Original Article

Advanced directives of will: legal and educational challenges in the nurse's view

Isabela Saioron[1], Flávia Regina Souza Ramos[2], Felipa Rafaela Amadigi[3], Paola da Silva Diaz[4]

[1] Nurse, Master in Nursing. Student of the Nursing Graduate Program Universidade Federal de Santa Catarina, Doctoral level. Florianópolis, SC, Brazil. E-mail: isabelasaioron@gmail.com.

[2] Nurse, Ph.D. in Nursing. Full Professor at Universidade Federal de Santa Catarina. Florianópolis, SC, Brazil. E-mail: flavia.ramos@ufsc.br.

[3] Nurse, Ph.D. in Nursing. Adjunct Professor at Universidade Federal de Santa Catarina. Florianópolis, SC, Brazil. E-mail: felipaamadigi@yahoo.com.br.

[4] Nurse, Master in Nursing. Student of the Nursing Graduate Program at Universidade Federal de Santa Catarina, Doctoral level. Florianópolis, SC, Brazil. E-mail: enfpaoladiaz@gmail.com.

Received: 10/05/2016.
Accepted: 09/11/2017.
Published: 12/15/2017.

Suggest citation:
Saioron I, Ramos FRS, Amadigi FR, Diaz PS. Advanced directives of will: legal and educational challenges in the nurse's view. Rev. Eletr. Enf. [Internet]. 2017 [cited __/__/__];19:a44. Available from: http://dx.doi.org/10.5216/ree.v19.43587.

ABSTRACT

The Advanced directives of will (ADW) are documental registries which the individual describes the procedures that he or she would like to be submitted or not. The objective of this article is to discuss the emerging challenges to use the ADW in ethical-legal and educational terms from the nurse's view. An exploratory qualitative study composed of semi-structured interviews with 19 nurses from the Intensive Care and Medical Clinic of a University Hospital. We conducted the data analysis folling the Discursive Textual Analyisis technique. Two main categories of challenges associated to ADW emerged: Legal challenges related to ADW adoption in Brazil and Educational and knowledge challenges related to ADW adoption; besides other results also reported here. The taboo related to death, the lack of legal backing and professional training related to terminality and autonomy of the patient, arise as challenges to promote and to use ADW in the studied reality.

Descriptors: Advance Directives; Nursing; Education, Nursing; Liability, Legal.

INTRODUCTION

During the 60's decade in the United States of America, the lawyer Luis Kutner proposed the protection of the individual death right through the adoption of what it was called the living will. He believed in this document to solve conflicts between physicians and family members regarding care provided to a terminally ill patient[1-3].

The living will was the precursor of the tool known nowadays as the Advances Directives of Will Directives (ADW). The ADW is a documental registry in which the individual manifests the procedures that he or she would want to be submitted or not, in certain circumstances, exposing their positions about future procedures[1,4]. In this document, the author can leave explicit his wishes in case of incapability to verbally

manifest them as a result of a future disease condition, therefore exercising autonomy[5].

Although its use is regulated in Brazil under the Resolution 1.995/2012 of the Medicine Federal Council (CFM) since 2012, the ADW are still little known by health professionals nowadays. Such lack of knowledge can create uncertainties among workers in case they face this document at some moment in their work routine; which, can create conflict with institutionalized technical knowledge[4,6].

The little familiarity with ADW can be in part a reflex of the paternalistic posture, which normally excludes the patient from the decision making referring to treatments that will be used[5]. Another remarkable aspect would be the difficulty of health professionals to deal with the death of patients under their care, once their academic training is still influenced by curable practices, for the lack of prepare in dealing with the terminality and, for the perception of death as a failure[6].

Beyond the assumption, it is important to note that, regardless of the Resolution 1.995/2012 regulation of the CFM, the ADW still not have legal backing in Brazil[4,7], once the resolutions from the CFM guide only medical practices considering the wishes expressed by the patient about his care. Another fragility to consider is the existing gaps in the national literature about the ADW application and the challenges that can arise with its use, specially in the work routine of nurses.

