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Project: Palliative Care – My Care, My Right

Needs and Barriers of Implementation of Palliative Care Services in Montenegro

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Abbreviations

CSO – Civil society organization

MONSTAT - Statistical Office of Montenegro (in original: Zavod za statistiku Crne Gore)

IOCCP - Institute for Oncology of Clinical Center Podgorica, Montenegro

MZCG – Ministry of Healthcare of Montenegro (in original: Ministarstvo zdravlja Crne Gore)

CCM - Clinical Centre of Montenegro

WHO – World Health Organization

Introduction

Wider Picture: Project background

The project *Palliative Care - My Care, My Right* is created thanks to joint effort of regional network established by three CSO from Serbia, Albania and Montenegro - *Belhospice* Serbia, *Ryder* Albania and *Civic Alliance* Montenegro. The regional network was established in 2019 with aim to work on common challenges in palliative care - through sharing experience, advocating for policy changes and expand national and regional networking. The project *Palliative Care- My Care, My Right* is the first operative step of the regional network.

The main idea of the project is to enhance regional cooperation among CSOs in order to promote civic space to protect one of the most vulnerable groups - patients with life limiting prognosis and their families. The enhancing the capacity of CSOs is seen as the key element that could play a vital role in future implementation of systemic palliative care and protection of human rights of the patients with life limiting illnesses and their families in Serbia, Albania and Montenegro. Because, in all three countries (Serbia, Albania and Montenegro) palliative care is in early stage of development and the population aging rapidly increasing as well as the incidence rates of life threatening illnesses (such as cancer, neurological and cardiovascular diseases), the improvement of infrastructure, services and network capacity building is seen as a developmental priority.

The focus of this phase of the project was identification of needs/barriers through participatory research with key stakeholders – providers and/or receivers of palliative care (patients and members of their families). In each of three countries was conducted national survey in order to understand specificities of local societal and institutional context in which institutional and CSOs intersect and providers and receivers of palliative care interact.

National survey: Montenegro

The survey was focused on social actors (providers and receivers of palliative care) involved in the process of medical and social care of patients who require palliative care, living in the territory of Montenegro. The main starting premise of this survey was that it is impossible to formulate adequate healthcare and social policies that regulate the field of palliative care without, on one side, precise insight into real needs of the palliative patients and their caregivers, and on the other side insight into institutional and CSOs capacities to bring and participate in this process. In this sense, one of the research priorities for our project team was the need to hear, articulate and make visible the voices of different stakeholders involved in the process of palliative care of patients with different health issues, and also to recognize, map, systematise, and articulate the real health, social and other problems of the patients, members of their families, institutions and CSO's activists and to offer recommendations that will lead to their mitigation and/or inter-systemic¹solution in the future.

Empirical data were collected in two phases. In the first phase the data has been collected through in-depth interviews with palliative care providers (doctors, nurses, medical technicians, caregivers, social workers, psychologists, policy makers), as well as the patients themselves and their family members. The focus of this research phase was to reconstruct the needs and potential barriers in their satisfaction that patients who receive palliative care, members of their families and palliative care providers perceive as important. In the second phase we shift our research focus on actual institutional/organizational capacities and resources that could potentially contribute to future network (national and regional) of systemic palliative care and protection of human rights of the patients with life limiting illnesses and their families. In this phase the data has been collected through desk analysis and in-depth interviews with the representatives of institutions and CSOs that are, in different ways, involved into field of palliative care.

¹Inter-systemic – because most problems that these patients face arise from the fact that the jurisdictions of certain social subsystems and concrete actors employed therein have not been clearly defined.

Method and Sample

Survey sample

In order to ensure the sample representativeness, we have stratified the sample according to the following criteria:

- (1) *Interviewee's identity*, i.e. the position of the interviewee in the palliative care process. In this sense, we have stratified the sample into three strata: (a) patients/recipients of palliative care and their family members, and (b) employees in healthcare and social care institutions and CSOs dealing with the provision of palliative care (providers).
- (2) *Interviewee's gender*.
- (3) *Interviewee's place of residence*. In this sense, we try to cover three regions in Montenegro – (a) Podgorica, the capital city and the biggest town in Montenegro, (b) the north of Montenegro and (c) the south/ the coast of Montenegro.

Our assumption was that with such an approach we would be able to cover a broad range of problems faced by palliative patients, living inside different subcultural contexts in Montenegro.

In the selection of concrete interviewees, we relied on the professional expertise, experience and the insider's position of employees in *Civic Alliance*, CSO from Montenegro which performed selection of the interviewees and in-depth interviews with them. The selection of the interviewees was following two different subsample plans: (a) selection of receivers/beneficiaries of palliative care (patients and their family members), and (b) selection of the providers of palliative care.

The representativeness of the receivers/beneficiaries of palliative care subsample was following primarily the idea of capturing the gender (one half women and one half men) and geographical (one third interviewees from Podgorica, one third from the north and one third from the south of Montenegro) variety of reactions on challenges, and secondary (if it is possible to perform in the field) the variety according to other interviewees' characteristics (marital status, age, social strata, occupation etc.).

The planned subsample of the providers of palliative care was following the other logic of sampling. Because, the field of palliative care supply is relatively poorly explored in Montenegro, especially outside institutional system, we decided to apply chain-referral sampling. As a non-probability sampling technique, chain-referral sampling, enables mapping of the current supply of different palliative care services available to patients and their families in a significantly shorter time. We identify the initial interviewees/providers of palliative care in our interviews with palliative care beneficiaries/receivers. These initial interviewees provide us referrals to additional interviewees who are employees or activist of different CSOs involved in the process of palliative care. In the focus of this part of the research were institutional/organizational capacities and resources of the intuitions and CSOs which, in various ways, participate in palliative care process on the territory of Montenegro. The research tries to identify overt and/or hidden capacities and resources of these institutions/CSOs that could potentially contribute to future network (national and regional) of systemic palliative care and protection of human rights of the patients with life limiting illnesses and their families. We choose the method of chain-referral exponential discriminative sampling² in order to explore the current (institutional and CSOs) supply of palliative services in Montenegro.

The survey instrument³ was divided into three (for palliative care beneficiaries) and four (for palliative care providers) segments. The instrument for palliative care beneficiaries was organized around three major topics: (a) interviewees' understanding of the palliative care, (b) interviewees' perceptions of the quality of palliative care in Montenegro, and (c) different types of support to patients and their families in the palliative care process inside and outside the existing institutions, and (c) interviewees' opinions about the possible space for organized social action and social actors (institutions, CSOs and absent services) who should be the key bearers of future network for palliative care. The instrument for palliative care providers try to collect data about: (a) interviewees'/institution's/CSO's understanding of the concept of palliative care and its components, (b) institutional/CSO experiences in cooperation with other institutions/CSOs in the

² Exponential discriminative snowball sampling is the approach in which each subject gives to interviewer multiple referrals. However, interviewer do additional selection of referrals, according to current status of the research (already included institutions and CSOs and professionals/experts who are employed in them) (Dudoyskij, 2018).

³See Annexes 1 and 2 in the Appendix.

process of palliative care, (c) interviewees' insights about: potential discrimination, intra-organizational/intra-institutional and inter-organizational/inter-institutional tensions, the dysfunctionality of the existing health, wider institutional system and civil society, and institutional and organizational good practices, and (d) interviewees' opinions about the possible space for organized social action and social actors (institutions, CSOs and absent services) who should be the key bearers of future network for palliative care.

