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Moral-uncertainty-distress related to Advance Directives: a qualitative study

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Moral-uncertainty-distress related to Advance Directives: a qualitative study

Background: moral-uncertainty-distress (MUD) is defined as moral distress related to moral conflict about best course of action, impacting the clinical decision making process in morally complex situations. This study aims to correlate physician's perception about advance directives (AD) with presence or absence of MUD, identifying the impact that AD promotes on clinical decision making.

Methods: this is a qualitative, cross-sectional, exploratory study. Data was collected through semi-structured interviews with physicians of a hospital in southern Brazil. Interviews content was submitted to categorization analysis content technique by Laurence Bardin.

Results: eight physicians were interviewed. The analysis content identified two categories: (1) AD as a morally challenging element and (2) recognition of AD as instruments that exercises patient's autonomy. In the first, paternalistic attitude; insecurities in uncertain prognoses; uncertainty about patient values and motivations to write the document; and little previous knowledge about AD, were elements of MUD for physicians. In second category, autonomy in AD was seen as *prima facie* principle and as shared autonomy.

Conclusion: although AD were comprehended as instruments of exercise of patient's autonomy by the participants, some elements were morally challenging for them, which can be a source of MUD to physician during decision making process.

Keywords: moral distress; autonomy; bioethics; physician

Background

Moral-uncertainty-distress (MUD) is defined by Fourie (2018) as a kind of moral distress related to uncertainty or moral conflict about what is the best course of action to be followed. The MUD in this case differs from moral distress related to moral constraint or, as suggested by Fourie (2018), moral-constraint-distress, whose definition is close to the concept of moral distress originally proposed in 1984 by Andrew Jameton. In Jameton's (2013) concept, moral distress was mainly related to moral constraint in nursing practice. Several authors have criticized this model for not contemplate the moral conflict, moral dilemma or other morally challenging situations, experienced by health professionals, which do not necessarily include institutional constraint, but can also lead to negative feelings (residual or not) to any health professional (3–5).

Fourie (2015) argues that moral distress should be understood as a health professional's psychological response to morally challenging situations, such as limitation of action and/or moral conflict, and should differ from psychological distress, which would not have a moral cause. Although the concept of moral distress has emerged related to nursing practice, any health professional is susceptible to it, including the physician (1). In that case, moral distress can manifest through negative feelings like guilt, impacting the clinical decision making process in morally complex situations (1,4,6).

Another challenge is the fact that, for measuring moral distress, the available validated instruments in Brazil or in other countries consider only moral distress related to situations of moral constraint, and don't take the MUD, or other forms of moral distress, into account (7–13).

In the context of morally challenging situations, despite advance directives (AD) being instruments that aim to help patients exercise their autonomy and health professionals in the decision making process (14), some elements can bring distress to the physician. Those include: the way how the AD was written; patient's beliefs; culture and values at the time of writing; complexity and uncertainty about the clinical context of the patient; and the construction be done based on a hypothetical situation. These are elements that can lead to insecurity to physician at a time of clinical decision (15,16).

In Brazil, we have also other challenges. Until now, we have no specific law or either a standard model for AD. The instrument was validated by Brazilian Medical Federal Council in resolution n° 1995, dated by august 2012, and it's in consonance with the Brazilian Federal Constitution (17). However, application of AD in Brazilian clinical practice it is far from being ideal. The resolution defines AD as a “set of wishes, previously and expressly manifested by the patient, about healthcare and treatments that he/her wants or not to receive when he/her is unable to express, freely and autonomously, his/her will” (free translation from Portuguese) (18). It can be registered in a formal document or even in medical records, as long as there is no standard form for register in Brazil (17). Going beyond the legal aspects of the AD, even in countries such as the USA, with almost 30 years of history since its proposition, the AD still face criticisms regarding key aspects of its composition (19).

