Primary Medical Assistance, offered to family doctors.<sup>92</sup>

However, from the discussions with the family doctors, we have identified that many do not know about the training courses in palliative care within the USMF (State University of Medicine and Pharmacy).

For example, in a discussion a doctor explained: "Patients and their relatives do not know what palliative care means, nor do I know how to properly explain them, but I understand what this is and give them help from what I know from practice. I should go to training to know more, but I don't know where I can learn it..." [FG7, doctor, 60 years].

The study has determined that in many districts the function of oncologist is filled by other specialists who do not have the necessary professional training, especially regarding the correct management of chronic pain.

We could not identify relevant sources containing provisions on the topic of continuing education in the field of palliative care for children.

As palliative care is an area that requires a complex approach, it is required an assessment of the training needs from the point of view of the reform requirements and the palliative field as a whole, or it requires an active civic and other actors' involvement, than those in the medical field such as of psychologists, social workers, volunteers, etc.

We regret to note that some legal entities, which have an important role to play in palliative care services, such as the National Agency for Social Assistance, have not had training for palliative care social workers to date. According to the answer of the ANAS (National Agency for Social Assistance) of 29.08.2019, no training program is available for the level of continuous training of social workers in the field of palliation and no specific training programs in the pediatric palliative field are developed / approved.

https://msmps.gov.md/sites/default/files/program emc 2019.pdf

<sup>91</sup> Buta G., Bradu A., Pogonet V., Carafizi N., Ignat R., Curocichin Gh. Palliative care in the Republic of Moldova reality and perspective. Available at <a href="https://ibn.idsi.md/sites/default/files/imag-file/24-29-1.pdf">https://ibn.idsi.md/sites/default/files/imag-file/24-29-1.pdf</a>

### 7.4. Current knowledge and skills for providing palliative care

Family doctors

According to the data collected in the quantitative research, the majority of the respondents from the urban area - 90.1%, as well as from the rural ones - 93.6%, mentioned that they encounter barriers in the provision of the palliative care service. Most often have been reported barriers related to knowledge in the field of palliative care. The most common barrier encountered by family doctors is the lack of training, this aspect was mentioned by half of the respondents from the urban area and practically by all from the rural area.

During a focus group discussion, a doctor acknowledged: "it is difficult to serve these patients because I do not have training courses in palliative care, but there are a lot of such patients, which is why I strive to provide prescriptions for pain relief medicines, and to provide care advice to relatives." [FG7, doctor, 54 years].

Another doctor confirmed the same situation: "I offer this service based on the practice I have, if I had been trained in this aspect, I think that the medical act would have won." [FG4, doctor, 45 years].

Another barrier mentioned by family doctors (53.8%) is the lack of ability to communicate with the patient in the terminal phase. And one third of the respondents, out of the total that was included in the research, consider the lack of ability to communicate to the patient a serious diagnosis and an unfavorable prognosis as a barrier in the provision of the service, or this is inevitable when a palliative service is offered. The ones described above confirm that family doctors do not know the recommendations in the field in force <sup>93</sup>.

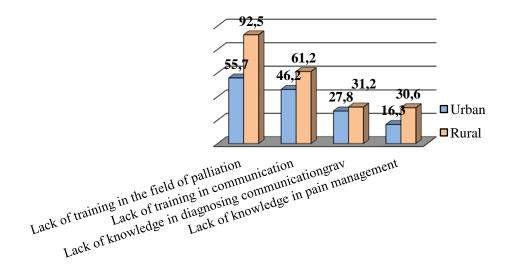


Figure 7.3. Barriers reported towards the provision of palliative care, the field of knowledge (%).

<sup>93</sup> "Guide on the application of the procedure of communication and counseling of patients", approved by the Order of the MSMPS (Ministry of Health, Labor and Social Protection) number 425 of March 20, 2018;

During a discussion a family doctor told us: "...The patient who has an incurable disease is less receptive, or at times does not want to talk to us, and I do not know how to properly talk to him, to make him understand that I want to help him. I only prescribe anti-pain medication, if I were to improve, I think it would be easier with such patients..." [FG4, doctor, 62 years].