Method

The collected empirical data has been analysed with the aid of discourse analysis. Just like any discourse analysis, this one also focused on the language and meanings produced through speech using language (interviewees' testimonies/narratives), because language is not a neutral medium used "just" for communication and the exchange of information. Language is a social field within which our knowledge of the world around us is actively formed. In this sense, the discourse analysis used in this research did not treat the language used by interviewees as just a reflection of the reality, but as a medium which controls this reality and organises it for us (Tonkiss, 1996:246). The narrative of each individual interviewee is seen as a place where social meanings are articulated and reproduced, and certain (personal and social) identities are formed.

The discourse analysis of the empirical material focused on two central topics. One being:

- a) *Interpretative context* (Tonkiss, 1996:249) (in our concrete case, it is constituted within a limited area where the everyday lives of palliative patients take place, shaping also the narrative(s) on palliative care), and:
- b) *Rhetorical organisation of the narrative* (Tonkiss, 1996:250).

The interpretative context relates to the social circumstances within which a certain narrative is formed, since each narrative is constructed within a specific social context to which its authors are always adapting in a certain way (consciously or unconsciously). In this sense, the research of the interpretative context implies a type of quest for meanings which can be found and understood only if you go "beyond the narrative" in the analysis (Tonkiss, 1996:249) and search for an interpretation which stems from the concrete social and cultural context inside which, in our case,

the interviewees' narrative was created. On the other hand, the analysis of the rhetorical organisation of the narrative implies a quest for a specific matrix of arguments, which on the one side arises from a chosen interpretative strategy, and on the other side from an opinion-based, theoretical and/or ideological discourse (which can be induced from the outside, as a part of the broader strategy of adapting to a condemning institutional context within which it is often impossible to exercise the right to a certain type of healthcare and social service which the beneficiaries perceive as important) within which the Interviewee lives, acts and thinks. Understanding this interpretative context and structure of argumentation within the narrative is particularly important for illuminating specific identity positions of interviewees which are constituted within these specific local and (extra)institutional environments, which once again need to be understood in order to recognise and articulate the real meanings of existing and non-existing standards for the provision of palliative care and the respect of human rights of palliative patients.

Realised sample

The empirical data on which the analysis was based have been collected with the use of in-depth interviews with stakeholders that have been involved in the process of palliative care, either as its beneficiaries/receivers (patients and their family members) or providers (employees/activists of different institutions and CSOs, or persons who participate in the process of creating public policies which include problems and their operationalisation on the field, which are connected to palliative care). According to the sample plan presented in the one of the previous chapters it is performed all together 20 in-depth interviews – 11 with palliative care receivers and 9 with palliative care providers.

In the following tables we will describe the main characteristics and limitations of the palliative care receivers' subsample. These characteristics and limitations point to the main problems concerning, on the one hand, the availability, institutional and non-institutional capacities of palliative care, and on the other hand, the cultural context within which this process takes place.

In our research we try to articulate the absent voice of palliative care beneficiaries, which is why we predominantly targeted palliative care patients and secondary, if the patients are not in the condition to participate in the interview their family members (see table 1).

Table 1. – Distribution of the palliative care receivers according to their identity

Interviewee's identity	Palliative care receivers
Patient	8
Family member	3
Total	11

Source: The project *Palliative Care - My Care, My Right*

The majority of sampled interviewees were women (see table 2). Although this sample has an unbalanced gender structure, it clearly depicts a cultural context in which care work for the infirm is always linked to traditional constructs of femininity.

Table 2. – Distribution of the palliative care receivers according to their gender

Gender	Palliative care receivers
Male	1
Female	10
Total	11

Source: The project *Palliative Care - My Care, My Right*

Concerning the distribution of the interviewees according to the place of residence it could be seen that more than half of them lives in Podgorica, more than one third on the coast of Montenegro and only one interviewee in Northern Montenegro (see table 3). Unfortunately, this distribution corresponds with distribution of the institutions and CSOs who are involved into palliative care process.

Table 3. – Distribution of palliative care receivers according to their place of residence

Place of residence	Palliative care receivers
Podgorica	6
Northern Montenegro	1
Southern Montenegro	4
Total	11

Source: The project *Palliative Care - My Care, My Right*

The majority of the sampled interviewees are married (see table 4).

Table 4. – Distribution of palliative care receivers according to their marital status

Marital status	Palliative care receivers
single	2
married	7
widow/widower	1
divorced	2
Total	11

Source: The project *Palliative Care - My Care, My Right*

However, the sample characteristic of the biggest concern is the distribution of the interviewees according to their education. According to the last census data: „of the total population aged 15 and over, 260277 or 52% have completed secondary school education. Of that number, however, 27285 are currently attending college. 17% of the population of Montenegro has a college or university degree, whether it is ‘old’ or ‘New – Bologna’ higher education system.” (MONSTAT, 2012) The research sample do not follow this distribution (see table 5).

Table 5. – Distribution of palliative care receivers according to their education

Education	Palliative care receivers
Elementary school	0
Secondary school	4
Higher education	7
Total	11

Source: The project *Palliative Care - My Care, My Right*

The second stakeholder whose voice we have tried to articulate are palliative care providers. As it is mentioned above in selection of the palliative care providers we apply another technique of sampling - chain-referral exponential discriminative sampling. In interviews with palliative care receivers we identify *Institute for Oncology of Clinical Center Podgorica* (in further text IOCCP) as an important node of palliative care in Montenegro. Therefore, we choose this institution as a starting point of our chain-referral sampling. Our research sample include 9 professionals who are dealing with palliative care in Montenegro. Through cross-referral sampling we identify two healthcare institutions and one CSO that are active palliative care providers – IOCCP, Institute Simo Milosević in Igalo and CSO “Zračak nade” (“A Ray of Hope”) from Pljevlja. Among our interviewees there were medical doctors, specialists in oncology, internal medicine, junior doctors on specializations, as well as social workers. 6 of them were women and 3 of them men. The oldest interviewee was born in 1954, and the youngest 1991.

Evan this cursory glance at our research sample shows certain structural interpretative limitations of our analysis. The most important are two: (1) first relates to the absence, of interviewees among palliative care receivers who completed elementary education, and underrepresentation of those who completed secondary education. As it could be seen from the census data these two categories make up a significant part of Montenegrin population (up to 82% - about 30% of those who either do not have elementary education or completed only elementary education and 52% of those who completed secondary education), which in real life are faced with the biggest difficulties arising from social deprivation and marginalisation; and (2) second relates to the underrepresentation of the interviewees from the Northern Montenegro among both strata (palliative care receivers and providers) within research sample. In this sense, it is important to point out that the results of this survey should be understood through this perspective.

Survey Results

Palliative care is an interdisciplinary specialisation which is based on the desire to improve the overall care for patients suffering from incurable diseases which significantly reduce a person's lifespan. Specialists dealing with palliative care aim on the one hand to mitigate the patients' suffering and improve the quality of their lives, and, on the other hand, to provide support to their families (Gelfman, Meier, Morrison, 2008: 23). The basic aim of this survey was to try to understand how palliative care in Montenegro looks and what kinds of challenges the social actors who are involved in this process in different ways are facing. In this sense, in the survey, we aimed to understand the specific positions of different social stakeholders – patients, their family members and also doctors, nurses and technicians, activists of CSOs dealing with the provision of palliative care.

