

SOCIOLOGICAL STUDY OF SOCIAL,  
MEDICAL AND LEGAL STATUS OF PATIENTS

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**Sociological study of the social, medical and legal status of patients**

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## Introduction

Palliative care is an integral part of modern medicine and aims to relieve pain and suffering symptoms and to improve quality of patients' lives.

Over a long period of time there was no structured treatment approach to palliative care patients in Georgia. The first outpatient palliative care institution (hospice) was established in 2005. Nowadays, palliative care can be offered to patients either in hospices, or at home.

Two beds of palliative care exist in each of the following cities: Kutaisi, Batumi and Zugdidi. Palliative care services in the mentioned departments are available to our citizens in the frame of a state program (State program of diagnostic and treatment of oncological diseases)

Domiciliary palliative care became available in 2004 under the grant financed program. Since 2005-2006 domiciliary palliative care was financed by the state. In Tbilisi palliative care is performed by the two mobile teams, which have possibility to cover simultaneously 70 patients. The services are fully financed by the state .<sup>1</sup>

However, apart from the medical side, the legal issues and protection of the rights of the palliative care patients are also essential.

The rights of palliative care patients may be discussed in two aspects: Understanding their rights within the context of equality and non-discrimination<sup>2</sup> , as well as in the context of the patients' rights with special health care needs. Rights of palliative care patients are defined in Health Law. The ethical and legal dilemmas frequently occur with respect to palliative care patients. Accordingly, the medical personnel must be appropriately informed upon their rights, in order to avoid violation of patients' rights by negligence or some other reasons. As the field of palliative care is just being introduced in Georgia, the issue of the adequate protection of patients' rights is still subject to debates. All the more so, very often the patients do not get comprehensive information about their rights or they try to retain their liberal attitude toward their physicians.

The overarching goal of the presented sociological research is to study the rights of palliative care patients. In terms of content, this research consists of various components: a) Palliative patients' (or their guardians') awareness about the specific nature of palliative care, their rights and different kinds of privileges. b) Legal status of a patient with regards to medical facilities and personnel. c) Social status of palliative patients (public perception, access to various resources, etc.).

<sup>1</sup> Domiciliary Palliative care component for incurable patients is financed within the frame of Primary Health Care State Program.

<sup>2</sup> The issue is marked out, as this type of discrimination may be even more acute with regard to certain groups of palliative care patients (such as HIV/ AIDS patients); Patient's sexual orientation, their lifestyle and the disease itself may become the reason for a careless, offensive and oppressive attitude from medical personnel (for whom the information is available).

## Access to pain relief treatment in the context of human rights

The right to health is a fundamental part of our human rights, which is guaranteed by both International<sup>3</sup> and National<sup>4</sup> law. As countries have different levels of resources for supplying quality health services to their citizens, or complying with other standards, the right to health is considered as a right of “progressive realization”. This means that in the process of policy planning and implementation the states should maintain their permanently evolving and a progressive tendency of realization of the right. As Georgia has already ratified the mentioned convention, (May 3, 1994), the government has an obligation to provide necessary conditions for implementing the right.

It should be noted, that while discussing the right to health, the Committee on Economic, Social and Cultural Rights<sup>5</sup> identifies core obligations of government that should be met despite the scarcity of resources and none of justifications will be accepted. They are the following:

- To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- To provide essential drugs, (as defined under the WHO Action Program on Essential Drugs);
- To ensure equitable distribution of all health facilities, goods and services;
- To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the healthcare needs of the whole population.

As morphine and codeine (as analgesic medications) are included in WHO Model List of Essential Medicines, countries are obliged to provide these medications under the right to health. This implies both physical and financial accessibility.

Therefore, the government should establish an efficient system for supplying and purchasing of pain reliever, should adopt and implement the strategy for the development of palliative care services and special attention should be given to unacceptability of any discrimination with regard to vulnerable and marginalized groups (HIV-infected patients, for instance).

The Committee on Economic, Social and Cultural Rights calls upon the government to give priority to the development of the palliative care services.

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<sup>2</sup> International Covenant on Economic, Social and Cultural Rights”; “Convention on the Rights of the Child”

<sup>4</sup> Constitution of Georgia; The Health Care Legislation

<sup>5</sup> Committee on Economic, Social and Cultural Rights (CESCR) is the body of independent experts that monitors implementation of the International Covenant on Economic, Social and Cultural Rights by its States parties. The Committee was established under ECOSOC Resolution 1985/17 of 28 May 1985 to carry out the monitoring functions assigned to the United Nations Economic and Social Council (ECOSOC) in Part IV of the Covenant.

## Pain Treatment comprehended in the context of patients’ right to be free from cruel, inhuman and degrading treatment

Apart from the fact, that the signatory power<sup>6</sup> are liable for prohibiting the use of torture, cruel, inhuman, and degrading treatment or punishment under their jurisdiction, the states also have to take steps to protect persons from pain, related to their health condition.

The UN Special Rapporteur on torture, cruel, inhuman and degrading treatment and punishment, in his joint letter with the UN Special Rapporteur on the right to health (December 2008), called upon for governments to take reasonable measures to eliminate torture, cruel or degrading Treatment, as the failure of ensuring the accessibility of pain treatment leaves millions of people suffering from severe and prolonged pain, which raises a question whether the states have adequately discharged their obligations to protect the right to be free from Cruel, Inhuman and Degrading Treatment.

The following circumstances are considered as barriers that impede availability and accessibility to pain treatment:

- When Government fails to ensure an effective system of supplying pain relievers
- When Government fails to develop and implement an appropriate policy for pain management and palliative care services (dissemination of information among appropriate audience).
- When regulations for pain relievers’ supply and turnover are extremely restrictive
- When the medical staff is in fear because of their responsibility of prescribing pain relievers
- When healthcare professionals are not adequately trained.

The research aims to identify the barriers and attitudes towards them.

### KEY FINDINGS

According to survey results, the population in need of palliative care is basically middle-aged. Though the patients’ profession does not definitely provoke their incurable diseases, however some correlation still exists (there were far too many among the patients being in an unfavorable working conditions).

Palliative care is just being implemented in Georgia. Hence:

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<sup>6</sup> Torture and Inhuman or Degrading Treatment or Punishment Convention for the Suppression" and its Additional Protocol

✓ Palliative care for incurable patients is mainly implemented at home (46.1% of patients received palliative care services at home only; 40.2% of them received mentioned services both at home and in various medical facilities/hospices).

✓ We face the problem of delivering information to the patients and their family members. No adequate attention is paid to the issue at any level (which implies the training of medical personnel, as well as making television commercials, publishing information booklets and etc.).

The following correlation issues should be considered in order to improve conditions for incurable patients:

- I. The issues of involving an incurable patient in palliative care should be raised as timely as possible (though, since the patient is admitted to palliative care, the service is delivered mostly in a timely manner).
- II. The problem of informing patients about their diagnosis. In this terms, the following aspects may be distinguished:
  1. Information delivery directly to a patient.
  2. Information delivery to a palliative patient's guardian.
  3. Influential factors for delivering patients' information.

The problem timely delivery of information: According to the legislation, telling the truth to the patient is one of the guiding principles, as in case of delivering information with the delay or keeping the patient uninformed deprives them the opportunity to choose among various available options for treatment/relieving the pain. However, the Law provides an exception for covering up information from a patient (if telling the truth will negatively be reflected on patients' health), though the difference between these two choices is quite fragile and in Georgian reality decision making frequently depends on subjective factors. This may be considered as a barrier to delivering information by medical personnel. Accordingly:

- ✓ The majority of patients (41.2%) are misinformed about their diagnosis;
- ✓ 65% of them noted that the information about patients' diagnosis is accessible only for guardians. Almost one third of them assert that the information has been provided to guardians as well as to patients.
- ✓ In addition, unlike the guardians, the offered information is obscure for more than half of the patients (58.3%). The information was comprehensive and appropriate for almost all of the guardians.

According to the survey, there are two factors, impacting the patients' awareness of their diagnosis: 1. whether the patient receives palliative care services at home or in hospice and 2. Education level of the patients (guardians). Hospice patients with higher education degree turned out to be much more aware of the issue than those who were receiving home care service and those with low education levels.

- III. It should be considered that in accordance with the Patients' Rights Act, without patients' consent, the medical staff has no right to disclose diagnosis or other information concerning diagnosis, to anybody (There are some exceptions according to Patients' Rights Act). However, in Georgia, according to the established traditions, this requirement is frequently neglected, as from the

medical staff (at family members' insistence or in order to spare the patients) as well as from the patients' relatives. (Without the patients' consent, information about their diagnosis is mainly available for guardians – 78.3%). According to the survey, respondents do not consider this fact an invasion of privacy.

Awareness of the problem is further strengthened by the following factors: 1. Respondents are not familiar with the nuances of palliative care. 2. Awareness among medical personnel is very low. This is determined by the fact that a distinct demarcation process between palliative care and basic treatment has only just begun:

- ✓ The share of respondents, who claim that they have no information about any component of palliative care, ranges from 40 up to 60%.
- ✓ In terms of awareness, it's not decisively important, whether a patient receives palliative care at home or in hospice facility (nearly a fifth of guardians of the patients, receiving palliative care services in hospice, have no information not only on various components of palliative care, but about palliative care center and hospice as well), though the guardians of hospice patients are a bit more informed than guardians of palliative home care patients.
- ✓ While evaluating the components of palliative care, the most properly estimated regulation by the respondents was one in line with pain relief—the most prominent indicator of palliative care. However, the respondents have unclear perception of pain management as of other components of palliative care. Respondents from hospices stated that they know nothing about pain assessment, though 89.8% of patients had pain and without pain assessment they could not receive opioids.
- ✓ Respondents deemed inadequate such essential components of palliative care, without which palliative care loses its meaning – social and psychological aspects.

Consequently, apart from the guardians, there is a need of enhancing awareness of medical personnel, especially when the staff members are the main informers of patients' guardians in palliative care issues. Although the training courses for medical staff is held permanently, it is still necessary to improve above mentioned component and to develop capabilities of the responsible persons.

The issue of obtaining drugs, which is one of the most important components of pain management, is more or less solved by target research group. Only 6% of patients had some problems in this regard. The main reason of facing this problem was their financial condition (for instance, lack of finances for transportation in order to receive medicines for patient).

The survey results clearly demonstrate that palliative care patients and their guardians are somehow indifferent to the legislation. Such an attitude extremely complicates the issue of defending palliative patients' rights if necessary. In the terminal stage of illness, the patients' sufferings may be amplified due to lack of information about their rights, as they may not know what types of services they should receive or how to obtain them. Additionally, approval of the law is observed in 39.6% of those who are more or less familiar with the legislation, while 28.3% of them found it difficult to answer.



The respondents reported low awareness about the activities (linked with palliative care) of various institutions, such as the Ministry of health, Cancer Centre, Institute of Hematology, Cardiology Center and others, while the informed respondents' attitude is not so positive. Due to this, organizations are obliged to take the relevant measures with respect to the target group. The respondents feel more loyal toward the palliative care related non-governmental organizations and the National Cancer Center.

71% of the respondents reported that generally, palliative care services were available for their patients. Taking into account the lack of awareness on the part of the respondents, we may suppose that the high share of service availability is due to the following facts: 1. Selected patients have access to a variety of benefits and programs. The respondents (due to the tradition) sometimes do not realize the importance of receiving certain services (e.g. psychological services – 72.6%). 28.3% of the respondents, whose patients had no access to at least one of the services, stated that the major problem was that their finances have been insufficient.

The problem of insufficient finances is in line with the insurance issue. The vast majority of respondents do not have health insurance, while the insured patients' increased percentage (34%) is due to the charity insurance. It's less likely that the substantial part of palliative care services will be financed by the insurance package (this solution would be unprofitable for the insurance companies), though the insurance for palliative patients would be helpful for different needs (a clear proof of the above mentioned is the fact that the guardians of those patients possessing health insurance are quite content with the terms of their insurance packages, however, the fact that palliative services are not financed becomes the reason for their discontent). Increased role of state authorities would fix the problem (various advantages, extending the scope of the programs).

Because of the vague conception of palliative care itself, the respondents have much the same point of view of the major distinguishing factor between the palliative care and symptomatic treatment – a multi-disciplinary approach. The respondents consider that the denoted approach includes the engagement of a doctor, nurse, guardian or therapist only (which is a result of a systemic problem – uncertain dissociation of palliative and evidence-based treatment, “traditional approach” and the low level of awareness).

The assessment of the medical personal, their qualification and the conditions in the hospital is generally positive (though it should be considered, that the respondents could not make the evaluation in the context of palliative care, because they have a vague idea about the nature of palliative care). National Clinic is most negatively evaluated. In the same clinic there were observed many cases of demanding extra cost apart from official payments. This indicates the need of enhancing the role of the government in terms of systemic changes.

The palliative patients' living conditions are rated as below average (but still living conditions have higher coefficients with comparison to “social” issues). Unemployment among the capable patients is the biggest problem, the solution of which would serve as a positive incentive for them. 82.2% of the patients are unemployed, 60% of them have never been employed before.

Apart from the employment-related problems, one of the most pressing issues is a financial problem that makes it difficult to facilitate the timely admission to necessary services, as well as to accept them at the appropriate levels.

Palliative patients mainly have contact with the members of the “first group” (family members/relatives), as well as with the medical staff. Relations are generally positive or neutral. However, the religious factors have a great impact on revealing relationships to certain groups – as stronger believer are the patients, as less negative relations they have to various groups.

The vast majority of the respondents indicate the “passive friendliness” of the society and the medical staff toward the palliative patients.

Palliative care services are generally funded by the family, which is facing financial problems. The patients have no availability for state benefits, except for opioids, basically due to the lack of information. Once again this points to the necessity of enhancing the role of the authorities.

And finally, is the core goal of palliative care, alleviating the patients' pain and suffering, achieved in today's environment? And what are the factors affecting it?

The majority of the respondents (68.2%) stated that after receiving palliative care services the patients' condition has been more or less relieved. The improvement of palliative patients' quality of life is based on the atmosphere where the services are more or less fully accepted – as in hospices for instance.

The obtained data demonstrates the necessity of developing palliative care services including all the components, especially the psychological and social elements, the need of involvement and extension of the palliative care scope (home delivery services) and information campaign development as well. The line of demarcation should be drawn - both medical staff and the patients should know when the curative treatment is to be ceased and when the palliative care may be commenced.

## Research Methodology

**Survey Type:** Quantitative social research

**The Method:** Face to face interview

- ✓ To visit palliative patients at hospices
- ✓ To visit palliative patients at home

## General Union:

Palliative care patients

### The volume of the selected data:

Region	Quantity	%
Tbilisi	473	70.2
Qutaisi	80	11.9
Telavi	41	6.1
Batumi	80	11.9
Total sum	674	100

In Georgia palliative care patients are identified with cancer patients. Selected survey respondents mostly are caregivers of cancer patients.

### The Selection:

In accordance with the survey specification:

- ✓ Choosing a random sampling method was impossible. Consequently, the database selection was based on data available from hospices and social service organizations (information about opioid recipients).
- ✓ Since the patient on terminal stage of illness, due to his psychological and physical condition, was not capable of answering the survey questions, the selected respondents were the patients' **guardians**.
- ✓ Because of the fact that the number of palliative patients on terminal stage is constantly changing, the guardians of the patients who had already died have been also selected.

According to the sampling distribution, margin of error is at 95% – 3.7% of the general population.<sup>7</sup>

**Data coding and computer entry:** The respondents' responses to open questions have been classified and formalized by giving them their codes (quantitative indices). The encrypted responses have been entered into the network variables, created for each specific survey.

**Data processing and analysis:** The survey data have been processed with the help of the Statistical Package for the Social Sciences (SPSS), providing statistical data in the form of tables and diagrams. Statistical data analysis has been

<sup>7</sup> The error is calculated based on the statistics of National Health Program, which stated that, every year approximately 25000 people in Georgia are in need of palliative care.

conducted by different methods of univariate (frequency distribution, indicator of central tendency) and bivariate (cross tabulation, correlation) analysis.

### Demography

As prompted by the survey:

- ✓ The surveyed palliative care patients (primarily oncology patients) are equally distributed according to gender.
- ✓ The given selection shows that palliative care patients are mostly older than 55 years of age people.
- ✓ Among the patients with incurable diseases are dominating those whose activities are mainly related to heavy manual labor (e.g. Turner, Maid, Handyman, Print Shop Worker, Street Cleaner, Electrician, Factory Worker, etc.) and those who are in an unfavorable environment for health.

However, we cannot unequivocally argue that the patients' activity is directly proportional to their diseases:

- ✓ An equal share (16% approximately) have intellectual figures and athletes, as well as those patients who have never been employed (though there should be considered that athletes are at high risk because of the traumas that can cause the diseases).
- ✓ Additionally, the share (12.3%) of the respondents whose activities are related to the construction sector has been revealed.

## I. Involvement in palliative care

According to the survey, in most cases **cancer is being unveiled when a patient is close to terminal stage:** The diseases have been revealed only during the last 12 month for every second patient. Only 15% is the share for those patients whose disease has been detected earlier than 4 years. 30% of respondents indicated 2 or 3 years.

As it turned out, palliative care mostly takes place at home: The vast majority of the patients (46.1%) under the guardianship of the respondents have been receiving only the home care services; 40.2% of them have received services at home, as well as in other medical facilities/hospices and 13.6% of them in medical centers/hospices only.

A majority of guardians consider that for the patients who are under their guardianship the most desirable place for receiving palliative care services is the home (the share of such cases is approximately 80%, as for guardians, as well as for the patients).

The absolute majority of the patients (94.2%) have been receiving palliative care services during the last 12 months. For 88.1% of them palliative care has been delivered permanently (it has not been intermittent).

**Palliative care has recently taking place in Georgia. In recent years this service has been completely replaced by family doctors service and custody of family members. That's why the guardians as well as the patients prefer to receive this type of services at home. As it was already mentioned, there is a correlation between these factors and the problems with awareness.**

87.5% of the medical centers decided to involve the patient in palliative care only after researching the patients and their family members' condition. Only 4.5% of them stated that an informal way was used to involve the patient in palliative care.

A patient condition assessment is mainly carried out by the medical staff (the guardians firstly named the polyclinic staff as an appraiser, while in the second place the medical staff of the hospital was designated).

It should be noted that almost every second patient got involved in palliative care in the final stage of the incurable illness. Almost a quarter of the patients only after the diagnosis of their incurable disease have been set and 14.2% of them, after receiving unsuccessful treatment.

*The qualitative research findings show that:*

1. *Medical personnel stated that at various medical facilities there are different ways of offering paliative services. In particular, in the Institute of Hematology there is no a clear marked out difference in palliative and symptomatic treatments. In the National Centre for Tuberculosis and Lung Diseases it depends upon the situation whether the patient is hospitalized or receives palliative care services at home, although in such cases the guardians are provided with the information about how to take care of their patients. The department of palliative care at the National Cancer Center is the exception where a psychologist is also involved in the process of palliative care. At the AIDS and*

*Clinical Immunology Research Center palliative care services are offered when the patients' co dition is extremely aggravated. In the Cardiology Center (A.Aladashvili's clinic) the information about palliative care is available for patients and their guardians.*

2. *The guardians reported that the patients under their guardianship have mostly been receiving paliative care at home. The members of the Family Guardian Focus Group have not been informed about palliative care. "The only recommendation I have received was about how to take care of my patient, and that was of great importance to me. I have not got any other information (palliative care components are meant)," reported one of the participants.*

According to the survey, timely involvement of palliative services is more or less observed. 80.4% of the respondents noted that it took them maximum 2-3 weeks to involve in the offered palliative care. About 13% of them have received delayed treatment.

As expected, almost all respondents (97.3%) noted that the patients' family members are involved in the process of palliative care.

**So we can draw a conclusion:**

- ✓ **The assessment of palliative care patients and their families' condition, involvement of patients in palliative care and provision of pertinent services do not extend beyond its official scope (however this fact may not be linked to the degree of awareness);**
- ✓ **Certain inertia can be observed in relation to palliative care. Particularly, because of the little scope of palliative care services and due to lack of awareness of the citizens, as well as of the medical personal, the family still plays a fundamental role in providing above mentioned services (including physical and spiritual/psychological care).**

**The basic problem is to be involved in palliative care as timely as possible, immediately after finding out that the patient is incurable.**

## II. The level of awareness

### 1.1. The level of awareness among patients about their diseases<sup>8</sup>

A clear picture has been formed with regard to the patients' awareness about their diseases:

- ✓ More than a third of the patients (36.4%) have got comprehensive information about their diseases, 21.4% of them have an approximate, and the largest percentage of the patients (41.2%) is misinformed.

<sup>8</sup> See appendix for more detailed statistics of this chapter: charts 2.1-2.5; tables 2.1.-2.10



✓ The guardians whose patients have been receiving only home care services (in other words, who have not used hospice services) turned out to be a bit less informed than the respondents, who were the guardians of the patients receiving not only home care services, but also had an access to the services of various medical facilities/hospices.

✓ In a given situation, Convent of the Transfiguration is an exception, where the patients have got complete information about their diseases. Moreover: After being diagnosed they address the hospice at convent.

**Hence, the factor as to where the patient is receiving palliative care services has a decisive impact on the patients' awareness about their diseases, though this is not the only impacting factor.**

The education level may be also considered as one of the impacting factors: As the survey shows, patients with high education level are better informed about their diseases, than those with average level of education (especially those with incomplete secondary education).

According to the results of the research, the information about the patients' diagnosis is available only for guardians (65%), though almost a third of the guardians noted that the information has been provided not only for them, but also for the patients under their guardianship.

**It should be noted that while providing information about diagnosis the patient's consent is not an inhibiting factor for the medical personal. Without the patient's consent the diagnosis are available to 78.3% of the guardians only (however, nearly a third of the respondents noted that there have been the cases of providing information to patients).**

*How much proper are the diagnosis and related prognosis delivered to the patients and to their guardians?*

For over half of the patients (58.3%) the information is obscure, in contrast to the guardians: For almost all of the guardians the information is clear.

The guardians of those patients, who have received only home care services, indicated that their patients' were not informed (covering up real picture) upon their diagnosis. The percentage is relatively low in the cases of those respondents whose patients were receiving not only palliative home care services but also had access to palliative services in various palliative care facilities/hospices.

78.7% of those respondents noting that the patient was provided inaccurate information about the diagnosis stated that the main reason for withholding this information was the guardians' request and desire not to worry the patient.

Only 19 patients refused to receive information about their diagnosis and the major reason for such decision was their fear of being diagnosed with life threatening illness.

The overwhelming majority of respondents (90.4%) noted that the doctor explained the details and nuances of the treatment. The small share of respondents, who were not satisfied with the doctor's explanation of the treatment process, complained about their incompetence and indifferent attitude.

If we consider the fact that the survey was conducted with guardians who were fully informed about diagnosis of the patients under their guardianship, the obtained result is logical.

**Should the patients with incurable diseases initially be aware of their diagnosis?**

Every second respondent looks positively at this issue: 22.7% of them think that the patients should be informed about the diagnosis of an incurable disease. According to 28% of respondents' the personality should be definitely considered before informing them about their diagnosis. (It should be noted that the patients who were under guardianship of the respondents of this group, have not been informed about their diagnosis). 42.4% think that it is intolerable to deliver such information to patients, as their sufferings will increase. (One part of this group of respondents – 15.3%, may be discussing the issue based on their own experience, because the patients under their guardianship have been informed of the diagnosis). In this respect, there is no difference in the respondents' data whose patients have been receiving only home care services or in other medical facilities as well.

In the qualitative research process experts noted that along with the country's development process palliative problem becomes a social problem, like in the West.

*"In the West the issue is linked to economy and business – the patients may have to resolve the issue of heritage or some other problems... Similar tendencies in Georgia is already observed."*

*"In the West, if a doctor withholds a diagnosis from a patient, the patient and his family will make an appeal. Here in Georgia, doctors are putting themselves at great risk... If he informs the patient, the relatives will gripe about... This is the problem... How one can deliver the information to the patient... Radical changes should be made in mentality, so that the information is properly perceived."—the participants reported.*

*"Should the patients know their diagnosis? And thus begins the series of the issues like legal, financial and etc. All over the world the main aim of the medicine is that the patient should feel well, while in Georgia the major goal is that the patient should exist..."*

**The starting point of palliative care is the patients' awareness about their diagnosis (especially timely), which determines all other significant components. For instance, protection of palliative patients' legal rights, the opportunity of choosing hospital, doctor and treatment means, reducing suffering, improving quality of life (including life prolonging), etc.**

**Accordingly, the data shows that:**

✓ **Patients' awareness on the incurable diseases is low and this automatically reflects on the patients' rights of having the opportunity of using foregoing factors. Palliative home care and relatively low level of educational qualification have a negative impact on patients' awareness.**

✓ **Attitudes of medical personnel can also be considered as one of the impeding factors for patients' awareness: Preferring consideration of humane factors and ignorance of the patients' – withholding the diagnosis and delivering the information to guardians without the patients' consent.**

## 1.2 The level of awareness about palliative care in general<sup>9</sup>

The results of the research showed that the share of the respondents who reported that they had no information about this or that component<sup>10</sup> of palliative care is ranging from 40 up to 60%. In comparison with other components, the respondents considered themselves more informed about characteristics of palliative care patients (detailed information on this component has 17% of them). It is not surprising if take into account the fact that the respondents were the guardians who took care of the patients.

If we compare the respondents' awareness (due to self-esteem) according to the place where the patients under their guardianship have been receiving palliative care, we will get the following results:

✓ The rate of the awareness of those respondents whose patients have been taking palliative care services at home is lower compared with those who have been receiving services in various medical facilities.

✓ Approximately a fifth of the guardians of those patients who have received hospice services, have not got any information not only on various components of palliative care, but also about medical centers and hospices; (61.5% of the respondents who have received hospice services indicate the full or more or less complete awareness about hospices). Accordingly, the awareness level of those patients who have not been in hospices is low.

For the majority of respondents **the main source of information** about palliative care is medical staff of polyclinic/hospital (mostly medical personnel of hospitals). Besides, every second respondent (from the group, members of which have got some information on palliative care) indicate one source of information, while 6.1% of them marked out two sources of information. In addition to medical personnel, an informal circle of friends has been indicated.

*During the qualitative study the representatives of different medical institutions have reported the following: In the case of AIDS and TB, the information is available only for the patient and family members according to the situation, as in the beginning no one knows how events will develop.*

*Palliative care team of National Cancer Institute spoke about the importance of proper communication with patients: "Mostly the patients need care, no matter it will be a food or communication care... Their disease is usually associated with pain and other unpleasant symptoms and our obligation is to release these symptoms and to justify their hopes... And that's why communication is of great importance."*

In order to identify the level of awareness about palliative care more accurately (objectively), the respondents were given a set of statements. They should evaluate whether the given provisions described

<sup>9</sup> See appendix for more detailed statistics of this chapter: charts 2.6 -2.9; tables 2.11 – 1.12.

<sup>10</sup> Particularly the questions were raised about the components of palliative care, such as taking care of palliative patient, palliative care centers/hospices, various assistances and benefits and nutrition during palliative care and so forth.

palliative care. This was a kind of **testing** of the respondents (the provisions have been assessed by the group of the respondents who reported that they had certain kinds of information about palliative care).

*Statements were formulated as follows:*

*Whether the palliative care...*

- ✓ *Provides pain relief for the patients with incurable diseases?*
- ✓ *Provides free meal for the patients with incurable diseases?*
- ✓ *Provides social and psychological assistance for the patients with incurable diseases?*
- ✓ *Provides care and treatment for any critically ill patient?*
- ✓ *Provides treatment for the patient with incurable diseases?*
- ✓ *Provides discounts on medicines and some medical procedures?*

The obtained data has revealed:

- ✓ Estimation of statement which links pain relief to palliative care was straight forward and correct by the respondents
- ✓ Generally, the respondents who have been receiving palliative care in various medical facilities / hospices evaluated statements more correctly than others (though essential deficiencies among these respondents have been observed).
- ✓ A significant share of respondents could hardly evaluate statements. Especially in case of those respondents whose patients have been receiving home care services;
- ✓ A social and psychological assistance in palliative care for incurable patients have been deemed as "incompatible" by a significant number of respondents (26.8% of those receiving home care services only and 45.6% of those receiving hospice services).
- ✓ It is noteworthy that respondents by mistake identify palliative care with care of those patients with any other severe diseases. In this case the share of both groups of respondents with correct answers is almost equal.

