

Adriana Paladi, Victoria Federiuc

11 The Principle of Autonomy in Palliative Care: The Moldavian Perspective

11.1 Introduction

Advancing medical technology has made it possible for many people to live longer than ever before. However, when the possibility of curing patients no longer exists, care should not be discontinued, but rather should shift to comforting the patients and their families. This type of care, labeled palliative care, is defined by the World Health Organization (WHO) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹

Palliative care aims to improve the quality of life of patients. Good quality of life is usually related with control of symptoms and avoidance of treatment side effects, but it is more than that. While defining this concept, it is necessary to encompass the individual’s (patient) perspective on biological comfort, social and psychological well-being, as well as spiritual integrity. Thus, any palliative intervention requires a focus on the person whose quality of life is at stake, because the description of quality of life is best made “in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions. A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience.” (Calmen 1984, 124–5).

In other words, quality of life designates the subjective perception of one’s life, measured in the context of personal experience and expectations, as there is no obvious general standard for it. Two different patients could have entirely different views of the best quality of life, even if they have the same illness. Thus, the satisfaction or contentment of patients in terms of end-of-life care (among others) will depend on how their personal expectations are fulfilled (Jackson et al. 2001).

Accordingly, palliative care involves knowing the patient’s personal priorities, encouraging the patient’s realistic goals (appropriate to the medical condition), and helping the patient to reach these goals via physical, psychological, social, and spiritual interventions (Rummans and Bostwick 2000; Pantilat et al. 2008).

¹ WHO definition of palliative care available on: <http://www.who.int/cancer/palliative/definition/en/>

Focusing on personal perspective while establishing the measure of the best quality of life for each patient suggests a strong interconnection between palliative care priority and the principle of autonomy. Respect for autonomy emphasizes the idea of individual decision-making. Shared medical decisions allow the patient to maintain control over his/her own life, strengthening the patient's perception of being treated with dignity. The beneficial outcomes result from the patients' involvement in health-care decision-making (Epstein and Street 2000).

Presuming to know without asking what quality of life is desired by a patient is morally wrong. It violates the patient's autonomy and, consequently, is a form of disrespect toward the dignity of the patient. Ignorance of the patient's perspective may lead to actions or omissions that do not meet the patient's needs and goals and may even be harmful for them.

Consequently, it seems obvious that the respect for individual autonomy is an indispensable condition for achieving the priority of palliative care – namely, enhancing patient's quality of life.

Nevertheless, there are scholars who underline the local character of the principle of autonomy. For instance, Daniel Fu-Chang Tsai documents that the emphasis of Western medical ethics on autonomous decision-making is not shared by all cultures (Fu-Chang Tsai 2008). The individualistic approach to autonomy is a Euro-American value and cannot be ethically applied in all settings (Sargent and Smith-Morris 2001).

In this article, we are not going to challenge the plausibility of this anthropological claim; our intention is to argue that the disrespect for individual autonomy in palliative settings, in a country with strong paternalistic and communitarian traditions as Moldova, could result in health professional's incapacity to act in the patient's best interest, similar to countries with old liberal traditions.

To that extent, we will explore the reasons and effects of the lack of honest communication and noninvolvement in decision-making on patient's quality of life, challenging the assumptions that founded the physicians' decision of hiding incurable diagnoses. Furthermore, a model, included recently in Moldavian health-care professionals' education, of honest sensitive communication with patients and some of its advantages are presented.

11.2 Principle of autonomy

Individual autonomy usually refers to the capacity to live one's life according to reasons, values, preferences, and interests that are taken as one's own and not distorted by external forces. Beauchamp and Childress highlight that at least two conditions are essential for autonomy: liberty (independence from controlling influences) and agency (capacity for intentional action). Consequently, at the minimum, personal autonomy encompasses self-rule (self-governance) that is free

from both controlling influence by others and limitations that prevent meaningful choice, such as inadequate understanding (Beauchamp and Childress 2013, 101).

Applied to palliative care, the principle of autonomy requires that patients' wishes be respected and that they be helped to participate in decisions about their care, to the extent that they are willing and able. When patients are unwilling to or incapable of making their own medical decisions, this principle requires that the decisions taken by a patient's legal representative be based on the patient's earlier wishes.

