Ethical and legal aspects in palliative care in Romania

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Abstract: Ethical and legal aspects are important within a holistic approach to palliative care and they require the study of what is already exists in current practice. An increased awareness of such ethical and legal aspects specific to palliative care through qualitative studies and by closely monitoring them can lead to new attitudes and professional skills that will positively impact patients’ quality of life as well as the quality of the medical services offered.

Key Words: ethical and legal aspects, palliative care, legal support.

INTRODUCTION

The ethical and legal aspects generally presented in the universal contexts of palliative care need to have more specifically national touches within the social and medical context of Romania. This idea is also emphasised by specialist literature: “It is necessary that discussions and the solutions offered take into account the specific context in order to be realistic and practical. Concepts need not a literal translation, but to become enriched by the national context” [1]. Studies carried out at the Regional Institute of Oncology in Iasi between 2016-2018 have pointed out ethical and legal issues that affect patients, their families and the medical staff and have shown a lack of coherence within a system that aims to offer a holistic approach. The specific nature of the ethical and legal aspects is associated by some authors with the explicit or implicit need for ‘a Christian model of bioethics for the Romanian context” [2]. Such a model turns completely upside down the general approaches offered by palliative care in other cultures. For example the Christian view about life and death will fundamentally impact issues such as euthanasia, assisted suicide, facing illness and death and the care for one’s life. In the same way the Christian concept of freedom gives different meanings to issues such as autonomy, decisional act, rights, responsibility, risk and research [3].

Certain areas such as informed consent, confidentiality, the protection of personal data and the equal access to services without discrimination have benefited from important progress so far. However, there are still significant gaps in the legal and social support offered to patients in palliative care. Such difficulties are more specifically related to: financial aspects (debts, credits, etc), wills, inheritance, children’s custody, funeral, death certificate, marriage situation, legal protection from the extended family in case of abuse and putting in practice the instructions and the services established by law [4].

Even though the social worker’s remit should cover aspects such as the assessments of needs of the people who require their service, setting intervention priorities, assessing the available resources, identifying the resources that will best support personal needs, developing an individual plan of intervention, establishing the communication between the assisted person and the required agencies, monitoring the intervention and evaluation of the intervention results both for the assisted person and the medical service (Rădulescu, 2004) [5], in actual fact the social worker’s support focuses mostly on social aspects such as: identifying the level of disability according to the Framework of Complex Evaluation of People with Disability, claiming all the legal rights according to Law 448/2006, applying for the entitled

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pension and the disability pension according to their legal entitlement (Law 263/2010), applying for social benefits according to Law 416/2001, advising the family how to obtain all the medical certificates from the Department of National Health, supporting the family with claiming the funeral expenses and from the Department of National Public Pensions [6], obtaining identity documents and death certificates. The social worker focuses less on services such as support for developing the skills for an independent life, professional advice, psychological support, etc. The reasons given for the above are the lack of such specialist services or the lack of information about how such services could be accessed. As a tertiary level is missing, legal support is therefore not accessed as people's physical and mental resources become too limited to initiate such a process given the excessive bureaucracy and the large number of documents and institutions that need to be contacted.

In order to address the gaps identified above, the Hospice of Hope Foundation in Brasov – which is a major institution offering palliative care services at national level – has initiated projects such as "Fist Steps in Adding Legal Services Component for Palliative Care in Romania" which aims to increase the quality of life for people with long-term chronic conditions and their families through access to information and advice so that they can benefit from the rights given by law. Another project aims to identify the level of need and the rights given by law for people with progressive, incurable and long-term conditions and their families and especially for the recognition of their legal right for palliative care in Romania, so that these services represent not just a legal right written in a Law Article, but a National Programme of Health which can provide care when and where it is needed [7].

Abuse is another complex issue that has legal implications. Some of the more vulnerable situations are: people whose income is taken away against their will, or face other types of financial abuse, people who are forced to leave their homes, those neglected and abandoned without any help, the homeless, the drug addicts who don't receive adequate support for their addiction and those at risk of physical abuse, emotional abuse, sexual abuse, etc. as well as individuals suffering from mental health illnesses or social difficulties who do not receive specialist support or those who do not receive adequate pain killers [8].

In Romania patients diagnosed with cancer are not at all monitored when discharged from hospital and have no legal rights. According to Law no. 17/2000 regarding social support for elderly people, there are a few situations which could require specialist social support, however these are to be accessed only by an elderly person who: "has no family or any other carer, has no home and no means to acquire a home through their own financial resources, has no income or limited income, cannot look after themselves or is in need of specialist care, and is unable to meet their social and medical needs due to their illness or their physical or mental condition" [9]. However, such legal provision does not address the lack of such services in certain areas and does not solve issues about accessing such services when they are needed.