Therefore, would it be an AD previously built by a patient a cause of physician's MUD at the decision making process? Our hypothesis is that MUD is present in these situations through moral discomfort at the moment of decision making. To answer this question, it's necessary to understand the physician's perceptions about AD.

In this way, this study aims to analyze the Brazilian physicians' perceptions about AD, correlating it to the presence or absence of MUD, according definition of

moral distress proposed by Fourie (2015). We also aim to identify the impact that AD promotes on decision making, describing the moral motivations that determine the physician's conduct towards an AD. Recognizing these issues, it is possible to help in physician's clinical decision making process in order to mitigate the potential MUD, as well as mitigate the risks of therapeutic obstinacy and disrespect to patient's autonomy.

Methods

This study is qualitative, exploratory research, with data collected through interviews, and its content analyzed according to Bardin's method. The interviews were done between April and May of 2019.

Eight physicians, selected for convenience, who were working at a tertiary hospital in the city of Curitiba, southern Brazil, were interviewed. The inclusion criteria was physicians who provide direct assistance e management of care of patients admitted at the hospital's ward, ICU and/or emergency unit and rapid-response team. We used a semi-structured script for interview, divided in two steps: (i) data for sociodemographic characterization of participants, like gender, age, year of graduation and place of practice inside the hospital; (ii) questions about the AD, including previous experiences and simulation of a clinical decision making situation. In the second step, was presented an AD of a patient previously admitted at that hospital and obtained with patient's permission, and the patient's identity was camouflaged. Then the participant was asked: "how you would stand as this patient's physician in an emergency situation?". The AD used was from an elderly male patient, made and registered in 1994, but presented to the hospital health team by the patient himself in 2018. We transcribe bellow the AD content (free translation from Portuguese):

“In case of heart problems in my body, I don’t want coronary artery bypass or heart transplant. I don’t want either my physical life prolonged artificially by use of machines. I want to leave conscious to the other side of life. I’m conscious of what I’m asking for. My wife is in full agreement with what is written here. Respect my will, just as you would like them to respect yours. Thanks for your comprehension”.

In sequence, the study participant was questioned “how do you feel when facing this patient’s AD?”. The approval for this study was given by Research Ethics Committee of Pontifícia Universidade Católica of Paraná. Each study participant was identified with an alphanumeric code (P1 to P8) – ‘P’ referring to ‘physician’ and the sequential numbers distributed according to chronological interview sequence. The analysis material was organized and the interviews fully transcribed. Free translation from Portuguese and simple spelling correction were performed in order to facilitate reading and analysis, being careful about not to change the content transmitted in the participants' speech.

The analysis content proposed by Bardin (20) was the method of choice for this study. This method allows to analyze the content of communications by systematic techniques and procedures, aiming a description of the message content in the speeches and its interpretation with methodological rigor. The Bardin’s categorization analysis process is segmented in three steps: pre-analysis, material investigation and treatment of results. In the first step, pre-analysis, analysis material was organized – interviews were fully transcribed, and a “free reading” of material was performed, when our first hypothesis and guiding questions began to emerge, as well as the categories related to them. In the second step, material investigation, a deep analysis of interviews content was made, in order to categorize speech clippings, called registration units, into respective categories and subcategories. The third step, treatment of results, comprises

inference and interpretation of speeches content, considering the hypothesis of this study.

Results

The sociodemographic data were organized according to gender, age, years of professional practice and physician's sector of activity in the hospital. A total of 8 physicians participated in the study, including hospitalist physicians (n = 7), and physicians who worked at emergency unit or ICU (n = 2) – there was one physician who worked in more than one hospital sector. About gender related, we had two female physicians and six male physicians. The median age was 43 years, with an interquartile interval of 36 to 48 years. The median of years of medical graduation was 18 years, with an interquartile interval of 10-24 years.

