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mgr Jan Waresiak

discipline: sociological sciences

Pontifical University of John Paul II in Krakow

Title of the dissertation

"Hospice as an institutional form of help and social support for the patient and his family in the terminal stage of the disease - legal and family aspect."

Summary

The dissertation was dedicated to palliative and hospice care, as a challenge that every family has faced, is facing or will face in the future, as well as various forms of institutional support that society can provide so that the family can meet this challenge as best as possible. Proposals for changes to the current legal status regarding palliative and hospice care have been proposed in order to facilitate its functioning and its further development.

The first chapter of this work is a traditional bow and tribute to previous generations. The current generation is not the first in the generational relay that is trying to respond to the challenges related to the needs of providing care for sick people.

The second chapter of the work presents issues and related doubts and controversies regarding delicate issues of euthanasia, passive euthanasia, persistent therapy, expressing the patient's consent to admission to palliative and hospice care, and providing information to relatives about the health condition, which always arouse great emotions. Initially, such a chapter was not planned to concern very general matters. The aim of the dissertation was to focus solely on the "here and now", i.e. look at the current legal regulations regarding palliative and hospice care in Poland and propose possible changes or introduce additional solutions that would facilitate and improve the performance of palliative and hospice services.

It is obvious that in every society there is some form of legal system that regulates the life of the community in various areas of its functioning. Standards are usually tailored to the needs of that community. They take into account customs and various types of conditions in which the community functions, including the natural conditions in which a given community lives. Some solutions may seem incomprehensible, although in certain conditions, in a specific community, they work. Well-constructed legal standards should be practical, guaranteeing the achievement of specific goals with the least possible inconvenience and lowest costs. However, standards that are impractical and do not take into account needs not only do not make it easier to achieve the intended goal, but may even make it more difficult and introduce artificial obstacles, thus preventing the full use of social potential and available resources, both human and material.

It sometimes happens that legal norms issued by the Legislator, despite undoubtedly sincere intentions, do not meet the needs of practice because they are based on theoretical assumptions and not on practical observations. Such norms undoubtedly include the ban on the operation of smoking rooms on the hospice premises. The noble idea of taking care of one's health by avoiding smoking is completely meaningless and even harmful in a hospice. Such a standard was probably issued without consulting the environment and is impractical, which was described in the justification for the abolition of this legal standard.

Recognizing the obvious truth that the most practical solutions are created after seeking the opinion of practitioners who face various types of difficulties in their daily work and can point to effective solutions, a query regarding this very issue was sent to almost five hundred hospices and hospitals with palliative care units. This issue, i.e. what difficulties they encounter in their work in the area of legal regulations. 34 centers responded. These were often telephone conversations, because for people running hospices, this form of contact and sharing their observations and proposals was the most convenient. Many stated that they did not have time to respond in writing because their numerous responsibilities prevented them from doing so. Therefore, they prefer talking via electronic means as the fastest way to express their position.

As a result of these conversations, the idea of including a chapter on such delicate issues as euthanasia or persistent therapy was developed. Members of hospice teams encounter such dilemmas every day in their practice. Similar challenges, of course, also exist in hospitals, especially in intensive care units and in the treatment of severe cases, but in