Recognizing the complexity of the theme, we questionned: how do nurses perceive challenges refering to ADW, in case they are applied to their professional practice? Thus, our objective was to discuss challenges emerging from the use of ADW in ethical-legal and educational terms from the nurse's view. Although such challenges can be present in different work contexts, we chose one assistance scenario where terminal situations are common, in this case, the Intensive Care units and Medical Clinics.

METHODS

We conducted an exploratory qualitative study, using semi-structured interviews as the data collection instrument applied to 19 nurses, including residents, workers from the Intensive Care Unit and the Medical Clinic I and II of a University Hospital located in the South region of the country. We chose these hospital units because they are the ones dealing more with serious situations and/or terminality, where ADW can be used. We chose nurses as participants due to the importance to explore this theme specifically among them; as they are closer to the patient and their companions, and, they can face higher emotional distress caused by direct contact with the suffering of the other[8]; besides the precariousness of studies about this theme with these professionals.

We submitted the study to the Ethics in Research with Human Beings Committee of Universidade Federal de Santa Catarina (Protocol nº 1.353.986). It was approved, and we respected all ethical aspects foreseen in the Resolution 466/2012 of the National Health Council[9].

We used the snowball technique to invite participants to take part in the study. Initial participants indicated other participants, and so on until there was qualitative saturation of data[10]. Three nurses refused to participate in the study. We conducted the interviews after participants read and agreed with the Free

and Informed Consent Term.

We conducted the data collection between January and March of 2016, and the interviews were conducted at their work place. We audio-recorded them, and after, we fully transcribed the content. To guarantee the anonymity of interviewed participants, the speeches were named using the letter "P" (professional), followed by the number of their interview's sequence (P01, P02, sucessively).

We used the method Discursive Textual Analysis (DTA) composed of four focuses: breaking the texts or unifying process, emphasizing the main constituting elements, after careful reading; establishments of relations, consisting on the creation of categories; capturing the new emerging where the obtained comprehension is clear and, finally, the self-organized process, which tries to establish theoretical interlocutions and new comprehensions about the studied phenomenon until certain moment[11].

We used the software Atlas ti to support the DTA steps, once the fragmentation processes and later unifying of data were compatible with the tools offered for this resource. Thus, we classified and grouped the data based on similarity, electing the analytical categories that would promote the capturing of a new emerging one; that is, comprehension obtained through the interpretation of the theme and, the creation of a meta-text, of possible criticisms and data validation, interpreting the meaning and relating them to the original corpus.

RESULTS

Most interviewed nurses were women; they had previous experience and more than one Graduate level course completed. Most referred to not know the ADW and their use in Brazil. Therefore, there was a need for previous explanation about the theme.

From the nurse's speeches, it was possible to group the challenges represented by the ADW in two main categories, acconrding to Chart 1 and 2: Legal challenges related to ADW adoption in Brazil and Educational and knowledge challenges related to the ADW adoption.

Chart 1: Summary of findings from category 1.

<table>
<tr><th colspan="2">Legal challenges related to ADW adoption in Brazil</th></tr>
<tr><td rowspan="2">Although there are favorable manifestations regarding the importance to know the patient's wish, professionals mentioned feeling the need to protect themselves from possible legal issues. The speeches demonstrate insecurity to</td><td>[...] When there is no law, we get a little afraid, 'am I doing the right thing? Is this correct? Does that goes by the oath I took?' this is still a bit complicated. If this were in the law, it would be more respected; it would be easier to accept them because they are legal. Not having this backing, we think twice, it creates insecurity because you don't know what can happen later (P01).</td></tr>
<tr><td>[...] you have your opinion there, the patient's written wish, I think this is interesting until a certain point. This really has a certain influence, but in reality at the end, in a terminal situation, not having</td></tr>
</table>

follow the patient's wish without having a low regulating ADW.	*legal backing. Unfortunately, we would have to take legal measures and not only supported by his opinion. [...] to professionally defend the team as a whole and the hospital. It there was backing, the situation would be different [...] (P05).*
	[...] until you have law enforcement, maybe we will stay only on the guide, because it's all right, you can even have an idea of what the patient wants or not, in a situation that you have to decide with urgency, maybe that will be the most decisive factor, but there is the legal issue. Then the professional, if the professional sees that there is a matter that needs interveniton, the professional will intervene afraid that later will have a judicial issue (P07).
	I think its complicated to not have a law, because where we live, everything is law, so if the family wants to take it to court that the patient was not assisted, was neglected, the team can respond for that because there is no law, so, from my perception, it would be very hard [...] For the professional, it does not give any safety, the professional feels sort of insecure to act as the patient wishes (P11).