Availability of palliative care

On the legislative level government of Montenegro recognises the importance of availability of general healthcare services and palliative care as one of its important parts. This is evidenced by two documents adopted by the Montenegrin government in the last 10 years - *Master Plan for Health Development of Montenegro 2015-2020*, Ministry of Health of Montenegro (*Master plan razvoja zdravstva Cene Gore 2015-2020*, Ministarstvo zdravlja Crne Gore) adopted in 2015, and *National Cancer Control Program*, Ministry of Health of Montenegro (*Nacionalni program za kontrolu raka*, Ministarstvo zdravlja Crne Gore) adopted in 2011. In one of them it is said:

“Universal health coverage is one of the most powerful principles of public health that can reduce health disparities between different population groups. Universal health coverage means that all people have access to the health care they need, including: promotion, prevention, treatment,

rehabilitation and palliative care (underlined IJ), without financial risks for users, in exercising the right to health care.” (MZCG, 2015: 23)⁴

Even though in terms of legislation, state of Montenegro recognises the need to organise the service of palliative care for this extremely vulnerable category of patients, and also the rights of patients to get palliative care if they suffer from incurable diseases⁵, especially for cancer patients. The both documents address the importance of establishing palliative care as an integral part of the health care of cancer patients.

“**Priority 2:** refers to increasing the availability and quality of treatment, greater professional training of health professionals and associates for the treatment of cancer patients, improving the availability of diagnostic procedures (mammography, colposcopy, colonoscopy), therapeutic procedures (surgery, radio and chemotherapy), drugs, as well as adequate palliative care (underlined IJ) for all citizens.” (MZCG, 2015: 25)⁶

“... Palliative care of oncology patients is one of the most important aspects of national cancer control programs, from the moment of diagnosis of malignant disease, during its entire course, including support to the family in the period of mourning, after the death of the patient.” (MZCG, 2011: 24)⁷

However, in reality, at least according to the statements of our interviewees, this right is *not easily consumed in practice*:

“Palliative care does not exist in our country, what I imagined to be palliative is that a person dies and let's ease his suffering, but that's not all. Long before I got sick, I had a patient in my family.

⁴ In original: “Univerzalna zdravstvena pokrivenost (universal health coverage) je jedan od najmoćnijih principa javnog zdravlja kojim se mogu smanjiti razlike u zdravlju među različitim populacionim grupama. Univerzalna zdravstvena pokrivenost podrazumijeva da svi ljudi imaju dostupnu zdravstvenu zaštitu koja im je potrebna, uključujući: promociju, prevenciju, liječenje, rehabilitaciju i palijativnu njegu (podvukla IJ), bez finansijskih rizika za korisnike, pri ostvarivanju prava na zdravstvenu zaštitu.” (MZCG, 2015: 23)

⁵ This is also supported by the following documents: (1) *Master Plan for Health Development of Montenegro 2015-2020*, Ministry of Health of Montenegro (*Master plan razvoja zdravstva Crne Gore 2015-2020*, Ministarstvo zdravlja Crne Gore) adopted in 2015, and (2) *National Cancer Control Program*, Ministry of Health of Montenegro (*Nacionalni program za kontrolu raka*, Ministarstvo zdravlja Crne Gore) adopted in 2011. In these documents palliative care is explicitly referred.

⁶ In original: “**Prioritet 2:** odnosi se na povećanje dostupnosti i kvaliteta liječenja, većom stručnom osposobljenošću zdravstvenih radnika i saradnika za tretman oboljelih od raka, poboljšanje dostupnosti dijagnostičkih procedura (mamografija, kolposkopija, kolonoskopija), terapijskih procedura (operacije, radio i hemo terapija), lijekovima, kao i adekvatnoj palijativnoj njezi (podvukla IJ) za sve građane.” (MZCG, 2015: 25)

⁷ In original: “... palijativno zbrinjavanje onkoloških bolesnika predstavlja jedan od najvažnijih aspekata nacionalnih programa za kontrolu raka, od trenutka postavljanja dijagnoze maligne bolesti, tokom njenog cjelokupnog toka, uključujući podršku porodici u periodu žalosti, nakon smrti oboljelog. (MZCG, 2011: 24)

My father died of lung cancer. The doctors diagnosed him and just sent him home. We didn't even know what to do with him then. Unfortunately, even today in Montenegro, real palliative care does not exist.” (patient)

„No one in the hospital will accept a dying patient if there is no therapy for him.“ (family member)

„On the positive list are all the drugs, even the expensive ones we need. But we do not have palliative care. At this moment, I am on the "third line". When I get to the "fifth line" the doctors will tell me to go home and that's it, now let yours work hard and keep working.“ (patient)

“Palliative care services are not available to patients in Montenegro. I think it would help if there were brochures that the oncologist would give when we came to him, and that the brochure had telephone numbers through which the patient or a family member could get information.” (daughter)

In the reality of the existing healthcare and social care system, this right often remains only a possibility that most patients and their family members can never experience. Most interviewees complain about the elementary *lack of information*:

I have not been informed that in Montenegro there is this type of treatment of patients, as well as appropriate institutions that would conduct palliative care for both patients and family members. (patient)

“No information available. I have absolutely no information about this type of treatment and that it is available in Montenegro, although I have a family member who has been suffering from an incurable disease for two years.” (family member)

“... medical workers have not presented us with the possibility of being entitled to palliative care.” (patient)

Sometimes, experienced and/or dedicated *doctors* compensate this systemic deficiency, which in individual healthcare trajectories of patients can make a difference between survivor and death:

“Palliative care is not very accessible. Most people do not even know what information they can get about services. Much depends on what kind of doctor you have. If the doctor is good, he/she will give you all the necessary information, if your doctor is someone who is easily annoyed, the thinks will be even worse.” (patient)

Those who have not been lucky enough to come into contact with medical workers who think outside the framework defined by the institutional acts on job systematization and the job descriptions contained in them remain without important information:

“... doctors work hard, but patients lack information. We could not find privately, to pay, to go and get information on what and how to do after chemotherapy. After the first chemotherapy, I got thrombosis and ended up in the hospital... because no one told me what to use before chemotherapy.” (patient)

“People have no information on how to live with the disease, how to eat and everything else.” (wife)

The consequence of this lack of information is that patients gather the necessary information through informal channels, which can often mean that they receive it in a fragmentary and unsystematic form.

“I think that people are most informed by someone from the environment telling them that, who may have heard somewhere or had experience with it. Not everything that is learned in this way is usable.” (patient)

In that sense, it would be rational to consider raising the intra-system capacities and develop *formal channels of communication* (within both healthcare and social care system) for palliative patients and their family members through which they could receive reliable necessary information.