The unpleasant emotional condition which I feel at the time of the service was frequently mentioned as a serious barrier in the provision of palliative services, by half of the family doctors. In the focus group discussions, the doctors told us the following:

"The sufferings are different, that of the family and that of the patient, I do not know how to cope, sometimes I also need counseling." [FG2, doctor, 40 years].

"The first visits I make at home, when he / she cannot come to the reception, he / she has his/ her eyes full of hope, and I do not know how to behave, I cannot detach myself, my soul hurts." [FG6, doctor, 49 years].

"...I'm afraid he / she might read despair on my face..." [FG8, doctor, 62 years].

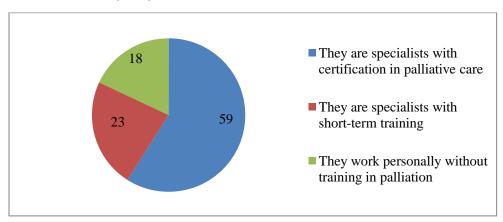
"...I cannot explain to the patient why I do not give him / her any other treatment, but I offer him / her narcotics, I come to cry, I cannot work with such patients..." [FG3, doctor, 46 years].

"...It is difficult for me to master the emotions, when I know that last week was somehow, and today is with an incurable diagnosis, no one has taught me how to overcome the mood." [FG4, doctor, 38 years].

The lack of experience in the field represents a barrier for one third of the family doctors in the urban area, whereas in the rural area, only one doctor in ten considers the lack of experience a difficulty in providing this service. And this aspect can be related to the group of young staff, with the traineeship of up to 10 years, which mainly work in the urban environment.

### Staff of the hospital institutions

From the reports of the managers of district hospital institutions, the presence of the trained staff, with special certification in the field of palliative care, from 1 to 5 specialists is stated in 20 hospitals (59%); in 8 hospitals, the staff involved in providing palliative services have only short-term training (23%); in 6 hospitals, none of the staff involved in palliative care has special certification in the field (18%).



# Figure 7.4. Qualification of medical staff involved in palliative care at district hospitals level (%)

At the same time, we mention that a large part of the managers (62%) indicated among the barriers that prevent the provision of quality medical care the lack of qualified staff.

#### CONCLUSIONS

- 1. The study determined a **high risk of human rights violations**, determined by the **limited access and insufficient palliative care services** at all levels of assistance. However, the State has the obligation to dispose of a sufficient number of goods and services in the field of health, and these, in their turn, will be accessible to every person from a geographical, economic, equitable point of view and through a wide information. Limited access and insufficient palliative care services reflect the lack of a national policy for the development of palliative care services in the Republic of Moldova and their integration into the health system of the Republic of Moldova.
- 2. The study determined a **fragmented approach** in providing palliative care due to the **lack of strategic planning for organizing and financing the palliative care services**, not taking into account the real needs of the population and ensuring the continuity of the assistance offered.
- 3. The study finds that for the most part, palliative care in the Republic of Moldova is interpreted primarily in the context of the care provided to the oncological patient, and the patients with non-oncological diseases, especially children, have extremely limited access to palliative care.
- 4. Although the multisectoral approach is a prerequisite for organizing palliative care according to international recommendations, the research has determined that **palliative care is placed solely on the responsibility of medical assistance**, other sectors being not at all / very poorly involved (social and psychological assistance, clergy, volunteers, etc.).
- 5. The study identified gaps and barriers in pain management for palliative patients, especially at primary medical assistance level. Only 1/5 of the interviewed family doctors assess pain and initiate opioid treatment which substantially reduces the population's access to anti-pain medications used, especially those in the rural area. In such circumstances, we find a *serious violation of the patient's right to avoid suffering*. Moreover, in patients who present severe pain, the failure of the state to provide adequate palliative care can be also considered a cruel, inhuman or degrading treatment.
- 6. Provision with opioid drugs is carried out without proper planning based on real needs (DCI (drug names), quantities, forms). At national level was determined an unclear process of recording and planning of the purchase and distribution of opioid drugs. It is not clear the algorithm or method of calculating the quantity of these drugs, but also for the inventory of medicines.
- 7. The research has determined **serious gaps in the financing process of palliative care services**. The costs contracted by the CNAM (National Health Insurance Company) do not cover the actual expenses (consumables, transport, staff salary, parapharmaceuticals, etc.). At the same time, although the number of palliative care providers is insufficient, they are