More particularly, the requirement of patient involvement in health-care decisions obliges physicians to act as partners by maintaining open and frequent communication about a person's health condition, available care options, and prognosis to ensure the person or their representative fully understands the information. Clear information enables the patient to make decisions in accordance with his/her beliefs, values, and interests, and the physician is obliged to respect the patient's informed decision, even if these differ from the family or the health-care professional's views. Respect for patient decision leads to long-term trust between physician and patient, increasing patient compliance to treatment, enhancing outcomes, and elevating mutual satisfaction. In other words, autonomy grounds the model of the doctor–patient relationship in which “patients are thought of as equal partners in their treatment, in which treatment is given only with the informed consent of patients, in which patient satisfaction is an important indicator of professional adequacy”. In this model of doctor–patient relationship, autonomy is seen as a precondition of genuine trust (O’Neill 2015, 18–9).

11.3 Moral requirement of patient information

As mentioned, the principle of autonomy places a responsibility on the doctor to ensure that his/her patient is fully informed. Complying with this requirement raises practical difficulties when a patient diagnosed with life-threatening illness is considered. Even now, many physicians are not ready to break bad news to patients².

Cases in which physicians avoid open communication with patients that have life-threatening medical condition are not uncommon. Vladimir Poch and Andrada Pârnu (2013) point out that many physicians mistakenly hope that someone else will inform the patient about life-threatening conditions (another colleague). As this never happens, patients are frequently left ignorant.

An empirical study on 137 patients with unfavorable diagnoses (patients with chronic obstructive pulmonary disease [COPD], acquired immune deficiency

² The concept of bad news is associated in this article mostly with information about terminal diagnosis, even if, generally, it is understood as “any news that drastically and negatively alters the patient's view of her or his future” (Beauchamp and Childress 2013).

syndrome [AIDS], and cancer), family members, health-care workers, and physicians reveals that honest communication is seen by all participants as an important aspect of palliative practice. This study emphasizes, at the same time, the patients' unmet need of information about their diagnosis, witnessing indirectly the lack of honest communication in palliative care practice. In the study, a patient with COPD confessed, "Dr ____ has never told me my illness was serious. I've asked him, but he doesn't answer." (Wenrich et al. 2001, 869). Many health professionals consider, in principle, that patients have to be informed about their diagnosis, but only few of them disclosed bad news in practice (Grassi et al. 2000).

11.4 Some reasons for covering up bad news

Physicians may find it difficult to discuss issues around end-of-life situations because of the strong attachment with the dying patient and family developed during the long medical practice. Diverse forms of concerns also may preclude physicians from communicating openly with dying patients, such as fear to confront their own mortality and fear of displays of emotions (i.e., fear of emotional outbursts, fear of experiencing significant stress, fear of being blamed as a messenger of sad news, fear of not being prepared to manage the patient's emotional reactions, fear of iatrogenic complications in the patient's situation) (Anderson 2000; Ptacek et al. 1999).

Communication with dying patients is affected by cultural differences as well. Many cultures do not support the idea of full disclosure of bad diagnoses or prognoses, while others require disclosure to family members or community leaders. Health-care professionals outside the Western cultural tradition often conceal serious diagnoses from patients, because of four primary reasons: 1) discussion of serious illness and death is an expression of disrespect for the belief that individual destiny is determined by God (Filipino culture); 2) open communication of serious illness is inhuman because it may provoke unnecessary depression or anxiety in the patient (Chinese culture); 3) physicians are expected to maintain patients' optimism and direct disclosure may eliminate it (Bosnian culture); 4) speaking aloud about a condition makes death real because of the power of spoken words (Navajo) (Searight and Gafford 2005).

All these cultural reasons (except the last one) are reflected in the paternalistic approaches to physician–patient relationship, which places a higher value on beneficence and nonmaleficence relative to autonomy. Within this approach, physicians are allowed to interfere with patients' wishes if the interference brings greater benefits or prevents serious harms. Professional competence gives physicians authority to decide on behalf of the patient what is better or worse for them.