Raising institutional capacities for palliative care

The Montenegro healthcare system is structured as a centralised star network. The central node of the network is the Clinical Centre of Montenegro (CCM) located in Podgorica. The health care system is consisted of: (a) primary healthcare institutions (local healthcare centres), (b) secondary healthcare institutions (general hospitals and two special hospitals) and (c) one tertiary healthcare institution - CCM. The palliative care is integrated into existing healthcare system without specialized palliative care departments within its institutions:

“In our country, there is no organized palliative care in public healthcare institutions. For this purpose, the existing capacities at the CCM Clinics and the Institute for Oncology are used, as well as the departments of General Hospitals and two Special Hospitals. ... There are no... Departments in healthcare institutions that are specialized only for palliative care. In primary healthcare, the

service of the chosen doctor and the patronage service perform examinations and application of therapy at home, prescribed by a doctor- subspecialist.” (oncologist)

Such a structural solution at the system level in individual patient treatment trajectories produces significant problems:

“The patient is treated in fragments, at different levels of healthcare: primary, secondary and tertiary ... therefore patient must turn to different healthcare institutions.” (doctor-oncologist)

“In Montenegro, information is scarce and available only through the service of the chosen, family doctor. The patient’s path through institutional system in these situations is unclear. The most of the support is reduced to interventions in the emergency center in case of worsening of the patient’s condition. It often happens that due to inadequate information and inadequate care, the family brings a patient who is in the terminal phase of the disease to the emergency center or hospital to die, ie the death occurs immediately after arriving at the healthcare institution.” (doctor)

“... hospital, center for social care, healthcare center, are not networked and because of that patients just circle.” (patient)

“Patient has to visit several different institutions. It seems that the healthcare system in Montenegro is not interconnected at all, but also the system in general. It is impossible to complete everything in one institution. Only the family and patients know how challenging this is.” (family member)

This is especially visible in situations when the patient's condition includes the use of pain therapy, which, at least according to the testimonies of our interviewees, is not always available to everyone.

“We really didn't have any help, we even took the patient to private doctors and hired private medical staff to include the therapy at home.” (family member)

“I think that rural areas do not have adequate home treatment, including access to pain therapy.” (doctor)

“There is no outpatient clinic for pain therapy in healthcare centers, not even in CCM.” (doctor)

In this regard, it would be necessary to make additional efforts to find a solution that would establish broken links between different parts of the system - health institutions and centers for social care, primary healthcare institutions and those in the field of secondary and tertiary healthcare - between the selected, family, doctor from the local healthcare center and home treatment services and a doctor-specialist who, within the institution of secondary and/or tertiary healthcare, diagnosed the disease and monitors the case of a particular patient.

„It is certainly not enough to inform the population about the right to this form of healthcare service alone. It is also needed to introduce the ways in which patients and their family members could achieve this. There is a big difference in what is defined by law and rights, in relation to what the practice is and what patients encounter, as well as their family members.“ (professional worker)

Because, many patients face various forms of social deprivation that the system, as it is at the moment, does not recognize as a problem that affects the availability of certain palliative care services. Below are a few illustrative examples of social deprivation based on:

(a) geographical deprivation

“I had to receive therapy at 2 AM to come to Podgorica at 8 AM to receive chemotherapy, and I had to go for therapy at 2 AM and then so tired to Podgorica.” (patient)

(b) material deprivation

“Who has money has, who does not die at home.” (patient)

(c) lack of social capital

„I know they don't accept those who have no help unless you have a really strong 'protection'“ (patient)

(d) pressure to react within a limited time frame

„ ... inability to obtain the necessary medical treatments at a state hospital at an adequate time. That is, if the patient has a need for daily therapy, which is procured through the Fund, ie refunded, you do not have time to wait for several months for MMR, scanners, etc. (patient)

Although the *Master Plan for Health Development of Montenegro 2015-2020* tried to mitigate many of these problems related to palliative care and devise ways to overcome them: "unfortunately, previously defined strategic goals and program activities have not been achieved in Montenegro." (doctor)

Support systems outside institutions

“In general, cancer patients in the terminal phase of the disease are treated ‘nothing more can be done’ ... it means that, goals aimed at alleviating suffering and ‘dying with dignity’ have not been recognized.” (oncologist)

In the current circumstances related to palliative care in Montenegro, which is characterized by a relatively reduced, curative approach to medical care, a large part of the burden of palliative care is taken over by the *family*.

“I have no help, except from other family members. The doctors just made the diagnosis and we didn't have any kind of help from them, nor from other institutions.” (patient)

“We have provided all these types of help at our own expense to a family member suffering from an incurable disease (talking to a psychologist, clergyman, physiotherapist, often receiving infusions to strengthen the body, technical aids...) (family member)

“The state provides a lot, but a lot the family ends up alone.” (family member)

“I can say that in general the position of patients whose life is endangered is very bad, their condition and care depend on family members. “ (patient)

“I also want to emphasize that not everyone is able to have the help of their family. Some patients are left to fend for themselves, and unfortunately without the help of their families they are sentenced to a shorter life span.” (patient)

On the other hand, palliative patients and their family members are, due to the specific cultural context of Montenegro within which family values such as togetherness, family solidarity and care for community members are highly valued, highly responsive to this, by the legislator, not articulated request that imply taking on a significant portion of the burden of palliative care for a dying family member. However, those who experience this see the need to look for some new solutions:

“The family should contribute, but I think that the state is obliged to provide someone who would instruct us what and how to do. We were without information for literally a month and learned information from the internet.” (family member)

“It would be the best if it could be established cooperation between state bodies and the family. In this way, the family can foresee what they really need, and on the other hand, the state authorities can provide timely assistance. (patient)

“I think that a family member who takes care of a sick person should have some kind of financial compensation - salaries, because they are mostly unable to work, because they often have to take care of a sick person 24 hours a day.” (patient)

Unfortunately, the majority of the interviewees among stakeholders relevant for the palliative care recognized only two – the state/institutional system and the family.

“I believe that the NGO sector cannot deal with these issues, but that only the state should deal with the provision of these services. We are all witnesses that in Montenegro there is an increasing number of patients suffering from an incurable disease without adequate help.” (patient)

Minority of them, mostly professionals, who recognize importance of introducing the CSO sector into process of palliative care believe that their contribution could be substantial:

“The role of the CSO sector is important through raising awareness of the importance of palliative care, guiding public healthcare policies and helping to organize a professional care system. Such organizations can operate through volunteer work, where they would help patients, their families, through patient care, and help with daily activities, which significantly hinder the daily functioning of the seriously ill and families.” (doctor)

“In my opinion, CSOs can, within palliative care, organize patient care services and other daily activities related to making life easier for patients and their families. CSOs do not need to take on the roles of health facilities.” (doctor)

Toward distributive network of palliative care providers

The rising societal demand in different aspects of palliative care⁸ opens a question of a new societal conceptualization of its supply. According to the insights of our research the existing palliative care “supply condition” is far from satisfactory, especially outside the healthcare system node – Podgorica. The majority of primary healthcare institutions (within and outside the node and especially those on the North of Montenegro) do not have either organizational⁹ or human¹⁰ capacities to provide an adequate palliative care supply to the patients who locationally gravitate to these institutions.

⁸ “There is a tendency to increase the number of examinations of oncology patients and hospitalizations at the Institute of Oncology, especially in the last 11 years, when the new building of the Institute was opened. The incidence of malignant diseases in Montenegro over the past five years is constantly increasing and ranges just over 3,000 patients per year. Over the past 11 years, the number of examinations of cancer patients has increased from 12000 to 18000 annually.” (oncologist)

⁹ Specialized units dedicated especially to palliative care.