- contracted at a reduced capacity. This can lead to a reduction in the number of providers, which is extremely modest and discourages the emergence of new providers.
- 8. The research found **conditions that were not in conformity with the national standard of palliative care** in the IMSPs (Public Medical-Sanitary Institutions) providing hospital palliative care. There have been *determined cases of serious violation of the human dignity of the patient* when providing palliative care (the palliative care ward of the SCM (Municipal Clinical Hospital) number 4). The institution is contracted by the CNAM (National Health Insurance Company) for the provision of palliative care, although it is not accredited for providing such care.
- 9. The research reveals an acute insufficiency of trained staff for the provision of adequate palliative care services at all levels of medical assistance, both for the staff with higher education, as well as for the medical staff with secondary and inferior studies. There are no training programs in palliative care for inferior medical staff and the specialists from the non-medical fields (social assistance, psychology, clergy etc.). The training program for medical staff does not cover pediatric palliative care.
- 10. There are no official data on the number of people in need of palliative care, the number of those who have received palliative care, the number of people who have been given adequate pain control and the number of those who need it, the number of beds destined for palliative care and the database of existing palliative care providers. At the same time, is not known the volume of funding for palliative care offered at various levels of assistance.
- 11. It is not ensured the continuity of palliative care. The study attests the lack of intra and intersectoral communication (social, community assistance) on the assistance and evidence of the patient in palliation.
- 12. There is no concept regarding the path of the pediatric patient who needs palliative care.

#### RECOMMENDATIONS

#### TO THE GOVERNMENT

- 1. Declaration of palliative care as a priority in the Government's work program, with the initiation of concrete actions to ensure unlimited access to all patients with terminal or life-limiting diseases and their families to specialized palliative care services, which respond to the needs of patients.
- **2.** Taking the necessary measures to accelerate the implementation of the commitments made at the 67th World Health Assembly regarding the consolidation of palliative care as a component of integrated treatments throughout the life course.

# 3. MSMPS (Ministry of Health, Labor and Social Protection)

- 1. Development / adoption of a public policy document / strategy on the development of palliative care services and their integration in the health system of the Republic of Moldova, with the development of an Action Plan containing the actors responsible for the planned measures, adequate financial resources, with the establishment of indicators for monitoring and assessing the implementation of the plan and budgets.
- 4. Review of the existing normative framework on the organization of palliative care services (National Standard of Palliative Care, national clinical protocols, etc.) in order to ensure a multisectoral approach, according to international recommendations, so as to ensure their integration into the health system as well as and in the one of social assistance and the continuous intra- and inter-sectoral communication excluding the limits established per / patient / year.
- 5. Creating a specialized structure at national and territorial level, which could be financed from both the funds of the CNAM (National Health Insurance Company), and from the funds allocated for the social field, with the direct involvement of the LPA (Local Public Authority). It will have a database, disaggregated by age, gender, type of illness, etc., to provide relevant information on the real needs of the population (children, adults) of palliative care, for strategic planning of palliative services, including financial, medication and consumables.
- 6. Development and support of hospice type institutions, including pediatric ones, according to international recommendations, with the identification of their financing mechanism.
- 7. Development and support of a pediatric institution / hospital ward for separate pediatric palliative care for children with oncological and non-oncological diseases, with adequate training of specialized staff, both medical and non-medical.
- 8. Review the normative framework in the field of keeping, recording and releasing opioid analyses in order to ensure respect of the patient's right to avoid suffering by eliminating the restrictive barriers that impede access to the special regime medication.