Chart 2: Summary of findings from category 2.

Educational and knowledge challenges related to the ADW adoption	
Regardless of acknowledging that the law would be of great importance, few participants clarify that alone, it would be insufficient, and it would have the need to spread the ADW. In the professional context, it would be necessary to broaden the discussions about ethics and terminality in permanent educational actions, as well as, to deepen these discussions during training, fighting the technicist and paternalist	*I think that for the professional to take the best way would be the specialization courses, I think it would be something more instructive [...] for example, the Health Ministry does its booklets, guides, and it is something we read, it is reliable, we update ourselves every year, so I think that from the moment that we have more studies, and to be spread and discussed with professionals, maybe it is even more valid for us to digest this whole process, inserting it in our work culture instead of a law coming from the top to bottom, little discussed, being a normative [...] I see that we have many paths to get to this ideal point that is not only the law (P17).*
	During my training, I had as a whole one class about death, one morning and nothing else. I got to really know more during the residency [...] Who is daily at the unit is the nurse, we have to deal with this [...] It focuses too much on the procedure and nursing goes a lot beyond that (P13).

training.	*Wanting it or not, we are still trained to re-establish people's health. [...] To respect the person's decision is very difficult. There is not one human inside this clinic that respects it agreeing; we respect it disagreeing. It is very sinister for you to leave with this ambiguity [...] We approach the terminality issue very poorly [...] when new people arrive, and they realize the number of people that die, they get horrified. Because it is not taught as a natural thing. As incridible as it seems, dying is natural (P15).*
	We have a very biomedical training, so we are used to intervening a lot in the patient, to check vital sign, to take curative measures, heroic measures. And a patient that you will care for his comfort, that you are not going to act a lot about the disease but only to the quality of life, we still find a lot of barriers among professionals (P18).
	[...] Now I'm going to graduate school for transplantation and it was the first time that I really learned about how to deal with the family in that death process [...] we had to know how to approach, how the family members behave, what is grief, to try to understand that certain behaviors are expected (P19).

As it is possible to notice, the unawareness of the ADW and the lack of legal backing linked to the poor approach of terminality during academic training, traditionally connected to curing and technicality expose a complex and challenging reality experienced by nurses who work with patients experiencing dying/death process. This situation seems to create insecurity in these professionals, besides limiting the ADW function to simply additional information, without serious relevance to direct therapeutic measures.

DISCUSSION

The ADW has a great obstacle for its application: they are little known by nurses and other health professionals, highlighting the importance to broaden discussions about them[12]. The challenges that came in part represent something new in the assistance context in Brazil[13], but is also refers to old limitations, regarding the contemporary western culture that puts life as something with absolute value[5]. It is also recognized a relative lack of interest from society when human terminalty, which end up reinforcing to see death as a failure or sinonim of indignity by the professionals[14].

After clarifying about the ADW concepts, its applicatin and its current situation in Brazil, participants manifested a significat unsafety feeling due to the lack of legislation, besides feeling like confronting an ethical dilema when they analyse the adoption of ADW taking in consideration the Ethics Code of Nursing

Professionals.

In 2009, there was a trial to regulate the theme in Brazil, with the presentation of the law project nº 524/2009. However, it was filed because of the end of the legislative mandate in 2014[15], in a way that the Resolution 1.995/2012 of the CFM stays alone as the document that has the ADW in the country[4].

The difficulty to create laws capable of contemplating situations involving the autonomy of the terminality in such clear way is not a reality restricted to Brazil. Portugal and Spain have similar difficulties until this date, regardless of having the ADW regulamentation in their laws[1-2]. This turbulent context is explained by our cultural constitution, that influences different sectors of the society, including the legislative, which has as primary objective to protect life, making it difficult to create laws favoring the protagonism of individuals when facing the dying process. Besides the risk of having ambiguous and confusing laws, giving margin to many interpretations in a trial to favor this protagonism. Thus, the difficulty to articulate the life-freedom binomial and to establish when a value needs to be submitted to the other is not rare, specially when the State tends to have a paternalist posture[16].