¹⁰ Experts in different areas of palliative care (psychologists, social workers, caregivers, legal advisors etc) and doctors, specialists of palliative care.

This situation requires additional imaginative effort and structural interventions into existing concept of palliative care in the Republic of Montenegro. In the present moment structure of palliative care network follows the structure of healthcare system. Montenegro healthcare system is organized as “centralized star network” (Galloway, 2010:288) with one central node (tertiary healthcare institution – CCM) around which gravitate different (secondary and primary) healthcare institutions. However, in reality, this network is not equally available to all citizens of Montenegro. Those who live outside central node, in smaller towns and villages, especially those on the North, who are in particularly difficult condition that requires more frequent therapy changes, who are not capable to move independently ... etc are more depend of the quality of the palliative care that could receive within their homes. But, the capacities of Montenegro healthcare system to offer that kind of supply is limited. In other words, the demand for palliative care is high and the only way in which the existing system of palliative care could fulfil it is to incorporate additional supply outside the institutional system. In that way the existing network of palliative care will be: (a) enrich with additional palliative care services, and (b) geographically expended to areas where palliative care is less accessible (smaller towns and villages), without significant upgrading of the existing institutional capacities. In ideal case the future Montenegro palliative care network should structurally evolve during the time into “distributive network” (Galloway, 2010: 288) in which every particular node¹¹ will be capable to autonomously makes decisions about palliative care of the concrete patients. This means that in such a network, organization and control would be widespread and integrated throughout the network, within which there would be relative equality of nodes, two-way character of their interconnections, high level of redundancy, and general lack of internal hierarchy (Galloway, 2010: 288). Certainly, such a project is impossible without raising awareness of the importance of providing palliative care grounded on human rights and personal dignity of patients and their families, as well as on dedicated work on raising the competencies in palliative care of employees in institutions and CSOs.

¹¹ Institution or CSO that is a part of the network.

Recommendations

For institutional system:

- Defining a NEW *Master Plan of Healthcare System Development* and new strategic goals related to palliative care. (*Nota bene*: The existing Master Plan expire in 2020)
- The special position of persons at the end of their lives and in difficult health conditions should not mean that their legal protection is reduced because of their weakness. On the contrary, they require additional protection in every regard. Dying patients should enjoy all basic patients' rights in accordance with the law. There should be no discrimination with regard to health or social status, such as with marginalised groups, for example.
- Human dignity should be considered a top priority when it comes to dying patients, and all other values should be measured against it, since it is a right guaranteed by the Constitution.
- It is necessary to continue working on *legal regulations, protocols and good practice handbooks*, which will contribute to better practice in working with dying patients.
- Enable palliative medicine specialists to *prescribe medications*.
- It is necessary to revise the existing Rulebook on specialisations and subspecialisations and enable additional education in this branch of medicine (with at least a *subspecialisation in the medicine of pain and geriatrics* since these two subbranches are perhaps the most important for palliative care)
- Constitute palliative care units' network on secondary and tertiary healthcare level that could provide necessary medical services and cover the whole territory of Montenegro.
- Formulate and adopt appropriate legal regulations/guidelines about which patient requires what kind of accommodation and in which duration. This regulation should also contain a *list of diagnoses which imply accommodation in specialised palliative care units*.
- *Increase the number of employees in palliative care units and units for home care* in order to make the care for palliative patients in institutions and at home adequate.

- Dying patients certainly require support of the family and if it is possible, limitations for *visits* to units for palliative care should be cancelled (isolation of unit so as not to disturb other patients).
- Formulate *special norms for palliative medicine* as a medical branch.
- Formulate *protocols in centres for social care* for the care and accommodation of palliative patients.
- Ensure *psychosocial support* to patients and their family members within each unit for palliative care.
- *Recognize informal carers' rights at a policy level and low* by introducing: psycho-social support programs, respite care programs for family members, financial assistance and direct support in equipment.

For civil society sector:

- Systemic identification of CSOs that deal with various aspects of palliative care of patients and their family members and creation of the *Register of the CSOs providers of palliative care*.
- The Register should include the information about: (a) CSO, (b) type of services that provide (including the geographical region in which it operate), and (c) name(s) of experts/professionals (including their professional and educational competencies) who provide these services.
- The Register should be available to all healthcare institutions and social care institutions, healthcare professionals, patients and their family members.
- Formulate and adopt *appropriate program of the services for CSOs licence service providers*, legal regulations/guidelines about the ethical and professional standards that CSOs should meet if they want to become a part of the network.
- Formulate and adopt appropriate legal regulations/guidelines about future links and jurisdictions between institutional stakeholders and the CSOs in the field.

- Create *subnetworks of CSOs* according to the type of the service – homecare, day-care and supported housing, on regional (within Montenegro 3 geographical regions) and national level.
- CSOs should create programs as a *support to informal carers* – self-care plan guidelines how to care about the patients in homes, develop programs and support to enable free of charge equipment for the patients who stay at homes in order to support family and patients’ resilience.
- Train *community volunteers* in providing support for carers and patients.

General recommendations:

- Create regional Western Balkans network (peer to peer among institutions and CSOs) to exchange experiences and increase knowledge in palliative care.
- Promotion of the CSO’s examples of good practice of models of palliative care in Western Balkans context. The research identifies *Belhospice* (Serbia) as the bench mark model of such a practice in terms of service provision and trainings and advocacy, *Civic Alliance* (Montenegro) as a model for advocating system improvement regarding palliative care needs and fundamental human rights and dignity of end of life patients with life limiting prognoses, and *Ryder* (Albania) as a model for service provision and advocacy for improvement of quality of the palliative care services in the region. The Western Balkans network will provide necessary infrastructure for professional exchange of the models of service provision, engagement of the volunteers, trainings for medical, social care professionals and licence service providers, public awareness and advocacy actions.

Appendix

Literature

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Research Instruments

A. Annex 1 - Guide for in-depth interview: PALLIATIVE CARE BENEFICIARIES/RECEIVERS

Projekat: *Palliative Care – My Care, My Right*

Research on Needs and Barriers of Implementation of Palliative Care Services

Vodič za razgovor: tematske oblasti i okvirna pitanja
(KORISNICI PZ I ČLANOVI NJIHOVIH PORODICA)

I tematska oblast: PALIJATIVNO ZBRINJAVANJE

Svrha: U ovom delu razgovora treba prikupiti informacije od ispitanika (korisnika palijativnog zbrinjavanja i članova njihovih porodica) na koji način razumeju *koncept palijativnog zbrinjavanja* i šta su najveći problemi sa kojima se suočavaju.