Paternalism has a long historical tradition and deep roots in collective thinking and perceptions of doctor–patient relations. Nevertheless, in the past decades, globalization of conventional medicine, wide acceptance of this Western legal

requirement, and the increase in patients' awareness of their rights have weakened its position. However, the process of transition from paternalistic to nonpaternalistic approaches to practicing medicine is very slow. Changing mentalities is very difficult and, many times, occurs together with replacement of generations.

11.5 The case of the Republic of Moldova

The Republic of Moldova is a country with continuing strong paternalistic and communitarian tradition. In 2005, the Parliament of the Republic enacted the Law of Health No. 263-XVI, Article 11(5), which emphasizes the following: "Medical information on the health status (condition) of the patient and the proposed medical intervention, including the risks and potential benefits of each procedure, the possible effects of refusal of treatment, alternatives, prognosis and other medical information, must be presented by health services providers in a clear language, respectfully and accessible to the patient, minimizing professional terminology". After 10 years, despite being granted by law to have access to information, many patients with bad diagnoses are not adequately informed. For example, a recent study conducted on 228 patients in the chemotherapy ward of the Oncology Institute from Chisinau (Moldova) reveals that only 62.1% of those surveyed knew their cancer diagnosis. The remaining patients did not know about their life-threatening illness. These patients had general information about carcinomas, polyps, and cysts but did not really understand their conditions (Clipca 2016).

There are no published empirical studies about the causes of hiding the diagnoses from incurable patients in Moldova; however, the reason for the tendency to hide serious diagnoses, most fervently invoked by Moldavian physicians in private or formal discussions, is the unwillingness to harm the patient. This reason is based on assumptions that telling the complete truth about a terminal diagnosis a) could have a negative impact on patients' physical, psychological, and spiritual state; and/or b) could take away all hope and optimism of patient. Are these assumptions justified? Does communication about lethal diagnosis have a negative impact on patient well-being? In order to answer this question, let us undertake a consequentialist analysis of a clinical case common in Moldavian health-care practice.

Mrs. R, a 39-year old mother of two children, is admitted into hospital with abdominal pain. The medical examination shows that she is suffering from an incurable pancreatic cancer, with a few months to live and with great suffering before her. Although the woman has specifically asked to be told exactly what she was facing, the physician informs her that the results of the examination are not conclusive and that he will see her weekly as an outpatient. Instead, the physician informed her husband, privately, about her diagnosis – this is a traditionally assumed practice. In Moldova, the family is very involved in the process of caring for a sick member and usually takes care of dying relatives.

Whether the culturally supported physician's decision is beneficial or harmful for the woman and her family is being established through the consequences that would result from it.

One favorable consequence of not telling the truth is that the patient could feel better immediately after the appointment. Nevertheless, improvements in well-being are likely to be short term because pain persistence could rapidly burn it down. Alternatively, painful existence may lead the patient to doubt the professional competence and honesty of the physician. Uncertainty felt by the patient concerning her health condition may generate stress, anxiety, and depression. Lack of information withdraws her chance for coping and planning the future, a situation that could have negative consequences on her entire family. If kept far from the truth, the patient would not be able to make an adequate decision, decisions that would serve her best interests. At the same time, an undue burden is put on the husband, who almost obviously would not be able to deal appropriately with the information acquired, along with handling the stress and anxiety resulting from it.

Therefore, deception leads to much more unfavorable consequences than favorable consequences, and the physician's decision is not in the benefit of the patient and her family; even vice versa is true. Thus, the assumption about the negative impact of disclosing information is unwarranted in this case and in many similar other cases.

Another important question is whether information about lethal diagnosis takes away the patient's hope? An inquiry into this phenomenon is required to answer the above question.

Even if it could be defined in many ways, the concept of hope designates at least the individual's belief that his/her needs, wishes, or goals are being respected. Individual hope is quite dynamic, it is changing all the time because the individual's needs and goals are as well, reflecting the mutability of life circumstances. For instance, at the time of life-threatening diagnosis, the patient may hope for survival, but at the end of the illness trajectory, he/she may hope to not be ignored (Chichinov 2006).

Sullivan (2003) claims that hope at the end of life can come in various forms: hope for comfort, dignity, intimacy, or salvation. On the other hand, hopelessness is not simply the absence of hope, but attachment to a form of hope that is lost. In the palliative context, as well as in any other health-care contexts, patients may lose hope but also may find another hope when they are able to explore positive possibilities of the new circumstances of life and break their attachment to the lost forms of hope.