hospices such difficult situations occur every day because these institutions deal with the care of people in the terminal stage of illness, which ultimately (if this person or her legal guardians do not give up hospice care) always ends in death. For the family, it is a dramatic time, saturated with strong emotions, especially when a child dies or a parent who orphans small children or teenagers with his death. Families often demand that they continue or undertake various types of medical activities despite the lack of any chance of even a slight improvement in their loved one's health. In this way, despite their sincere intentions, they often prolong the enormous suffering of the person closest to them. Relatives in these dramatic moments, themselves overcome with mental suffering and emotionally exhausted, sometimes cannot accept rational arguments and there are situations when any attempts to explain to them the patient's situation and the fact that taking further medical action only prolongs the suffering, they treat as such. as if the care staff were "soaked in anesthetic" and wanted to "murder" their loved one. Members of care teams are trained to understand that the words spoken are not fully thought out, but are only an expression of despair and helplessness in the face of a hopeless tragic situation and are spoken under the influence of great emotions, but do not, despite everything, , to some extent, in such situations there is always a question about the limits of when the care justified by the patient's health condition ends and when iatrogenic actions begin, which are persistent therapy, i.e. de facto a form of torture of a seriously ill person who needs constant medical interventions. , which do not help in any way, one is not allowed to die in peace and with dignity. Employees who create care teams in hospices have the right to feel that - despite everything - they are doing the right thing. For this reason, the second chapter includes a point covering a brief attention to the teachings of the Catholic Church regarding both euthanasia and persistent therapy. The introduction of the point regarding the position of the Catholic Church is justified by the fact that in Polish reality the Catholic denomination has been the dominant denomination for a thousand years and as such has a significant influence on shaping social awareness. Regardless of each person's personal worldview. Almost always, even people with a different worldview, express it in opposition to the teachings of the Catholic Church. Therefore, the teachings of the Catholic Church are of great importance in shaping moral attitudes and peace of conscience of people caring for the sick, including the terminally ill. The purpose of this point is to indicate that not every life extension using the latest technological achievements serves the good of the patient and may in essence not be life prolongation, but agony prolongation.

This chapter also raises the issue of the patient's right to respect for his or her right to privacy and the resulting restrictions on providing information to other people about his or her health condition, and the right of loved ones to know this truth, which in its essence is a kind of natural right. Attention was drawn to the limitations resulting from the regulations contained in Polish law, which does not take into account the entire wealth and often very complicated interpersonal relationships and treats these matters in a very artificial way, often putting both relatives, care staff and the management of hospice institutions in a very difficult position. In conversations with people encountering this type of difficult situations, the law limiting the ability to provide information about the patient's health condition was often described as "sick". Recognizing the validity of the reported observations and arguments, a section has been included (for comparison with solutions in Polish law) containing an overview of solutions regarding the above issue in other legal systems. Some of the solutions used in the legal systems of other countries could be successfully incorporated into the Polish legal system or serve as an inspiration to develop your own solution.

The third chapter of the dissertation presents palliative and hospice care in the form that currently exists in Poland and which is the result of the development of the palliative and hospice philosophy as a specific form of care for terminally ill people in cases where medicine has recognized its helplessness and abandoned causal treatment, as well as developed based on this concept of practical solutions. Various types of specialized institutions were presented, ranging from palliative medicine clinics, through home hospice, stationary hospice, and hospital palliative care units. Attention was paid to the clear separation of hospices for children and adults, as well as to the specific model of care addressed to families in which children who are about to be born are diagnosed with a serious, life-threatening lethal defect. This model of care is called "perinatal hospice", although it is not a hospice in the traditional sense of this concept, i.e. a specific place where care is provided to terminally ill people, as in the case of an inpatient hospice or a hospice team which, as part of the hospice, home health care provider provides assistance to the patient and his family in their place of residence.

It should be emphasized - and this may not have been made clear enough in this dissertation - that modern hospices must meet many formal conditions in order to function in accordance with the law. As people who run hospices agree, it is currently simply not possible to establish a local hospice solely using volunteers. From time to time, initiative groups willing to create a hospice in their community come to well-known hospice centers