Thus, to deal with the authors of ADW that have therapeutic possibilities is particularly challenging, as the sense of responsibility and the emotional involvement with the clientele can create conflicts and even sufferring when facing the request to limit the investiments asked by these authors[10-21].

Although the results from our study showed that nurses feel insecure with the lack of laws regulating the ADW in Brazil, the current literature brings that the creation of laws does not soften challenges referring to this documentation, in virtue to the difficulty to favor the self-management of the patient during sickness and death[16].

Professional training during undergraduate, in permanent educational activities or during graduate school, can help nurses to cope with terminality. Thus, the professional developement should continue permanently and independently to the creation of laws and resolutions, in a way to find viable solutions to challenges related to ADW. Similar to the legal backing, the knowledge is the indispensible base for the safe action of professionals in problematic situations. In this sense, many studies reveal the need for a better approach about the autonomy and terminality since academic training. The strong curative and technical appeal of this formation, in addition to insufficient prepare to cope with limits of the intervention, makes difficult to accept death and to create frustration feelings in health professionals[6-8,14,17-19].

Despite recognizing that terminality is a little addressed theme during the academic training of health professionals in general, it is recognized that nurses compose one of the professional categories that act closer to the patient and their companions. Due to that, they are more emotionally strained because of the proximity and contact with the suffering of the other[8]. Because this is a complex theme and due to the nurses role in health teams, maybe this is one of the categories that have been most sensitive to the interest of curriculum changes to deepen the ethical debate involving autonomy, the ADW, and its strands, besides themes involving terminality and its relation with culture, health, disease, and death.

CONCLUSION

From the speeches of participants, it was possible to identify the challenges that nurses foresee about the applicability of ADW in their practices. We noted that nurses do not know much about ADW, and this lack of awareness reflects the reality that affects not only these professionals to whom death is still a taboo, but the autonomy of patients also have little stimuli, and the technicism prevails on labor activities.

Within the identified challenges, the fear to face legal processes in virtue of the absence of legislation for the ADW was expressive in participant's speeches. We note here the importance of nurses to feel safe so advances related to the health-patient professional relationship can be consolidated.

One way to favor the safety of these professionals would be the information. The fact that professionals described the need for training and to braden discussions about terminality suggests a primordial deeper approach to the theme starting since academic training. The ethical training based on values is needed to sustain a safer performance, to respect and promote the autonomy exercise of people in need of care and also, to stimulate legislative changes.

REFERENCES

1. Alves CA. Diretivas antecipadas de vontade e testamento vital: uma interface nacional e internacional. In: Pessini L, Bertachini L, Barchifontaine CP, editores. Bioética, cuidado e humanização. São Paulo: Loyola; 2014. p. 137-57.
2. Dadalto L. Reflexos jurídicos da Resolução CFM 1.995/12. Rev Bioética [Internet]. 2013 [cited 2017 dez 11];21(1):106–12. Available from: http://doi.org/10.1590/S1983-80422013000100012.
3. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. Rev Bioética [Internet]. 2013 [cited 2017 dez 11];21(3):463-76. Available from: http://doi.org/10.1590/S1983-80422013000300011.
4. Conselho Federal de Medicina. Resolução Nº 1.995, de 09 de agosto de 2012 (BR) [Internet]. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. Diário Oficial da União. 31 ago. 2012 [cited 2017 dez 11], p. 269-70. Available from: http://pesquisa.in.gov.br/imprensa/jsp/visualiza/index.jsp?data=31/08/2012&jornal=1&pagina=269&totalArquivos=272.
5. Bermejo JC Belda RM, editores. Testamento Vital: diálogo sobre a vida, a morte e a liberdade. São Paulo: Loyola; 2015. 99 p.
6. Santana JCB, Santos AV dos, Silva BR da, Oliveira DC dos A, Caminha EM, Peres FS, et al. Docentes de enfermagem e terminalidade em condições dignas. Rev Bioética [Internet]. 2013 [cited 2017 dez 11];21(2):298-307. Available from: http://doi.org/10.1590/S1983-80422013000200013.
7. Kovács MJ. A caminho da morte com dignidade no século XXI. Rev Bioética [Internet]. 2014 [cited 2017 dez 11];22(1):94-104. Available from: http://doi.org/10.1590/S1983-80422014000100011.
8. Hermes HR, Lamarca ICA. Cuidados paliativos: uma abordagem a partir das categorias profissionais de saúde. Cien Saude Colet [Internet]. 2013 [cited 2017 dez 11];18(9):2577-88. Available from: http://doi.org/10.1590/S1413-81232013000900012.
9. Resolução No 466 do Conselho Nacional de Saúde, de 12 de dezembro de 2012 (BR) [Internet]. Aprova as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Diário Oficial da União. 12 dez. 2012 [cited 2017 dez 11]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html.
10. Baldin N, Munhoz EMB. Snowball (Bola de Neve): uma técnica metodológica para pesquisa em educação ambiental comunitária. In: Anais do 10º Congresso Nacional de Educação [CD-ROM], 2011, Curitiba, Brasil.
11. Moraes R, Galiazzi, M. Análise textual discursiva. Ijuí: Unijuí; 2011.