**Previously made conclusions have been further reinforced by these data: It is not of crucial importance whether the patient gets treatment at home or in hospice (however, hospice care services still have some positive impact on patients). Considering the fact that the respondents get information mostly from medical personnel, first of all we have to talk over their awareness about palliative care issues or discuss their superficial attitude toward the palliative patients' awareness.**

**There are close relationship between palliative care and community development. Therefore, the lack of information about palliative care is an acute problem. As it has turned out, most of the respondents are equating symptomatic treatment to palliative care and know nothing about the fact that palliative care should include social and psychological aspects as well. This fact indicates that there is a gap in health care system, moreover that palliative care and basic treatment is clearly marked out from each other in various medical institutions.**

### III. Are they familiar with the health legislation and have they ever applied to the court?<sup>11</sup>

The implementation of patients rights and palliative care is regulated according to the following laws operating in Georgia: “Law on patients rights”, “Law on Health Care”, “Law on Medical Activities”, “Narcotic Drugs, Psychotropic Substances, Precursors and Drug Assistance Law”, as well as by other law, orders, and their additional protocols, regulating a certain sector of the Health Care. These laws comprise various aspects of care and treatment of the patients with terminal stage diseases, such as informing patients about the incurable diseases and offering palliative care services to them, maintaining confidentiality, protecting and implementing medical standards, easing the pain and etc.

In 2008, Georgian National Parliament adopted amendments and additions to the four above mentioned law, the main goal of which is the development of palliative care in Georgia and its integration into National Health System. In addition, relatively modern and liberalized regulations about appointment and subscription of opioids were established according to #17, #18 and #96 joint orders, issued on 28th of January, 2010 and #55, issued on 26th of February, 2010.

As for the respondents (guardians of palliative care patients): The vast majority, 82.5% of the respondents is not familiar with the law of palliative care, only 9.1% of them know it poorly. The majority of the small group of the respondents (7.8%) who is more or less familiar with the law of palliative care, acknowledge that the law is good, though some of them state that actually it is not fulfilled.

There are a very insignificant number of facts, when the patients’ family members or their relatives have taken an appeal to any instances in order to protect the rights of palliative care patients:

- ✓ Only 13 respondents confirmed this fact (97% of them have not applied);
- ✓ The main reason why they appealed the court was the delay or receiving no services at all.
- ✓ In most cases, the problem for which the patient’s family members and relatives appealed to certain instances, have not been resolved.

In order to explain why the family members and relatives of palliative patients did not appeal to certain instances, the respondents identified the following reasons:

- ✓ The major part, 70.8% of them consider that there has not been such a problem due to which the intervention of the court was required. (It should be noted that these figures have been compared with the index assessing respondents’ satisfaction with various medical services and medical staff. As a result, a substantial imbalance has not been identified).
- ✓ Approximately 11% of them had no expectations that their rights would be protected.

- ✓ 9% of them despite their intention did not know to whom to appeal.

*Qualitative analysis revealed a low level of awareness about the legislation in the group of palliative patients’ guardians.*

*“We do not know our rights and have no idea what we should claim... When it is known, we will ask for what we really need...” stated one of the participants.*

**There is a lack of awareness about the rights of palliative patients and this problem leads to:**

- ✓ **A wrong perception or evaluation of the patients’ legal status, as well as of the violation of their rights. Particularly, a person may not know that a certain incident is a violation of patient’s rights and therefore do not evaluate the fact as an infringement.**
- ✓ **Accordingly, the rate of protecting the rights by appealing the court is low.**

#### 1.3. Assessment of pain intensity<sup>12</sup>

The survey results show that:

- ✓ The absolute majority of patients (89.8%) had pain which caused suffering;
- ✓ However, only a third of this group of patients’ guardians (35%) have heard about the assessment of pain intensity;
- ✓ 26% of them indicated that pain intensity assessment have been performed, and almost every second respondent from this group stated that the evaluation have been implemented several times.

In this regard, the difference between those patients who have been receiving palliative home care services only and those who have been receiving services in various medical facilities/hospices was not detected.

A very small number of the respondents know what pain level of their patients was indicated on pain scale (average level is 3.33).

A small number of those respondents, who have heard about pain assessment but pain intensity assessment have never been performed for the patients under their guardianship (such are 12 respondents) mostly found it difficult to state the reasons, while some others pointed out the lack of information (“we knew nothing about the possibility of pain assessment and therefore we have not requested for it”, “we have only just entered”).

<sup>11</sup> See appendix for more detailed statistics of this chapter: charts 3.1 -3.6

<sup>12</sup> See appendix for more detailed statistics of this chapter: charts 4.1 - 4.4



**Proceeding from the fact that without pain assessment one should not prescribe pain relievers, we may say that the major problem for palliative patients is the lack of information. In addition to this fact there is an indifferent attitude of medical staff towards the awareness of patients and their family members about pain management.**

#### **1.4. Consumption and availability of medications<sup>13</sup>**

In terms of pain management timely access to medicines and the availability is of great importance.

All patients, who were suffering from severe pain (90% of the respondents), have been taking pain reliever. The largest share of drug consumption falls on opioids.

An absolute majority, 93.3% of those patients, who have been taking pain killers, have obtained all the necessary medications. Only 6% of them reported that some of the medicines were not available for them, mainly because of their financial condition (basically, lack of finances for transportation in order to receive medicines for patient). An insignificant number of the respondents indicated a problem with bureaucratic barriers and lack of information.

*Exactly the same fact was pointed out by one of the guardians of palliative patient, who was the participant of the focus group at the same time. He was not satisfied with drug funding, which was not even proportionate to their prime cost.*

*One of the members of medical staff noted, that some patients have no idea that opioid pain reliever are funded by the government.*

Nearly the same figures were revealed in regard to getting the medicines without delay: The vast majority got their medicines in time, and those who had some problems with getting prescribed medications in time, identified that the main reason for the delay was their finances (In this respect, the principal difference between those patients who have been receiving palliative home care services only and those who have been receiving services in various medical facilities/hospices was not detected. Though, among home patients the rate of getting some medications without consulting a doctor is slightly higher).

Only a small number of respondents (5.5%) claimed that their physicians have refrained from prescribing pain medications on account of their indifferent attitude and caution due to the health condition of a patient.

82% of the patients have never taken pain medications without a physician's consent. The small share of respondents noted that some medicines and their dosages have not been confirmed by a doctor.

*Has the patients suffering been relieved after involving in palliative care?*

<sup>13</sup> See appendix for more detailed statistics of this chapter: charts 4.5 – 4.13

A clear majority of guardians (68.2%) say that palliative care more or less eased the patients' sufferings. Slightly less than a fifth of them state that the degree of suffering is the same (it is interesting that it makes no significant difference whether the patient received palliative care at home or in other medical facility/hospice).

**Pain mitigation is a key determinant of effective palliative care. Hence:**

- ✓ **Tools for putting pain assessment into practice needs to be improved: Very often palliative care patients are not informed about pain assessment, which may indicate the presence of system defect;**
- ✓ **Due to the fact that the selected respondents mainly were the guardians of those patients, who received pain medications, we cannot discuss the issue – how much the situation has changed since the relatively liberalized rules for appointing and subscribing opioids has been established<sup>14</sup> in 2006-2007. Nevertheless, there is a small share of respondents who, in spite of all the conditions, failed to gain (or could not obtain in a timely manner) all the necessary medicines, which is due to their low financial capability.**
- ✓ **There is a certain group of palliative patients (18% - according to the survey) who receive medication and calculate drug dosage without consulting a doctor. On the one hand, this can be caused by an existing mistrust towards the medical staff and on the other hand, because of the fact that the physicians very often subscribe lower doses of the drug due to their fear of law.<sup>15</sup>**
- ✓ **Consideration of the majority of the respondents indicate that the development of palliative care is of great importance, as these kind of services either reduce patients suffering or in extreme cases has not worsen.**

## **V. Evaluation of the activities of various institutions <sup>16</sup>**

The activities of various institutions have been rated by the respondents with respect to palliative care provision. These institutions are:

<sup>14</sup> Minister of Health Resolution #157, dated 10th of July, 2008; #17, #18 and #96 joint resolutions, dated 28th of January, 2010; Resolution #55, dated 26th of February, 2010

<sup>15</sup> A doctor has the right of prescribing a certain number of opioids according to the law. If patients require additional doses, dilemmas arise: On the one hand, the physician knows that the selected dose is not sufficient to reduce the patient's suffering and he has an obligation to assist the palliative patient, but on the other hand, prescribing an extra dose pose a problem with the law. Although changes were made to the law in the years of 2008 and 2010 (which makes it relatively liberal), the problem at this stage still exists.

<sup>16</sup> See appendix for more detailed statistics of this chapter: chart 5.1.

- ✓ The Ministry of Health, Labor and Social Affairs of Georgia;
- ✓ National Cancer Center;
- ✓ AIDS Center
- ✓ National Center of Tuberculosis and Lung Disease
- ✓ The Children's House
- ✓ Cardiology Center
- ✓ The Institute of Hematology
- ✓ Palliative care related nongovernmental organizations

Evaluation was carried out on a five point scale (from -2 up to +2), where “+2” indicated “very positive”, while “-2” -- “very negative”. Scale have a neutral point – zero. If count data is greater than zero, then it corresponds to positive field values and if it is below zero, then it coincides with negative field values.

As it turned out, the vast majority of the respondents are not informed about the activities of various institutions in relation to palliative care. Most of all they possess information about The Ministry of Health, Labor and Social Affairs of Georgia and National Cancer Center;

Except for the palliative care related nongovernmental organizations and National Cancer Center, all other values were in negative field of the scale (though, these two institutions are also close to neutral-point scale);

**The respondents' strongly negative attitude towards the palliative care related institutions, as well as the fact that they are not informed about their activities at all, indicate that the role of the government and the public sector needs to be intensified.**

## VI. Accessibility to the components of palliative care; Insurance and other allowances

### 6.1. Accessibility to the components of palliative care<sup>17</sup>

The respondents were asked, whether the patients under their guardianship have had an access to the following services:

- ✓ Outpatient examinations
- ✓ Chemotherapy
- ✓ Radiotherapy
- ✓ Inpatient treatment
- ✓ Pain management

<sup>17</sup> See appendix for more detailed statistics of this chapters: 6.1-6.4

- ✓ Medications
- ✓ Medical staff, providing home care services
- ✓ Therapy service
- ✓ Psychologist service
- ✓ Homes for the aged

The majority of respondents (71.7%) stated that the patients under their guardianship have had an access to those services of palliative care which they required:

Overall, the share of those respondents, whose patients has not received at least one of the components of palliative care, stands at 28.3%.

It should be noted that the majority of respondents (72.6%) have never used the services of psychologists, while the rest of them had no access to these services;

For the majority of respondents (70%) there was no need for therapy services or medical personnel who would implement palliative care at home. **The last case is much more likely to result from traditional factors – the guardian believes that the patient's family is the key actor of palliative care.**

The respondents, for whom at least one of these services is not available, report that the main reason is **insufficiency of funds** (in case of any services). The difference revealed only in case of psychological service, where the low awareness is nominated as the main reason.

*In regard with insufficient finances quantitative research with different target groups has revealed the following:*

*Experts noted that palliative care is generally associated with significant financial expenses. If we compare western countries with Georgia, palliative care abroad is undertaken mainly by charitable and religious organizations, as opposed to Georgia. That's why the importance of the role of the government is increasing in our country. In addition, it is important to expand the scope of palliative care and not to include only cancer.*

*As the physicians say, the patient has a long way to go through until severe pain is commenced (ranging from simple analysis to chemotherapy and nutrition) and very often in the terminal stage the patients' finances is not sufficient for mitigating the pain. Also there are frequent cases when due to lack of money the patient cannot even visit a doctor and hereby timely diagnosis is difficult to set.*

*“People try to suffer without bothering others, try not to use palliative care program, in order to avoid unnecessary costs. Sometimes they come in such a condition that we have to give an injection right in the corridor. They cannot even reach the ward”—stated the representative of department of palliative care of the National Cancer Center.*

*Some guardians expressed their satisfaction with the “European standard” medical institutions and services. Discontented part of the guardians indicated on high prices, informal taxes, poor conditions and indifferent attitude of physicians.*

As for the patients' satisfaction with the required services that were available for most of the respondents, according to average indicator, the following data was obtained:



- ✓ All the listed components of services (except homes for the aged) turned out to be in positive field of the scale.
- ✓ Most of the indexes are near to the point “+1”

Evaluation was carried out on a five point scale (from -2 up to +2), where “+2” indicated “very positive”, while “-2” -- “very negative”. Scale have a neutral point – zero. If count data is greater than zero, then it corresponds to positive field values and if it is below zero, then it coincides with negative field values.

#### According to the fact that currently palliative care covers only oncology:

- ✓ **State supported programs and benefits are available for the patients of this group. Consequently, the problem of access is more or less solved, especially with regard to medicines (opioids);**
- ✓ **In terms of patient care positive changes have been identified. Implementation of palliative care undoubtedly had an impact on these changes;**
- ✓ **These data once again demonstrates the necessity of strengthening social-psychological factors in palliative care and informing the recipients of these services about their importance.**

#### 6.2. Insurance and other allowances<sup>18</sup>

Overall, 34.1% of palliative patients are insured. Almost half of them have charity care policies, while the rest of them have medical insurance (corporate or individual).

According to the survey results, 24.5% of palliative patients’ families are registered in the database for vulnerable people (living below poverty line). This means that they have appealed to the government (namely, the social service agency) for assistance.

Those families, who are registered in the charity database, receive assistance on the basis of the evaluation made by the social service agency: 52.7% of them get financial aid (less than 57000 rating point) and 65.5% of them – medical insurance (policy/voucher); 18.2% of the patients receive the pension. It is noteworthy that 12% of the registered patients are unable to receive assistance.

The great majority, 83% of the guardians of those patients who obtain health insurance report that they are satisfied/ more or less satisfied with the terms and conditions of the offered medical insurance package.

**33% of the insured patients stated that palliative care was partially funded by the insurance company.** The overwhelming majority of this group is satisfied/more or less satisfied with the terms and conditions of their medical insurance.

<sup>18</sup> See appendix for more detailed statistics of this chapter: chart 6.5 -6.11.

The small numbers (13%) of those patients, who are dissatisfied with medical insurance package, designate such factors, which are in a close correlation with their financial condition: Insurance packages do not include those basic services that are of great necessity for the patients. Only 11 respondents indicate the existence of bureaucratic barriers.

*While implementing a qualitative research with respect to palliative care, there turned out to be the following types of insurance related barriers (focus group – physicians):*

*When the insurance provides full or partial funding of a certain service and the insured patient has to pay the full amount, which will be subsequently covered by the insurer. Because of the existing bureaucratic barriers of the insurance system (visit to a doctor, who should issue a form 100, to submit the completed form to the insurance company, get the invoice from the insurer, to deliver it to the administration in order to make the calculations, etc.) the patients prefer to pay the full amount, to those multiple visits to the insurance companies. Especially, when concerning the urgent cases and the requirement of an insurance package is that the patient at first should pay the whole amount and only after that the insurer would reimburse them. The family members do not really have a time to speak about the low and the protection of their rights.*

*Cancer Center representative noted, “it is such a pointless way, that not only the patient with forth stage of cancer, but I am a healthy and even I cannot go through all these procedures... One of the patient died before obtaining invoice from the insurer, though he had a private driver, but still.”*

*“Even those, who are working at parliament and have no barriers to overcome, find it difficult to go through this,” (representative of TB prophylactic center). As a result of this, besides the fact that there is a reasonable suspicion concerning to qualified services, the patients have lost confidence in the physicians as well.*

#### One may say that:

- ✓ **There are few patients using the insurance, their number is increased due to the medical insurance policy designed for vulnerable families;**
- ✓ **In insurance packages, components of palliative care are less defined. The category of beneficiaries of medical insurance, who indicated that the insurance package has partially funded palliative care services, showed their satisfaction. However, it should be considered that, on the one hand, in many cases all the components of palliative care are not included in the coefficient of the respondents’ satisfaction, and on the other hand, the main reason for dissatisfaction is already mentioned fact: The majority of palliative care services are not funded.**

*Who covers the cost of palliative care?*

According to the survey:

- ✓ Funding sources are mainly distributed between the family and the country’s authorities. (“partially funded by family” – 83%; “partially funded by the state program” – 72%); A certain share (33%) falls on health insurance as well.
- ✓ The number of those patients, who are fully funded by the family, is very insignificant (5%);

- ✓ The patients are entitled to the Government's health benefit program, which is mainly associated with opioid use. It should be noted that almost half of the respondents, who indicated the state program as a partial funding source, are not informed about the variety of available benefits.

Apparently, palliative patients are still dependent on the family's financial stability. The degree of state aid and involvement in palliative care process would be much higher if the following two conditions are satisfied:

- ✓ On the one hand, a significant improvement of the problem with regard to palliative care recipients' awareness is required.
- ✓ On the other hand, activation of the Government's role in the form of various programs/benefits is of great importance for palliative care system sustainability. It should not be limited only with regulating the supply of opioids (it should be considered that insurers' role in palliative care funding would hardly increase, due to the high cost of the denoted services).

## VII. Evaluation of medical institutions and the activities of medical staff in respect to palliative patients

### 7.1. Multidisciplinary or individual approach<sup>19</sup>

More than half of the respondents (55.2%) noted that palliative care was implemented by one physician. However, a significant number of the respondents (38%) indicate a multidisciplinary approach. In comparison with home care patients, twice as many respondents, who were receiving palliative care in medical facilities/ hospices, indicated that services were provided by a multidisciplinary team. While surveying hospital/hospice patients, approximately an equal share falls on multidisciplinary team and individual involvement. **This result is likely due to a medical facility – multidisciplinary approach is perceived as being surrounded by medical personnel.**

The assumption is supported by the analysis of the query as to who are specifically involved in palliative care:

- ✓ A doctor, nurse, guardian is mostly nominated. Sometimes – a physical therapist. The share of the rest of the listed contingent is a minor. *It is interesting that in this respect any essential difference has not been revealed between home care patients and those who have been receiving services in hospitals/hospices.*

<sup>19</sup> See appendix for more detailed statistics of this chapter: chart 7.1 – 7.4.

- ✓ For guardians a multidisciplinary approach is mainly associated with the services received from doctor, nurse, therapist or guardian. The respondents, nominating multidisciplinary approach, mainly indicate maximum four specific people, who were engaged in palliative care of the patient;
- ✓ The social-psychological component of multidisciplinary approach almost never gets mentioned.

As we see, while providing services for palliative patients we still face the problem of a systemic approach:

- ✓ In many cases, the essence of a multidisciplinary approach is not perceived correctly by the respondents.
- ✓ According to traditions, the patients' family still fully serves the function of a multidisciplinary team.
- ✓ It is obvious, that there is a lack of involvement of social-psychological factors (a psychologist, dietician, volunteer, cleric, etc.) in the implementation of a multidisciplinary approach.

During the qualitative research the question was raised on how the respondents imagine their "ideal" palliative care and who should be involved in it? The following considerations have been observed:

1. Palliative patients, "according to our traditions", should spend the last days of their lives together with family members, surrounded by caring atmosphere. Additionally, hospitalization of a dying man is related to a range of extra expenses and very often the family is unable to cover these expenses, especially when it is preceded by an expensive treatment and care procedures for palliative patients.
2. There must be a certain center, which will provide assistance to guardians, especially when one is employed and is restricted in time.
3. Volunteers, who will provide palliative care services free of charge to patients, because many families have no opportunity to pay for this kind of services, even in the case of access to palliative care centers; (One of the participant stated that there are people who simply want or their religion requires them to take care of other people. This process requires to organize them);
4. Existence of psychologist and psychological treatment;
5. The necessity of training and informing the guardians about palliative care in respect to palliative patient;
6. Existence of a pension, where the palliative care patients would be looked after;
7. It would be advisable if the faculty of palliative care exists, which will be specialized in a particular field, or at least it should be considered its vocational training level.

The experts indicated that the institute of volunteers should be developed: One of the components of palliative care is public involvement – volunteers. However, they noted that it was difficult to imagine how to develop a volunteer institution. It is possible to conduct a special training course for them, which would include medical, psycho emotional and social aspects of care. Since the palliative care is related to finances, with the inclusion of this component it is possible to achieve such results, when family members would live with less stress and would be able to have more free time, to work ( by improving the family's financial condition, the patient will have a positive effect).

As we see, the qualitative research data have been confirmed by the results of quantitative research: 1. Lack of information about availability of certain services and possibility of their usage; 2. Low financial capability of the patients' families.

## 7.2. The use of palliative care and evaluation<sup>20</sup>

The share of those palliative care patients who have not gone through at least one necessary procedure<sup>21</sup> is 12.6%. The main reason of not receiving the required treatment is financial problems. Besides, medication/treatment related intolerable side effects and lack of information about the necessity of certain form of treatment have been nominated.

*Has the patient's quality of life improved after receiving palliative care to the respondent's opinion?*

Respondents have had to evaluate the following locations of palliative care: Home, private clinic, retirement home, state clinic, monastery (these are the places where the patients receive palliative care).

*Evaluation was carried out on a five point scale (from -2 up to +2), where "+2" indicated "very improved", while "-2" - "very worsened". Scale have a neutral point – zero. If count data is greater than zero, then it corresponds to improved field values and if it is below zero, then it coincides with worsened field values.*

As it turned out, the home and the homes for the aged were placed in the field of below neutral grade (worsening). The highest coefficient has a hospice (+0.5), while the lowest – home (-0.37). **This once again confirms that currently the most comprehensive palliative care services are available in hospices, where a multidisciplinary approach is more or less implemented.**

The respondents should evaluate the attitude of the medical staff, which has provided various palliative care services to patients in various places.

*Evaluation was carried out on a four point scale: 1. "friendly"; 2. "neutral"; 3. "indifferent"; 4. "rude". The respondents could indicate "hard to answer".*

As it turned out:

- ✓ Friendly attitude toward the patients is apparent in all the listed palliative care institutions;
- ✓ Unequivocally positive assessment (100%) has the services received from monastery; Hospices are slightly behind.
- ✓ Relatively worse share have the state clinic; In this case, every fifth of the respondents indicate medical personnel's "neutral" attitude and approximately 10% of them indicate their "indifferent" and "rude" attitude.

The respondents also expressed their satisfaction with medical personnel qualification in places where they have been receiving palliative care services and with current living conditions in different medical institutions as well (hospice, private clinic, state clinic and monastery).

<sup>20</sup> See appendix for more detailed statistics of this chapter: chart 7.5 – 7.16.

<sup>21</sup> Implies the following procedures: Pain medications, chemotherapy, outpatient treatment and others

Evaluation was carried out on a five point scale (from -2 up to +2), where "+2" indicated "satisfied", while "-2" -- "dissatisfied". Scale have a neutral point – zero. If count data is greater than zero, then it corresponds to satisfied field values and if it is below zero, then it coincides with dissatisfied field values.

The survey shows that:

- ✓ Assessment about qualified medical staff, as well as about living conditions in medical institutions is located above the neutral point of the scale – in a positive field;
- ✓ The only case where the indicating figure is more or less approaches neutral point of the scale is the living conditions of the state clinic.
- ✓ Evaluation about medical personnel's attitude toward the patients seems a bit better, than the facilities condition assessment.

**Due to the fact that there is a correlation between improving the quality of life and easing the pain and that based on the research, palliative care have a positive impact on pain mitigation, the obtained result is quite logical.**

The majority of respondents noted that besides official taxes they have never been asked for paying any additional amount in hospitals, as well as at home. There was not found even a single case of this kind in monastery; only two respondents indicated incidents of this kind in respect to private clinics and hospices; 9 respondents with regard to home care services; as for the state hospitals there turned out to be 26 cases of this kind, though this rate is only 3.9% of the total amount.

In addition, the vast majority of respondents (88%) stated that while providing palliative care services the **violation of patient confidentiality have not been observed.** Despite this, more than half of the respondents of this group noted that the diagnosis has been provided without patients' consent and in most cases the information was available for guardians only. It is noteworthy, that 11% of them found it difficult to answer.

**According to the fact that the patients, who have received neither of the components of palliative care, were not included in the selection, obtained results are quite realistic, in particular:**

- ✓ **There is a small number of those patients who in spite of their need have not took advantage of any component of palliative care (due to lack of funds);**
- ✓ **There is a difference between private and public institutions in respect to quality services. The respondents' positive attitude is directed to private and specialized institutions (hospices);**
- ✓ **It is obvious that when it comes to giving out information related to patient's diagnosis, most of the respondents have no information on palliative patient rights. Cultural context is operating here, where providing the patients' diagnosis without their permission (even for a guardian) is not perceived as a violation of their rights, moreover, it seems to be considered as a norm.**



## VIII. Living conditions and related problems of palliative care patients

### 8.1. Social conditions of patients' families<sup>22</sup>

*Evaluation was carried out on a ten point scale (from -5 up to +5), where “-5” indicated “very poor conditions”, while “+5” -- “very good conditions”. Scale have a neutral point – zero. If count data is greater than zero, then it corresponds to good conditions field values and if it is below zero, then it coincides with poor conditions field values.*

According to the respondents' assessment, indicators of social condition of the patients' families are as follows:

- ✓ The rate of living conditions is higher than neutral rate: Provision of electricity/gas, potable water, accommodation, central heating;
- ✓ Food provision is close to the neutral point of the scale;
- ✓ Supply of medicines, finances and health care is also near to the neutral point of assessment, though “poor condition” is between negative data point values.
- ✓ Employment is the most problematic issue for the respondents.

The vast majority of palliative care patients (82.2%) have not been working, since the diagnosis of incurable diseases was set. The respondents from this group pointed out the following reasons for unemployment: 60% of them have never been employed, 10% -- pensioners, 19% of them were physically unable to work.

### 8.2 The most significant issues in terms of palliative care<sup>23</sup>

The respondents were asked to name two of the most important, palliative treatment related problems. A summary of both problems has revealed:

- ✓ 21% of them indicated that they do not have any problem in this regard (these data coincide with the indicators that show the patients' satisfaction in respect to different services of palliative care);
- ✓ 32.6% of the respondents maintain that the basic problem is lack of money;
- ✓ In total, approximately 9% is the share of palliative care related problems, such as incorrect diagnosis and treatment (4.2%), medical staff competence (2.5%), medical neglect and staff indifference (2.1%). If we compare these results to indicators of the respondents' satisfaction with different palliative services, obtained data are quite realistic.
- ✓ It is notable that 24.8% have found it difficult to answer.

<sup>22</sup> See appendix for more detailed statistics of this chapter: charts 8.1 – 8.3.

<sup>23</sup> See appendix for more detailed statistics of this chapter: chart 8.4.

<sup>24</sup> The respondents were asked open questions: 1. “Please, designate the most significant problem regarding palliative treatment process?” 2. “Identify the second problem according to its importance”

The obtained data does not differ from data of those problems which were designated in the first place.

**Thus, the patients' financial and social conditions can be assessed as below average. According to the survey, this fact is determined by the correlation of the following factors:**

- ✓ **The employment problem (a very small number of the respondents reported that they had no desire to work);**
- ✓ **Financial problems, which is also related to palliative patient rights – their involvement in a normal way of life;**
- ✓ **Above mentioned factors are closely related (for some of the respondents) to a qualified health care accessibility problems/inability.**

### 8.3. Communication of palliative care patients with different groups<sup>25</sup>

Respondents claim that the patients under their guardianship mostly have friendly relations or are well-deposed toward those people with whom they have relationship. Indicators of positive relationship are almost identical to the group of people (so called “primary group”), with which the patients have emotional connections (family members, neighbors, relatives, as well as medical staff).

According to the survey, only a small number of respondents claim that the patients have strained relations with above mentioned group of people. However, it should be considered that the share of those patients, who have tense relationship with their family members, is 10%. Besides, there is a high rate of neutral relations with relatives, neighbors and medical staff.

Palliative care patients have limited relations with their cooperators. The vast majority of patients have no relationship with this group of people. **This once again underlines the existing unemployment among the palliative patients.**

**Degree of religiosity** has some influence on patients' attitude to different groups of people: As it turned out, the patients who are “active” believers (performing a religious rituals) have less strained relations with all the above mentioned groups, than those who are “passive” believers or irreligious. Accordingly, relatively high share falls on this group, in terms of their favorableness rating.