Okvirna pitanja:

1. Kako biste **opisali** šta je to palijativno zbrinjavanje?
2. Da li ste znali da je palijativno zbrinjavanje pristup koji poboljšava kvalitet života pacijentu i članovima porodica koji se suočavaju sa bolešću koja ugrožava život? (Izraz bolest koja ugrožava život odnosi se na pacijente sa aktivnom, progresivnom, uznapredovalom bolešću za koje je prognoza ograničena.)
3. Da li se u CG sprovodi palijativno zbrinjavanje za pacijente i članove porodica?
4. Kakav je po Vašem mišljenju **kvalitet** palijativnog zbrinjavanja u Crnoj Gori?
5. Ko obezbeđuje palijativno zbrinjavanje pacijenata (država ili porodica)? Ko je po Vama dužan da obezbedi ovu vrstu usluge?
6. Koje sve **usluge** bi trebalo da budu dostupne u okviru palijativnog zbrinjavanja pacijenata, a koje su u realnosti dostupne građanima Crne Gore:
 - (a) medicinska nega
 - (b) usluge socijalnih radnika
 - (c) usluge fizioterapeuta
 - (d) psiholog
 - (e) podrška ustanova zdravstvene i socijalne zaštite u smislu dobijanja medicinsko-tehničkih pomagala
 - (f) podrška duhovnika
 - (g) nešto drugo. Navesti šta?

7. Da li su po Vašem mišljenju informacije o ovoj vrsti usluga dostupne u Crnoj Gori? Na koji način se, prema Vašem iskustvu, pacijenti/članovi porodica **informišu** o dostupnosti ovih usluga u Crnoj Gori?
8. Koju vrstu usluga, po Vašem mišljenju, je neophodno obezbediti za teško obolele osobe koje borave u kući?
9. Da li smatrate da je potrebno obezbediti neki vid podrške i za članove porodica/negovatelje koji brinu o oboleloj osobi?
10. Koju vrstu usluga/podrške, po Vašem mišljenju, bi trebalo obezbediti za negovatelje/članove porodica obolelih?
11. Da li smatrate da NVO sektor može da pruži usluge palijativnog zbrinjavanja? Pod kojim okolnostima, ili bez obzra na okolnosti?
12. Da li ste znali da je palijativno zbrinjavanje osnovno ljudsko pravo?
13. Da li ste znali da palijativno zbrinjavanje obuhvata period od dijagnoze bolesti do kraja perioda žalosti zbog gubitka člana porodice?
14. Da li ste znali da palijativno zbrinjavanje obuhvata pored liječenje simptoma bola pacijenta, socijano, emocionalno i duhovno stanje pacijenta i članova porodice?

II tematska oblast: PROBLEMI NA TERENU

Svrha: U ovom delu razgovora trebalo bi ohrabriti ispitanika da preispita sopstvena iskustva vezana za rad u okviru procesa palijativnog zbrinjavanja i pokaša da identifikuje mesta:

- (a) potencijalne diskriminacije,
- (b) unutarorganizacionih/unutarinstitucionalnih i medjuorganizacionih/medjuinstitucionalnih napetosti,
- (c) disfunkcionalnosti postojećeg zdravstvenog, šireg institucionalnog sistema i civilnog društva
- (d) institucionalnih i organizacionih dobrih praksi

na osnovu iskustva unutar vlastitih organizacija/institucija, ali i na osnovu komunikacije (lične i organizacione/institucionalne) sa drugim organizacijama/institucijama.

Okvirna pitanja: PACIJENTI I ČLANOVI PORODICA

1. Da li u bolnici/klinici/domu zdravlja u kome se lečite postoji **savetovalište** za korisnike palijativnog zbrinjavanja i/ili članove njihovih porodica? Ako da, da li ste koristili usluge savetovališta i u kom obimu? Kakvo je Vaše iskustvo vezano za rad savetovališta, kako radi, da li pomaže i sl? Kakvo je iskustvo osoba koje poznajete sa savetovalištima pri bolnicama, ili nekim drugim ustanovama/organizacijama? Koliko je, po Vašem mišljenju, uopšte artikulisana potreba za ovom vrstom usluga kod korisnika?
2. Da li pacijent unutar jedne ustanove može da dobije svu neophodnu pomoć i negu ili mora da posećuje **više različitih zdravstvenih ustanova**? Koliko i zbog čega?
3. Da li pacijenti kojima je potrebno palijativno zbrinjavanje, prema Vašim saznanjima, imaju **prednost** kod zakazivanja pregleda i čekanja na zakazane preglede u različitim zdravstvenim ustanovama koje posećuju? Da li mislite da je to u redu i pod kojim uslovima?

4. Kolika je po Vašem mišljenju potreba za **stvaranjem posebnih odeljenja za palijativno zbrinjavanje** u okviru postojećih zdravstvenih ustanova?
5. Da li Vam je poznato, na koja odeljenja postojećih bolnica umirući pacijenti mogu biti primljeni na kratku hospitalizaciju radi ublažavanja bola ili nekog drugog zdravstvenog problema na teritoriji CG?
6. Prema Vašim iskustvima, koliko su zdravstveni radnici i kog stručno-obrazovnog profila, koji rade u postojećim zdravstvenim ustanovama, otvoreni prema potrebama palijativnih pacijenata?
7. Kakva je uloga **socijalnih radnika** koji rade u bolnicama i zdravstvenim ustanovama, u palijativnom zbrinjavanju pacijenata? Kakvi su bili Vaši kontakti sa socijalnim radnicima I da li ste ih uopšte imali?
8. Kakva je, po Vašem mišljenju, uloga **centara za socijalni rad** u pružanju zdravstvene nege (pitanja starateljstva, vršenja roditeljskog prava, (upućivanje na) sprovođenje individualnih ili porodičnih psihoterapija)?
9. Gde vidite prostor za unapređenje znanja i veština zaposlenih u institucijama sistema u oblasti palijativnog zbrinjavanja?

SAMO ZA ČLANOVE PORODICA/NEGOVATELJE:

10. Da li ste imali/imate bilo kakvu sistemsku podršku/pomoć u palijativnom zbrinjavanju osobe o kojoj brinete? Od koga/kojih institucija i pojedinaca? O kakvoj pomoći/podršci se radi (materijalnoj, servisnoj/uslužnoj, psihološkoj, duhovnoj ili nekoj drugoj)?
11. Šta Vam je predstavljalo/predstavlja najveći teret/izazov u palijativnom zbrinjavanju osobe o kojoj brinete?
12. Da li mislite da su potrebe članova porodice palijativnih pacijenata/negovatelja dovoljno prepoznate?
13. Da li ste imali bilo kakvu sistemsku podršku/pomoć nakon smrti osobe o kojoj ste brinuli? Kakvu?

III tematska oblast: POGLED U BUDUĆNOST

Svrha: Pokušaj da se uspostavi veza između individualnih fragmentarnih iskustava palijativnih pacijenata i članova njihovih porodica i mogućih pravaca delovanja u budućnosti u svrhu poboljšanja socijalnog položaja palijativnih pacijenata, članova njihovih porodica i podizanja kvaliteta palijativnih usluga. Smisao ovog dela razgovora je da ispitanici pokušaju da mapiraju prostor moguće organizovane socijalne akcije i detektuju socijalne aktere (institucije, organizacije i službe) koje bi trebalo da budu ključni akteri ovog procesa.

Okvirna pitanja:

1. Na šta bi, po Vašem mišljenju, trebalo usmeriti napore za poboljšanje kvaliteta palijativnog zbrinjavanja u CG?
 - (a) prevenciju incidencije bolesti
 - (b) podizanje dijagnostičkih kapaciteta zdravstvenih ustanova
 - (c) edukaciju i senzibilizaciju: zaposlenih u zdravstvenim ustanovama za palijativno zbrinjavanje pacijenata (edukacija drugih lekara i medicinskog osoblja, kao i zaposlenih

pravnik i ekonomista koji su na neki način povezani sa sistemom - u zdravstvenim institucijama, državnoj administraciji i lokalnoj samoupravi, bankama i osiguravajućim društvima) i organizacijama civilnog društva.