A special type of abuse is domestic violence. Different sub-types are: direct physical abuse (slaps, shakes, pinches, beatings, depriving of medical equipment, etc.), indirect physical abuse (administering medicines that have not been prescribed, for example sleeping pills, etc), sexual abuse (violation of private space, intimate relations without consent, etc), emotional or mental abuse (verbal aggression, indifference or disgust, lack of empathy, social isolation, threats of physical violence or other punishments, swearing, humiliation, etc.), financial abuse (unauthorised use of one's inheritance, unauthorised sale of one's estate, persuading or forcing someone to make financial gifts, withholding money or valuable objects in order to obtain financial advantages etc), neglect (neglecting the daily care requirements, neglecting the need for hygiene and help in general, not providing the necessary food and water, bed sores due to the poor hygiene for people immobilised in bed), threats to abandon or put the person in a home, other forms of abuse carried out against the will of the elderly person [10]. Even though clear legal provisions are put in place nationally with regard to domestic violence (e.g. Law no. 217/2003 for prevention and extinction of domestic violence, republished; Romania's Juridic Code, republished, with subsequent modifications and additions; Law no. 211/2004 regarding certain measures to protect victims of crime, with its subsequent modifications and additions; Order no. 383/2004 issued by the Ministry of Work, Social Solidarity and Family regarding the quality standards for the social services aimed to protect victims of domestic violence; Order no. 384/306/993/2004 issued by the Ministry of Work, Social Solidarity and Family, Ministry of Home Affairs and Ministry of Health regarding the approval of a Procedure aimed to prevent and monitor instances of domestic violence; Order no. 304/385/1.018/2004 issued by the Ministry of Home Affairs, Ministry of Work, Social Solidarity and Family and Ministry of Health regarding the approval of the Instructions for Organisation and Performance in centres in order to prevent and eliminate domestic violence; Government Order 1156/2012 regarding the approval of the National Strategy for prevention and elimination of domestic violence between 2013-2017 and the Operative Plan for implementing the National Strategy for prevention and elimination of domestic violence between 2013-2017)

MATERIAL AND METHOD

The research methodology stems from qualitative research from which we have used the 3 types of interviews identified in the specialist literature (Converse and Schuman, 1974; Spradley, 1979; Patton, 1980; Gorden, 1980; Douglas, 1985, etc): 1) informal conversation, 2) guided interview, 3) standardised interview with open questions [12].

Informal conversation was used in order to establish interactions with the chosen participants from the target groups as well as to obtain the demographic data used in the study – as that data was not taken from a secondary analysis of the medical records of the participants or other documents.

Interviews were unique and individualised (“face-to-face”), containing a main part and follow-ups. Patients were interviewed using a semi-structured interview type, based on an interview template as guidance. A standardised type of interview with open questions was constructed for the medical staff, the psychologist and the priest.

The following criteria were used for the selection of participants for the target groups: target group 1 was selected from the patients already under the care of the Palliative Care section of IRO, Iasi; target group 2 was selected from the families of the patients under the care of Palliative Care section of IRO, Iasi; target group 3 was selected from the employees of IRO, medical staff involved in the palliative care services offered to the patients in the target group 1.

The study was carried out following the approval of the Ethics Committee for Research from the Regional Institute of Oncology Iasi and following the informed consent given by all the participants in the study. Participants were informed about the study, its aim as well as the use of the data they provided. Participants had the option of leaving the study at any point during the research and were reassured about their full identity protection through the use of anonymous quotes. All participants’ contribution to the study was voluntary.

The sample for the semi-structured interview was gathered from interviews with 7 patients; the sample for the standardised interview came from interviews with 11 medical staff (3 doctors, 7 nurses, 1 kinaetho-therapist) 1 psychologist, 1 priest and 7 family members.

RESULTS

As a result of the selective coding of the interview data, the ethical and legal aspects were then grouped according to the variables which were considered reference points: patient, family, medical system. Some of the ethical and legal needs identified by the patients in the interviews were regarding the following: the need for end of life planning, “planning everything, leaving everything in order, all settled” (R7 [13], nurse), the need to have all the information given in order to manage such planning “Things have been only half said, things are said only in part, which creates ambiguity and uncertainty. One cannot plan, one doesn’t know what decision to take, etc, if something has not been said clearly and fully” (R1, doctor).

