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Ethical dilemmas associated with pain management in a female patient with a femoral bone tumour. The role of the patient's family in making treatment decisions in Poland

Abstract

We discuss the problem of the continuation of analgesic treatment in an 87-years-old woman with tumor of the right femur who suffered from very severe pain, but was unable to make her own decisions. Her son objected to the course of management proposed by the doctor and conflicting situation led to the discontinuation of treatment with strong opioids. The complexity of the situation reported here point to the necessity of taking advantage of the opportunity to turn to the guardianship courts for a ruling.

Key words: cancer pain, opioids, patient rights, guardianship courts

Adv. Pall. Med. 2010; 9, 4: 135–140

Introduction

The issue of obtaining consent for treatment from a patient by his doctor appeared and changed as medicine was developing and the patient-doctor relationship was changing. From the beginnings of medicine, provided the patient was not the sovereign or some other high and mighty person in this world, all medical decisions were up to the doctor. The patient surrendered to his doctor en-

tirely. New philosophical and political concepts of the human being that emphasised his autonomy and, therefore, his exclusive right to decide for himself brought about some radical changes in this area. Laws have, therefore, been adopted that ensure the patient's rights to express his will and be involved in all the diagnostic and therapeutic decisions related to him; "The mere fact of becoming a patient cannot deprive the person of any of his human rights or civil liberties" [1]. Patient

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Advances in Palliative Medicine 2010, 9, 135–140

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rights are a reflection and integral part of human rights in the broad sense.

The principle of autonomy and self-decision becomes particularly significant in the case of a sick person. The situation of the patient in relation to the medical staff is characterised by dependence and asymmetry of information, which renders making decisions about the person's health and life difficult. In this situation, the doctor is not only the party providing the service but also the party who decides on the type of service provided. This imbalance is considered the justification for the doctor's domination over the patient. However, experience shows that it is not always the case that all doctors act solely for the benefit of their patients, and the exercising of patient rights is aimed, among other things, at protecting patients from malpractice. Furthermore, the fundamental objections as regards this paternalism result from the question of whether one person, however well-informed, can and has the right to decide what is good for another person capable of making his own decisions.

In Poland, the principle of rendering health services upon previous provision of consent by the patient is expressed in and governed by numerous legal acts.

Since June 2009, the fundamental legal act in Poland has been the Patient Rights and Patient Rights Advocate Act (PRA), according to which a patient has the right to die in peace and dignity [2]. The PRA also guarantees (the patient or his legally acceptable representative) the right to obtain information, in an understandable language, regarding the following: the patient's health, the diagnosis, the proposed and possible diagnostic methods, the proposed and possible therapies, the foreseeable consequences of using or failing to use them, the treatment results and the prognosis. The doctor may be relieved of this obligation only at the patient's request. The doctor can provide the above information to other persons only with the patient's consent (Article 31 paragraphs 1–3 of the Medical and Dental Professions Act [MDPA] [3]; Article 19 paragraph 1 point 2 of the Healthcare Establishments Act [HEA] [4]).

According to the PRA, the patient has the right to give consent for undergoing tests or for receiving other healthcare services upon being provided with relevant information by his doctor. Unless otherwise provided for by the applicable laws, the patient's consent may be given orally or expressed by the patient's behaviour, unequivocally indicating his willingness to undergo the medical activities proposed by the doctor (Article 31 paragraphs 1 and 7 of the MDPA; Article 19 paragraph 1 point 3 of the HEA).

A provision in Chapter 5 of the MDPA entitled "The principles of practicing the medical profession" reads: "The doctor can perform a test or provide other healthcare services, with the exceptions provided for hereunder, only after the patient has consented to it" (Article 32 paragraph 1 of the MDPA) and specifies the principles of providing the consent [3].

A further set of provisions governing the doctor's conduct in relation to the patient can be found in the Code of Medical Ethics (CME) [5], where we read the following: "The doctor has the freedom to select the methods of management he considers most effective. He should, however, limit the diagnostic, therapeutic and preventive activities to those activities which the patient really needs, in accordance with the current state of medical knowledge" (Article 6 of the CME). "The doctor should make every effort to provide his patient with humane terminal care and dignified conditions for dying. The doctor should relieve the suffering of a terminally ill patient until the very end and maintain, if possible, the quality of life of a dying patient" (Article 30 of the CME). "The diagnostic, therapeutic and preventive activities require patient consent. If the patient is unable to provide informed consent, the consent should be provided by his legally acceptable representative or the actual caregiver" (Article 15 paragraph 1 of the CME).

The implementation of these provisions in situations in which we are able to obtain consent from the patient is generally quite straightforward. The problem arises when the doctor is unable to obtain consent immediately from a patient with impaired consciousness or cognitive function and no legally acceptable representative available in a situation where the patient requires continuation of treatment. The CME indicates that in such cases consent should be sought from the patient's actual caregiver. However, if the actual caregiver objects to the course of management proposed by the doctor, a very difficult and potentially conflicting situation arises. The problem of the continuation of analgesic treatment in a female patient unable to make her own decisions that we report below illustrates the difficulties that may be encountered by treatment-providing healthcare professionals in the context of the specific aspects of the role of relatives in making treatment decisions in Poland.