*What are the public and the medical personnel's attitude towards the palliative care patients?*

Most of the respondents indicate that the society is compassionate, though 63.1% of them note that they are not actively assisting the palliative patients. There is little difference between the following considerations: Society is trying to help (19.4%) and the society is indifferent towards the palliative care patients (15.6%). Insignificant is the share of unfriendly attitude.

<sup>25</sup> See appendix for more detailed statistics of this chapter: charts 8.5 -8.9; tables 8.1 – 8.2.

Only 5.5% of respondents acknowledge the existence of medical personnel's unconcerned/contemptuous attitude towards the palliative patients.

Accordingly, it is logical when majority of respondents indicate different rates for services, equally provided by medical staff for patients.

**Thus:**

- ✓ **Relationship between palliative patients and society mostly is positive, but passive as well;**
- ✓ **Stigma is not the main determinant of this relationship and does not provoke indifferent attitude of medical personnel (in contrast to HIV/AIDS and tuberculosis);**
- ✓ **Patients are willing to engage in social activities (solving this problem would be considered as one step forward in improving the patients' quality of life).**

*Has the patients' spiritual –mental health condition changed after involving them in palliative care?*

38% of respondents state that nothing has changed. Improvement and deterioration rates of psychological state are not much different from each other (15% became more tranquil, 16.2% became more optimist, 12.9% became more aggressive/depressive). It is worth mentioning, that the patient's religiosity does not have any impact on this.

Data on the patients' inner mental state have been compared with the following parameters: Effects of palliative care on the reduction of patients suffering, as well as impact of palliative care on improved quality of life of patients.

As it has been revealed:

- ✓ Almost half of those patients, who noted that after involving in palliative care the patient's suffering has been or more or less revealed, indicate the deterioration of patient's inner mental state, or do not speak about any essential changes.
- ✓ According to the places, where the patient receives palliative care, respondents rated private clinics and hospices more positively than other facilities.

**Thus, it should be noted that:**

- ✓ To mitigate just physical pain is not enough for improving the patients' inner mental state. For this, inclusion of all the components of multidisciplinary approach (including psychologist, cleric, etc.) is necessary.
- ✓ This assumption is further reinforced by the fact that the patients feel spiritually comfortable in private clinics and hospices, where the multidisciplinary approach is more or less implemented.

## Appendix



## I. Involvement in Palliative Care

Diagram # 1.1

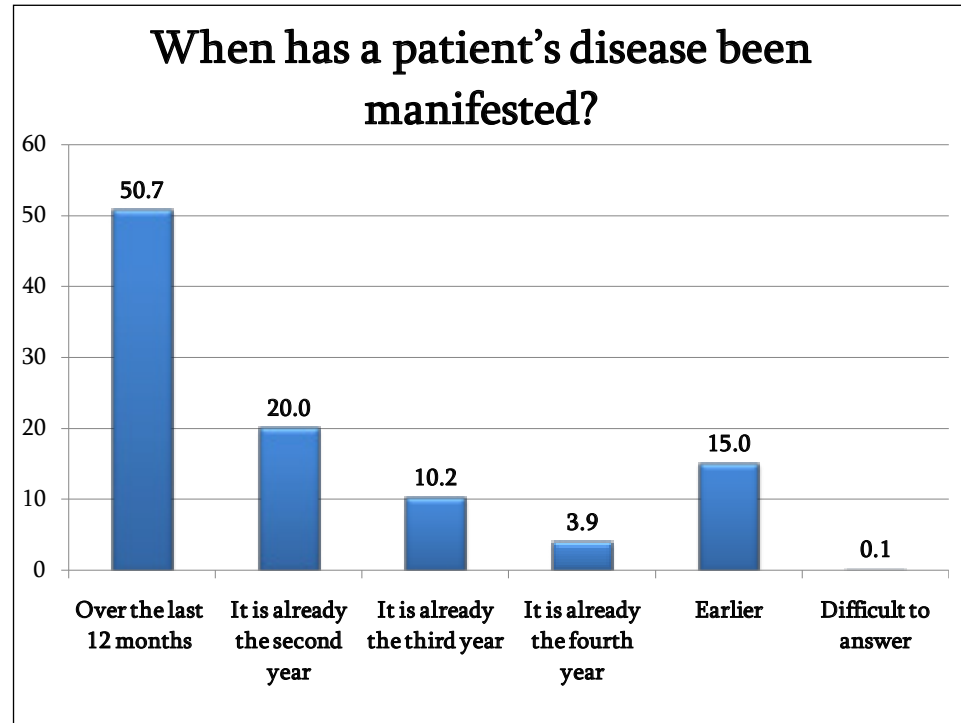


Diagram # 1.2

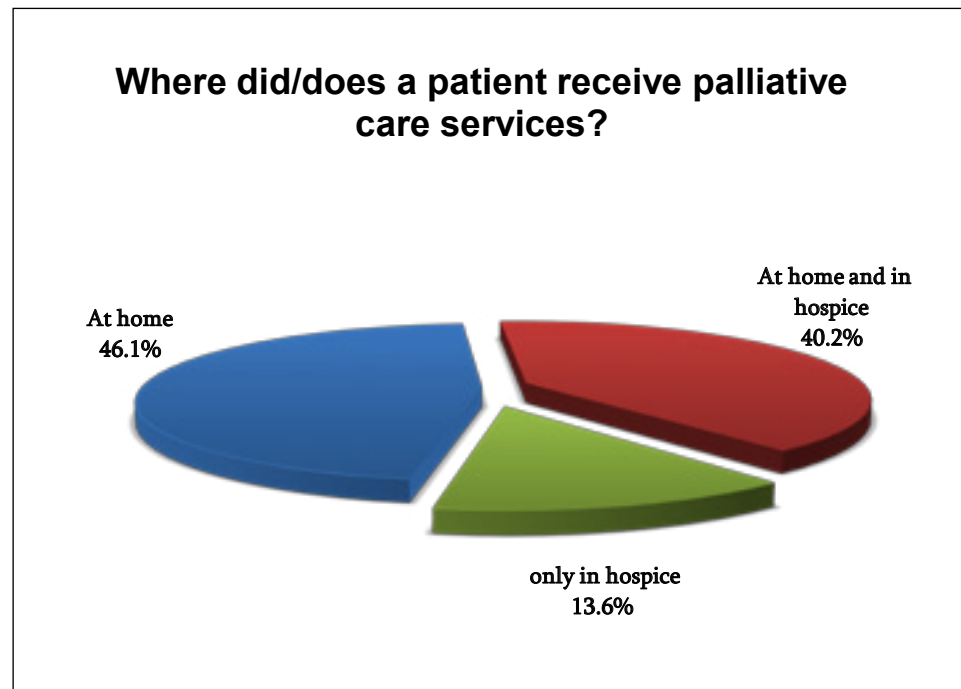


Diagram # 1.3

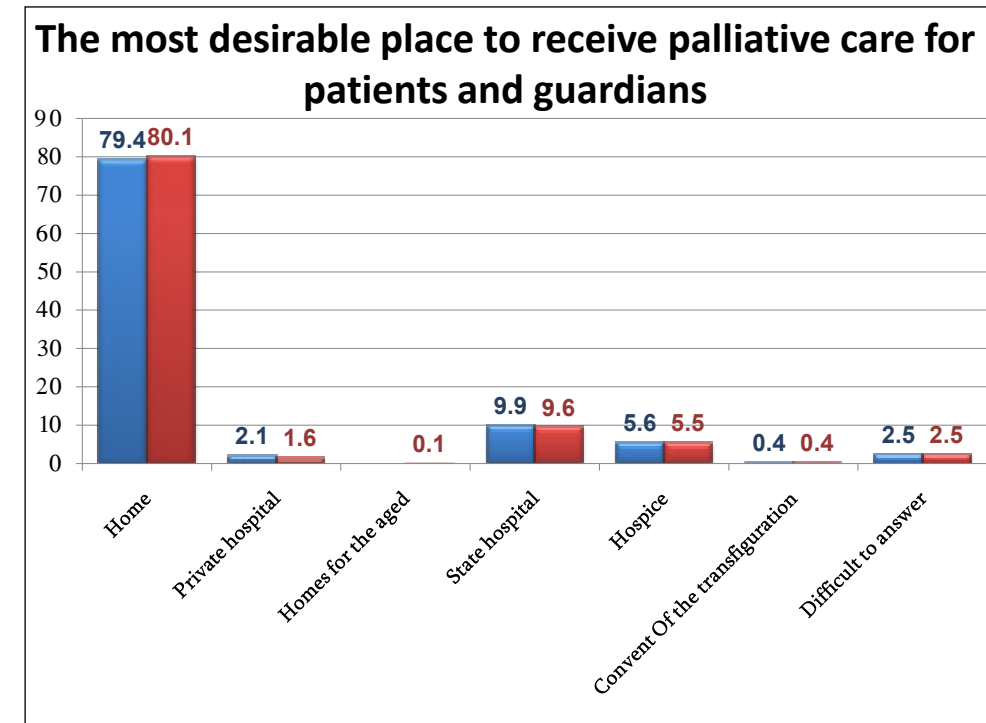


Diagram # 1.4

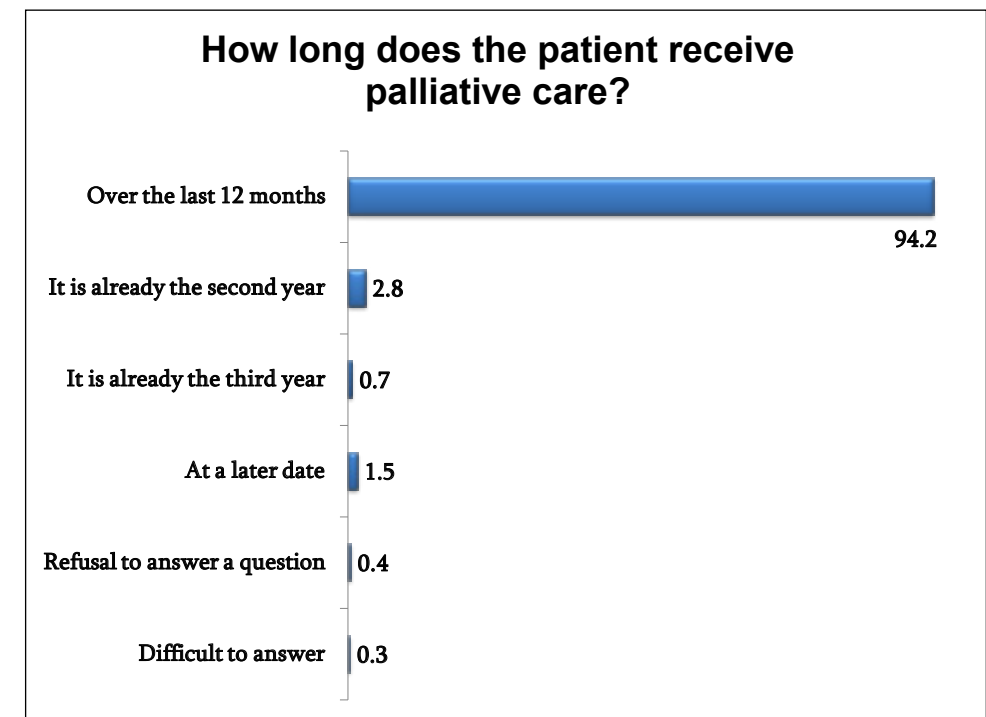


Diagram # 1.5

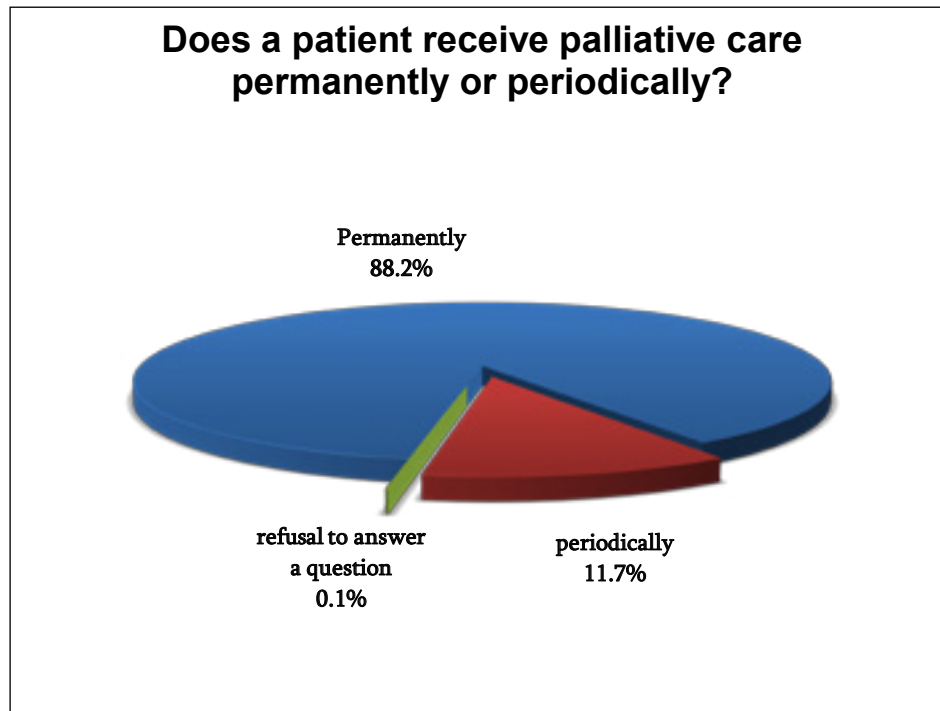


Diagram # 1.6

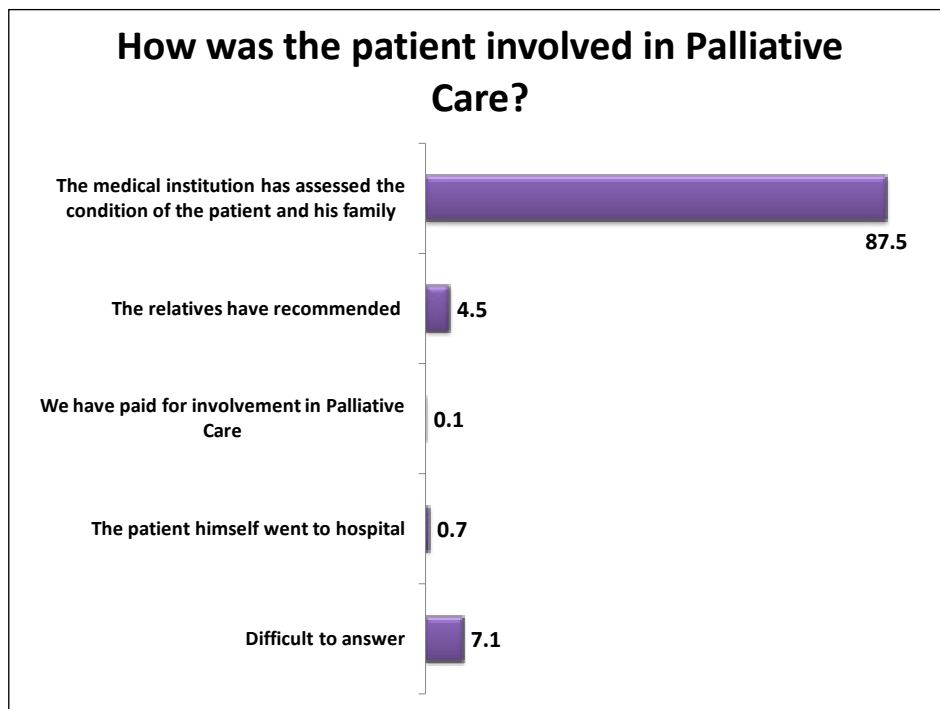


Diagram # 1.7

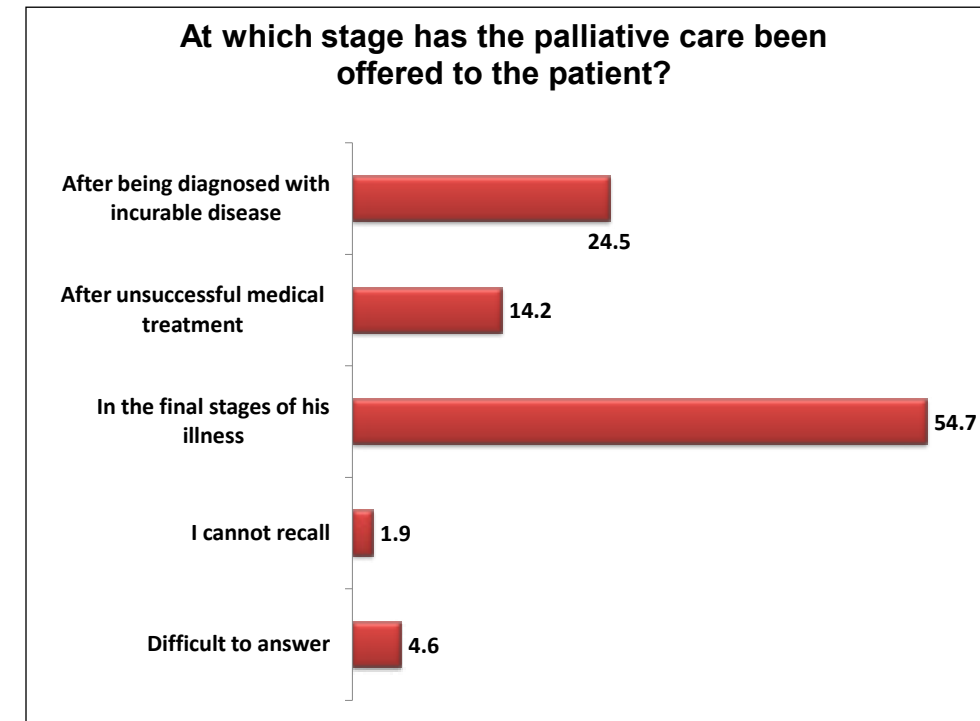


Diagram # 1.8

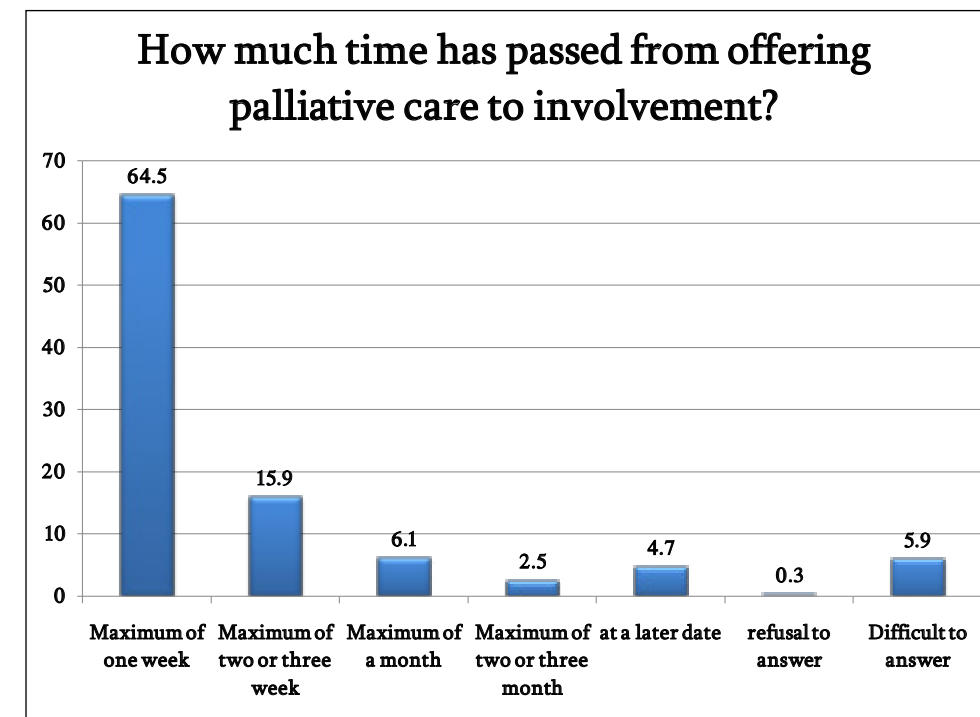
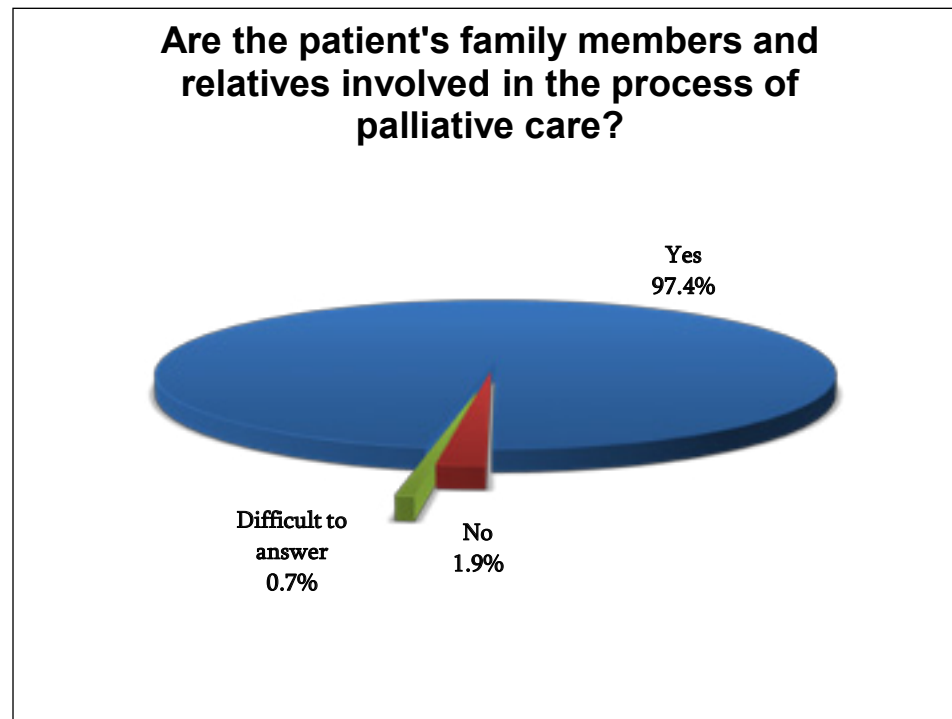


Diagram # 1.9



## II. Level of awareness

### 2.1. Awareness of patients about their disease

Table #2.1: The impact of the site, where the patient has been/is provided with palliative care (at home or outside the home) on patient's awareness

		A place where the patient is/has been provided with palliative care services	
		At home (%)	Besides home (%)
Awareness of the patient about his disease	Has got full information	29.6	42.1
	Nearly knows about his disease/Incomplete Information	21.5	21.2
	Has wrong information / is not informed	47.3	36.1
	Refusal to answer	1.6	0.6
	Sum	100	100

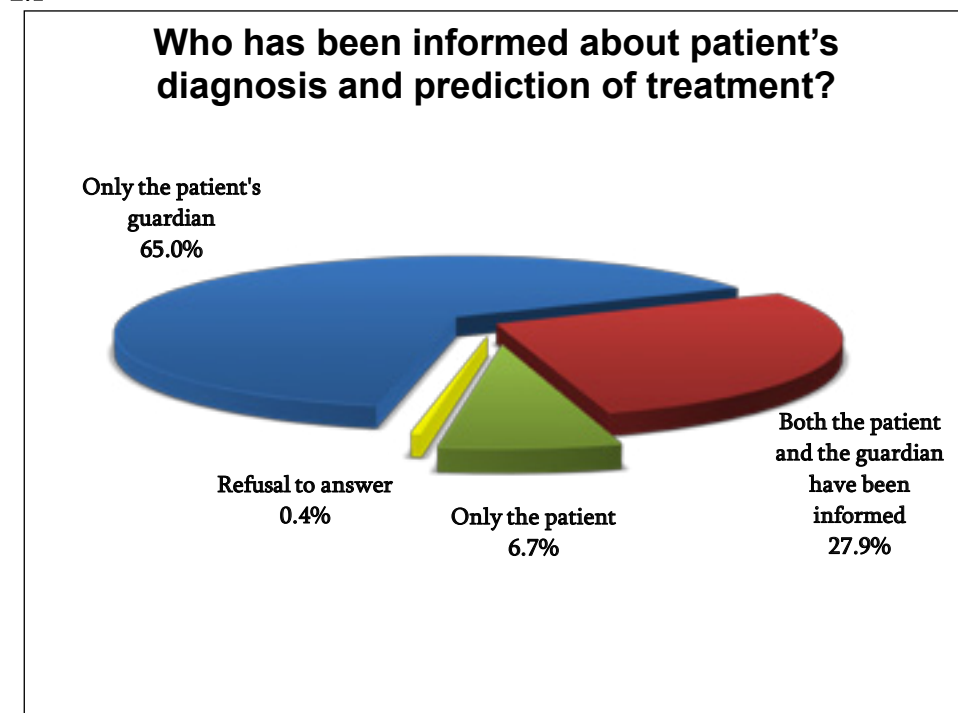
### Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	14.161(a)	3	.003
Pearson Correlation			-0.06525

Table # 2.2: The impact of the education level on patient's awareness

		Educational level of the patient					
		%	%	%	%	%	%
Awareness of the patient about his disease	Has got full information		16.7	29.4	39.2	33.3	42.9
	Nearly knows about his disease/Incomplete Information		33.3	23.1	20.8	33.3	19.4
	Has wrong information / is not informed	100	50.0	45.9	38.5	33.3	37.3
	Refusal to answer			1.6	1.5		0.4
		100	100	100	100	100	100

Diagram # 2.1



Table# 2.4: Correlation between the person who has been informed about the patient's diagnosis and prediction of treatment and a patient's consent to disseminate information

		Was the information disseminated without or with the patient's permission?			
		With the patient's consent	Without the patient's consent	Refusal to answer	Difficult to answer
		Row %	Row %	Row %	Row %
Who has been informed of the patient's diagnosis and prediction of treatment?	Only the patient was informed	62.2%	31.1%		6.7%
	Only the guardian was informed	9.8%	78.3%	1.8%	10.0%
	Information was available for both, the patient and the guardian	75.5%	14.9%	1.1%	8.5%
	Refusal to answer			66.7%	33.3%

Diagram # 2.2

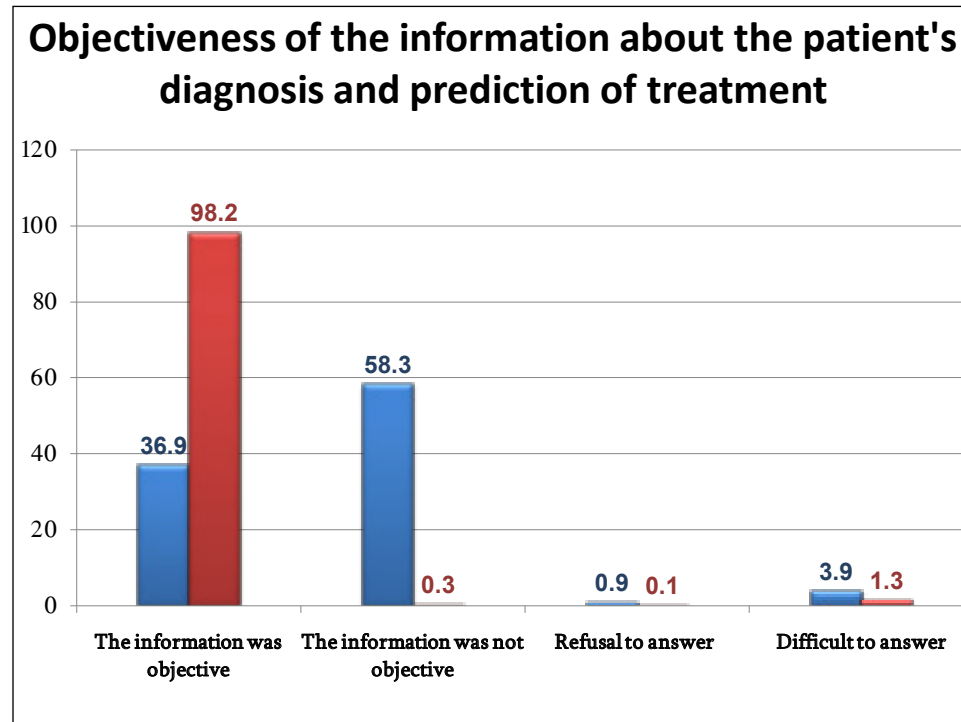


Table #2.6: The impact of the site, where palliative care services has been implemented on the objectivity of the provided information