As a result of Bardin's categorization process, two categories emerged from participants speeches: AD as a morally challenging element (n=6) and recognition of AD as instruments that exercises patient autonomy (n=4). Exploring the elements which could explain this first category, we found the following subcategories: paternalistic attitude in decision making (n=2), insecurities related to AD in context of uncertain prognoses (n=2), uncertainty about AD validity when considering patient values and motivations to write the document (n=4), and little previous knowledge about AD bringing discomfort to physician (n=2). By the same process, the second category was subdivided into the following subcategories: autonomy as a *prima facie*¹ principle (n=1)

¹ *Prima facie* in this context means an obligation or principle that must be performed, unless it conflicts, on a specific situation, with another principle of greater or equal importance (Beauchamp and Childress 2011, 50).

and shared autonomy (n=3). In table 1 we summarized these results, including all registration units, available as Additional file 1.

Discussion

AD as a morally challenging element

We observed that the express majority of the study participants brought in their discourse the AD as a morally challenging element. The paternalistic attitude showed by two participants refers to the concept in which the doctor, believing to know what is best for his patient considering his technical knowledge, imposes the medical indication over patient's values in the decision making, retaking the beneficence of Hippocratic oath, a form of strong paternalism. The patient's values and wishes are supplanted by physician's belief that not applying the medical intervention would cause irreparable harm to the patient (21). In this context, MUD would be related to the physician's discomfort in confronting the patient's values with medical indication at the time, understanding that a harm could come from respecting patient's decision and, therefore, patient's decision should be reviewed and modified. The participant P6 suggests this matter in his speech (free translation from Portuguese):

P6: "(...) many families want something and we, as professionals, may have a keener view of what that thing will bring."

Horn (22) conducted a qualitative study, in 2014, about the role of AD for physicians in England and France, looking for cultural differences in their perception about AD. The results revealed that, despite both countries had sanctioned laws about AD and patient's rights to refuse treatments at the same year (2005), French physicians tended to a more paternalistic view in decision making process, not considering patient's wishes if they had a strong opinion about medical decision. The author

interpreted this results by a cultural view, considering that Anglo-Saxon culture relies on the concept of respect to autonomy – therefore more affected by the idea of individual participation in decision making – while French culture tends to give priority to collective social values, rather than individuals. Considering that French has a Latin culture, as well as Brazil, it make us think if these similarities can be attributed to the current cultural context.

In a less paternalistic view about the issue, but still considering principle of beneficence, the moral challenge related to the prognostic uncertainty was also observed in the interviews. In uncertain prognoses, the conflict would be between physician's determination to respect the patient's autonomy and the possibility of going against the principle of beneficence. In this case, respecting patient's wishes but omitting an intervention that would result in benefit. The participant P7 brings this perception in his speech:

P7: "One thing that always bothers me is this doubt, how much of what is written there is in fact happening with the patient in front of you, and sometimes you may not do something you should have done. It's an ethical dilemma that has no solution."

On the other hand, the procedure itself, initially proposed by physician as a beneficent measure, could lead to bad outcomes or real harm considering the uncertain prognosis of disease. These two possibilities reveal the morally challenging decision making process in uncertain prognoses, which could result in MUD.

Some similar results can be seen in other populations. The conflict about being in accordance to an AD content in the context of prognostic uncertainty was seen by Leder and others (2015) in their study conducted in Germany. The authors showed that the physicians questioned the validity of AD of patients admitted to intensive care units (ICUs), due to the prognostic uncertainty faced in this condition, among other reasons.

The AD was then seen as guides on the patient's values and wishes in decision making process rather than their literal interpretation by the physician (23).

It is known that when writing an AD, the patient formulates his preferences based on his values considering his quality of life in current health conditions and/or a potential future situation, such as terminal illness (24). Therefore, AD is defined on a hypothetical future basis for patient, and this will not always translate into the reality of clinical practice. On the other hand, every individual has the right to be part of the deliberation process about decisions that could affect his life, and for this he must also have adequate information about unforeseen circumstances, since unpredictability are inherent in care (16). According to Nunes and Anjos (2014), it is a good procedure to review the document frequently at each occurrence, emphasizing that it can be rewritten whenever patient wants. However, even though necessary, it is a practice still poorly performed (25), something we could observe in the AD used in our study, which dated over two decades.