established at a time when the hospice movement was just emerging. This was especially the case during the educational reforms, when it turned out that as a result of changing the school network, in some towns there were buildings left after closed schools, which turned out to be unnecessary for educational purposes and could be adapted, for example, into hospice facilities. This enthusiasm was often extinguished by the information obtained regarding the huge number of regulations and formal requirements that must be met. As the interlocutors said: it is sad that sincere enthusiasm had to be cooled, but honesty demanded that we honestly inform them what formal obstacles the creators of the new hospice would encounter on their way. Often, after obtaining this information, the originators deviate from their original intention, being aware that they are unable to meet these requirements. Currently, the creation of a new hospice is possible by organizations that have appropriate resources, not only material, but also appropriate intellectual support (understood as the possibility of cooperation with people with specialist knowledge in various areas of law, accounting, etc.). To partially illustrate the scale of the problem, this dissertation includes a list of legal acts that every person running a hospice must be familiar with, to a greater or lesser extent, because they will be obliged to apply these provisions in their practice. The regulations concern both broadly understood medical matters, as well as, for example, construction law and the obligations arising therefrom (e.g. periodic inspections of buildings), the law regarding the protection of personal data, money laundering, or e.g. labor law provisions, etc.

The fourth chapter covers the issue of the role of the family as the foundation of a humanitarian society - the social unit in which a person is brought up and where his system of values that guides his life is formulated, as well as his sense of empathy and social sensitivity, which is the causative factor of the activity dictated by altruism known as volunteering, including such difficult volunteering as hospice volunteering, especially in its most difficult form, i.e. caring volunteering. All the difficulties faced by a family in which one of its members falls ill and a difficult period begins are presented, when all participants in this difficult situation realize the brutal truth that there is no hope for recovery and the terminal period begins, inevitably leading to death. , and the only thing that can be done is to provide the patient with palliative care, which is believed to alleviate suffering and ensure a dignified death.

At this point, it seems appropriate to draw attention to the fact that while hospices employ people with certain personality traits that somehow make it easier for them to cope with the difficult situation of caring for seriously ill people, who have appropriate knowledge

and training in the field of care. palliative and hospice care, and volunteers, especially those directly involved in caring for the sick, are also very carefully selected and trained, but members of the patient's family are not selected or trained in any way. This sad news simply comes upon them and they have to somehow cope with this difficult challenge. Having no training and no "sieve of suitability" for caring for a seriously ill person, they naturally become the first "palliative-hospice team". Often this is the only "team", because due to limitations in access to institutional palliative and hospice care - which was highlighted in this work, and the elimination of limits and restrictions was formulated as one of the demands for changing the law - they cannot practically count on no professional help. It should also be borne in mind that the care team in a hospice takes care of a stranger, so this obviously makes it easier to achieve a certain distance, which undoubtedly - with all the care and commitment - allows them to perform care duties at a lower emotional cost. Family members, however, take care of someone who is important to them, is one of them, with whom they are often connected with very strong emotional bonds, which, especially in relationships between children and parents, or between spouses, is an additional, very burdensome and in its own way emotional sphere, tragic element. Home hospice consists of two components: one is the hospice team, which visits the patient at home and provides instructions on proper care, and the second component is the family members who constitute the "care team" who, in fact, bear the main burden of caring for the patient. Members of the family care team do not come to work for the night or day shift, but live together with the patient, and have virtually no opportunity to "get out" of this situation, as a hospice employee who ends his shift can do.

It should be borne in mind that members of this natural care team are not always prepared for this difficult task. However, it is not only about purely caring or medical-related qualifications, because these can be learned relatively quickly with good will. However, it may happen that the difficulty in undertaking care is the fact that these people are not emotionally prepared to undertake such a task. While hospice workers or hospice volunteers who do not have a certain emotional stability are not allowed to perform such emotionally burdensome work, family members are faced with such a necessity in a natural way, without being asked whether they have the appropriate qualifications. If the period when it is necessary to provide the patient with palliative and hospice care is prolonged, it may happen that the family will not be able to cope with this task using only their own resources.

The chapter makes extensive use of literature on the role of the family as the first environment that takes care of a terminally ill member, and all the difficulties associated with

it. There are numerous quotes from recognized authorities confirming what most people simply feel, even if they cannot formulate it in the form of a scientific work.