Case report

An 87-year-old female patient in a very grave condition was transferred from the Geriatrics Depart-

ment to the Palliative Care Ward. During the hospitalisation the patient was diagnosed with a fracture of the right femoral neck, most likely secondary to a bone tumour. A Doppler ultrasound carried out for suspected thrombosis with a massive oedema of the femoral area and the pudendal labia revealed a bone tumour. The patient's general condition precluded further diagnostic evaluation and radical treatment. On admission the patient was emaciated, had grade 4 bedsores, logical contact with her was very limited, and she was suffering from severe and constant pain in her right lower limb which increased considerably during nursing activities. In view of the above, she was started on a continuous subcutaneous infusion of tramadol increased to the dose of 300 mg/day and the non-steroid anti-inflammatory drug ketoprofen at the dose of 300 mg/day. No pain relief was, however, achieved and the tramadol was changed to subcutaneous morphine at the dose of 20 mg/day. A minor improvement was achieved, but the nursing activities continued to be a source of suffering. The dose of the opioid was increased to 30 mg/day in a continuous subcutaneous infusion. The next day the patient was calm, did not report any pain, even during nursing activities, but maintained no logical contact.

The same day (Sunday), her son came to visit her for the first time. He had not contacted the doctors before, either at the Geriatrics Department or at the Palliative Care Ward. He asked to know what medications his mother was on and then demanded that the analgesics be discontinued because, as he argued, his mother had lost logical contact with the world outside her after she had been started on morphine. He also said that morphine was a narcotic drug which would only make his mother die sooner. Over the weekends, the on-call doctors at the Palliative Care Ward are doctors normally employed at the Department of Emergency Medicine. The on-call doctor tried to explain the patient's condition and the necessity of using analgesia due to the previously identified severe pain but the son would not budge. He left, having made an entry in his mother's medical notes saying: "I am Ms Z's son and demand that all the analgesic medication she is receiving should be discontinued and that all the treatment should be stopped. I am aware of the fact that discontinuation of the drug (morphine) will expose my mom to suffering. I take full moral and legal responsibility for this decision". The on-call doctor complied with the son's demands and discontinued the morphine. Thus the patient was treated only with already administered ketoprofen. This resulted in the ap-

pearance of pain several hours later. The next day (Monday), the patient experienced severe pain and contact with her was very difficult to maintain due to her suffering. The palliative care doctor started the patient on tramadol at the maximum dose (up to 600 mg/day) but the level of pain relief was still unsatisfactory. Constant pain at rest that increased during nursing activities was observed. The consulting psychiatrist diagnosed the patient with dementia and stated that the patient was unable to make informed decisions regarding her treatment and medication. A hospital lawyer was also asked to speak to the patient's son and explain the legal situation. The son did not change his mind and continued not to allow the doctors to give his mother morphine or any other strong opioids. Several days later the patient was discharged home at her son's insistence.

Discussion

The case we present here raised many questions and controversies among the staff of the Palliative Care Ward.

Can relatives affect treatment? Should relatives decide for the patient if she/he is unable to make decisions of her/his own? How far can the relatives influence the doctor's decisions? Was a mistake made in the management of this patient and, if so, who made that mistake?

The competences of a patient's relatives and other close persons have been narrowly specified in Polish medical law. The fundamental regulations are contained in the PRA and the MDPA. The CME adopted by the National Convention of Physicians and Dentists should be applied by doctors in matters not provided for in the two legal acts mentioned in the previous sentence.

Within the meaning of the PRA, a close person is a spouse, a relative or a second-degree direct-line in-law, a legally acceptable representative, a person living together with the patient, or a person indicated by the patient [2]. In this case the patient's son most definitely met these requirements. The legal acts referred to here do not give close persons any rights to give consent for the proposed treatment or to object to it. Article 31 paragraph 6 of the MDPA merely states that the doctor may provide information to a close person if the patient is, for instance, unconscious or unable to understand the meaning of the information provided to him, which most definitely was the case with our patient [3, 7].

According to Article 17 of the PRA, where the patient is, for various reasons, unable to make a deci-

sion, the decision is made by the legally acceptable representative of the patient unable to give consent. An adult patient who has not been declared legally incapacitated by the court does not usually appoint his legally acceptable representative. Close persons, such as the spouse, siblings, children, grandchildren, etc., are not an adult patient's legally acceptable representatives [2, 7]. Some of these persons may be considered the so-called actual caregivers, solely authorised to give consent for the patient to undergo diagnostic testing. In practice, this means that the competences of close persons, including family members, as regards treatment decisions related to adults unable to make their own decisions are comparable to the rights vested in third parties.