		Where was palliative care services provided to a patient?	
		At home	Besides home
Was the provided information about the patient's diagnosis and prediction of treatment objective?	It was objective	30.9%	42.1%
	It was not objective	63.0%	54.3%
	Refusal to answer	1.6%	0.3%
	Difficult to answer	4.5%	3.3%

Diagram # 2.3

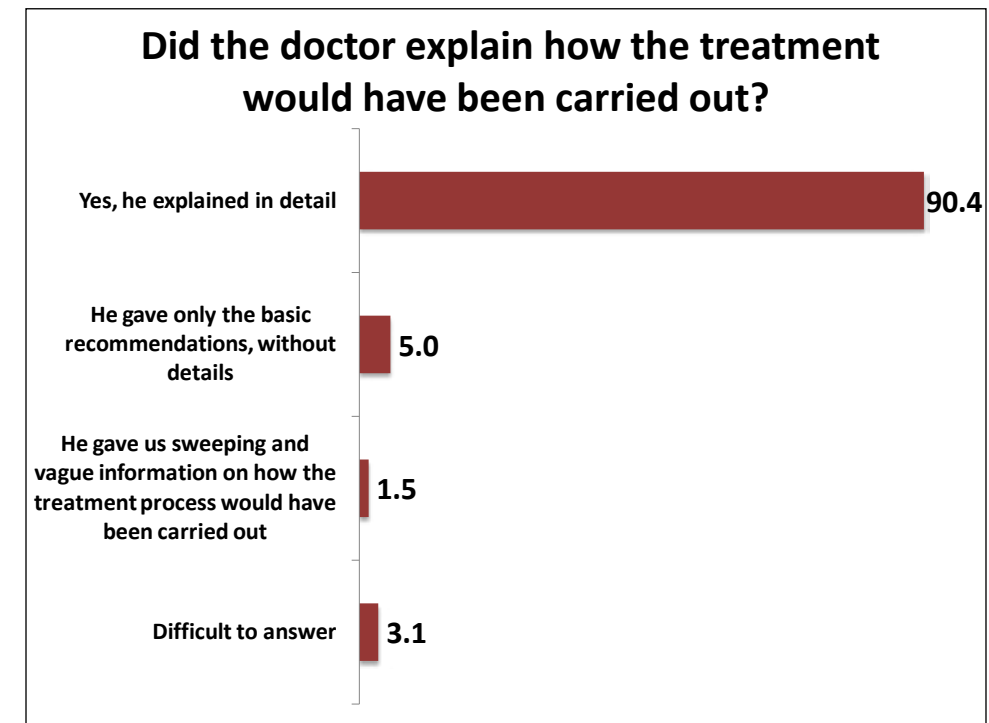


Diagram # 2.4

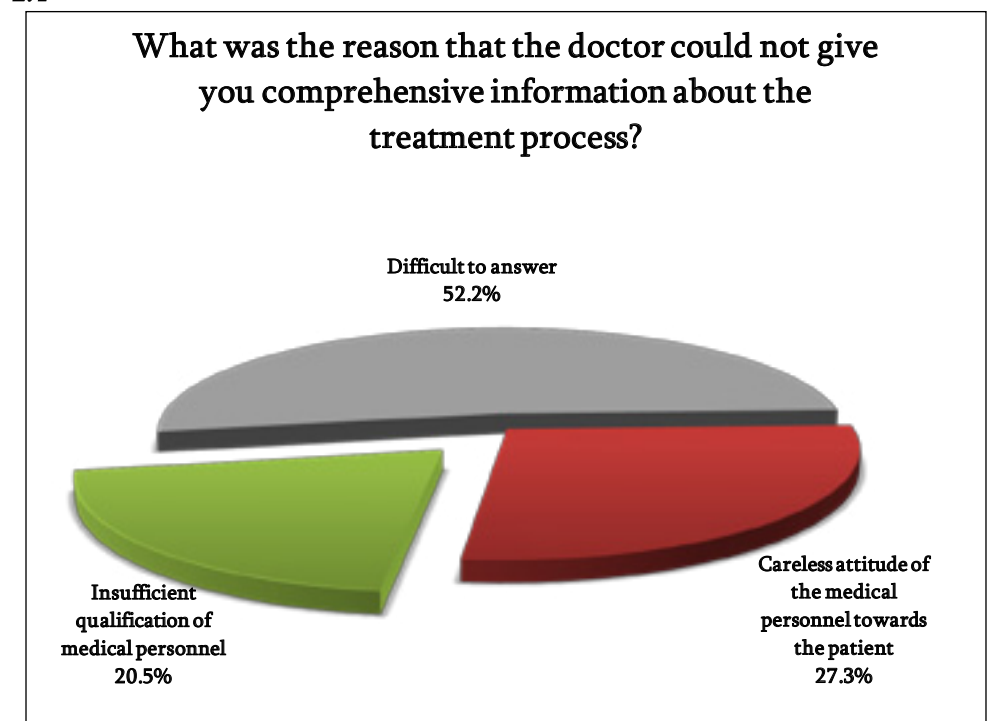


Diagram # 2.5

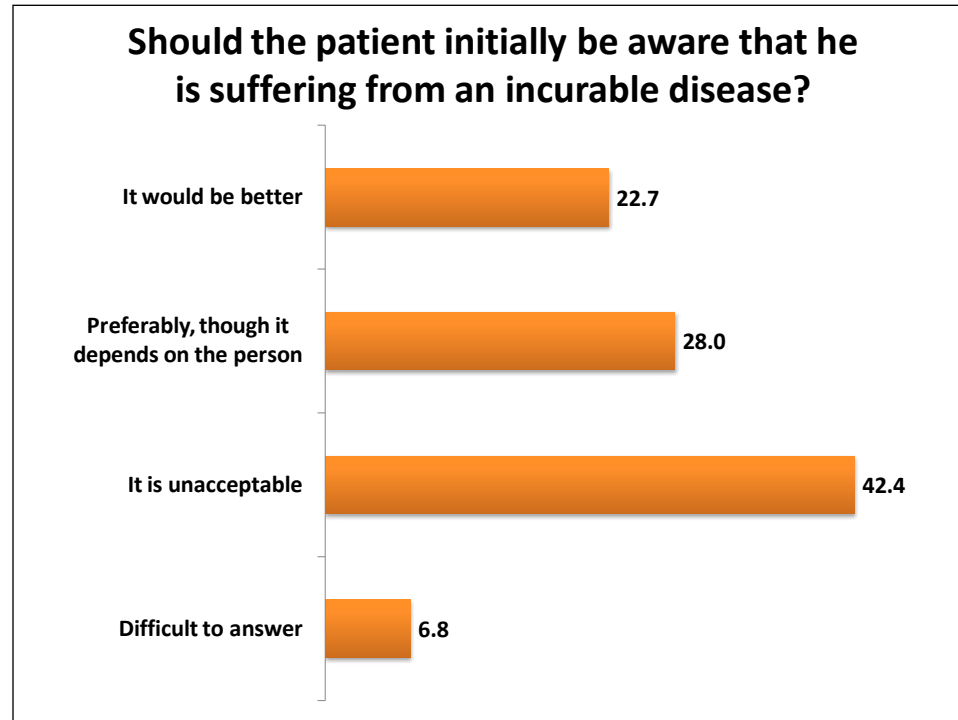


Table #2.10 : The influence of the impartiality of the provided information to the opinion whether the patient should initially be aware that he is suffering from incurable disease

		Was the provided information about the patient's diagnosis and prediction of treatment objective?			
		It was objective	It was not objective	Refusal to answer	Difficult to answer
Should the patient initially be aware that he is suffering from an incurable disease?	It would be better	42.6%	10.4%	16.7%	19.2%
	Preferably, though it depends on the person	32.9%	26.2%		15.4%
	It is unacceptable	15.3%	59.5%		53.8%
	Difficult to answer	9.2%	3.8%	83.3%	11.5%

## 2.2. The level of awareness about palliative care in general

Table #2.11

	How would you assess your knowledge of the Palliative Care?	I have full information (%)	I have more or less full information (%)	I have more or less incomplete information (%)	I have little information (%)	I have no information (%)	Difficult to answer (%)
1	About characteristics of palliative care	12.8	15.7	7.3	9.2	52.4	2.7
2	About taking care of palliative patients	16.9	23.9	7.0	9.1	41.1	2.1
3	About palliative care centers ("hospices")	8.0	10.5	5.6	10.5	59.6	5.6
4	About various aids (for example, discounts on medicines, medical procedures, etc.)	12.0	15.0	7.1	11.3	50.6	3.9
5	About nutrition for palliative care patients	13.5	20.2	7.1	9.5	44.2	5.5

Diagram #2.6: The impact of the site, where palliative care services have been implemented on patients' awareness

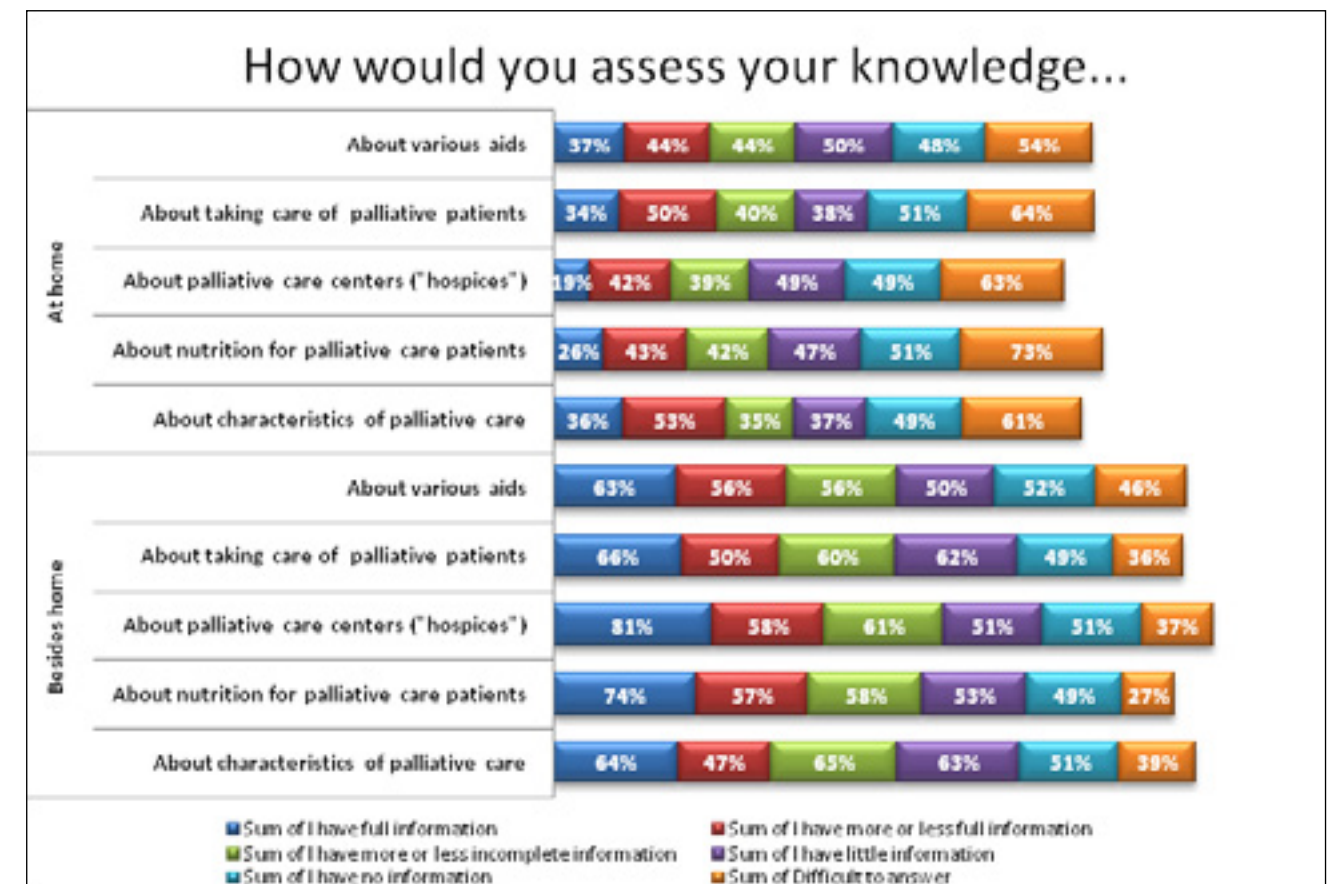




Diagram # 2.7

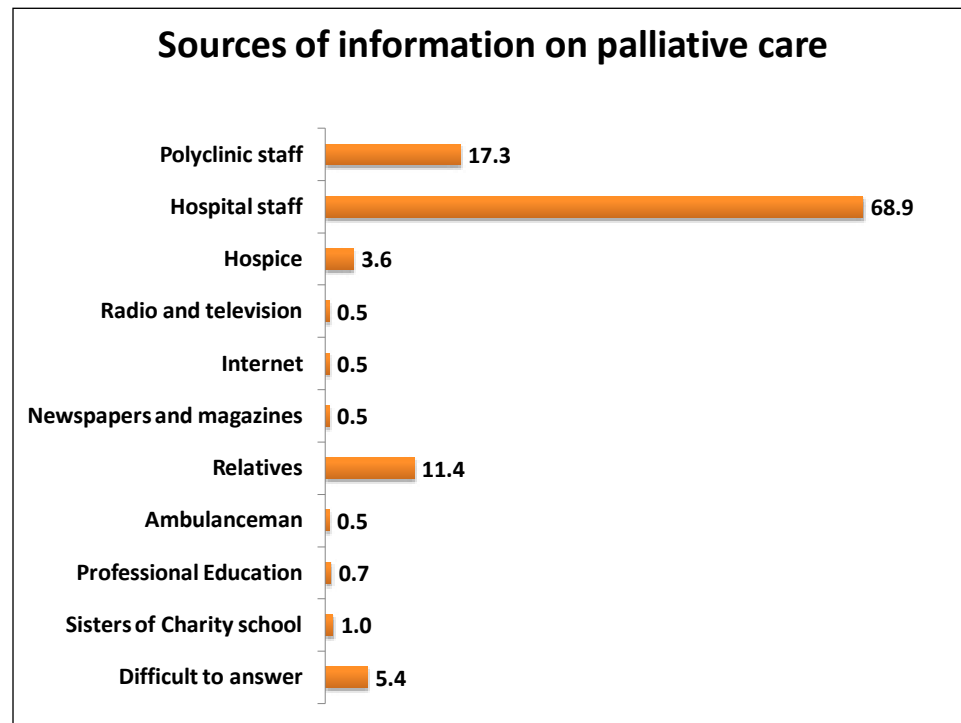


Diagram # 2.8

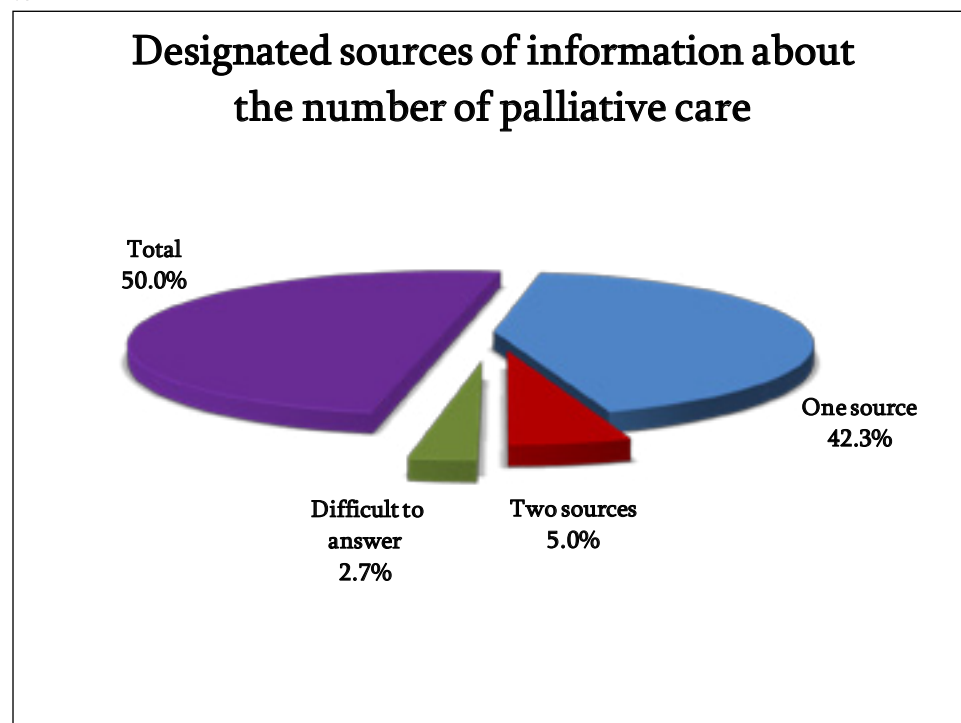
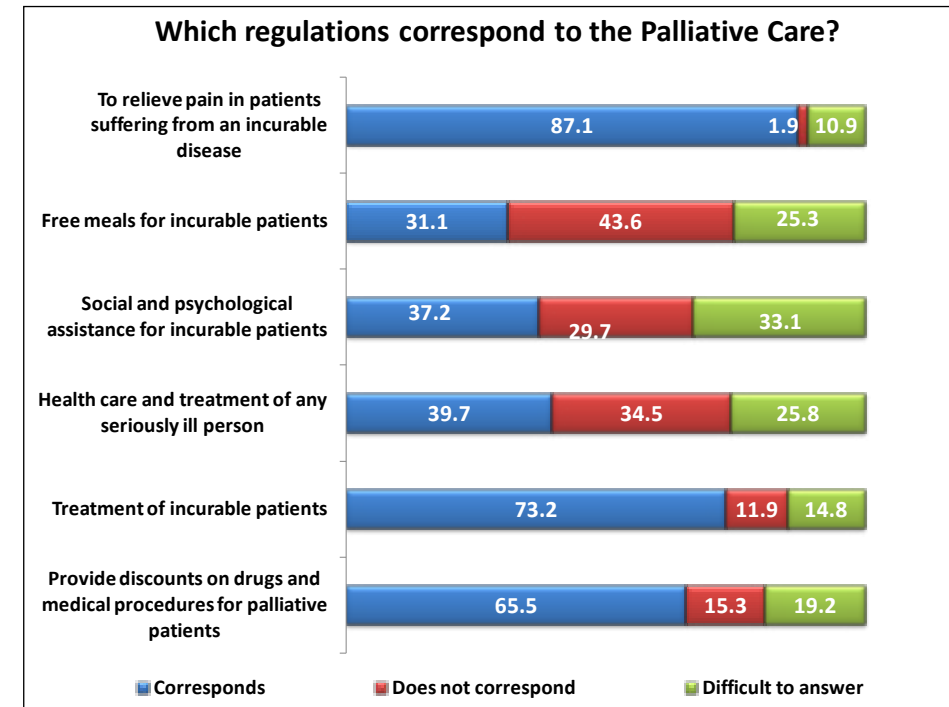


Diagram # 2.9



Note: The test - questions are not answered by the respondents, who stated that they did not possess any information about palliative care.

Table #2.12 : The impact of the site, where palliative care services have been implemented on patients' awareness

Do the following statements Correspond with palliative care?		The place where palliative care services has been implemented	
		At home	Besides home
To relieve pain in patients suffering from an incurable disease	Corresponds	79.8	93.0
	Does not correspond	3.3	0.9
	Difficult to answer	16.9	6.1
Free meals for incurable patients	Corresponds	16.9	42.5
	Does not correspond	51.4	37.3
	Difficult to answer	31.7	20.2
Social and psychological assistance for incurable patients	Corresponds	26.8	45.6
	Does not correspond	38.3	22.8
	Difficult to answer	35.0	31.6
Health care and treatment of any seriously ill person	Corresponds	38.3	40.8
	Does not correspond	32.2	36.4
	Difficult to answer	29.5	22.8
Treatment of incurable patients	Corresponds	55.2	87.7
	Does not correspond	22.4	3.5
	Difficult to answer	22.4	8.8
Provide discounts on drugs and medical procedures for palliative patients	Corresponds	50.8	77.2
	Does not correspond	21.3	10.5
	Difficult to answer	27.9	12.3

### III. Do they know the law on palliative care and have they ever applied to the court?

Diagram #3.1

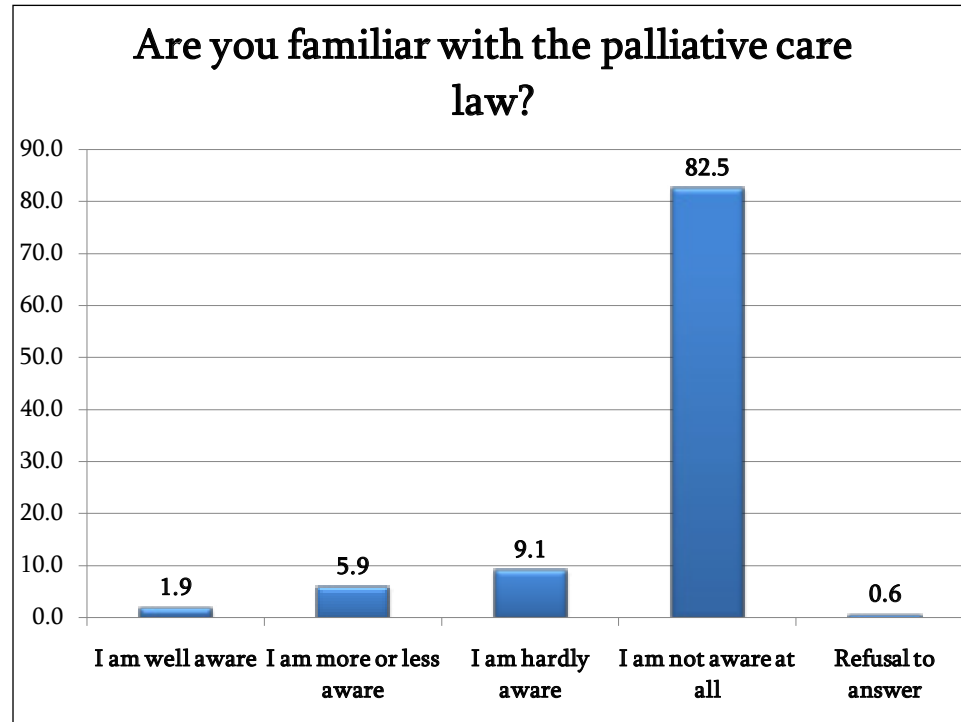


Diagram #3.2



Diagram #3.3

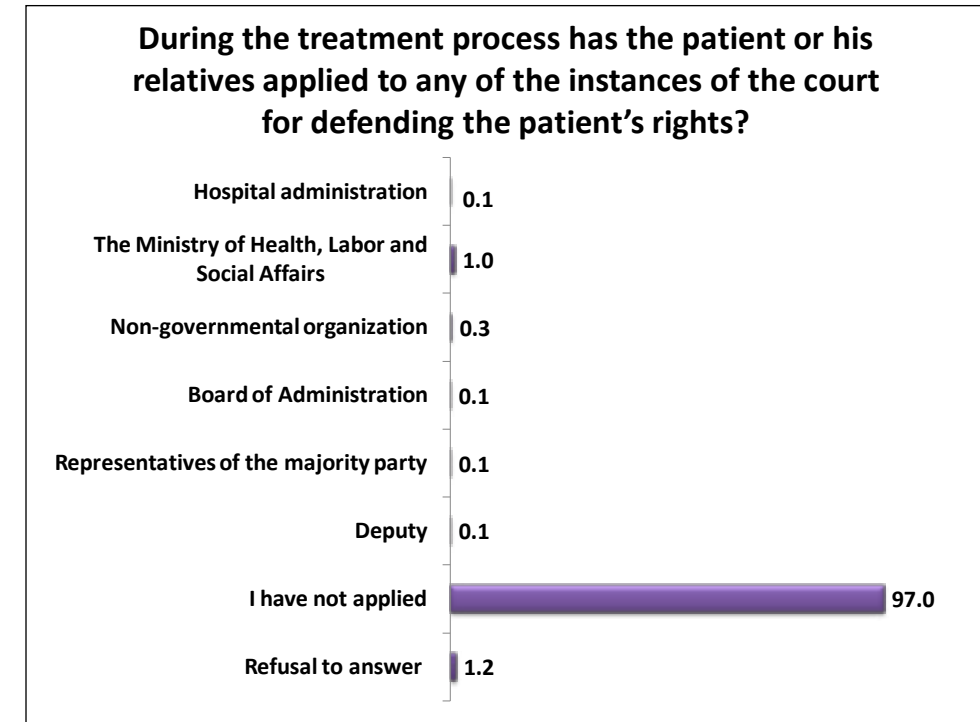


Diagram #3.4

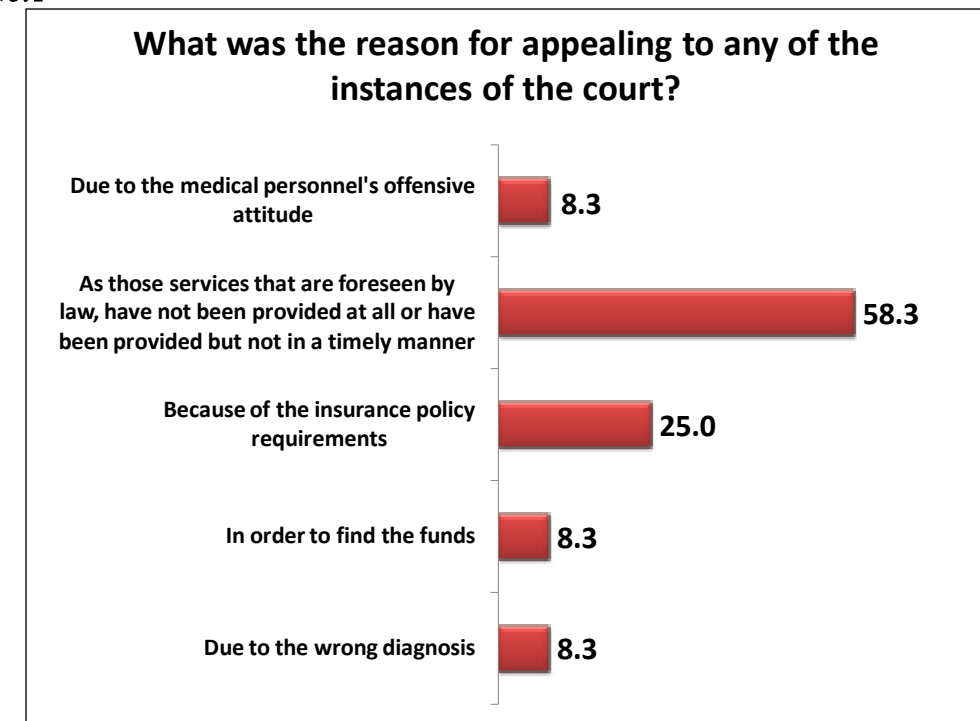


Diagram #3.5

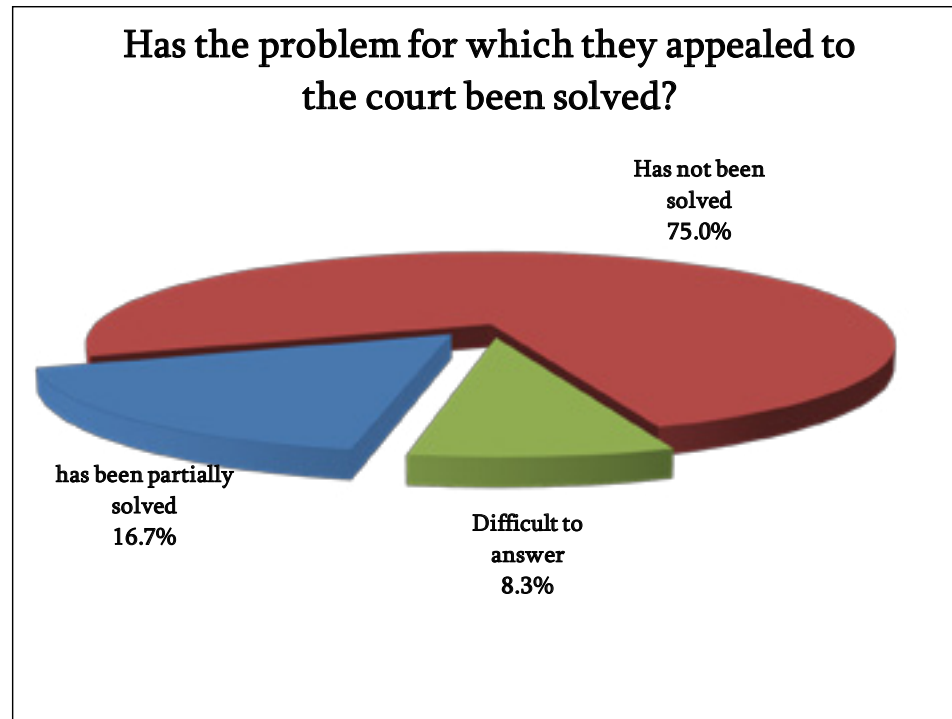
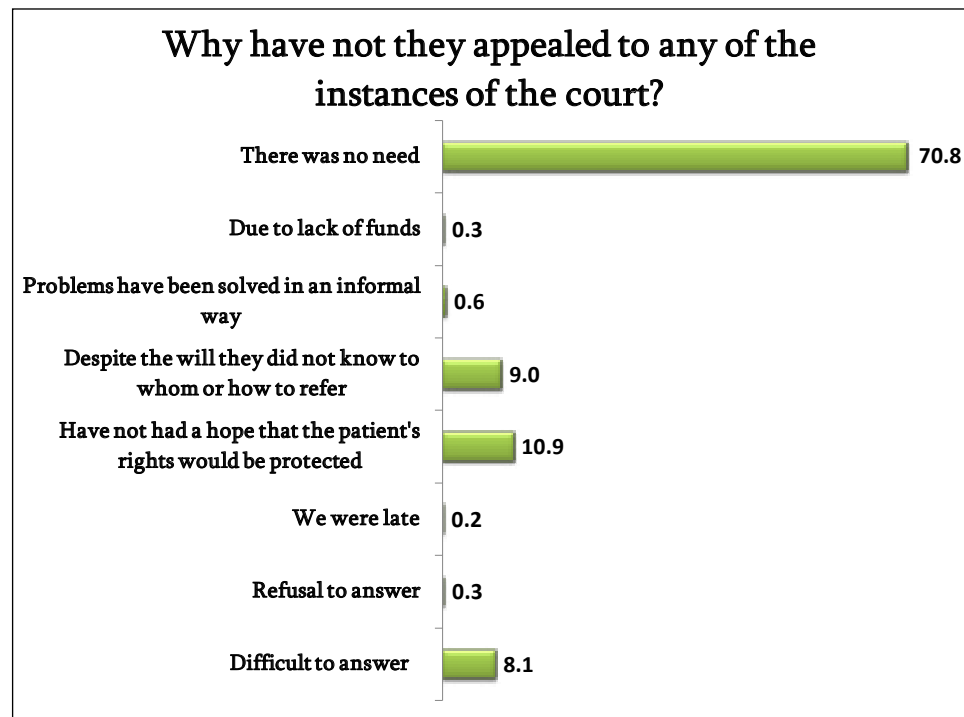