The quoted quotations, which are only a small fragment from the widely available literature on the subject, were deliberately selected in such a way because, to some extent, they reflect the observations and experiences of the author of this dissertation, who, together with his closest family members, was part of such a natural, family "team" for half a year. hospice" who organized and took care of a close family member suffering from cancer at home. The care had to become more intense and involved from week to week. Gradually, further care activities had to be undertaken as the sick person became more and more helpless, including care, hygiene, feeding, and dosing pain relievers. All this combined with daily observation of the degrading symptoms of the progressive disease and gradual loss of strength, and over time, limitation and ultimately complete loss of consciousness. The quotes quoted in the chapter, although very accurate, do not reflect the enormous emotional involvement and the kind of "maturation" of people caring for the sick, which progresses with the development of the disease and its subsequent stages. The experience of direct care for a seriously ill person allows you to feel what difficulties members of your closest family have to face, and to understand why your loved ones are able to perform with full commitment activities that seem terrible or even terrifying to most people. We often hear "I wouldn't be able to do something like that", "I would probably go crazy", etc. When suffering comes to the family and affects one of its members, most of them are able to adapt surprisingly well to the new role of caregivers and with the kind help of people who can provide assistance. professional, practical advice in the field of medical care, can properly take care of their sick loved ones.

When considering the role of terminal care in society and how important it is to create efficient institutions that make it easier for families to cope with such a difficult experience as caring for a terminally ill person, an introspective method was also used to some extent. It is one of the oldest research methods in psychology, which involves insight into oneself, i.e. the person conducting the research, and the feelings, thoughts and motivations that appear in connection with specific situations, assuming that in a similar situation similar feelings, thoughts and observations are experienced by also others, so they constitute a kind of norm. The cited literature quotations could not be included in this work. All the areas they covered and discussed could be described in the author's own words and it would be a very emotional journey - a kind of spiritual "Odyssey" that the author went through, a bit as if by "surprise",

because no one expected it. that the situation will develop and develop in this way. We often hear that various people, more or less known to us, have suffered from cancer, and after some time we learn that they have died. However, it always concerns "others", not us. We sympathize, but we observe it from the side and from a distance. When such a painful experience affects our family, there is a certain surprise: "what is it like cancer"?! how is this possible?! It was as if one of your loved ones getting cancer was something impossible, as if only "others" always suffered from cancer.

The experience of taking care of a sick family member as part of a natural palliative-hospice team prompted the author of this dissertation to become interested in the issue of palliative-hospice care and the difficulties associated with it. It concerned, among other things, the inability to use the help of the home hospice team. The difficulties resulted not from the lack of willingness on the part of the home hospice team, but from the limits of admission to the OPH and the fact that the home hospice could provide care for patients within a radius of thirty kilometers from its headquarters, which in this case exceeded the distance of the sick person's residence from the home hospice's headquarters. . Due to the above, it was necessary to cope without the help of hospice staff, which was a very difficult challenge for people who had no experience in caring for the sick.

The presented proposals for changing the law regarding, among other things, the abolition of admission limits to OPH and the abolition of the list of diseases that entitle to OPH coverage are the result of observations made during this period. The author of this dissertation, as a lawyer, naturally pointed out that the law will not eliminate the disease, but it can facilitate the provision of appropriate care, among others, by better use of forces and resources where they are necessary.

The terminal state seems exotic and a bit unreal. However, you should realize that this is a natural and inevitable situation. In every family, from time to time, a situation will occur that one of its members will pass away. If this does not happen in a sudden situation, in dramatic circumstances related to an accident, or if death is not a consequence of, for example, a heart attack, in which circumstances death usually occurs quickly, the period preceding death will almost always involve loss of strength and the need to be surrounded by care for a certain period of time preceding the actual death, which over time will de facto take the form of palliative and hospice care.