- (d) proširivanje postojećih institucionalnih kapaciteta (u zdravstvenim, ustanovama socijalne zaštite) za palijativno zbrinjavanje pacijenata (u smislu otvaranja novih ustanova, povećanja broja zaposlenih i sl.) i organizacijama civilnog društva.
 - (e) podizanje svesti stanovništva o neophodnosti organizovanja palijativne zaštite
 - (f) nešto drugo, navesti šta?
2. Šta bi po Vašem mišljenju najviše doprinelo poboljšanju kvaliteta usluga palijativnog zbrinjavanja u CG?
 3. Želite li nešto da dodate što smatrate da je važno za razumevanje različitih društvenih problema sa kojima se susreću oboleli, i članovi njihovih porodica, a nismo obuhvatili našim dosadašnjim razgovorom?

HVALA VAM ŠTO STE UČESTVOVALI!

- B. **Annex 2** - Guide for in-depth interview: PALIATIVE CARE PROVIDERS and members of CSOs that are dealinig with HUMAN RIGHTS

Projekat: *Palliative Care – My Care, My Right*

Research on Needs and Barriers of Implementation of Palliative Care Services

Vodič za razgovor: tematske oblasti i okvirna pitanja

Aktivisti i zaposleni u **civilnom sektoru i ustanovama**

koje se bave palijativnim zbrinjavanjem

(PRUŽAOCI USLUGA PZ I ORGANIZACIJE KOJE SE BAVE LJUDSKIM PRAVIMA)

I tematska oblast: PALIJATIVNO ZBRINJAVANJE

Svrha: U ovom delu razgovora treba prikupiti informacije od ispitanika (zaposlenih/angažovanih u organizacijama/ustanovama koje pružaju različite usluge vezane za palijativno zbrinjavanje) s jedne strane o tome: (a) na koji način razumeju *koncept palijativnog zbrinjavanja* i šta o njemu misle, a sa druge strane: (b) na koji način organizacija/ustanova, unutar koje ispitanik radi ili je angažovan, učestvuje/razume svoj doprinos u palijativnom zbrinjavanju i (c) šta su njene najvažnije i/ili nedostajuće kompetencije.

Okvirna pitanja:

A. Palijativna zbrinjavanje

1. Kako biste **opisali** šta je to palijativno zbrinjavanje?
2. Kakav je po Vašem mišljenju **kvalitet** palijativne zaštite u Crnoj Gori?
3. Koje sve **usluge** bi trebalo da budu dostupne u okviru palijativnog zbrinjavanja pacijenata, a koje su u realnosti dostupne građanima Crne Gore:
 - (a) medicinska nega
 - (b) usluge socijalnih radnika
 - (c) usluge fizioterapeuta
 - (d) psiholog
 - (e) podrška ustanova zdravstvene i socijalne zaštite u smislu dobijanja medicinsko-tehničkih pomagala
 - (f) podrška duhovnika
 - (g) nešto drugo. Navesti šta?
4. Da li su po Vašem mišljenju informacije o ovoj vrsti usluga dostupne u Crnoj Gori? Na koji način se, prema Vašem iskustvu, pacijenti/članovi porodica **informišu** o dostupnosti ovih usluga u Crnoj Gori?

5. Koju vrstu usluga, po Vašem mišljenju, je neophodno obezbediti za teško obolele osobe koje borave u kući?
6. Da li smatrate da je potrebno obezbediti neki vid podrške i za članove porodica/negovatelje koji brinu o oboleloj osobi?
7. Koju vrstu usluga/podrške, po Vašem mišljenju, bi trebalo obezbediti za negovatelje/članove porodica obolelih.
8. Da li smatrate da NVO sektor može da pruži usluge palijativnog zbrinjavanja? Pod kojim okolnostima, ili bez obzira na okolnosti?

B. Organizacija/ustanova ispitanika

1. Na koji način Vaša organizacija/ustanova učestvuje u palijativnom zbrinjavanju?
2. Da li se Vaša organizacija/ustanova bavi isključivo palijativnim zbrinjavanjem ili je to samo jedan deo Vaših aktivnosti? Ako usluge palijativnog zbrinjavanja čine samo jedan deo Vaših aktivnosti možete li da procenite koliki deo Vaših aktivnosti se tiče palijativnog zbrinjavanja (izraženo u %)?
3. Koju **vrstu usluga** pružate i ko su korisnici Vaših usluga? Da li pružate ovu/e vrstu usluga predominantno određenoj **vrsti korisnika**? Kojoj (npr. onkološki pacijenti, stari, oboleli od HIV-a, zavisnici i sl.)? Imate li neko objašnjenje zašto je to tako (npr. Da li je palijativnog zbrinjavanje integrisano u onkologiju?)
4. Šta od postojećih **zakona, strategija i akcionih planova** smatrate važnim za rad Vaše organizacije/ustanove? Iz kojih razloga? Da li ova postojeći pravni okvir na adekvatan način reguliše palijativno zbrinjavanje u Crnoj Gori? Zašto to mislite? Objasnite! (Da li NVO mogu da pružaju medicinske usluge?)
5. Da li je po Vašem mišljenju palijativno zbrinjavanje **dostupno** svim građanima u svim delovima Crne Gore?
Napomena za intervjuere: Postaviti pitanje za: sever, jug i centralni deo Crne Gore; selo-grad; mladi-stari.
6. Prema Vašim saznanjima sa koliko **jedinica za palijativno zbrinjavanje** (u okviru zdravstvenog sistema i/ili sistema socijalne zaštite) raspolaže Crna Gora? Koju vrstu usluga one nude i u kom vremenskom periodu? Da li Vaša organizacija/ustanova saradjuje sa nekom od ovih jedinica i na koji način?
7. Prema Vašim saznanjima da li su svim građanima Crne Gore dostupne **službe kućnog lečenja** i pod kojim okolnostima? Koju vrstu usluga koje su bitne za palijativne pacijente i njihove porodice ove službe nude? Da li ove usluge uključuju i **terapiju bola**?
8. Prema Vašim saznanjima da li pri svakom opštinskom Domu zdravlja postoji ambulanta za lečenje bola? Da li pri svakoj bolnici postoji ambulanta za lečenje bola?
9. S obzirom da smo već više od godinu dana zahvaćeni pandemijom COVID-19, kako je ona, po Vašem mišljenju, uticala na palijativno zbrinjavanje?

C. Kompetencije

1. Da li u odnosu na tip/tipove usluga koje nudite, Vaša organizacija/ustanova ima adekvatnu strukturu aktivista/zaposlenih (u odnosu na njihovu školsku spremu)?
2. Šta su, po Vašem mišljenju, (profesionalne i/ili ljudske) kompetencije koje nedostaju Vašoj organizaciji/ustanovi?

3. Da li postoji neki tip usluge koji biste želeli/smatrate da bi bilo važno da ponudite, a kao organizacija/ustanova niste u stanju?
4. Postoji li neki tip usluge ili kompetencije za koji smatrate da je bolje da se oslonite na resurse neke druge organizacije/ustanove? Koji? Zašto?