An issue identified at family level is the non-observance of the patient’s wishes which had been expressed in advance: “It didn't happen at all, it was the complete opposite of what the patient would have liked” (R1, doctor), “we need to respect the patient’s wish too because maybe […] it’s his last wish, maybe they don’t wake up the following day, or maybe they can’t talk to us anymore and then how will we feel the next day if his wish was not fulfilled” (R9, nurse), “certain things required by the family have nothing to do with the dying patient” (R2, doctor). Generally the data obtained from interviews as well as informal conversations, were about wishes regarding: hospitalization, treatments, where to die, bringing up children and looking after pets, but most of them related to religious aspects such as the attendance of the priest, the funeral, mourning: “it was very moving, a few days ago, before bringing him here, he talked to the elder daughter and he told her what to do, how to do it, so he gave her some last instructions” (R18, patient’s wife), “he said that our burial place is at Eternitate cemetery and there wasn’t a grave there and he asked me to go and have the grave made and I went and did that (R20, patient’s former wife), “they ask her to bring the priest, to talk to the priest” (R4, chief nurse), “he asked us not to do feasts, not to spend money on expensive funeral things, to do what is religiously appropriate and that’s it”, “he asked me not to wear black mourning clothes, not to wear them for more than 40 days” (R18, patient’s wife).

A delicate aspect for families is the lack of direct social support, the lack of legal regulation for this support to be put in practice: “no, nobody can help us with anything, […] we don’t find any understanding” (R20, patient’s former wife), the lack of legal support: “you go and try to solve a problem, to apply for his pension so that his kin can help him and you can’t do it”, “Social Services people tell me: ‘Madam, you can ask for it, but look this is the law from Bucharest, that's the law! That's the law and we can't give it to you. We apply the law no. 762 republished in 2007 and since then we don't have another one. Even though there is law no. 448 which comes with more amendments’ (R20, patient’s former wife), services which are not adequate compared to the level of needs: “they need to allocate some funds, they need to allocate a proper pension” (R20, patient’s former wife), “I don’t know who could come to help for 270RON. I don’t know why the law does not specify […] a companion” (R24, patient), the need for specialised services for social and medical care: “Somewhere to have a pensioners’ home, to have somewhere a place where we can live in peace, where we are cared for. I would have loved to be at home, in my bed and not to have to stay here. Even if not everybody is around me, at least I’m in my
own bed. But I can't. They don't help, the state doesn't offer such conditions. They charge enormous fees, there are no places, that's how it is” (R22, patient).

Regarding abuse, no specific examples were given, only potentially abusive situations were mentioned such as financial ones: “yes, relatives to come and visit, but no only when they would have a big inheritance” (R6, nurse), and often the fear of being abandoned was mentioned: ‘then you have no-one’ (R22, patient), “patients feel they are a burden for certain members of the family, friends, and they wish to hide this illness” (R5, nurse), “the fear of not being left on their own, this is very important, not to be neglected. They need a lot of attention and this is of course related to their fear of being abandoned” (R1, doctor).

Examples of domestic violence from the family towards the patient were not mentioned, only situations involving the patient: “they prefer to open up more with the medical staff, more than they do with the family, they think they burden them with their problems, and secondly they become more upset with their life, and sometimes they become aggressive towards their own family because of issues related to their illness” (R4, chief nurse).

With respect to the medical staff, the ethical aspect identified was connected to the patient's autonomy, which, in this context, tends to be delegated, as the relationship between the doctor and the patient is perceived as a paternalist one: “with the medical staff […] it is often a paternalist relationship, or they see it as such. They listen a lot to what the doctor says, even though, in such circumstances, in chronic conditions, the relationship should be based more on reflection or interpretation” (R1, doctor), “this is a paradigm that is used in Romania, a vertical one, the doctor is the authority who generates absolute answers, and the patient is somewhere, only a listener, passive and the one who has to follow the medical recommendations” (R13, priest), “of course, there are some who don't want to know and they delegate their autonomy and prefer someone else, usually a family member, to know about their illness, about how it will evolve, etc.” (R1, doctor).

As far as the medical system is concerned the main points relate to creating specialised medical and social services, the need for a legal framework which should regulate the delivery of social support and monitoring the cancer patients after they are discharged: “the transfer between services. There is a level missing, a big one, about what happens to the patient after they are discharged. After that there is complete blank, we don't know where they are, if they are at home, if somebody looks after them, makes sure they take their medicines, what happened to them, nobody knows nothing” (R1, doctor), “a palliative care patient needs monitoring daily, even 2-3 times a day, not just 10 days per month or whatever is currently provided by law” (R4, chief nurse), “the development and increase of care centres at national level because, as we know, there are very few, and the ones we have cannot support all the patients in need” (R5, nurse), “the development of services” (R12, psychologist).

CONCLUSIONS

The ethical and legal aspects pertaining to palliative care are directly linked to social, psychological and spiritual aspects, which is why palliative care needs a holistic approach. To reduce the negative impact of the issues mentioned above in the process of palliative care the following aspects should be covered: legal help for the end of life planning, psychological counselling of the patient in order to reduce their fear of being abandoned and their aggressivity, counselling the families to respect the patient's wishes and their autonomy, and developing communication channels between the medical staff. The improvement of the social and medical services has been found to be directly linked to the existence of a legislative basis for the social support in order to monitor patients and their ongoing needs.

Conflict of interest. The authors declare that there is no conflict of interest.

References

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