In palliative settings, when the hope for cure is lost, the primary task of caregivers is to redirect the hope of both the patient and the family toward something more realistic, such as hoping to have well-managed symptoms, to feel less pain in order to enjoy spending time with family and friends, and to accomplish any goals they have before their death. Lowey Susan suggests several palliative interventions that could foster patient and family hope, despite a fatal prognosis: keeping symptoms well managed, encouraging involvement in positive experiences that transcend

the patient's current situation, fostering spiritual processes and finding meaning, promoting reconciliation with others (positive personal relationship), assisting patient in setting realistic goals, and focusing the patient's attention on the short-term future (Lowey 2015).

All these interventions applied efficiently in end-of-life care show that it is incorrect to think fatalistically about end of life. Many things can be done to guide hope and increase the quality of life.

Accordingly, the assumption that disclosure of the terminal nature of their illness deprives patients of hope is also mistaken. Even more, there is good evidence that honest communication about health conditions enhances, rather than diminishes, hope because accurate information enables patients to feel empowered about their care and decision-making at the end of life (Davison and Simpson 2006).

If the assumption about the negative impact of honest communication on hope is wrong, it means that those Moldavian physicians who avoid informing their patient about an incurable diagnosis might not be aware that patients with lethal diagnosis or those who are imminently dying continue to hope. In this sense, Ivana Clipca (2016) suggests that physicians in Moldova do not have a clear understanding of the concept of hope, treating it just in terms of survival.

The case analysis, as well as the reflection/thought on the dynamic nature of hope, makes it possible to assert that dishonest communication with patients prevents the Moldavian physician from accomplishing his duty to act in the patient's best interest, i.e., improvement of quality of life. This supposition can be assessed considering empirical evidence. In 2011, with the support of the National Commission of Republic of Moldova for United Nations Educational, Scientific and Cultural Organization (UNESCO), a joint team of professionals from Great Britain and the Republic of Moldova published a study about the personal experiences of 102 families across the Republic of Moldova, families that have cared for their dying loved ones. The study concludes that "dying people suffer significantly, pain is often uncontrolled, while anger, isolation, depression, grief, and fear are often unaddressed by health service" (Kellehear et al. 2011, 95).

Even though this study did not aim to evaluate the gaps in communicating with dying patients, it allows us to think that one reason, among many others, for the great suffering of dying patients in Moldova is the lack of honest communication. It badly affects the dying patient's quality of life; particularly because in the condition of dishonest communication, the health-care professional cannot explore the patient's needs and preferences for end of life and, consequently, is not able meet them.

There are cases when telling the truth about the diagnosis and prognosis could be harmful for a patient's health. If the physician has good evidence for expected harm, then he/she also has the moral right to withhold that information. Nevertheless, this course of action should be carefully considered. In many other cases, as we have argued, the projected harm does not justify overriding the principle of autonomy.

11.6 Delivering bad news in a sensitive manner

Concealment of the truth excludes the patient from the decision-making process and is a violation of a patient's constitutional³ right to information and self-determination. At the same time, it is also a major obstacle to both fulfilling the patient's needs and increasing the patient's quality of life in Moldova. However, informing patients about the serious health problems should be done with tact and sensitivity.

When the information is delivered incorrectly, it could lead to undesirable consequences for patients and their families. Good communication skills, as well as high competence in delivering bad news, could be significant for avoidance of such consequences.

Learning general communication skills can enable physicians to break bad news in a manner that is less uncomfortable for them and more satisfying for patients and their families. A physician's attitude and communication skills have a crucial role in how well patients cope with receiving bad news (Vandekieft 2001).

Nowadays, there are many guidelines, protocols, and recommendations developed to help physicians deliver bad news. Many of them are adapted from a six-step protocol proposed by Robert Buckman (1984). Following this protocol's steps, individualizing their manner of breaking bad news in accordance with the patient's needs, physicians achieve four essential goals. The first one is gathering information from the patient that allows them to determine the patient's knowledge, expectations, and readiness to hear the bad news. The second goal is providing intelligible information in accordance with the patient's needs and desires. The third goal is offering emphatic support to the patient in order to reduce the negative emotional impact and to prevent exacerbated feelings of isolation. The final goal is to develop a strategy in the form of a treatment plan with the input from and cooperation of the patient, a plan that best meets the patient's needs (Baile et al. 2000).