II tematska oblast: SARADNJA SA DRUGIM ORGANIZACIJAMA/USTANOVAMA (mreža podrške)

Svrha: Posebna pažnja će biti posvećena saradnji organizacije/ustanove u kojoj ispitanik radi sa drugim organizacijama/ustanovama u procesu palijativnog zbrinjavanja.

Okvirna pitanja:

1. Imajući na umu sve što ste gore naveli možete li nam reći sa kojim organizacijama/ustanovama Vaša organizacija/ustanova saradjuje u pružanju usluga palijativnog zbrinjavanja i na koji način. Zašto?
(Napomena za intervjuera: Molim Vas da svaku organizaciju/ustanovu navedete pod drugim rednim brojem u transkriptu, a ispitanika za svaku pojedinačno pitate koju vrstu usluga/kompetencija njegova/njena organizacija/ustanova “pozajmljuje”!)
2. Da li se u svom radu više oslanjate na državne ustanove (zdravstvene, socijalne i sl) ili organizacije civilnog društva? Zašto?
3. Da li su po Vašem mišljenju ustanove na koje se oslanjate i/ili na koje bi mogli da se oslanjate ravnomerno rasporedjene na celoj teritoriji Crne Gore? Šta mislite o tome?

III tematska oblast: PROBLEMI NA TERENU

Svrha: U ovom delu razgovora trebalo bi ohrabriti ispitanika da preispita sopstvena iskustva vezana za rad u okviru procesa palijativnog zbrinjavanja i pokaša da identifikuje mesta:

- (a) potencijalne diskriminacije,
- (b) unutarorganizacionih/unutarinstitucionalnih i medjuorganizacionih/medjuinstitucionalnih napetosti,
- (c) disfunkcionalnosti postojećeg zdravstvenog, šireg institucionalnog sistema i civilnog društva
- (d) institucionalnih i organizacionih dobrih praksi

na osnovu iskustva unutar vlastitih organizacija/institucija, ali i na osnovu komunikacije (lične i organizacione/institucionalne) sa drugim organizacijama/institucijama.

Okvirna pitanja:

1. Da li u Vašoj organizaciji/ustanovi postoji **savetovalište** za korisnike palijativnog zbrinjavanja i/ili članove njihovih porodica? Ako da, da li pacijenti koriste usluge savetovališta i u kom obimu? Kakvo je iskustvo Vaše organizacije/ustanove, kako radi, da li pomaže i sl? Kakvo je iskustvo Vaših korisnika sa savetovalištimama pri bolnicama, ili nekim drugim ustanovama/organizacijama? Koliko je uopšte artikulisana potreba za ovom vrstom usluga kod korisnika?

2. Da li pacijent unutar Vaše organizacije/ustanove može dobiti svu neophodnu pomoć i negu ili mora da posećuje **više različitih zdravstvenih ustanova**? Koliko i zbog čega?
3. Da li pacijenti kojima je potrebno palijativno zbrinjavanje, prema Vašim saznanjima, imaju **prednost** kod zakazivanja pregleda i čekanja na zakazane preglede u različitim zdravstvenim ustanovama koje posećuju? Da li mislite da je to u redu i pod kojim uslovima?
4. Kolika je po Vašem mišljenju potreba za **stvaranjem posebnih odeljenja za palijativno zbrinjavanje** u okviru postojećih zdravstvenih ustanova?
5. Da li Vam je poznato, na koja odeljenja postojećih bolnica umirući pacijenti mogu biti primljeni na kratku hospitalizaciju radi ublažavanja bola ili nekog drugog zdravstvenog problema na teritoriji Crne Gore?
6. Prema Vašim iskustvima, koliko je zdravstvenih radnika/saradnika i kog stručno-obrazovnog profila, koji rade u postojećim zdravstvenim ustanovama, prošlo **obuku**, i unapredilo svoja znanja **o palijativnom zbrinjavanju**? Koliko često se edukacije/obuke obavljaju? Da li se obnavljaju/osvežavaju znanja već obučениh polaznika? Koliko često?
7. Koliko je **socijalnih radnika** i kog stručno-obrazovnog profila, koji rade u bolnicama i zdravstvenim ustanovama, prošlo obuku, i unapredilo svoja znanja o palijativnom zbrinjavanju? Koliko često se edukacije/obuke obavljaju? Da li se obavlja osvežavanje znanja već obučениh polaznika?
8. Kakva je, po Vašem mišljenju, uloga **centara za socijalni rad** u pružanju zdravstvene nege – pitanja starateljstva, vršenja roditeljskog prava, (upućivanje na) sprovođenje individualnih ili porodičnih psihoterapija.
9. Gde vidite prostor za unapređenje znanja i veština zaposlenih u institucijama sistema u oblasti palijativnog zbrinjavanja?

IV tematska oblast: POGLED U BUDUĆNOST

Svrha: Pokušaj da se uspostavi veza između fragmentarnih iskustava organizacijacivilnog društva i ustanovama koje pružaju uslugu palijativnog zbrinjavanja i mogućih pravaca delovanja u budućnosti u svrhu poboljšanja socijalnog položaja palijativnih pacijenata, članova njihovih porodica i podizanja kvaliteta usluga koje se nude. Smisao ovog dela razgovora je da ispitanici pokušaju da mapiraju prostor moguće organizovane socijalne akcije i detektuju socijalne aktere (institucije, organizacije i službe) koje bi trebalo da budu ključni akteri ovog procesa.

Okvirna pitanja:

1. Na šta bi, po Vašem mišljenju, trebalo usmeriti napore za poboljšanje kvaliteta palijativne zaštite u Crnoj Gori?
 - (g) prevenciju incidencije bolesti
 - (h) podizanje dijagnostičkih kapaciteta zdravstvenih ustanova
 - (i) edukaciju i senzibilizaciju: zaposlenih u zdravstvenim ustanovama za palijativno zbrinjavanje pacijenata (edukacija drugih lekara i medicinskog osoblja, kao i zaposlenih pravnika i ekonomista koji su na neki način povezani sa sistemom - u zdravstvenim institucijama, državnoj administraciji i lokalnoj samoupravi, bankama i osiguravajućim društvima) i organizacijama civilnog društva.

- (j) proširivanje postojećih institucionalnih kapaciteta (u zdravstvenim, ustanovama socijalne zaštite) za palijativno zbrinjavanje pacijenata (u smislu otvaranja novih ustanova, povećanja broja zaposlenih i sl.) i organizacijama civilnog društva.
- (k) podizanje svesti stanovništva o neophodnosti organizovanja palijativne zaštite
- (l) nešto drugo, navesti šta?
- 2. Šta bi po Vašem mišljenju najviše doprinelo poboljšanju kvaliteta usluga palijativnog zbrinjavanja u Crnoj Gori?
- 3. Želite li nešto da dodate što smatrate da je važno za razumevanje različitih društvenih problema sa kojima se susreću oboleli, članovi njihovih porodica i zaposleni u ustanovama/organizacijama civilnog društva koje pružaju usluge palijativnog zbrinjavanja, a nismo obuhvatili našim dosadašnjim razgovorom?

HVALA VAM ŠTO STE UČESTVOVALI!