The last chapter of the work is devoted to the importance of providing psychological help to the patient and family members, as well as broadly understood spiritual care. Man is a spiritual being and in the last stage of life leading to inevitable death, existential needs and thoughts arise - questions such as "what will happen next". Providing spiritual care is therefore very important, which is admitted even by people living in very secularized societies. For this reason, appropriate standards have been created as guidelines aimed at organizing professional spiritual care, which does not always have to mean care of a religious nature. In popular belief, spiritual care is treated as a form of religious care and often even these terms are used interchangeably. However, the concept of spiritual care has a much broader meaning, which is highlighted in this work. In Poland, the need to provide non-religious spiritual care is not yet as great as in more multicultural and secularized Western societies, but in the face of rapidly progressing changes in social awareness, including the departure from religion and religious practices, it will be an increasingly greater and inevitable challenge.

This dissertation formulates six postulates regarding the introduction of new or changes to the existing law. All proposed changes are a response to the difficulties faced by members of hospice teams in their daily work. Point 2 of the postulates is the author's proposal to allocate additional funds for the development of volunteering and education of the local society in which the hospice operates about what the hospice does and how important its existence is for the local community. Each postulate was very broadly justified. Therefore, the demands were included in a separate section entitled: Postulates de lege lata and de lege ferenda.

In this dissertation, attention was often drawn to how difficult and demanding it is to care for a seriously ill person. The terms used describe reality, but - especially for people not involved in medicine and who do not have daily contact with bedridden people - such general terms do not allow us to imagine what this care actually involves. In order to accurately present the picture of the situation, this work includes, in the form of annexes, proposals for standards regarding hospices and medical procedures that are performed during patient care. A simple, descriptive and emotionless listing of various procedures is very moving and even somewhat discouraging to a reader who has no previous experience of caring for seriously ill people. Familiarizing yourself with these procedures is undoubtedly worth your time and attention, as it allows you to understand that members of the hospice team witness enormous suffering every day and must perform emotionally burdensome care tasks to relieve the

patient's suffering. Taking the above into account, the inclusion of these studies in this dissertation, not in the form of a summary, but in the form of annexes containing the full content, was intentionally planned. In this way, the description of palliative and hospice care was presented in a very precise way (at least from the point of view of medical care).

The remaining annexes include: a proposal for a life protection program in the event of a diagnosis of a lethal defect during prenatal tests, the authors of which are the Dangls, the Charter of the Rights of a Terminally Ill Child at Home, the Document on the Apostleship of Charity and the Pastoral Care of the Sick developed by the Synod of the Archdiocese of Krakow. Reading these documents is so informative that it was advisable to include them without any abbreviations in an unchanged form as annexes. This is a fully intentional procedure, as it allows for a more complete picture of the hospice movement and palliative-hospice care itself. Omitting these texts or shortening them would be a great loss for the discussed issue.

The last three annexes are: a template agreement established by the National Health Fund, which is signed with entities providing hospice care, containing the rules for financing and settling public funds intended to finance the costs of palliative and hospice care, and exemplary solutions of internal law

The death of a person, and the period preceding it, is always a family experience. If the patient's relatives are not present, this fact is perceived even more painfully in the public consciousness as something absolutely sad and abnormal. Dying alone, relying only on the care of strangers, is perceived as the worst thing. This work emphasizes the fact that nothing can replace family. Family is a kind of phenomenon that nothing can replace. Law is very useful and if legal norms are well constructed, they can be very helpful, but no institution can replace the family.

During numerous conversations with people involved in the development of the hospice movement, attention was drawn to the fact that the hospice movement, which was rapidly developing in Poland, was based exclusively on volunteering for many years. The involvement of volunteers resulted in the development of palliative and hospice care in Poland in a way that was even held up as a model to be followed in other countries. Currently, however, some legal solutions are insufficient and even seem anachronistic and should be changed.

It would be valuable to conduct comparative research and compare the legal solutions in force in Poland with the way of regulating similar areas in other countries, which introduced palliative and hospice care in their area later than Poland, but, taking advantage of experience and observations, including Polish ones, they applied it in their own country. more modern and functional legal solutions.

A handwritten signature in blue ink, appearing to read "Jon David". The signature is fluid and cursive, with a large loop at the end.