Diagram #3.6



## IV. Pain Management

### 4.1. Assessment of pain intensity

Diagram #4.1

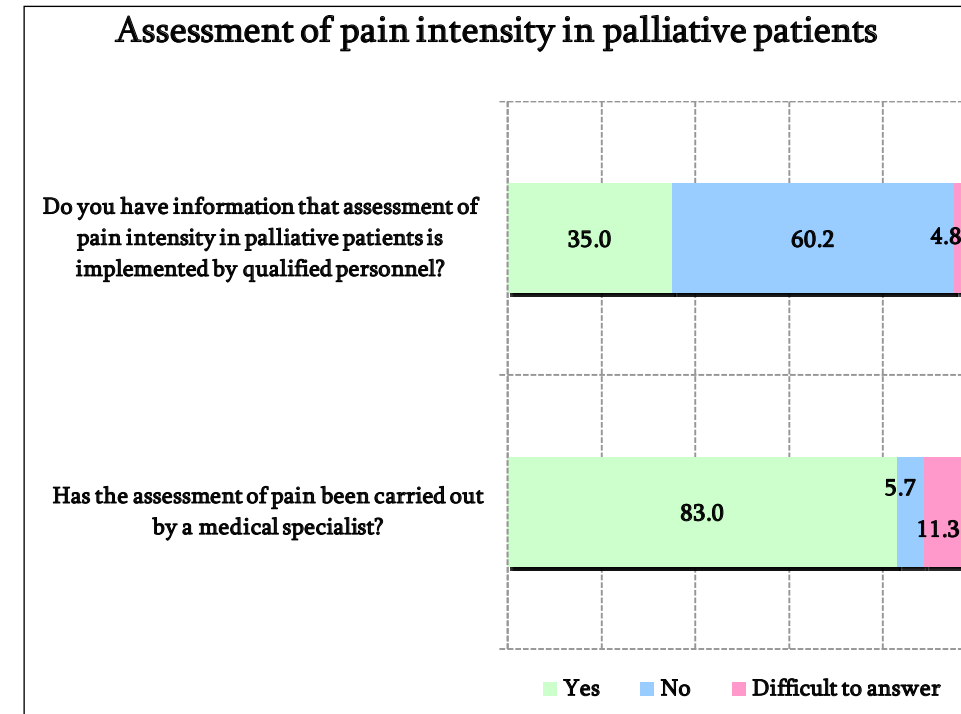


Diagram #4.2

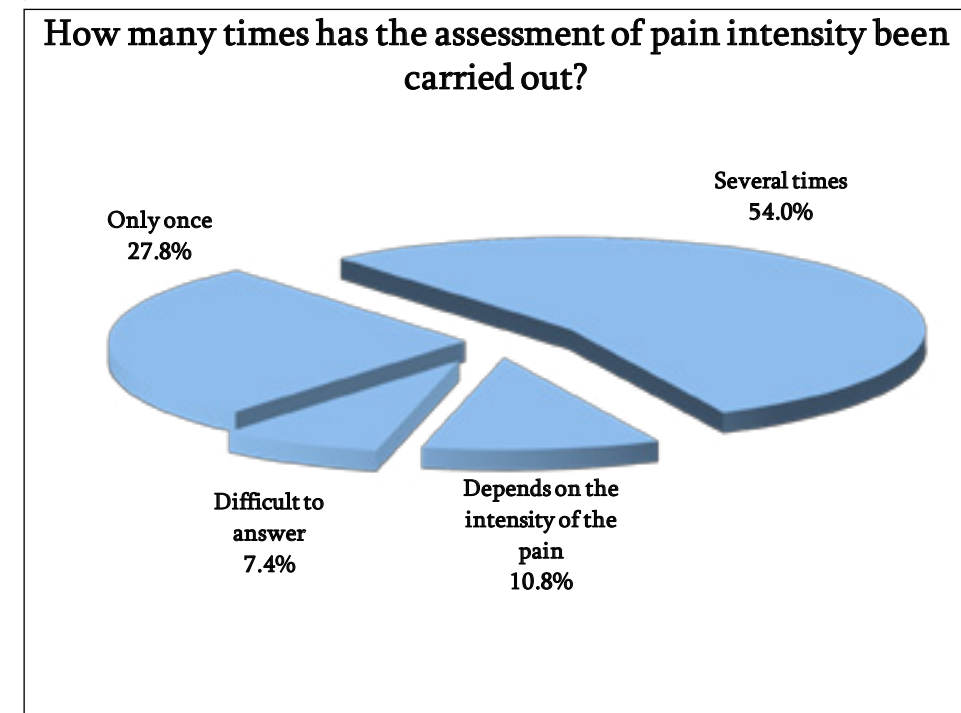


Diagram #4.3

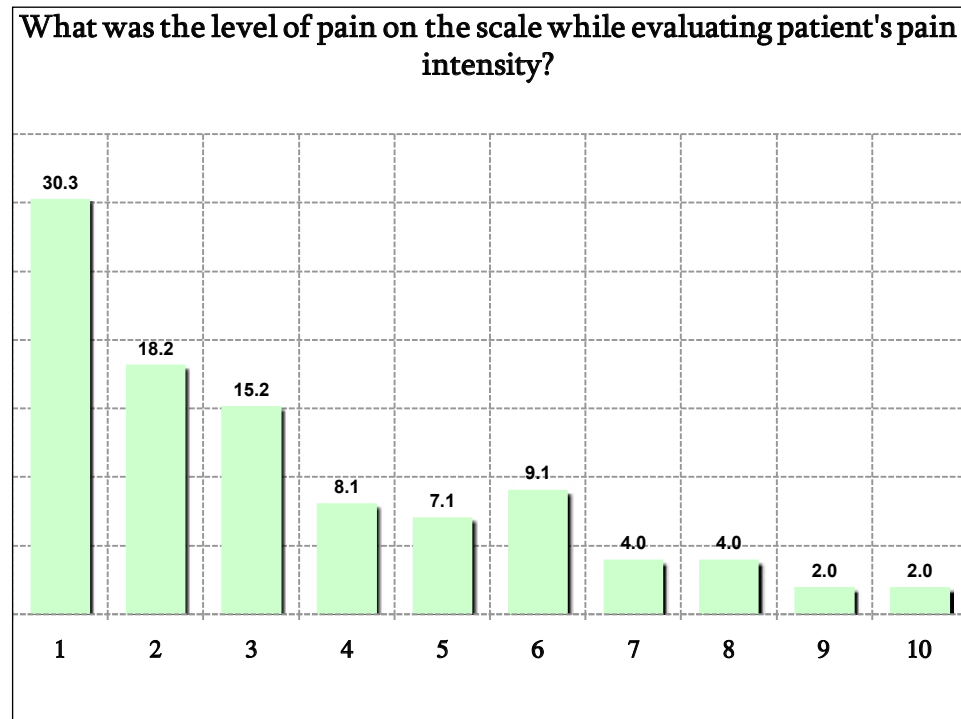
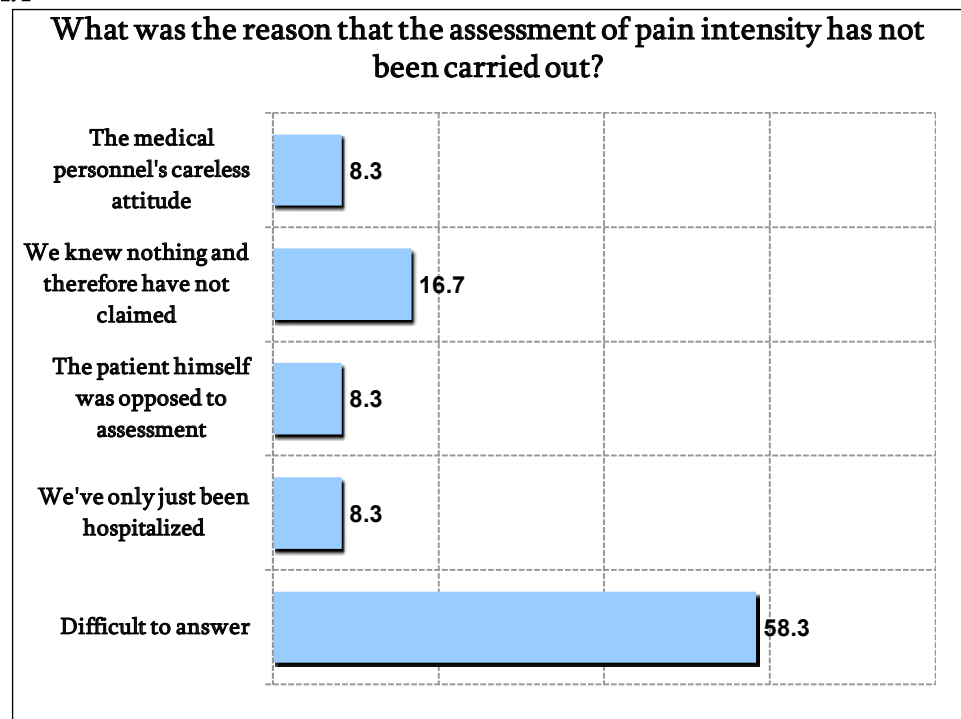