# MSMPS (Ministry of Health, Labor and Social Protection) / CNAM (National Health Insurance Company)

- 1. Ensuing a clear and adequate financing mechanism, which provides for periodic review and adjustment of costs covered by the CNAM (National Health Insurance Company) at the actual expenses, so that the providers can offer qualitative services, centered on the needs of the beneficiary.
- 2. Distinguished (separate) budgeting and contracting for palliative care services based on existing real needs.
- 3. Review of the contracting mechanism by the CNAM (National Health Insurance Company) of pediatric hospital institutions for palliative care offered to children with incurable non-oncological diseases, permanently hospitalized, being dependent on medical devices for maintaining their vital functions.
- 4. Ensuring transparency and continuous information of the population on palliative care services contracted in the country.

5.

## **CNAM (National Health Insurance Company)**

1. Exclusively contracting of palliative care providers who have accreditation certificates, issued by the competent accreditation authority.

2.

# MSMPS (Ministry of Health, Labor and Social Protection) / Chisinau Municipal Council / LPA (Local Public Authority) / heads of the IMSPs (Public Medical-Sanitary Institutions) CSs (Health Centers) / CMF (Centers of Family Doctors)

- 1. Ensuring the implementation of the normative provisions on the organization of palliative care services and ensuring the development of other types of palliative care (home care, specialized mobile teams, day center, etc.) for ensuring the access of all patients and their families to such services.
  - 3. Identification of the possibilities of transferring the palliative care wards / beds of the institutions that do not correspond to the National Standard of Palliative Care in institutions that have adequate conditions for such services, in order to ensure the respect of the human dignity of the dying patient.
  - 4. Obligation of the managers of the hospital medical institutions that provide palliative services to provide funds for the basic and continuous training of all the staff involved in this activity.

MSMPS (Ministry of Health, Labor and Social Protection) / AMDM (Agency of Medicines and Medical Devices)

1. Updating the national lists of essential and compensated medicines to include the necessary medicines in palliative care, in accordance with the List of Essential Medicines recommended by the World Health Organization.

# MSMPS (Ministry of Health, Labor and Social Protection) / USMF (State University of Medicine and Pharmacy) "N. Testemitanu"

- 1. Development and initiation of compulsory pain management courses for family doctors and hospital staff with palliative beds, including pediatric ones. The development of concrete indicators for monitoring the prescription of opioids, including in the form of pills.
- 2. Revision of the education curriculum for all health professions (nursing, pharmacy, pediatrics).
- 3. Recognition of palliative assistance as a specialty, which must be included in the training program at medical training level (residency) and specialization for the medical staff with secondary education.

# MECC (Ministry of Education, Culture and Research) / educational institutions, which train specialists in the field of social assistance, psychology, etc.

1. Revision of the education curriculum with the inclusion of the initial training programs in the field of palliative care for non-medical staff (social workers, psychologists) to ensure human rights in respecting human dignity.

# MECC (Ministry of Education, Culture and Research) / MSMPS (Ministry of Health, Labor and Social Protection) / National Agency for Social Assistance

1. Initiation of training programs in the field of palliative care, including pediatrics, for the continuous training of social workers.

# **ANNEXES**

ANNEX 1

# Questionnaire for the family doctors

1. You w	ork in the er	vironment:	1. Munio	cipality	2. Dis	strict center	3. Village (rural)
2. How o	ld are you?						
1)	<30 years	2) 31-40	years	3) 41-50 y	ears	4) 51-60 years	5) >61 years
3. Wat w	ork experien	ice do you ha	ive as a fa	amily doctor	:		
1)	<5 years	2) 5-10 year	ars	3) 10-20 yea	ırs	4) > 20  years	3
4. What i	s the numbe	r of population	on in You	ar records		persons.	
5. Is this	population c	oncentrated	in one sii	ngle settleme	ent?		
1.	YES 2. NO	)					
If You	answered N	NO, please in	dicate in	how many p	laces it	is scattered. Cir	cle a single variant.
2	3 4		5	more	than 5		
6. Do Yo	u have expe	rience in the	provisio	n of Palliativ	e Care	?	
	1. YI	ES	2	. NO			3. Another answer
If You a	nswered YE	S, how man	y patient	ts did you n	nonitor	and what illnes	ses prevailed in Your
patients u	ınder Palliat	ive Care over	r the last	5 years?			
7. Do Yo	u have traini	ing in the fiel	ld of Pall	iative Care?			
	1. YI	ES	2. NO				
If You	answered Y	ES, where w	vere you	trained (ther	e may l	be several answe	rs):
	1. Ur	niversity educ	cation				
	2. Po	st-university	educatio	n (residency	')		
	3. W	ithin the cou	rses of co	ontinuous me	edical e	ducation	
	4. Ot	hers					
8. Do Yo	u think You	need special	training	in Palliative	Care fi	ield?	
	1. YI	ES	2. NO		3. I do	on't know, I'm no	ot sure
9. Do you	ı work in the	e Palliative C	are team	?			
1. YES		2. NO 3.		Anothe	r answe	er	
10. Can	You give a	n appreciatio	on to the	role of the	family	doctor in prov	iding Palliative Care?
Choose o	only one ansv	ver.					
1.	She / he r	nust be the	main per	rson to prov	vide pa	lliative care, pro	ovide complex, active
	assistance t	to both patier	nts and th	eir families.			
2.	She / he l	nas just to p	prescribe	the necessa	ary med	dication, withou	t any other palliative
	services.						
3.	She / he m	ust not be inv	olved in	the assistan	ce of th	e terminal patier	ıt.
4.	Another an	swer					