In 2016, in the State Medical and Pharmaceutical University in Moldova, "*Nicolae Testemițanu*" – the integrated course of palliative medicine – was introduced, including a module on breaking bad news using a six-step protocol. Simulation with standardized patients on the graduate level and role-playing approaches on the postgraduate and vocational levels are used as the teaching methods. One year after the introduction of the course, some preliminary conclusions can be drawn. Thus, graduate students (the fifth-year medical students), as well as postgraduate trainees (family physicians mostly), easily follow the steps of the protocol (Emanuel, von Gunten, and Ferris 1999), which require the following:

1. creating an environment conducive to effective communication and confirming the medical facts of the case (Step 1);

³ Law of Health No. 263-XVI, Article 11(5) of the Republic of Moldova enacts this patient's right.

2. using the open-ended questions about what the patient and family know, understand, and feel about the patient's health (Step 2);
3. finding out what and how much the patient wants to know and, deciding on who should be designated to make decisions on the patient's behalf when the patient prefers not to receive critical information (Step 3);
4. giving the patient and family reassurances that they are not being abandoned through planning for the next steps (i.e., arranges for appropriate referrals, prescribes additional treatment, discusses about potential needs and sources of emotional and practical support, and establishes a time for a follow-up appointment) (Step 6).

However, they face difficulties in offering the information in a sensitive, but straightforward, manner; they fail often in avoiding both a steady monologue and medical/technical jargon, and checking periodically the patient comprehension (Step 4).

Moreover, trainees encounter difficulties in responding emphatically to the emotional reaction of standardized patients (Step 5). They often are not able to acknowledge the patient's emotions, to validate their legitimacy, and to give support to patients through a broad range of their reactions. The lack of emphatic competence instance among our trainees resulted in ignoring the patient's emotions through not allowing time for expression of his/her immediate feelings or in rushing the situation through by quickly starting the next step of the protocol, namely, "Summarizing and planning".

Thus, breaking the bad news in a straightforward and emphatic manner seems to be a very difficult task for many trainees. Moreover, if some of them hesitate to accomplish it during the educational process, they almost certainly will avoid performing it in a clinical setting. This state of reality reveals the necessity to empirically explore the deep cognitive, emotional, and cultural reasons behind this behavior and to construct the educational process on delivering bad news in accordance with the acquired findings to suit the context better.

11.7 Conclusion

The principle of autonomy in the context of providing medical treatment is considered to be paramount in liberal countries and is becoming increasingly significant in countries with communitarian traditions. It requires that physicians have open and honest communication with patients about diagnosis and prognosis to enable patient decision-making. Honest conversation, sensitively and competently navigated, results in a lot of advantages. It strengthens the physician–patient relationship and fosters collaboration among the patient, family, physicians, and other professionals. It allows the patient to express his/her wishes and needs, making them known and

able to be met. Honest and sensitive delivery of information enhances the patient's capability to make informed decisions about his/her care, as well as to maintain their personal dignity. At the same time, it allows patients to prioritize and prepare for the future and reduces bereavement suffering for those left behind. Open communication about health condition helps patients to harmonize their expectations to the objective reality (to the real state of affairs), to set realistic goals, and do the best to achieve them. Consequently, all these may finally increase the patient's quality of life.

Providing full information to the patient about his/her health condition when it concerns incurable diseases is a difficult task avoided by many Moldavian physicians, usually on the ground of suspicion that true information may inflict harm to the patient. However, there is evidence that the opposite is true. Dishonest communication precludes Moldavian physicians from knowing the patients' needs and to meet them in a palliative setting, which results in great harm for the patients. At the same time, appropriate disclosure of bad information by the physician requires communication skills and competence developed during special training, which has been inaccessible, actually, for Moldavian physicians until recently.

We are confident that culturally sensitive education of Moldavian physicians in this field will make them aware about the significance of the "principle of autonomy" and will increase their willingness to apply it in palliative practice for the benefit of the patient.⁴

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