Diagram #4.4



4.2. Using and obtaining medications

Diagram #4.5

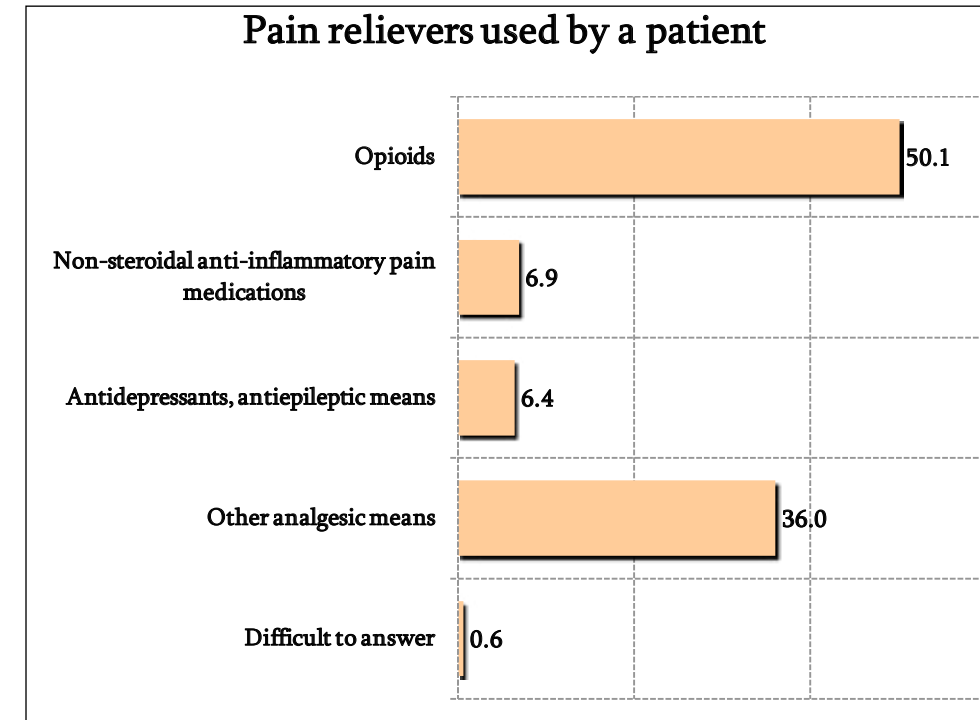


Diagram #4.6

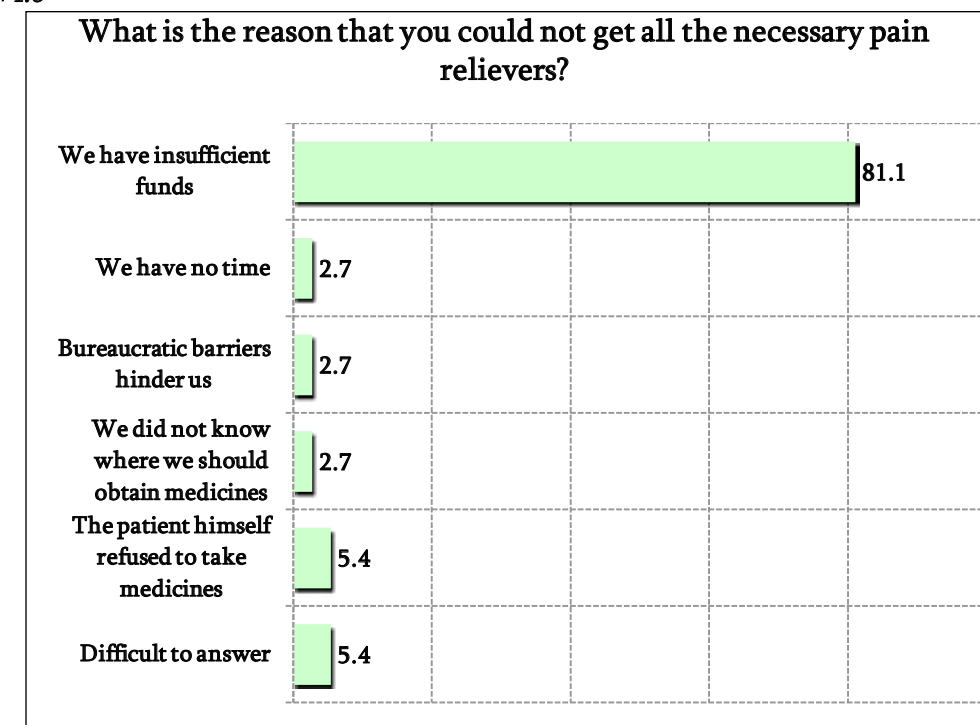


Diagram #4.7

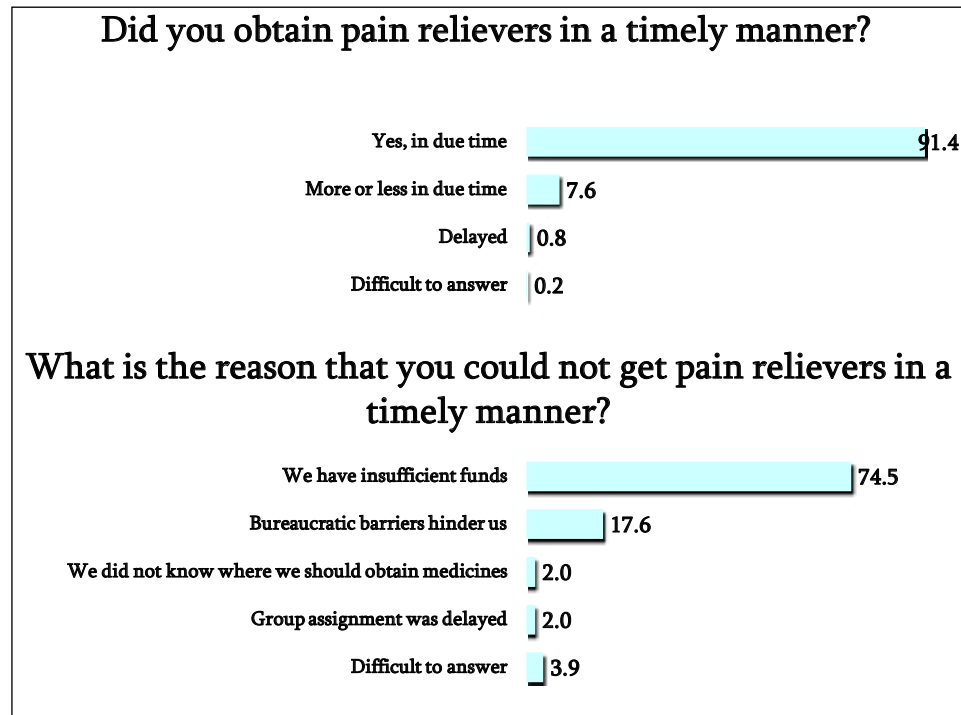


Diagram #4.8

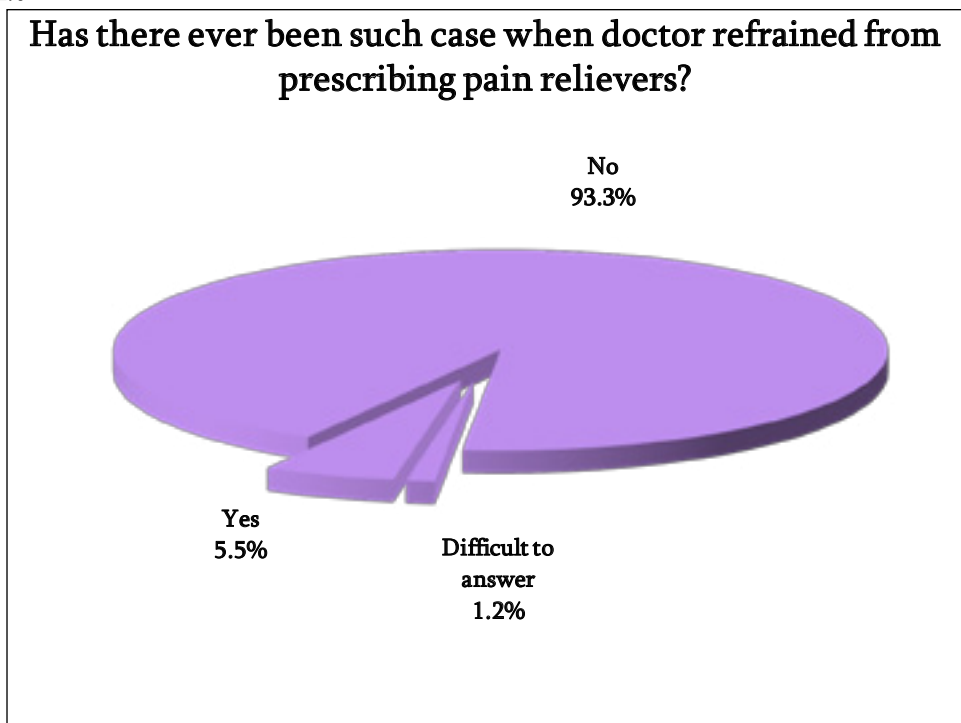


Diagram #4.9

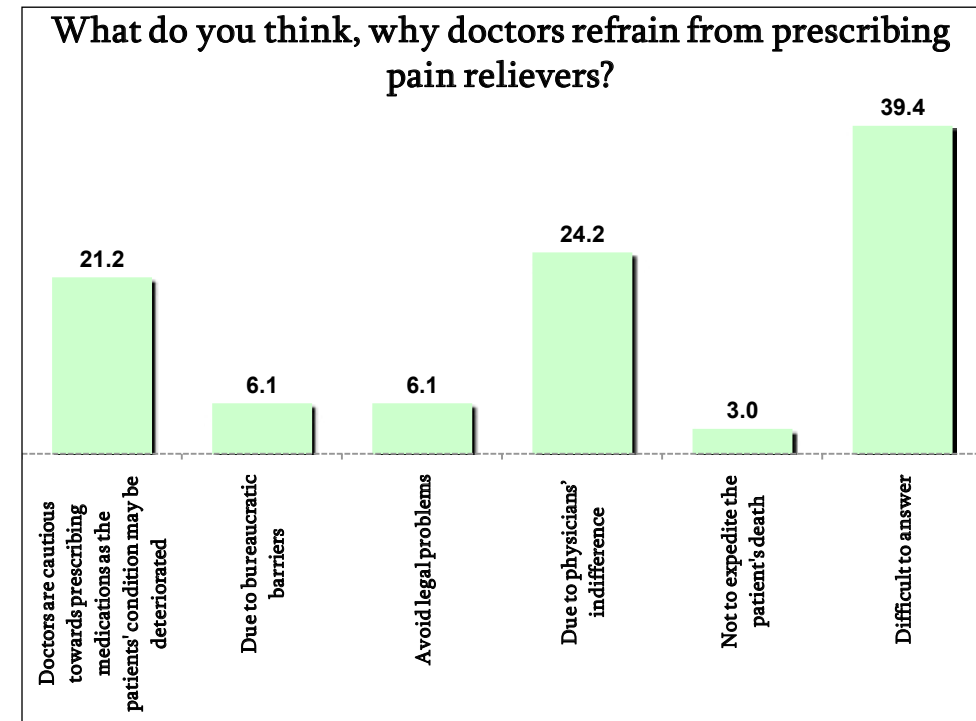


Diagram #4.10

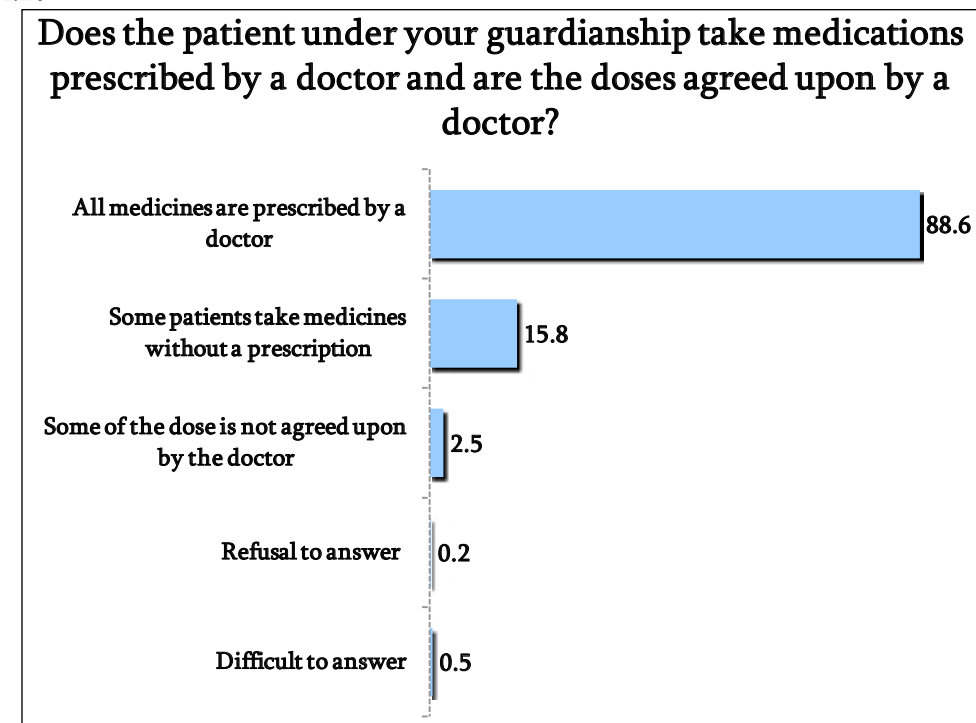




Diagram #4.11

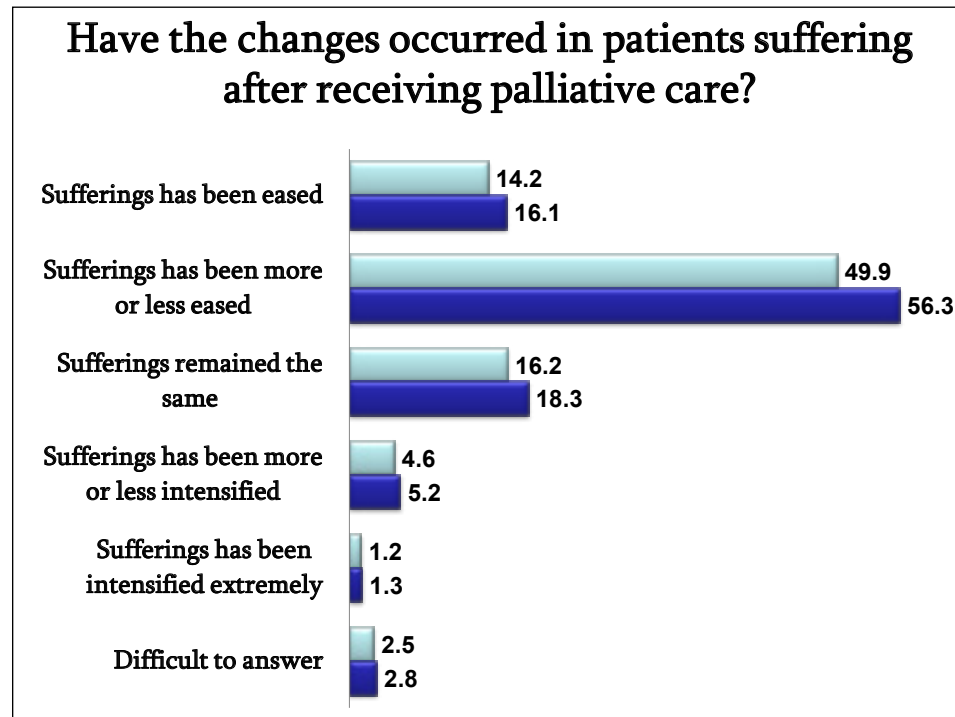
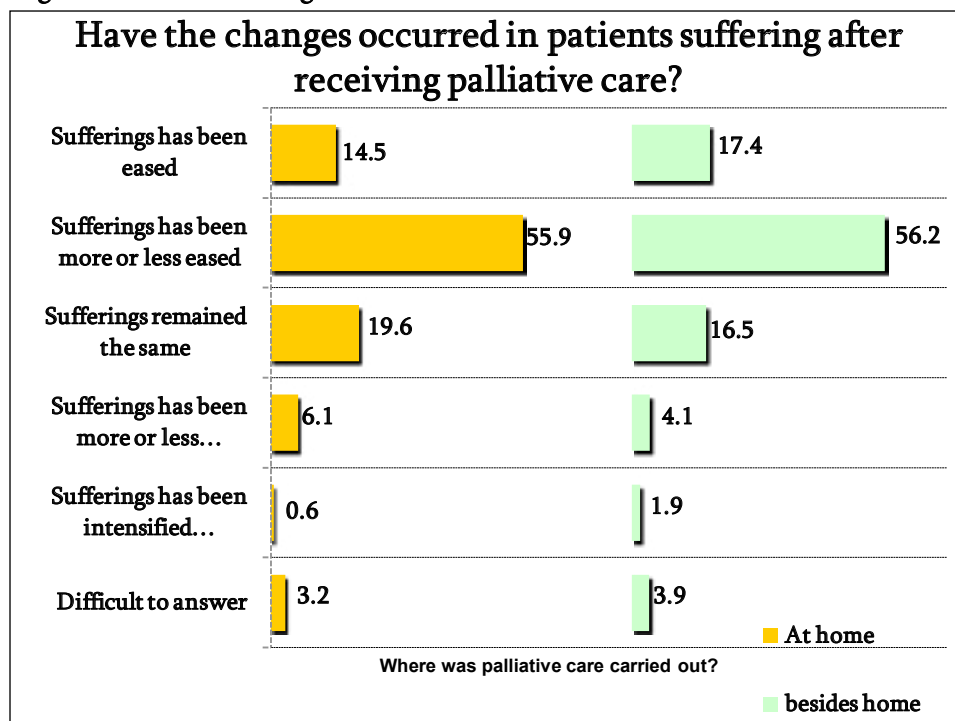
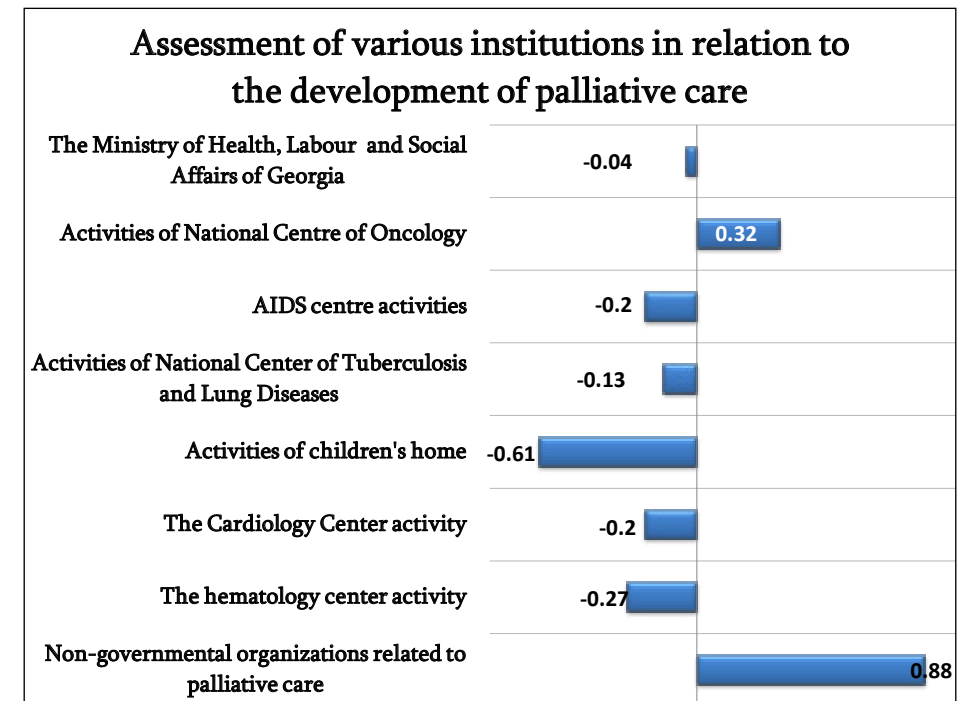


Diagram #4.12: Does the place, where the patient receives palliative care services, impact on mitigation of their sufferings?



V. Evaluation of the activities of various institutions

Diagram #5.1



NOTE: Except for the above mentioned two institutions in the first and the second paragraph, all other institutions have been estimated by minimum number of respondents. Varying number of respondents is from 11 up to 81

## VI. Access to palliative care components, insurance and other allowances

### 6.1. Access to palliative care components

Diagram #6.1

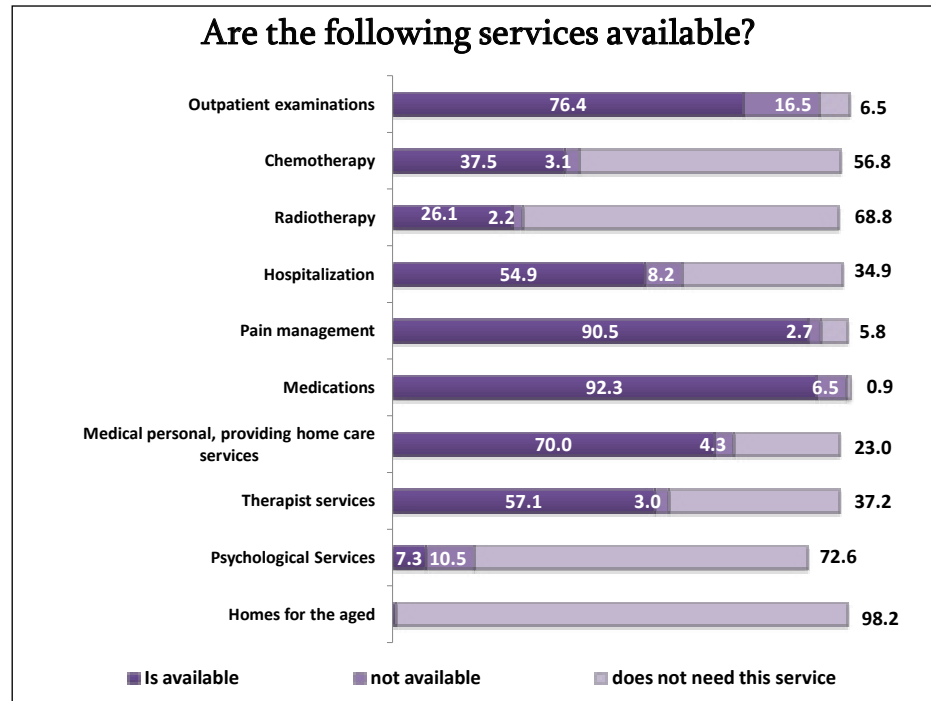


Diagram #6.2

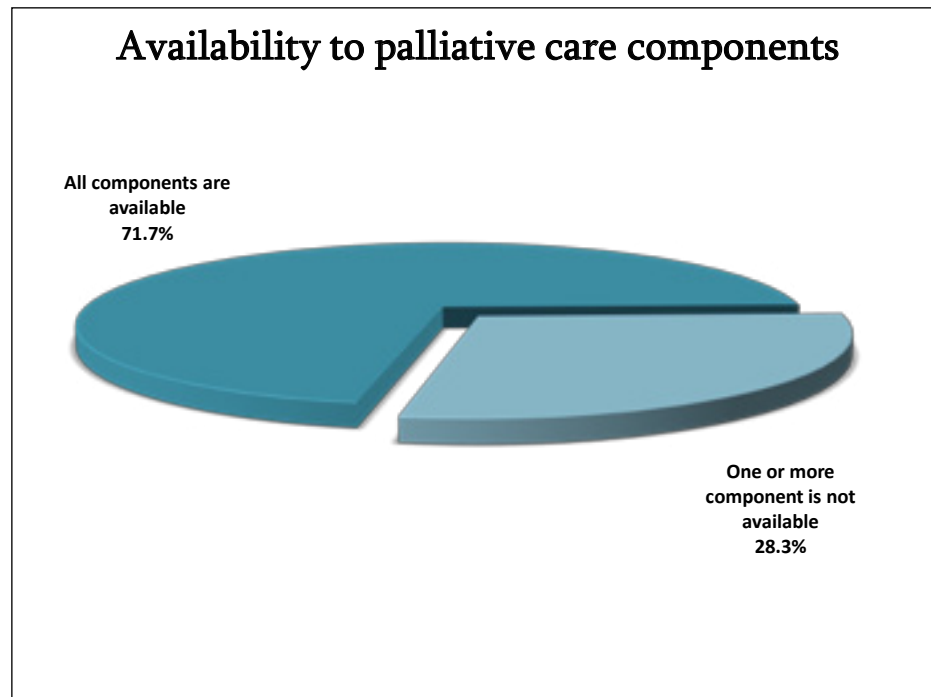


Diagram #6.3

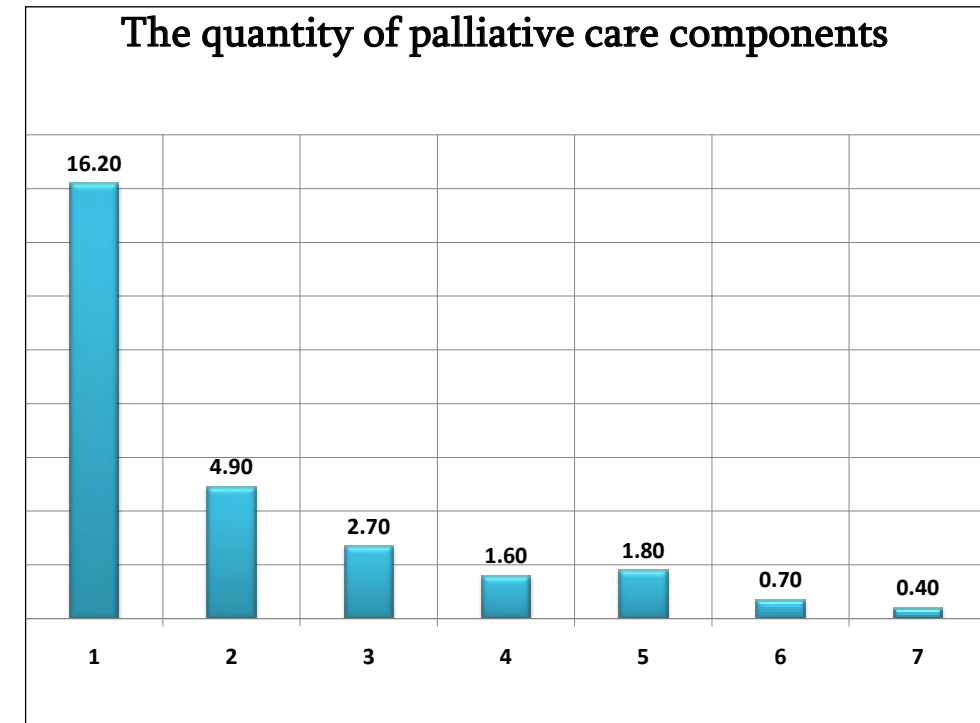
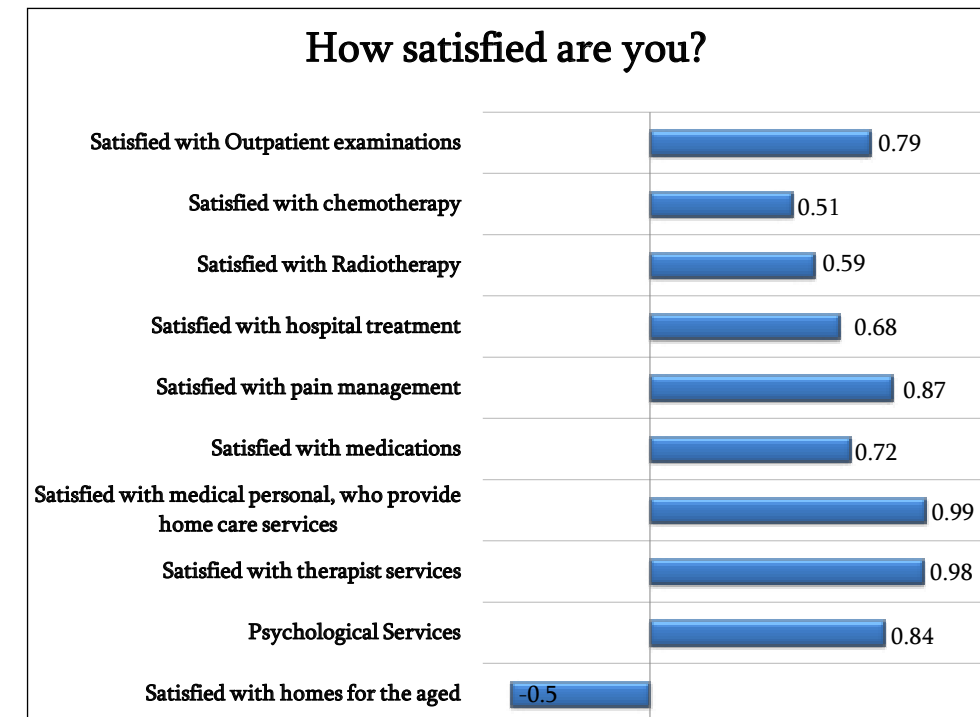


Diagram #6.4



Note: The share of those, receiving services of homes for the aged is very negligible.

6.2. Insurance and other allowances

Diagram #6.5

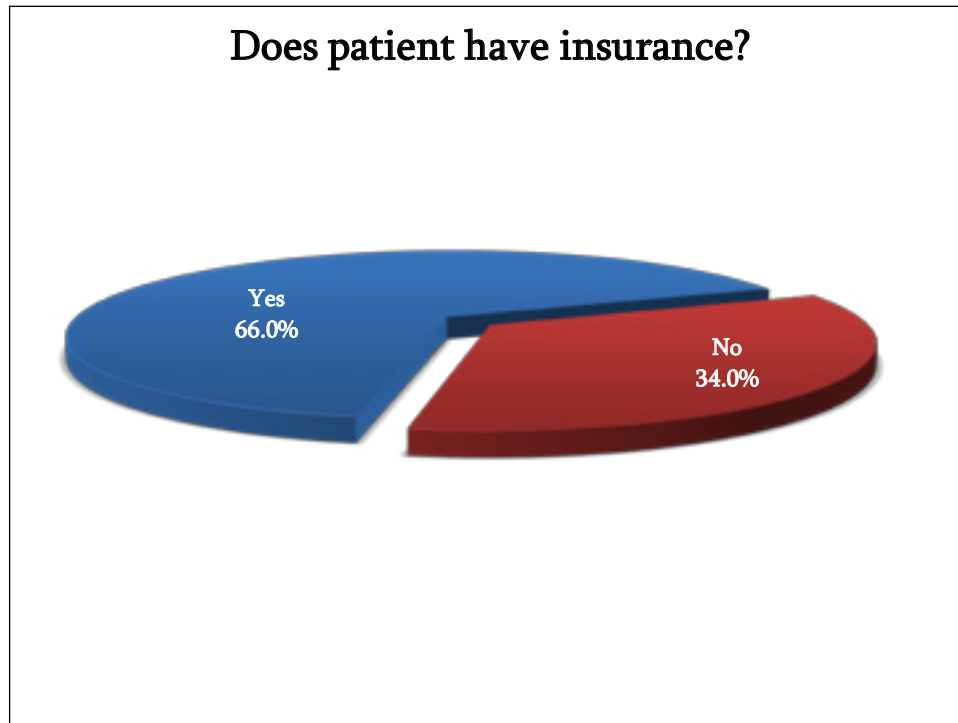


Diagram #6.6

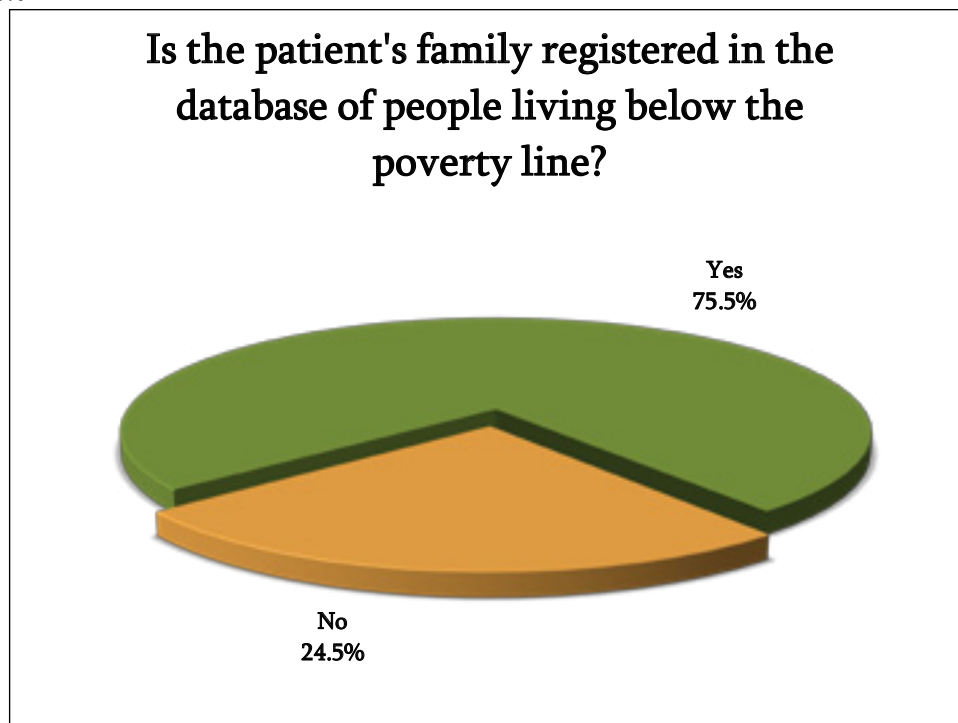
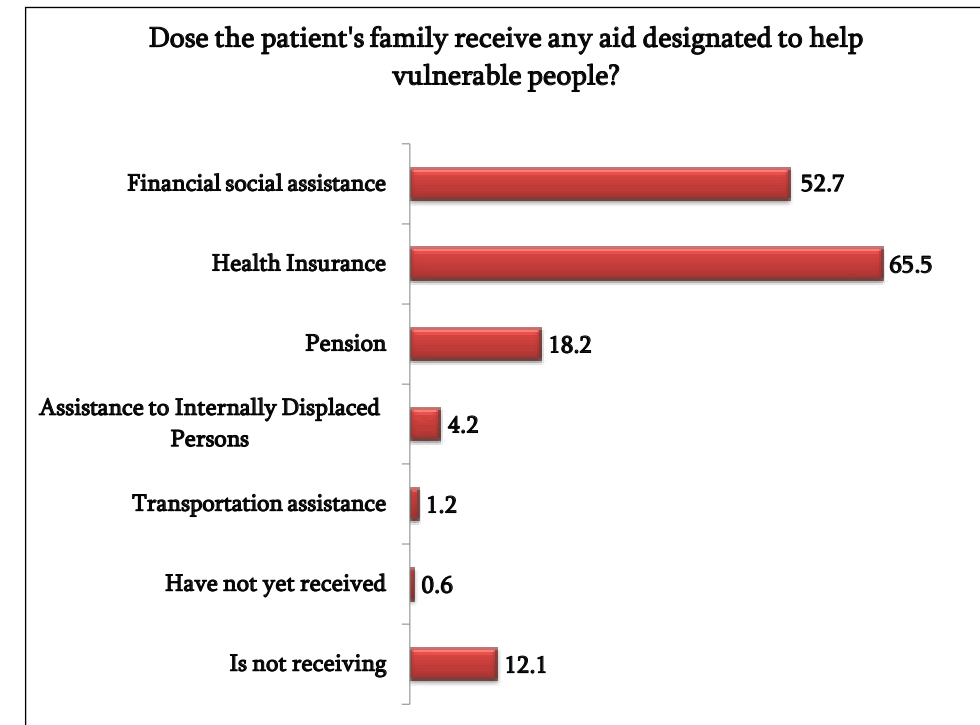


Diagram #6.7



Note: There were multiple response options available while answering this question, so the sum of answers exceeds 100%

Diagram #6.8

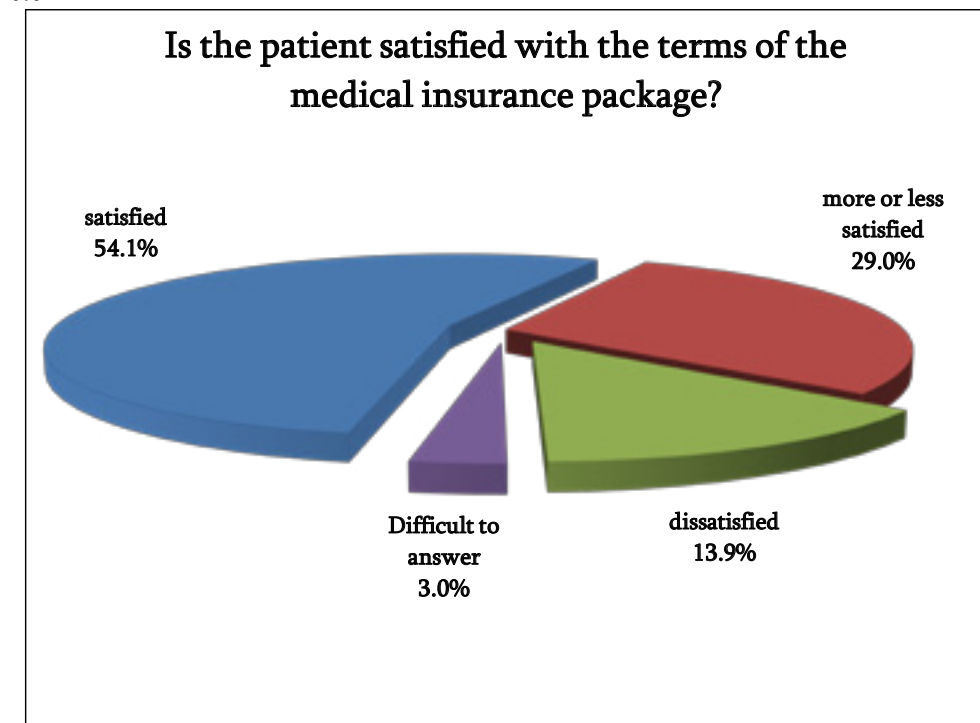


Diagram #6.9

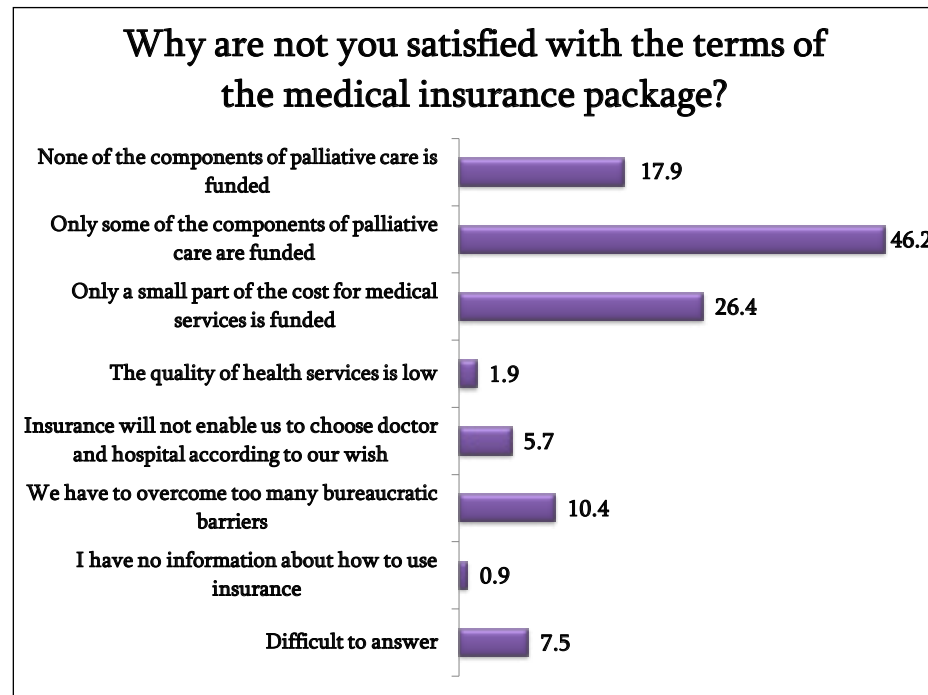
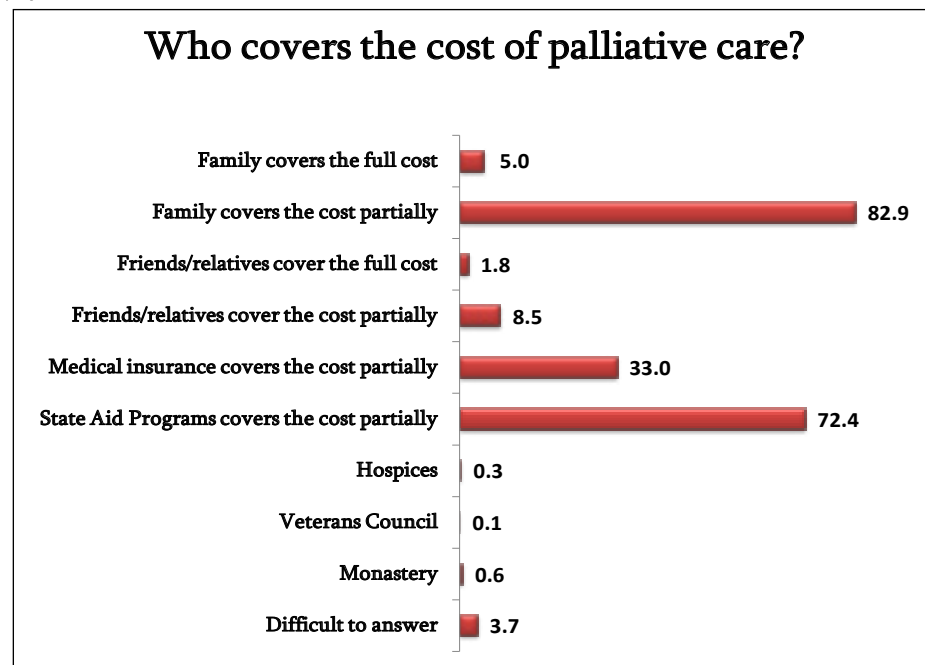
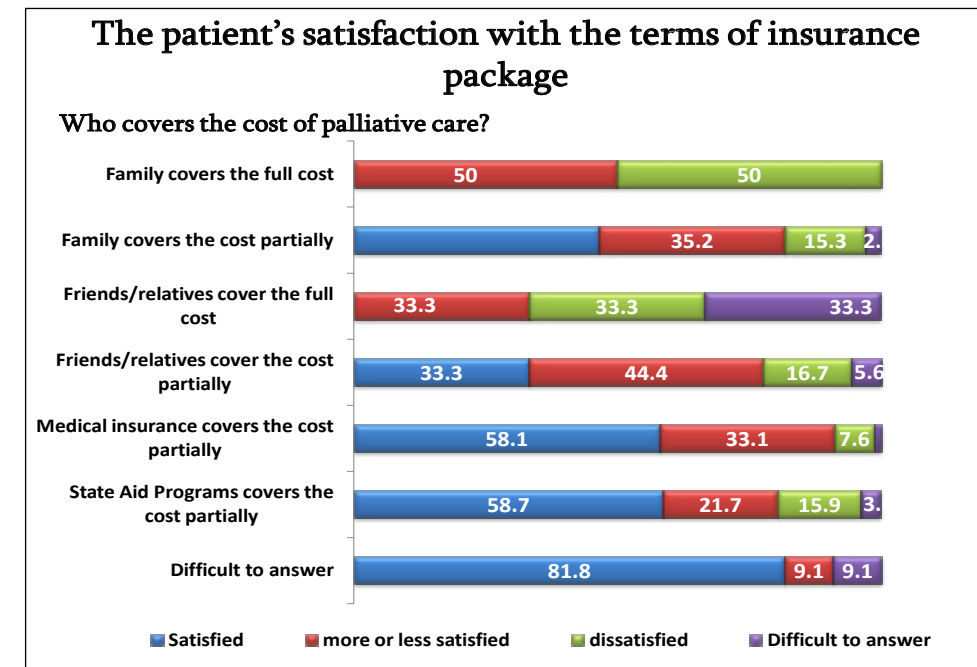


Diagram #6.10



**Note:** There were multiple response options available while answering this question, so the sum of answers exceeds 100%

Diagram #6.11 Does the patient's satisfaction with the terms of insurance package depend on the individual who covers the cost of palliative care?