11. Which of the p	patient's needs in Palliative Care do You have the capacity to meet? Choose one or							
more answer vario	ants.							
1. Prescription of anti-pain medication								
2.	Symptom control							
3.	Psychological support							
4.	Spiritual and emotional support							
5.	Family support							
6.	I do not offer services nor for a patient's need for palliation.							
7.	Other							
12. If You answer	ed with "I do not offer services nor for a patient's need for palliation", indicate the							
causes:								
1.	I do not consider it necessary to offer this service and family							
2.	I don't have enough time							
3.	I am not clear about the services that I shall offer to the family							
4.	I feel that I do not have the necessary skills to assist a patient in palliation							
	Other							
13. Who should	the family doctor collaborate with in the provision of Palliative Care service?							
Choose one or mo	re answer variants.							
1.	Oncologist							
2.	Psychologist							
3.	Social worker							
4.	Priest							
5.	Another specialist							
14. In Your prac	tice with whom of these specialists do You collaborate with when providing							
services to a patier	nt in palliation? Choose one or more answer variants.							
1.	Oncologist							
2.	Psychologist							
3.	Social worker							
4.	Priest							
5.	Another specialist							
6.	With none of them							
15. What are the l	barriers You encounter in providing Palliative Care service? Choose one or more							
answer variants.								
1.	Lack of training in the field of Palliative Care							
2.	Lack of experience in providing this service							
3.	Lack of ability to communicate a serious and unfavorable prognostic diagnosis to							
	the patient							
4.	Lack of ability to communicate with the patient in the terminal phase							
	The large number of population in the record							
6.	Lack of knowledge and experience in initiating treatment in pain syndrome							
	- • •							

	7.	Unpleasant emotional	condition	
	8.	I do not encounter bar	riers	
	9.	Other		
_		e palliative care, how?  ? Choose only one answ		nt in Palliative care take for You on
1. 30 min.		2.1 h-2 h	3. 2 h-3 h	4. more than 3h
17. How wo	uld y	you prefer to monitor	the patient in palliative	care? Choose one or more answer
variants.	•	•	1	
	1.	When prescribing anti	i-pain medication	
		Active at home of	<del>-</del>	
		I involve the nurse the	-	
		Only when I am called	•	
		· · · · · · · · · · · · · · · · · · ·	scussions with the patien	t
		•	with the patient's relative	
		I do not monitor the p	=	
18. Who init	iates	opioid anti-pain treatm	nent for the palliative car	re patient? Choose only one answer
option.			•	· ·
-	1.	I personally		
	2.	Only the oncologist		
	3.	Another answer		
19. If you do				at is the reason for? Choose one or
more answer	· vari	ants.	_	
	1.	I am not trained in thi	s field	
	2.	Fear of side effects		
	3.	I believe that only the	specialist should initiate	the opioid treatment
	4.	Another answer		
20. Do You a			in Palliative Care? Choo	ose only one answer.
	1.	Yes, by the method _		
	2.	No, because I do not l	know the methods by wh	ich pain is assessed
	3.	The patient taken into	Palliative Care has alrea	ady indicated anti-pain treatment by
		the specialist and does	s not require pain assessn	nent
	4.	I always seek the help	of the specialist for pain	assessment

21. Give an appreciation of the quality and barriers to pain management that you provide in

1. We have all the necessary painkillers sufficient for the needs of patients, I prescribe them

palliative care granted. Choose one or more answers:

without problems at the indications.