Regarding the patient's view of what is 'good' for himself, the patient's motivations when writing an AD were also questioned by some of the study participants, revealing itself an element of discomfort in decision making. In this context, the MUD would be related to physician's conflict between respect patient's wishes and the questioning about the negative influence of patient's previous experiences in what is expressed in the document. This perception is given by P6 in his speech:

P6: "(...) maybe in his mind is not clear or even biased by issues that he experienced, his life experience, people who died from heart disease or who had sequelae of interventions and he had witnessed and lived with these situations, and this has perhaps impacted negatively in him, in his experience, changing his view about the benefit of certain resources he could use and be benefited."

In fact, a physician who just met his patient will need time to understand and discuss about patient's motivations in writing an AD. Also, counseling a patient about his AD is not always possible to be done by all the doctors who once assisted the patient, and to comprehend the complexity of patient's biography demands time to listen. Difficulties in communication process between patient and physician can be a barrier in this context, as evidenced by Cogo and others (2016) in their qualitative study, in southern Brazil. In their study, physicians highlighted issues such as lack of time to communicate with the patient-family, as well as the importance of a proper method of communication of diagnosis and questions about the AD, in order to not cause negative repercussions to patient and his family (26).

We also identified the physician discomfort regarding AD due to lack of knowledge or little previous contact with the instrument. In this case, MUD would be related to physician discomfort for receiving a document which he has no knowledge about its function. The participant P1 gives an example of this matter:

P1: "I am not comfortable with this, because it is not a common document that you see in day-to-day life, by the way, it is an extremely unusual document, in 28 years of profession and I had never seen such a document, this is the first time I see one (...)"

Chehuen Neto and others (2015), in their cross-sectional study conducted in the Southeast Brazil, with health professionals (physicians and non-physicians), showed that only 37.89% of them had previous knowledge about AD. This result was similar to a previous study made in 2011 with medical professionals in Santa Catarina, in southern Brazil (27). Considering that Brazil still gives small steps towards the matter of AD, this kind of perception is not a surprise. But even in countries where the AD is already a legally bind document, difficulties about physician's knowledge are still present. A qualitative Swiss study published in 2015 investigated physician's perceptions toward

patient's AD by physicians in the context of elective heart surgery and showed that although physicians considered it a useful tool for exercising patient autonomy, many had difficulty stimulating or participating in the construction of the document. Among the reasons observed to this conduct were fear and lack of knowledge about the AD (28).

Recognition of AD as instruments that exercises patient autonomy

Although our study showed questions related to MUD in the participant's interviews, the recognition of AD as instruments for exercising patient autonomy was also present for half of them.

Considering the expression of the patient's wishes as one of the functions of AD, this perception is entirely justifiable and welcome. However, the concept of autonomy is broad, and encompasses dimensions that go beyond the common sense of 'freedom of action'. Autonomy as a *prima facie* principle is a concept that derives from Beauchamp and Childress's principles bioethics (21). Although being a broad term in its philosophical definition, the autonomous individual can be defined as that one capable of acting freely in accordance with his decisions, thus including two main characteristics: freedom from controlling influences and the ability to act intentionally (21). However, being autonomous is not synonymous with being an autonomous agent, since for this it is necessary the respect to autonomy, that is, to recognize the right of the individual to express their opinions, make choices and act according to their own needs, personal values and beliefs (21). Although being a *prima facie* principle, in the presence of conflicts with other principles such as beneficence, autonomy should not be considered in isolation or in an absolute concept and should not be understood as the sole source of moral rights and obligations to the individual (21).