**Note:** Data is calculated according to those respondents, who use the insurance package



## VII. The assessment of medical institutions and personnel with regard to palliative care patients

### 7.1. Multidisciplinary or individual approach?

Diagram #7.1

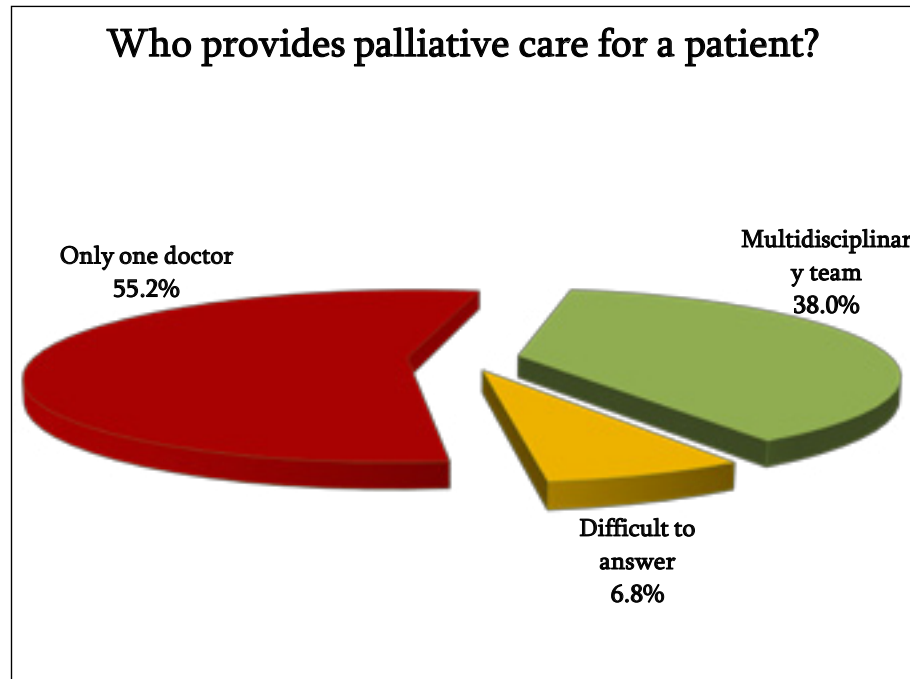


Diagram #7.2

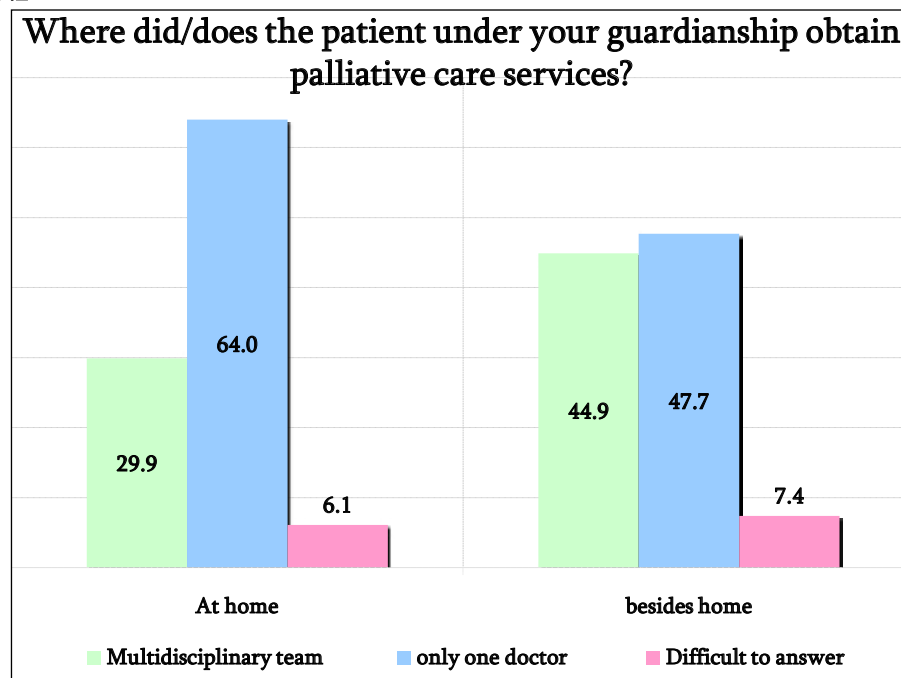


Diagram #7.3

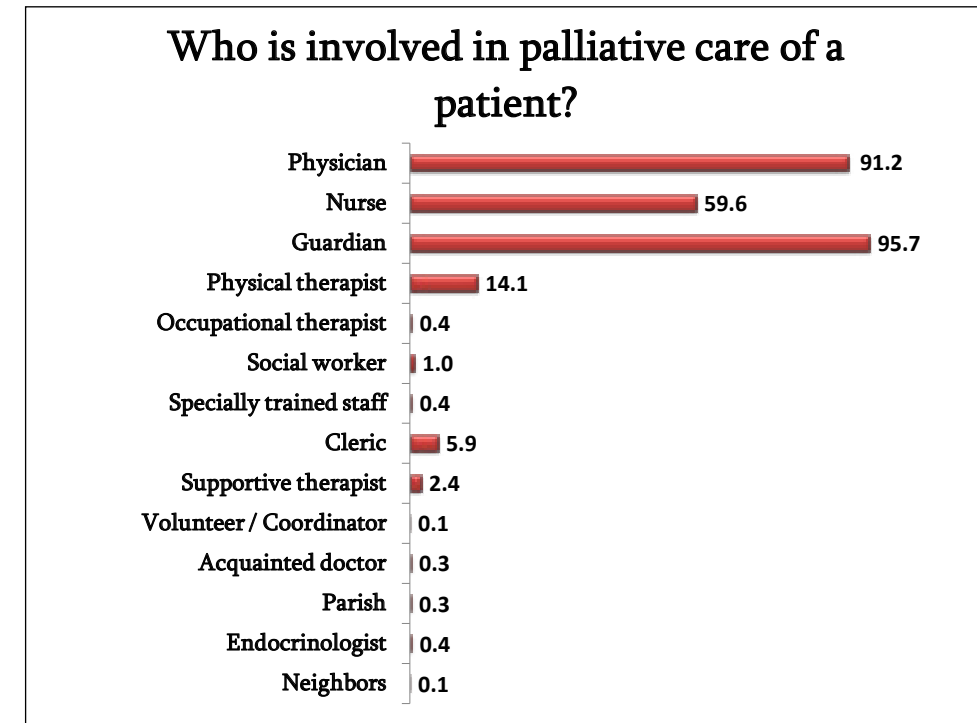
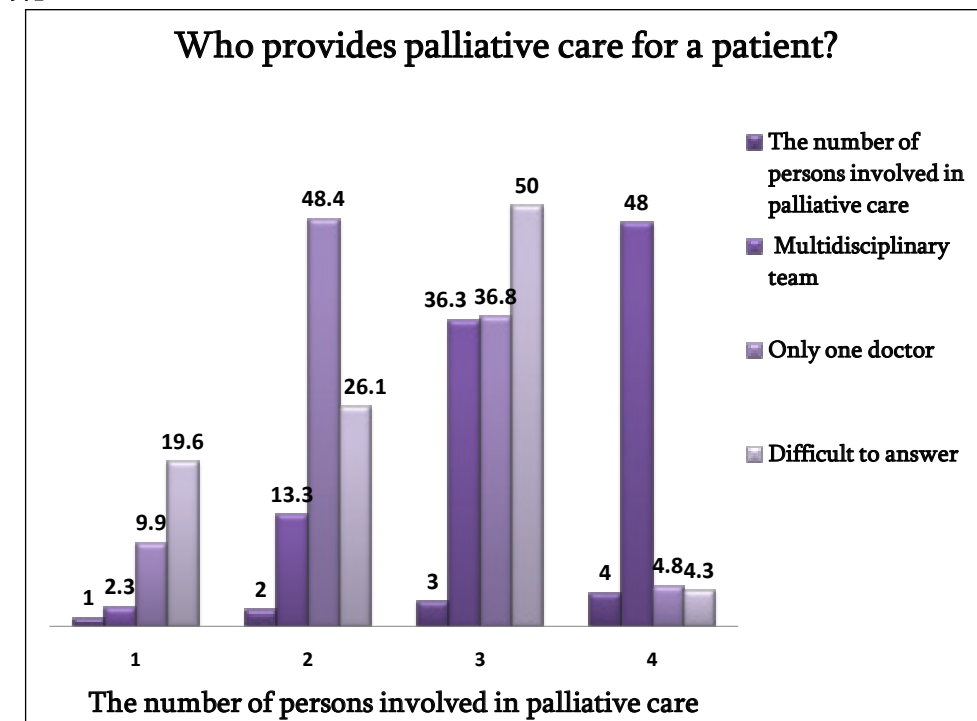


Diagram #7.4



### 7.2. Use of palliative care services and evaluation

Diagram #7.5

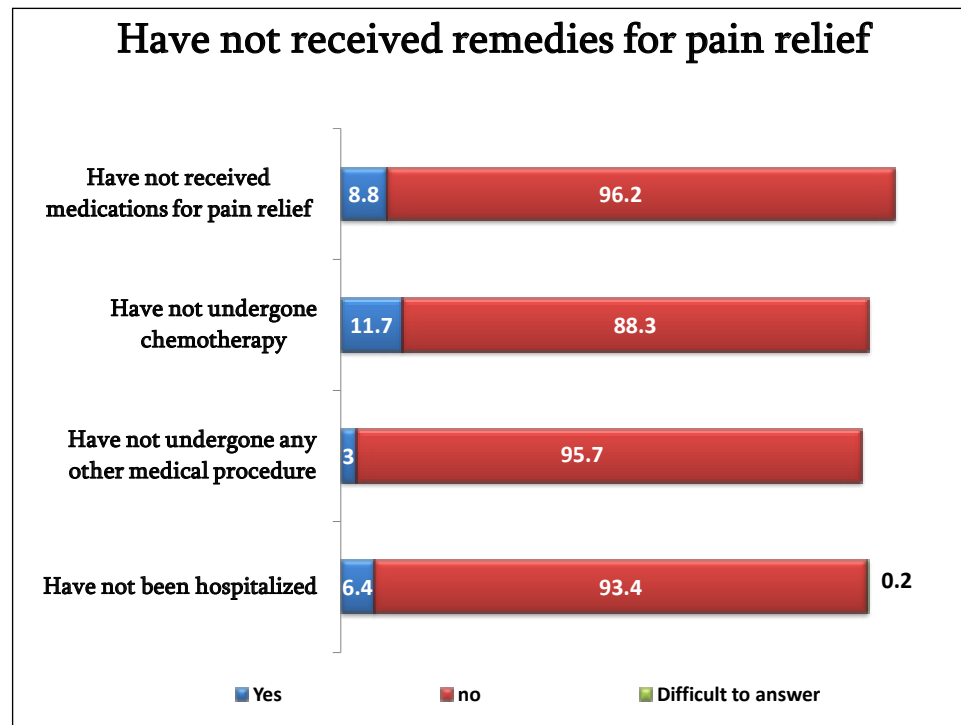
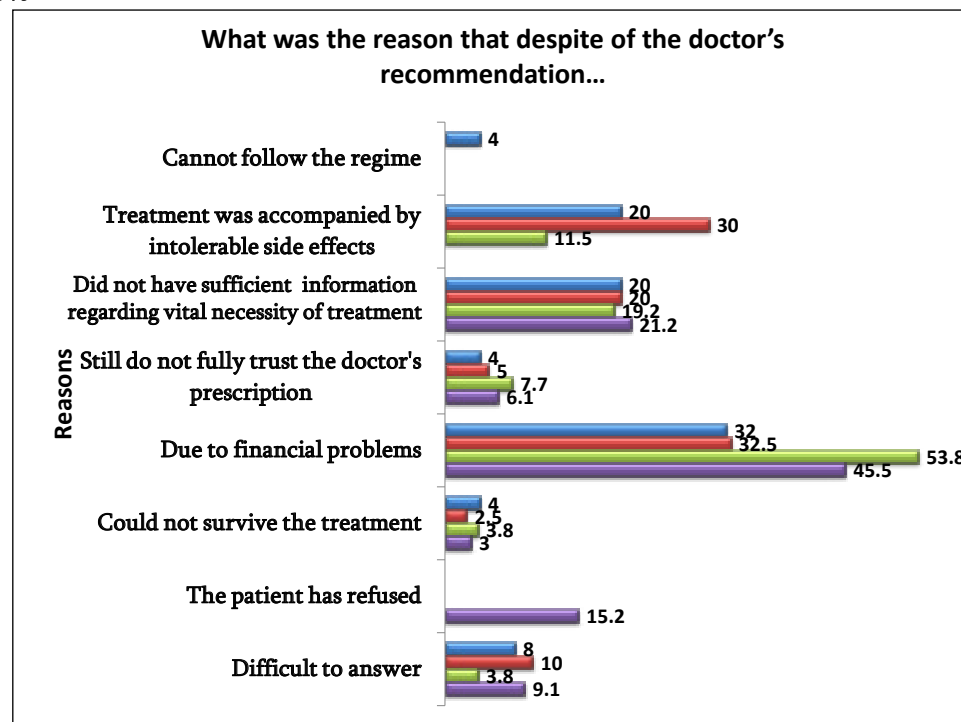
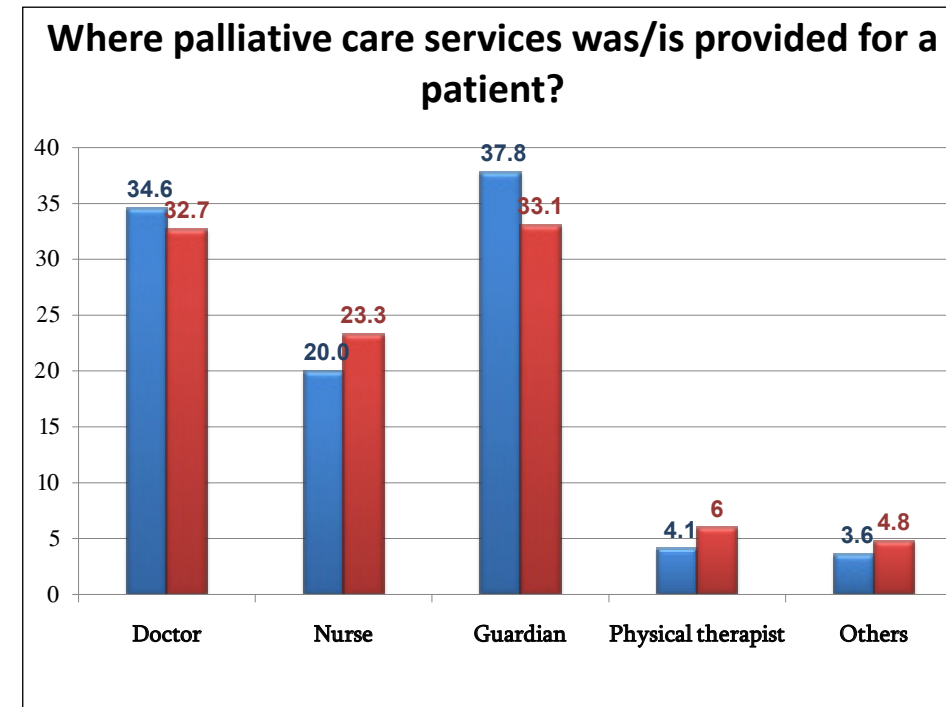


Diagram #7.6



Note: Results are calculated for those who were in need of any type of treatment and have not received it.

Diagram #7.7



Note: a) In the list of people involved in palliative care, only the first four listed persons had the highest share. The share of the rest ten was so low that they were united in the common name of "others" and there is the sum in the table.

Diagram #7.8

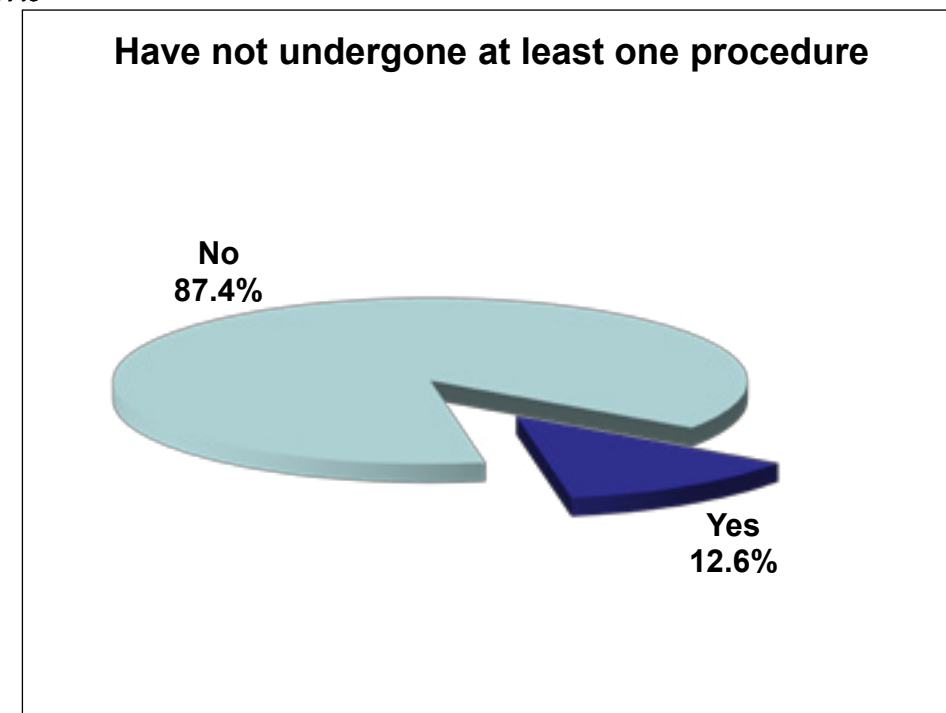
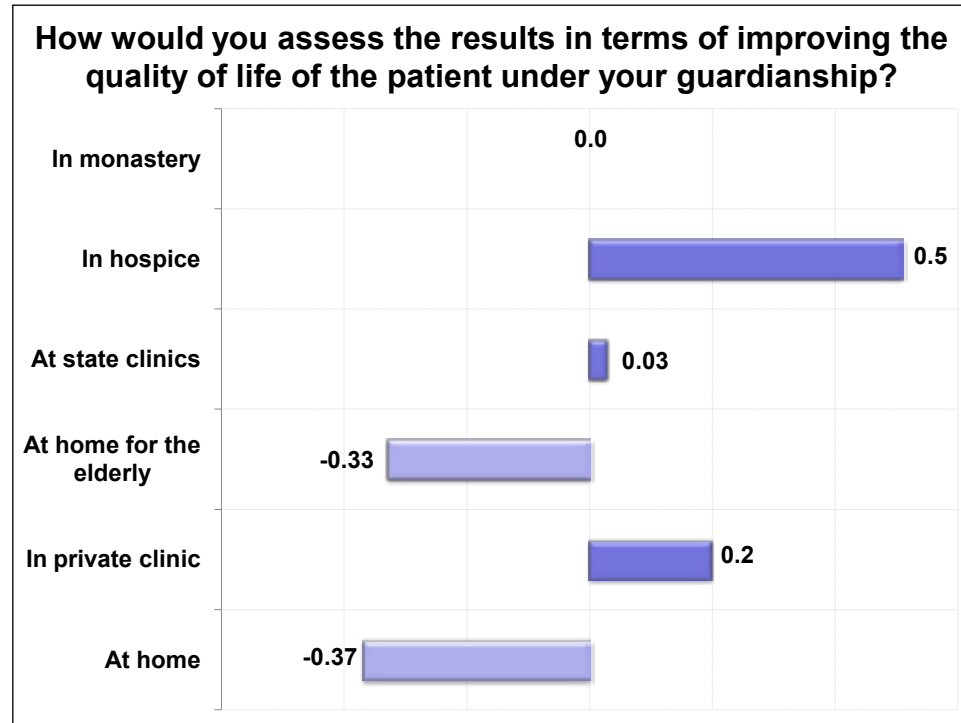


Diagram #7.9



Note: The share of those who have been provided by the services of home for the elderly and monastery is insignificant.

Diagram #7.10

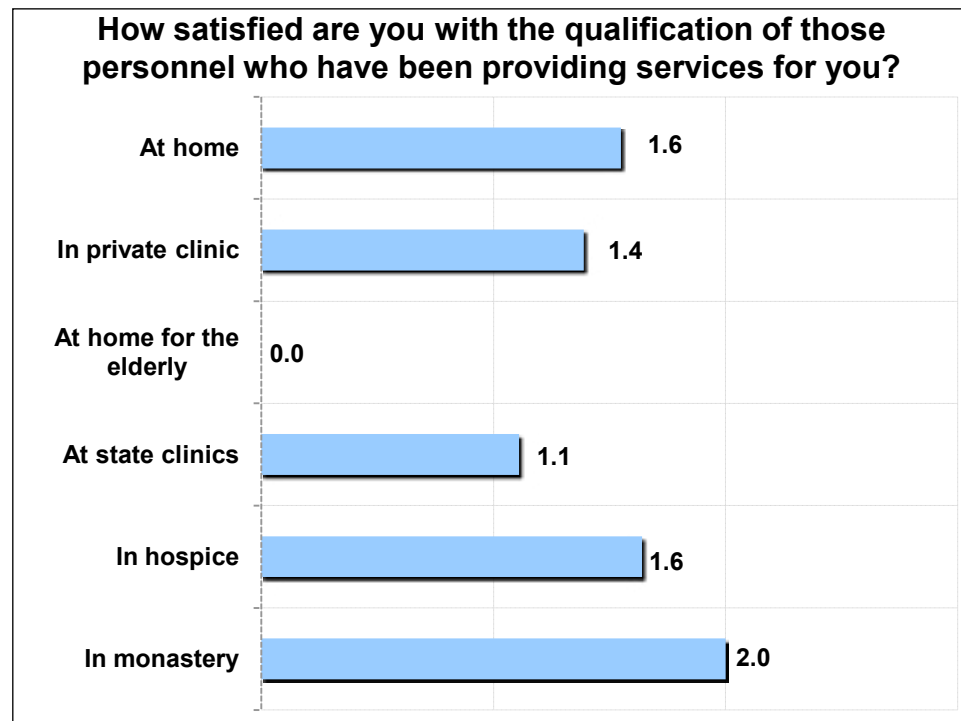


Diagram #7.11

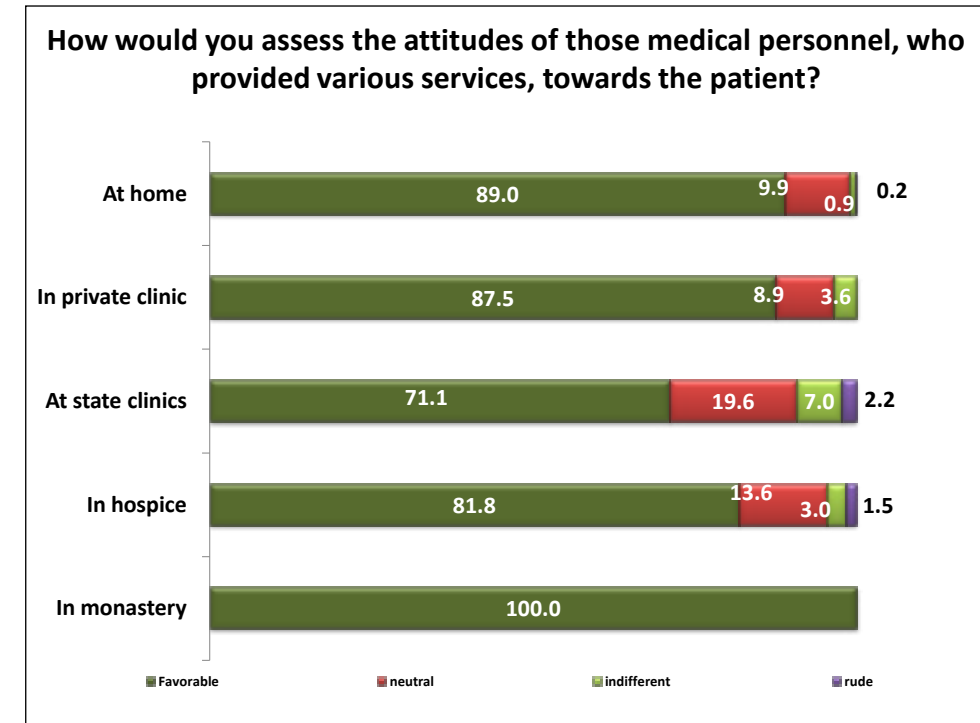
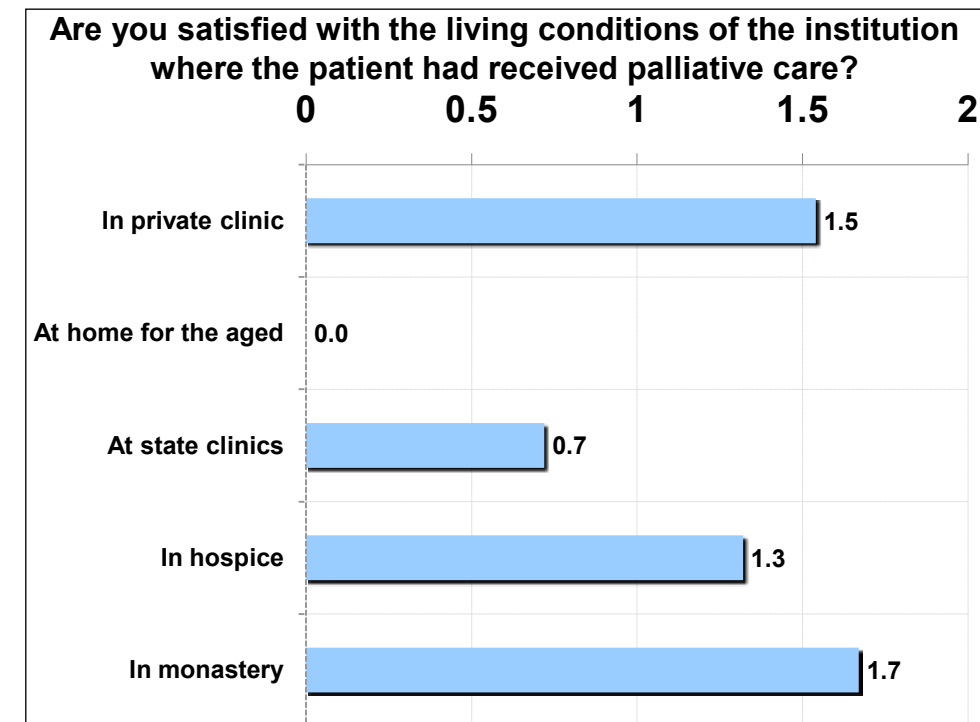


Diagram #7.12



Note: Only four of them have received palliative care services at home for the aged. Therefore, the coefficients were impossible to count.