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2. We do not have all the painkillers necessary for the needs of patients, I cannot prescribe then									
for indications.									
3. The lack of a pharmacy in the settlement where the patient lives are a serious barrier to his									
her access to anti-pain medication.									
4. I refrain from prescribing opioids for the fear that the patient will not administer the treatment									
correctly.									
5. Other									
22. Do you get used to refer to the palliative care ward of the district hospital of the patient in need									
of palliation? Choose only one answer.									
1. YES, I always do such referrals (see question 23)									
2. NO (see question 24)									
3. Another answer									
23. If you answered with YES, please prioritize by numbering from 1 to 5, where 1 is "most often"									
in which case you refer the patient for hospitalization in the palliative care ward.									
□ For treatment									
☐ To correct the treatment and the dose for opioids									
☐ To leave "respiro" place for the family									
□ When the general condition worsens									
□ Other									
24. If You answered NO, choose the cause. There may be one or more response variants.									
1. I do not know about this possibility									
2. I do not consider it necessary									
3. Patients often refuse hospitalization for personal reasons									
4. The patient's relatives refuse his / her hospitalization									
5. I do not have a transport means for transporting the patient to the hospital.									
6. I think that the Palliative Care service at home is more efficient.									
7. Another answer									
25. Give an appreciation to the activity of the palliative care section of the district hospital. Choose									
only one answer.									
1. I do not know about the activity of this section									
2. Assistance in this section leaves to be desired									
3. It is a section with qualified specialists, it offers quality services.									
4. Another answer									
26. Any suggestion on the provision of the Palliative Care service at the level of the Primary Medica									
Assistance is welcomed from You, and it will be useful for us to elucidate the problems in this									
chapter, for the development of some recommendations to strengthen this service THANK YOU									

# Interview guide for the family doctors

- 1. What are the barriers You encounter in order to provide the palliative care service?
  - ➤ In Your opinion, what are Palliative Care? What is Your role in providing Palliative Care?
  - ➤ What are the barriers (difficulties, loads, impediments) that You encounter in providing the palliative care service?
- 2. What are the barriers you encounter in the provision of palliative care service to the family / family members of the patient in Your care?
  - ➤ Which of the Palliative Care services do You offer to the patient's family?
  - What are the barriers You encounter when providing this service to the family?
- 3. What are the barriers You encounter in ensuring pain control and other symptoms associated with the disease when You provide the palliative care service?
  - ➤ What are the difficulties You face when initiating anti-pain treatment, and in particular with opioids, of the patient in palliative care?
  - ➤ Nonmedical factors, which influence the proper management of pain and symptoms in the provision of palliative care, are they a barrier in the provision of the service?
- 4. Is empathy a barrier in the provision of palliative care?
  - ➤ What is empathy?
  - ➤ Is empathy a barrier to the provision of the palliative care service?
- 5. What barriers do You encounter in the initial and on-going assessment of the social and psycho-emotional needs of the patient and his / her family in order to provide the palliative care service?
  - ➤ Do the psycho-emotional needs of the patient and his / her family create barriers to the provision of palliative care service?
  - ➤ What barriers do You encounter in order to meet the psycho-emotional needs of the patient and his / her family in the context of palliative care?
- 6. What are the communication barriers You encounter in the provision of palliative care service? Communicating a serious and prognostic diagnosis unfavorable to the patient, communicating with the patient in the terminal phase?
  - ➤ Is communication a barrier in the provision of palliative care service?

➤ Does the communication with the patient in the terminal phase, the communication of a serious and prognostic diagnosis unfavorable to the patient constitute barriers in the provision of the palliative care service?