The procedures in such situations are defined by Articles 32 and 34 of the MDPA. According to the law, where a patient who has no legally acceptable representative is incapable of making his own decision, the doctor, after carrying out tests, may provide further healthcare services only after appropriate authorisation has been granted by the guardianship court. This rule is especially important in the case of treatment discontinuation, with which it is often considered difficult (in public opinion) to distinguish between euthanasia and failure to provide medical assistance. In this case, the doctor should file the matter with the guardianship court [7]. When issuing the ruling, the court should take into account the provision of Article 20 of the PRA, which affirms a patient's right to dignity, including the right to die in peace and dignity ("A terminally ill patient has the right to receive healthcare services that relieve his pain and other sufferings") [2]. The guardianship court should also take into account the provisions of deontological acts which address doctors (the CME). According to the CME, in terminal conditions the doctor "is not obliged to undertake and carry out reanimation activities or use overzealous therapy and use extraordinary measures" (Article 32 of the CME). "The doctor should make every effort to provide his patient with humane terminal care and dignified conditions for dying. The doctor should relieve the suffering of a terminally ill patient until the very end and maintain, if possible, the quality of life of a dying patient" (Article 30 of the CME).

In everyday practice in Poland, hence in the overwhelming majority of situations, if close persons or the actual caregiver consent to the proposed course of action or do not object to it, the proposed course of action is followed by the doctors [6]. This results from the established tradition, according to

which the role of the patient's family is considered more important than following the rule of law. A particular example of such an approach and at the same time a considerable social and medical problem is the extremely frequent objection voiced by relatives to harvesting organs for transplantation from deceased persons. Such objections, although not legally binding in Poland, are commonly respected.

The actions taken by the on-call doctor, who undoubtedly complied with the patient's son's objection in good faith, was acting against the law and as a consequence the situation could be treated as an infringement of a fundamental right of a terminally ill patient, namely the right to have quality of life maintained in the terminal phase and the right to die with dignity [2, 5]. According to Article 4 paragraph 2 of the PRA, in the event of a culpable infringement of the patient's right to die in peace and dignity, the court may, at the request of the spouse, relatives or in-laws up to the second degree in a direct line, or at the request of the legally acceptable representative, order the doctor or the healthcare establishment to pay an appropriate sum of money for a socially-beneficial purpose under Article 448 of the Civil Code. It is, therefore, possible for another member of the patient's family to file such a demand. This claim may be directed against the healthcare establishment or against the doctor, if he is not employed by the healthcare establishment.

When evaluating the situation presented above, one should also take into account the fact that following the rule of law, as in continuing analgesic treatment or harvesting organs from a deceased patient against the relatives' will, may also put doctors at risk of being charged because of a conflict situation. Well-known and sensationally presented charges of euthanasia or the speeding up of the process of dying for a patient only to carry out a transplantation affect the behaviour of a patient's family. In society, and even among some of the members of the medical community, there is a persisting stereotype that morphine is a dangerous and addictive medication [8]. Where the decision regarding further actions must be made immediately, obtaining a court ruling is not possible. All the decisions made are, therefore, potential grounds for charges and claims. Where the positions of the treating physicians and the close persons are different, particularly in the situation of a conflict, the risk is very high and then, if possible, the decision should be made collectively. However, even in the case of unanimous positions, there is a small but significant risk of charges and claims being brought forward by the close persons,

who may base them on the undertaking or failing to undertake treatment being against the applicable laws [6, 9]. Any decision made by the doctor and his team must then be amply justified and documented.

The analysis of the various aspects of analgesic treatment in the situation described here goes well beyond the scope and aim of this paper. However, the patient was certainly experiencing severe adverse effects of morphine, such as excessive somnolence and confusion. Following the discontinuation of morphine, other methods of analgesia should be tried. Unfortunately, the subsequent development of the situation prevented the doctors from undertaking other attempts to achieve an optimal level of pain control.

Conclusion

The analysis of legal acts, particularly the MDPA, indicates that doctors can undertake treatment without obtaining consent only in situations where the value of the patient's health and life allows them to infringe another value, namely the right to self-decisions. The MDPA defines the course of action in the case of patients who, for various reasons (such as psychiatric illnesses), are incapable of expressing informed consent or have been deemed by the court to be completely incapacitated. In such situations, the doctor, prior to undertaking any medical activities, should obtain consent from

the patient's legally acceptable representative, and where such a representative is not available or cannot be contacted, the consent should be sought from the guardianship court. Where the patient needs to undergo diagnostic testing, the consent may be granted by the patient's actual caregiver. This is referred to as "substitute consent" and may only be given for routine medical activities that do not put the patient at risk. The complexity of the situation reported here and the potential charges and claims related to it point to the necessity of taking advantage of the opportunity to turn to the guardianship courts for a ruling.

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