However, the patient's values and choices do not always converge with those of physician, and the search for a shared decision between them can be a better way out in this context, in order to obtain the best course of action, as identified in the second subcategory in this study. The concept of shared autonomy, defended by Bergsma and Thomasma (29), is based on the mutual condition that exists between patient and doctor in context of disease and search for cure/treatment/care. Patient and physician would discuss priorities and alternatives in order to cure and/or restore the autonomy weakened by disease, based on mutual respect for freedom of both, reducing the asymmetry of this relationship. Thus, when decisions are discussed in order to be properly negotiated, division of responsibilities can be shared between them both (29).

This shared decision then seeks to create a balance between the physician who absolutely obeys patient's will and the one who imposes his notion of paternalistic good. In the modern view of this model, the physician exposes the medical issues and the possibilities of intervention, while the patient expresses his values, and both decides then by the course of action to be followed (30).

Implement a real shared decision model also faces challenges, primarily in moving away from the informed consent model, concept from which shared decision evolved. The common belief that it is up to physician to impartially and accurately disclose the medical facts, and to the patient to interpret the facts in accordance with their own values, disregards two important aspects: the relevance of the professional's values in care planning and that the doctor won't be able to expose the facts impartially to the point of not being influenced by these circumstances (30,31).

Therefore, respect for the patient's autonomy, values and beliefs, is an important ethical principle and a goal to be pursued along all the doctor-patient relationship. The shared decision requires an enforcement that truly includes patient, his family and

physician for final decision, considering that the physician will expose facts by aggregating his values and perceptions, and decision making by the patient will also be influenced by some factors related to his understanding about disease (30). A shared decision making could be, finally, a strategy for sharing responsibilities and values between physician and patient, and possibly helping to mitigate the potential MUD involved in this decision making process.

Limitations

This study has some limitations. The first one, AD used is from 1994, which may have influenced its interpretation by the study participants. However, we believe that, since there is no standard model of AD in our country so far, and because the patient himself presented the same directive in 2018, without modifications, the truth of its content justified its use in this study. Second, considering the study design and because it was conducted in a single hospital in southern Brazil with a limited sample of participants, we cannot extrapolate the results found as the thinking of the Brazilian physician, or even physician in general. However, this study can be an initial look at the issue of AD-related MUD in medical professionals, something little discussed in scientific literature yet.

Conclusions and future research

Although MUD is a concept not yet unanimous in the literature, it gains relevance when we consider the many moral conflicts present in clinical practice, and the moral conflicts experienced toward an AD are just one example. In our study, although the AD were comprehended as instruments of exercise of patient's autonomy by the participants, AD was also a morally challenging element for them, which can be a source of MUD to physician during decision making process and affect its use by

physician. Future researches will be needed under other methods in order to clarify the role of MUD in physicians. To understand how MUD manifests in physicians allows us to outline future studies that identify MUD-related factors, as well as the development of assessment tools that consider a broad concept of moral distress. Going beyond AD's issues, understanding MUD in the context of advance care planning can also provide answers about the consequence of physician's MUD in the patient care and also find strategies that could mitigate MUD not only for physicians but all health professionals.

List of abbreviations

AD: advance directives

MUD: moral uncertainty distress

DECLARATIONS

Ethics approval and consent to participate

All participants received and signed a written informed consent before the data collection. This study was approved by the institutional review board(s) at the Research Ethics Committee of Pontifícia Universidade Católica of Paraná, Brazil (CAAE nº 03223318.5.0000.0020).

Consent for publication

Not applicable.

Availability of data and materials

The authors declare that the data supporting the findings of this study are available within the article and its supplementary information files.

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Authors' contributions

URVCOR, LMS and CCP conceived the study, designed the methods, coordinated data collection. URVCOR and CCP interpreted the data and drafted the article. WS e UBPG contributed to final revision. All authors approved the final revision.

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Competing interests

The authors declare that they have no competing interests.

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Additional files

File name: Additional file 1.

File format: PDF

Title of data: Categorization of interview content according to Bardin Content

Analysis technique.

Description of data: the table fully describes the results of Bardin Content

Analysis technique done in this present study.

Supplementary Files

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