# Grid for assessing

# the accessibility and quality of palliative care services within the district hospitals

Numb	er o	f popu	lation	of th	e distr	rict		in	habitants					
The	nun	nber	of	hosp	ital	beds	expec	ted a	ecording	to	the	regulation	s in	force
				I.	- <b>A</b> ,	voilo	hility of	tha Dal	liative C	'ara (I	PC) cor	wico		
1	Th	e wav	of or				•			•	•	enter text)		
1.		•		0	- L				umber of			πιετ τελί)		
		_	_									rd of chron	ic dis	eases
			-			, ,						in other w		
	٥.	2. D	cus o	ı par	nanve	carc	(1 C) III	the nui		,	praced	in other w	arus,	as well.
	1	There		oro.	no.	nol	lliative	care	beds	in	the	e hospita	o.1	because
	4.	111010	-	are	no	pai	manve	care	beus	111	unc	nospita	aı	because
2	A =		o mol	hila t	00mg (	mooi	 olizad in	nallia	ivo oono	withi	n tha l	nospital? (n	n anl	with x"
4.				one t	eams s	speci	anzeu n	і раша	ive care	WILIII	n me i	iospitai: (//	nark	wiin "x
		enter i												
							1				1 1		.1	
	2.	Yes,	1n	. 1	the	num	iber (	of _	<del>,</del>	fu	nded	from	the	funds
2 3371		41			1. 4		1.		. 111 . 41		•41. •	41 . 1	•4 . 1	1 1
							-	-				the hosp	itai i	neaicai-
sanıta	•			•			• `		n, x or $n$	enter i	text):			
							111					• .		
	2.	The	staff	of	anoth	ner ]	palliative	e care	organiz	zation	who	intervene	on	request
					_									
	3.							Anothe	er					answer
<b>4.</b> Is tl	here	an ou	ıtpati	ent p	alliati	ve ca	re withi	n the h	ospital?	(mark	or ent	er text)		
	1.	No_												
2	2.	Yes,		wit	.h		bec	ls,	funded	1	fron	n the	•	funds

# II. Accessibility of the service

- **5.** The selection of beneficiaries of palliative care services is performed (there may be several answers, mark with "x" or enter text):
- 1. In the order of registration in the waiting list, based on the referral from the family doctor
- 2. In the order of registration in the waiting list based on the referral from the specialist doctor

3. Another answer 6. Patients are hospitalized on a palliative bed after the referral of the (there may be several *answers, mark with "x" or enter text)* 1. Family doctor 2. Specialist doctor in profile 3. Treating physician in the hospital 4. At the request of relatives 5. Another answer 7. How many patients have benefited from palliative care annually? 1. 2018 \_\_\_\_\_ 3. 2016 \_\_\_\_\_ 5. 2014 \_\_\_\_ 7. 2012 \_\_\_\_ 9. 2010 \_\_\_\_ 4. 2015 \_\_\_\_\_ 6. 2013 \_\_\_\_ 8. 2011 \_\_\_\_ 10. 2009 \_\_\_\_ 2. 2017 \_\_\_\_\_ 8. Indicate the coverage / use of the palliative bed per year \_\_\_\_\_\_% 9. Give an appreciation for the use of palliative beds in the given institution ( $mark\ with\ ,,x"$  or enter text): 1. They are overburdened, it's a long waiting list 2. They are insufficiently requested 3. Another answer 10. List the selection criteria for palliative care beneficiaries, applied in the given institution: (there may be several answers, mark with "x" or enter text) 1. Serious, incurable patients transferred from other wards of the hospital 2. Oncology patients in terminal stages 4.\_\_\_\_\_ 11. Describe the hospital's co-operation in palliative care with family medicine (mark with "x" or enter text): 1. There is no collaboration, the family doctor does the referral and the patient goes directly to the

- hospital for palliative care.
- 2. Family doctors in the district do not know about this service and do not direct patients
- 3. There is a permanent connection between the hospital and the family doctors by creating a waiting list based on the requests of family doctors.
- 4. Another answer
- 12. Do you think the district population knows about access to these services? (mark with "x" or enter text)
- 1. Yes, we frequently have self-referrals from relatives of serious and incurable patients
- 2. No, the population does not know