12. Chehuen Neto JA, Ferreira RE, Silva NCS, Delgado AHA, Tabet CG, Almeida GG, et al. Testamento vital: o que pensam profissionais de saúde? Rev Bioética [Internet]. 2015 [cited 2017 dez 11];23(3):572-82. Available from: http://doi.org/10.1590/1983-80422015233094.
13. Cassol PB, Quintana AM, Velho MTAC. Diretiva antecipada de vontade: percepção de uma equipe de enfermagem da hemato-oncologia. J Nurs Health [Internet]. 2015 [cited 2017 dez 11];5(1):4-13. Available from: https://periodicos.ufpel.edu.br/ojs2/index.php/enfermagem/article/view/5497.
14. Saioron I. Processo de ortotanásia em unidade de terapia intensiva: percepção dos profissionais de saúde [monografia]. Rio Grande: FURG; 2014.
15. Pona EW, Amaral ACCZM. Os (des) caminhos do testamento vital no Brasil: entre a legislação nascente e a regulamentação pelo Conselho Federal de Medicina. Revista da Sociedade Brasileira de Bioética [Internet]. 2013 [cited 2017 dez 11];9(supl.):240-1. Available from: https://rbbioetica.files.wordpress.com/2014/11/anais-do-x-congresso-brasileiro-de-bioc3a9tica-20131.pdf.
16. Gracia D. Ética y toma de decisiones en el final de la vida. In: Porto D, Schlemper B, Martins GZ, Cunha T, Hellmenn F, editores. Bioética: saúde, pesquisa, educação. Conselho Federal de Medicina & Sociedade brasileira de Bioética; 2014. p. 223-24.
17. Felix ZC, Costa SFG, Alves AMPM, Andrade CG, Duarte MCS, Brito FM. Eutanásia, distanásia e ortotanásia: revisão integrativa da literatura. Cien Saude Colet [Internet]. 2013 [cited 2017 dez 11];18(9):2733-46. Available from: http://doi.org/10.1590/S1413-81232013000900029.
18. Sanchez y Sanches KM, Seidl EMF. Ortotanásia: uma decisão frente à terminalidade. Interface - Comun Saúde, Educ [Internet]. 2013 [cited 2017 dez 11];17(44):23–34. Available from: http://doi.org/10.1590/S1414-32832013000100003.
19. Junges JR, Cremonese C, Oliveira EA, Souza LL, Backes V. Reflexões legais e éticas sobre o final da vida: uma discussão sobre a ortotanásia. Rev Bioética [Internet]. 2010 [cited 2017 dez 11];18(2):275-88. Available from: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewArticle/564.
20. Lopera Betancur MA. Nursing care of patients during the dying process: a painful professional and human function. Invest Educ Enferm [Internet]. 2015 [cited 2017 dez 11];33(2):297-304. Available from: http://doi.org/10.17533/udea.iee.v33n2a12.
21. Tschirhart EC, Du Q, Kelley AS. Factors influencing the use of intensive procedures at the end of life. J Am Geriatr Soc [Internet]. 2014 [cited 2017 dez 11];62(11):2088-94. Available from: http://doi.org/10.1111/jgs.13104.