Diagram #7.13

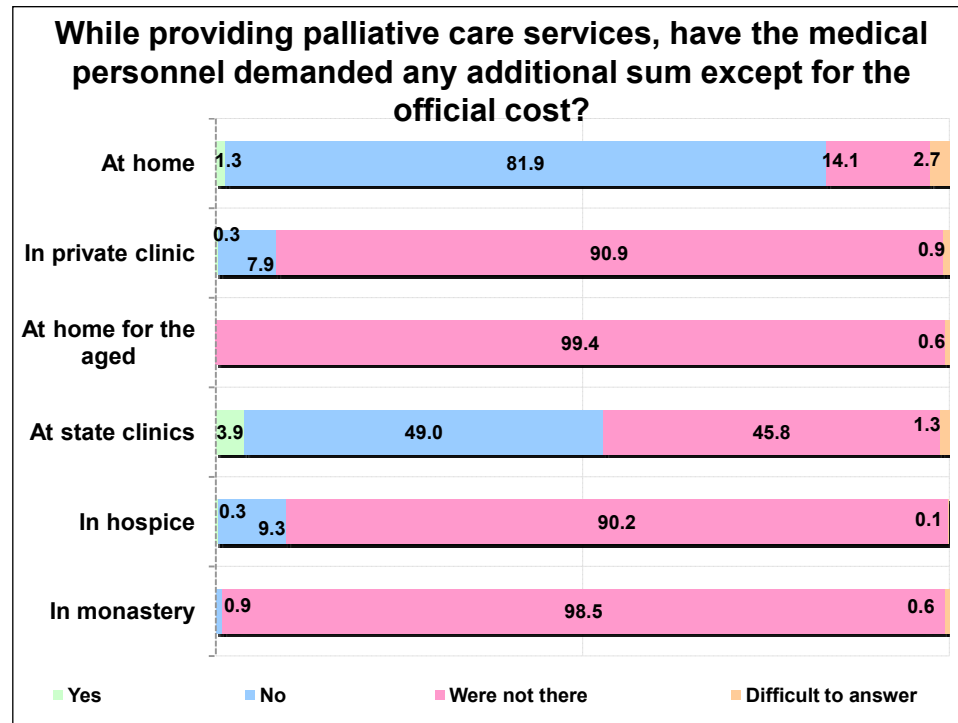


Diagram #7.14

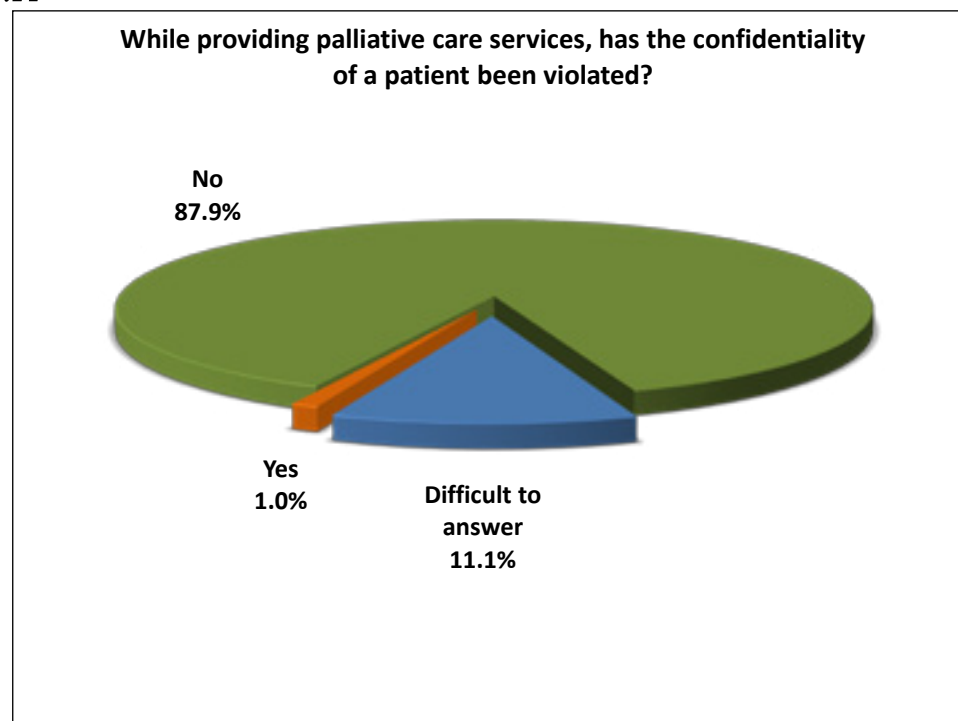
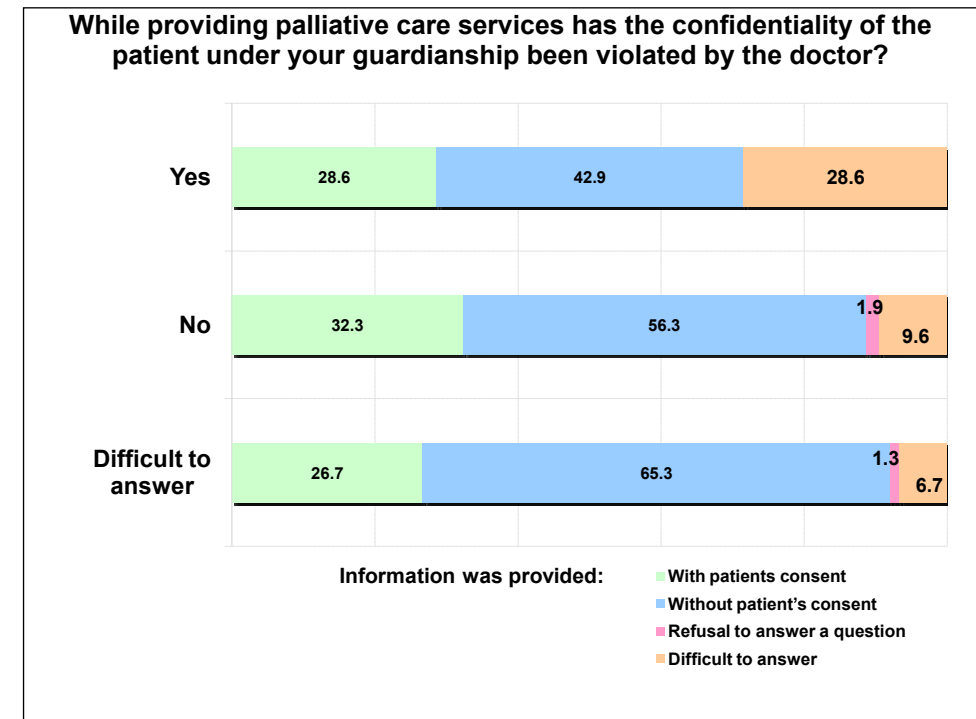


Diagram #7.15



## VIII. Living conditions and problems of palliative patient

### 8.1. Social status of the patients' families

Diagram #8.1

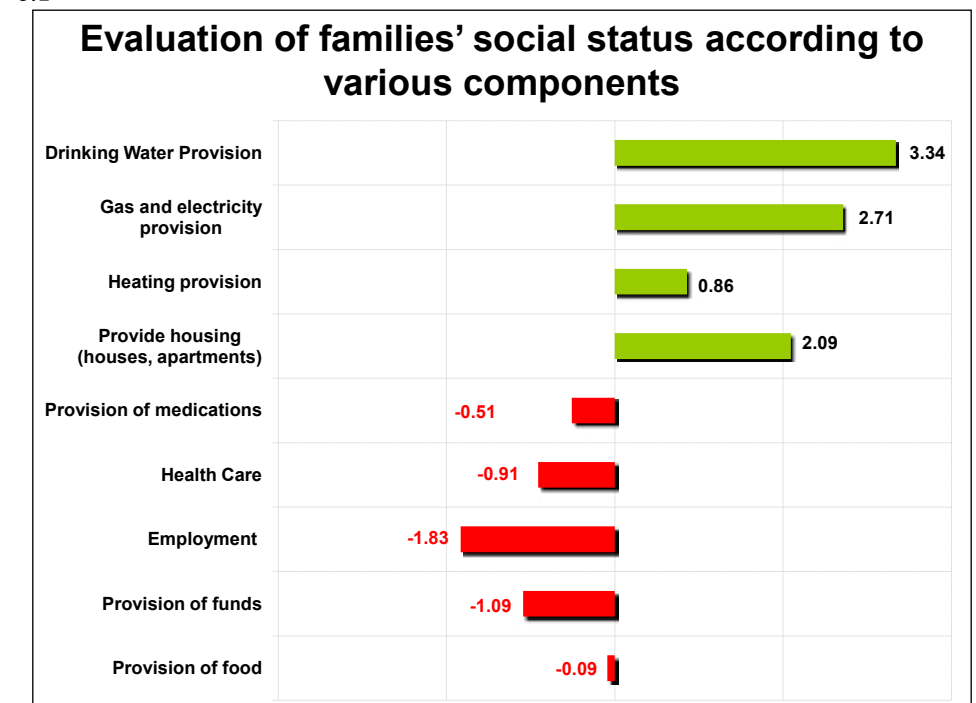




Diagram #8.2

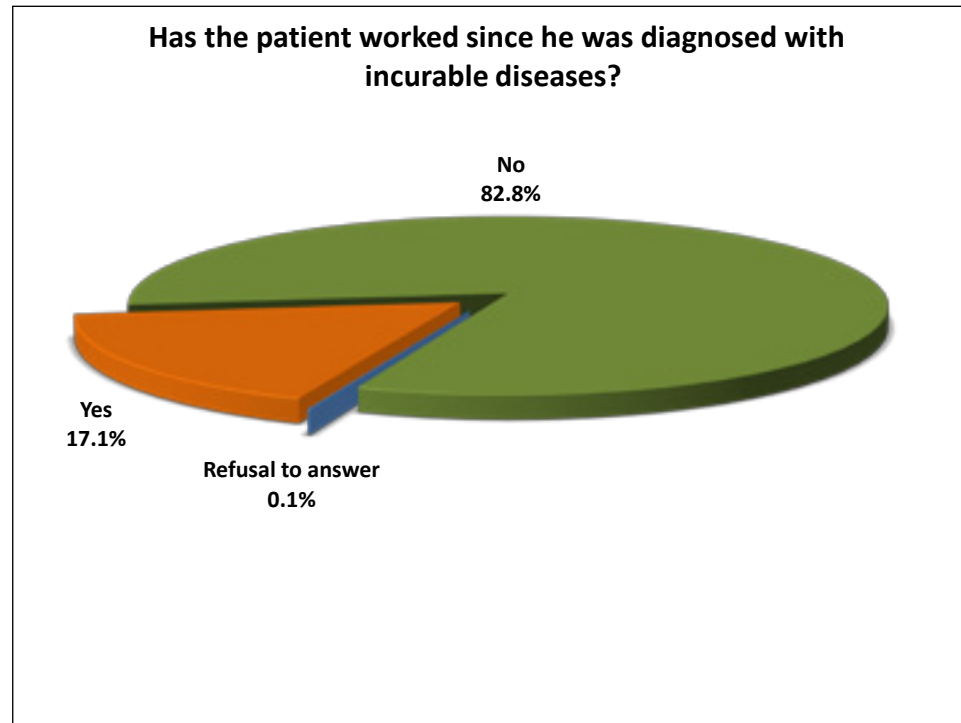
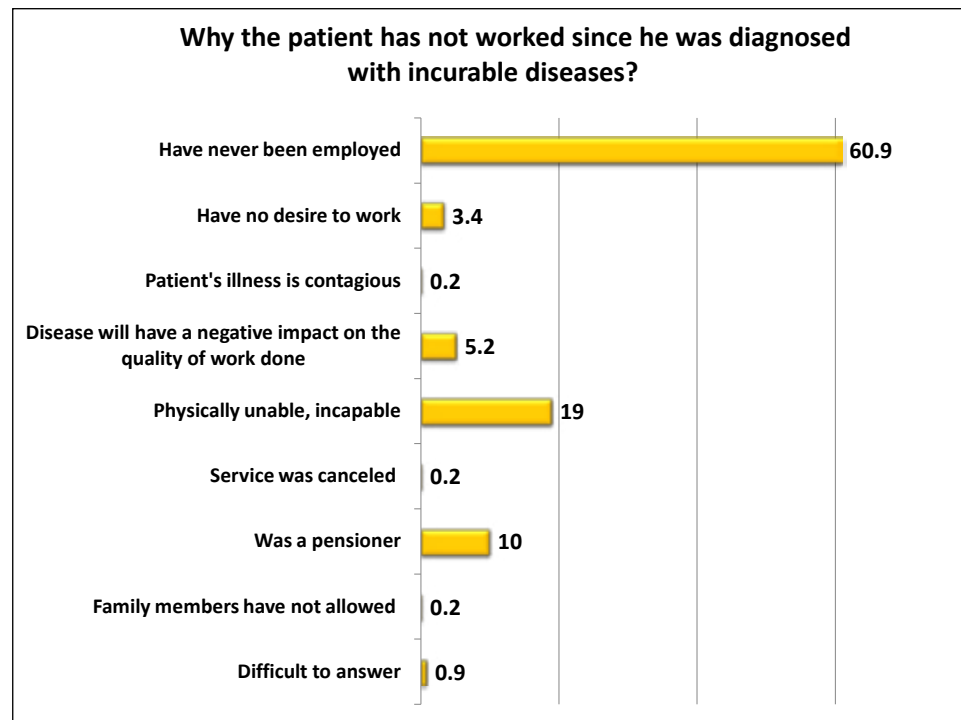


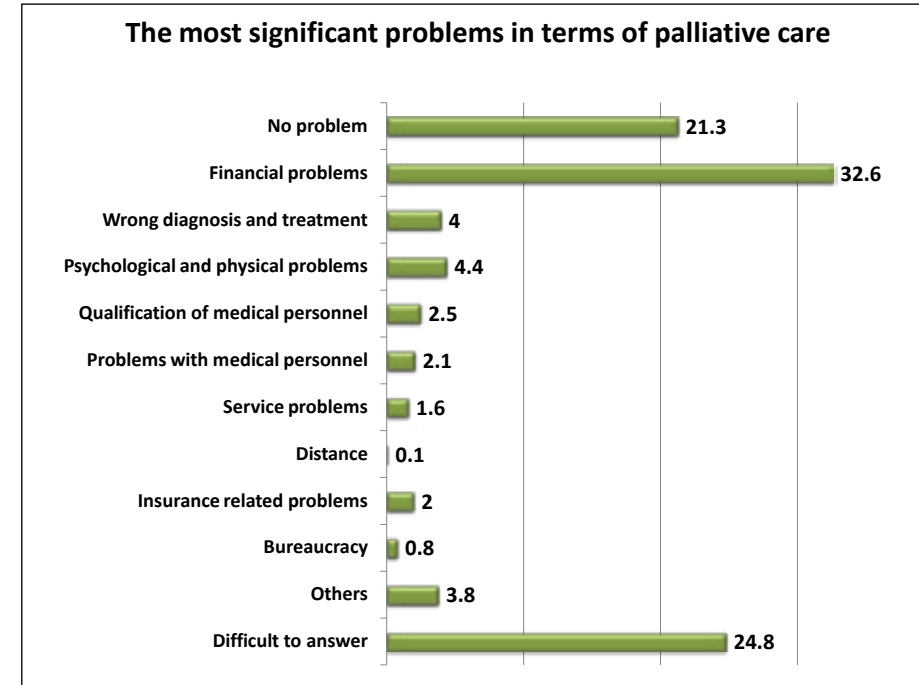
Diagram #8.3



**Note:** Results are calculated according to the groups, who replied that the patient has not worked since he was diagnosed.

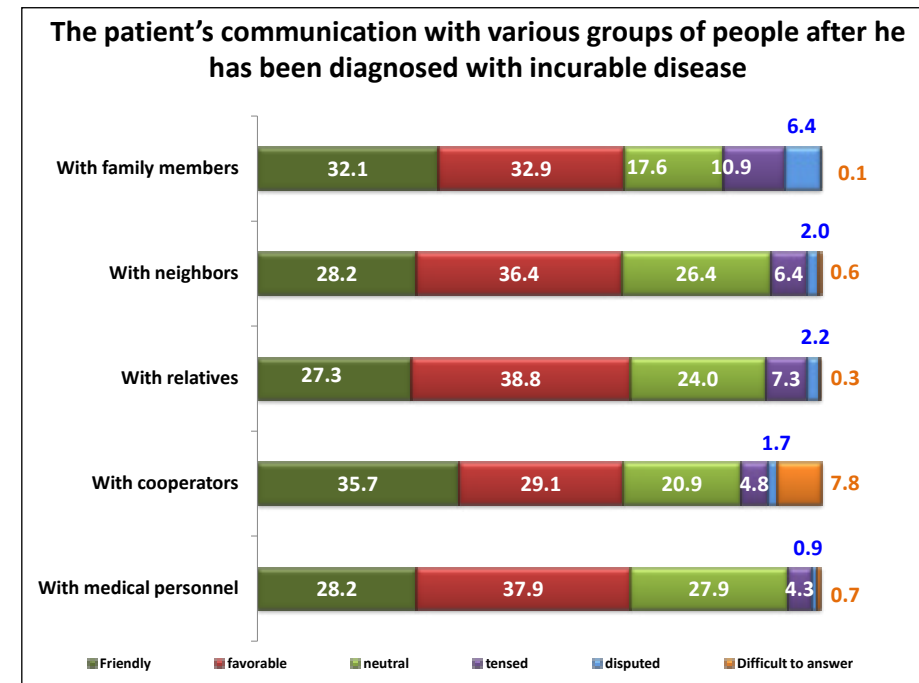
**8.2. The most significant problems in terms of palliative care**

Diagram #8.4



**8.3. Palliative care patients' communication with different groups of people**

Diagram #8.5



**Note:** Data is calculated according to those respondents who have a relationship with one or another group.

Table #8.1

The impact of the patient's religiosity on the relations with different groups of people				
		He is believer, though does not to live an ecclesiastical life	He is believer, and lives an ecclesiastical life	He is unbeliever
With family members	Friendly	28.4	42.0	34.4
	Favorable	32.9	35.0	28.1
	Neutral	19.3	13.4	15.6
	Tensed	12.7	4.5	14.1
	Disputed	6.7	5.1	7.8
With neighbors	Friendly	21.9	43.5	36.5
	Favorable	39.3	33.1	27.0
	Neutral	30.1	18.2	22.2
	Tensed	6.4	5.2	9.5
	Disputed	2.3		4.8
With relatives	Friendly	20.8	43.2	35.4
	Favorable	41.7	34.2	30.8
	Neutral	27.7	14.8	21.5
	Tensed	7.1	6.5	10.8
	Disputed	2.7	1.3	1.5
With cooperators	Friendly	30.8	50.8	52.9
	Favorable	33.8	32.3	11.8
	Neutral	26.9	15.4	17.6
	Tensed	5.4	1.5	17.6
	Disputed	3.1		
With medical personnel	Friendly	21.3	43.9	40.0
	Favorable	40.6	35.0	29.2
	Neutral	32.3	18.5	23.1
	Tensed	4.5	2.5	7.7
	Disputed	1.3		

Diagram #8.8

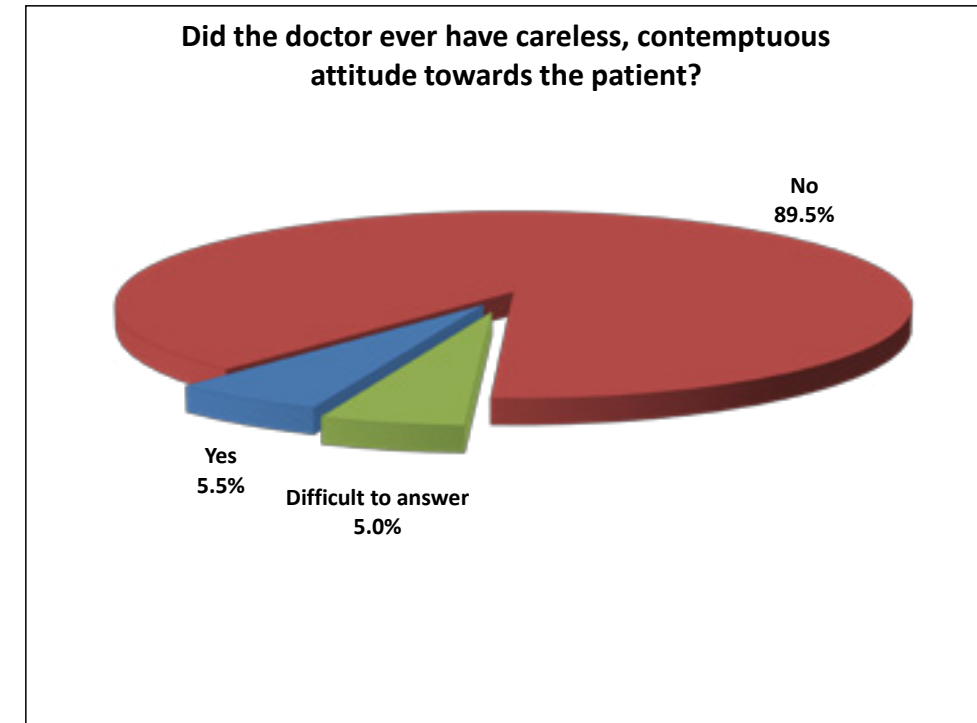


Diagram #8.6

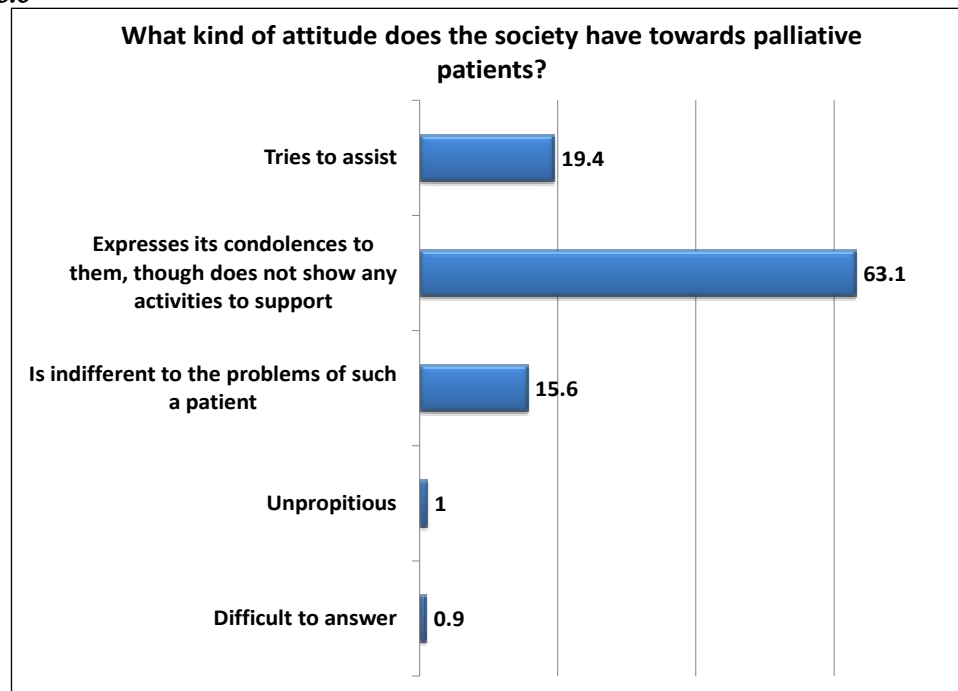


Diagram #8.8

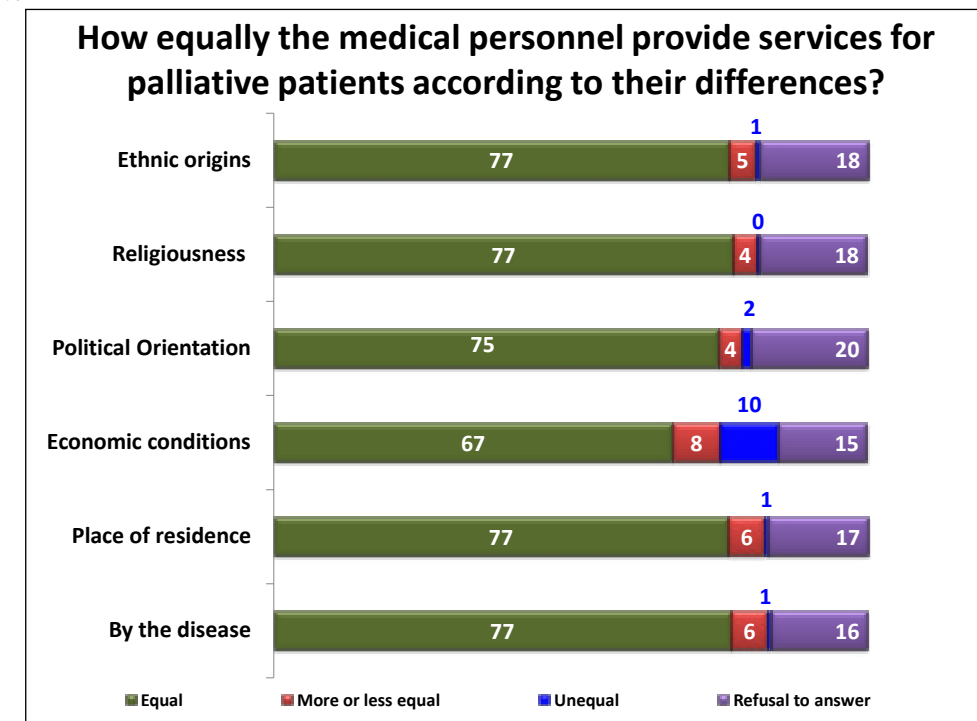


Diagram #8.9

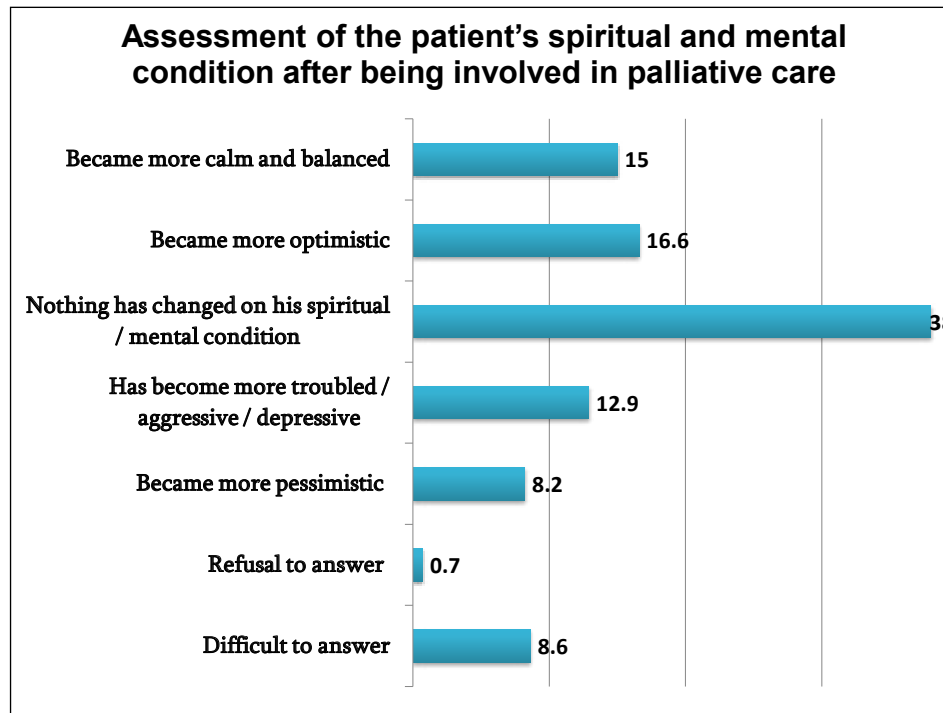


Table #8.2: The impact of the site, where the patient has/is received/receiving palliative care services, on his spiritual and mental condition.

Where does/ did the patient receive palliative care services?	Assessment of the patient's spiritual and mental condition after being involved in palliative care				
	Became more calm and balanced	Became optimistic	Nothing has changed on his spiritual / mental condition	Has become more troubled / aggressive / depressive	Became more pessimistic
At home	-0.17	-0.15	0.41	1.06	0.89
In private clinics	-1.00	-0.75	-0.19	0.14	-0.25
The palliative care department in state clinic	-0.31	-0.43	0.00	0.09	0.33
In hospice	-1.05	-0.93	-0.12	0.00	1.00

Evaluation was carried out on a 5 point scale (from -5 up to +5), where “-2” indicated “pessimistic attitude”, “-1” - Has become more troubled / aggressive / depressive; “0” Nothing has changed on his spiritual / mental condition; “+1” - Became more optimistic; “+2” - Became more calm and balanced



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