3. The population refuses to use this service								
4. Another answer								
III. Quality of the service  13. How are the standards regarding the organization of palliative care implemented in the institution?								
14. What is the area granted for a palliative bed in the institution?m <sup>2</sup>								
15. Number of palliative care beds per 1 doctor								
16. Number of palliative care beds per 1 nurse per shift								
<ul> <li>17. Do you have trained staff (with special certification) in the field of palliative care? (mark with "x" or enter text)</li> <li>1. Yes, we have specialized staff in palliative carephysicians, assistants (nurses)</li> <li>2. The staff involved have only short-term training</li> <li>3. No, the staff involved in palliative care have no special certification in the field</li> </ul>								
<ul> <li>4. Another answer</li></ul>								
19. The provision of medicines and consumables necessary for the provision of palliative care								
services is made from the ( <i>mark with "x" or enter text</i> ):  1. Means of the mandatory health insurance funds intended for this purpose  2. Means of the FAOAM (Mandatory Health Insurance Fund) with another destination								
3. Another answer								
20. Appreciate the degree of coverage with medicines and consumables needed to provide palliative care services (mark with "x" or enter text):  1. We have a satisfactory coverage with all that is required for the provision of the services of PC (Palliative Care)  2. It is only a partial coverage, we have insufficiency in  a)  b)  c)								
3. We do not have the necessary medicines and consumables for palliative care services								

21.	Give	an	apprecia	ation	for	the	quality	of	your	PC	(Palliative	Care)	service	within	your
hos	pital (	mar	rk with "x	or or	entei	r text	·):								

- 1. According to the standards in force, it meets the needs
- 2. It does not meet the needs of the population because
- 3. It does not meet standards because

4.	Another	answer

- **22.** Name the barriers perceived in the organization of the PC (Palliative Care) service in your institution (there may be several answers, mark with "x"):
- 1. Lack of qualified staff in the PC (Palliative Care)
- 2. Lack of space to meet the standards in force
- 3. Lack of funds
- 4. Lack of collaboration with the Primary Medical Assistance
- 5. Lack of medicines and consumables
- 6. Other (specify)

# In-depth interview plan

# I. Availability of PC (Palliative Care) service

**1.** The way of organization of the palliative care services: What is Your opinion about the efficiency of palliative care services provided in the chronic care wards compared to a specialized palliative care ward at the district hospital level?

### 2. Mobile teams specialized in palliative care within the hospital

Do you consider their presence in the hospital as a way to improve the quality of palliative care services? – "pro" arguments, "against" arguments.

### 3. Outpatient palliative care within the hospital

How do You see the way of organizing such an outpatient ward and what would be its impact on the coverage of district palliative care services? – "pro" arguments, "against" arguments.

### II. Accessibility of the service

- 1. What is the optimal way to select the beneficiaries of care services?
- 2. Give an appreciation of the use of palliative care beds in this institution, based on how they are located within the chronic care wards compared to a specialized section in this area. "pro" arguments, "against" arguments.
- **3.** Co-operation of the hospital in the field of palliative care with family medicine: What would be the modalities of ensuring the continuity of the provision of qualitative palliative care services for the patients in the territory and those discharged from the hospital?
- **4.** Degree of informing the district population about access to palliative care services: What ways to promote palliative care services do You consider appropriate at the district level?

#### III. Ouality of the service

1. Implementation of the National Standard of Palliative Care (Order Number 884 of 30.12.2010)

Do you consider this standard implemented within Your institution?

- 2. Trained staff (with special certification) in the field of palliative care a necessity or an option for Your institution?
- **3. Psychological counseling in patient care within palliative care services.** Do You consider effective counseling by a psychologist not trained in palliative care?
- **4.** Provision of medicines and consumables necessary for the provision of palliative care services What are the criteria for planning the need for palliative care services and for estimating the quantities of medicines and consumables needed for this purpose?
- 5. Your opinion regarding a possible regionalization of the provision of palliative care services vis-a-vis the current way of organizing the provision of these services at the level of district hospitals—,,pro" arguments, ,,against" arguments.