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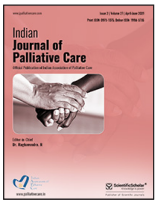

Review Article

The Mapping of Influencing Factors in the Decision-Making of End-of-Life Care Patients: A Systematic Scoping Review

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ABSTRACT

Decisions in end-of-life care are influenced by several factors, many of which are not identified by the decision maker. These influencing factors modify important decisions in this scenario, such as in decisions to adapt to therapeutic support. This presented scoping review aims to map the factors that influence end-of-life care decisions for adult and older adult patients, by a scoping review. The review was carried out in 19 databases, with the keyword 'clinical decision-making' AND 'terminal care' OR 'end-of-life care' and its analogues, including publications from 2017 to 2022. The study was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews. The search resulted in 3474 publications, where the presence of influencing factors in end-of-life decision-making for adults and the elderly was applied as a selection criterion. Fifty-four (54) of them were selected, which means 1.5% of all the results. Among the selected publications, 89 influencing factors were found, distributed in 54 (60.6%) factors related to the health team, 18 (20.2%) to patients, 10 (11.2%) related to family or surrogates and 7 (7.8%) factors related to the decision environment. In conclusion, we note that the decision-making in end-of-life care is complex, mainly because there is an interaction of different characters (health team, patient, family, or surrogates) with a plurality of influencing factors, associated with an environment of uncertainty and that result in a critical outcome, with a great repercussion for the end of life, making it imperative the recognition of these factors for more competent and safe decision-making.

Keywords: Palliative care, End-of-life care, Terminal care, Clinical decision-making, Withholding treatment

INTRODUCTION

End-of-life decisions are complex. They involve an interaction between the health team, patients, family members, or surrogates in a dynamic emotional environment, characterised by uncertainties.[1]

A decision is considered appropriate when we make it autonomously. For this to happen, three components must be present in this decision-making process: The intention, the understanding, and the absence of control over the decision. The intention is related to the planning which is expressed in the form of representation of the series of events proposed for the execution of the action.[2] The understanding involves learning a substantial amount of propositions and statements that describe the nature of the action, its foreseeable consequences, and possible outcomes.[3] Finally, the absence of internal and external controls may coerce the final decision. These controls influence unrestrained resistance and self-management capacities of the individual's own desires.[2]

Different factors influence these components of an autonomous decision. Scientific evidence shows that health professionals are influenced during the decision-making process[4] in different areas of health care.[5] End-of-life care decisions have a more challenging characteristic because they are made in a critical environment, with multifaceted uncertainties and technical and ethical repercussions of great importance.[6] In this sense, the scoping review aims at mapping the influencing factors of end-of-life care decisions of adult and older adult patients.

METHODOLOGY

The methodology of this scoping review was developed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist for scoping reviews.[7] The population, concept and context strategy[8] was used for the elaboration of the research question, where the population is the decision-maker in matters related to health;

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the concept is the influencing factor of the decision-making, and; the context is end-of-life adult and elderly patient. Thus, the guiding question was raised, 'What are the factors that influence the clinical decision-making of adult and elderly patients at the end of life?'

The search was carried out from January to April 2022; therefore, the following indexed keywords were searched: 'Clinical decision-making' associated with 'terminal care' OR 'end-of-life care,' in the Portuguese, English and Spanish languages in the following databases: Directory of Open Access Journals, ROAD: Directory of Open Access Scholarly Resources, Medline Complete, Wiley-Blackwell Full Collection 2013, BioMedCentral Open Access, Academic Search Premier, HighWire Press, HighWire Press (Free Journals), Sage Premier Journal Collection, CINAHL, SAGE Premier 2007, Freedom Collection Journals [SCFCJ], Single Journals, BMJ Journals, Freely Accessible Journals, Journals@Ovid Nursing Excellence and Quality Extended Journal Collection, MAG Online Library Internurse, Project MUSE - Premium Collection, Library, Information Science and Technology Abstracts, Oxford Journals Current Collection, restricted to peer review and to the period from 1 January, 2017, to 1 April, 2022, covering the past 5 years.

It was used, as an eligibility criterion, the presence of influencing factors citations in decision-making about adult and elderly patients in an end-of-life decision environment. The variables extracted from the articles were the objectives, type of research, population studied, data collection location (country) and also, information about the influencing factors mentioned and the parts involved evaluated (health team, patient, family members or surrogates, and the decision environment). The content-analysis method[9] was used to extract the influencing factors.

RESULTS

It was found 3.474 publications, which after the process of duplication elimination resulted in 1.355 articles. Out of these remaining articles, 1.199 publications in the title evaluation phase, 89 publications in the summary phase, and 13 fully completed publications were excluded from the study. Only articles that referred to influencing factors in the decision-making of end-of-life care of adult and elderly patients were included, totaling 54 publications (1.5%) used in the composition of the scoping review [Figure 1].

Among the 54 publications included, 61% show qualitative methodologies, 31% quantitative, and 8% with mixed methodologies. With an average article checklist quality rating of 91%. Consisting of averages of 91% and 90% in qualitative and quantitative publications, respectively, according to QualSyst qualifications.[10,11] The included studies have a global distribution, including North America, Europe, and eastern countries such as Japan, Taiwan, Australia, Singapore, China, and Pakistan.

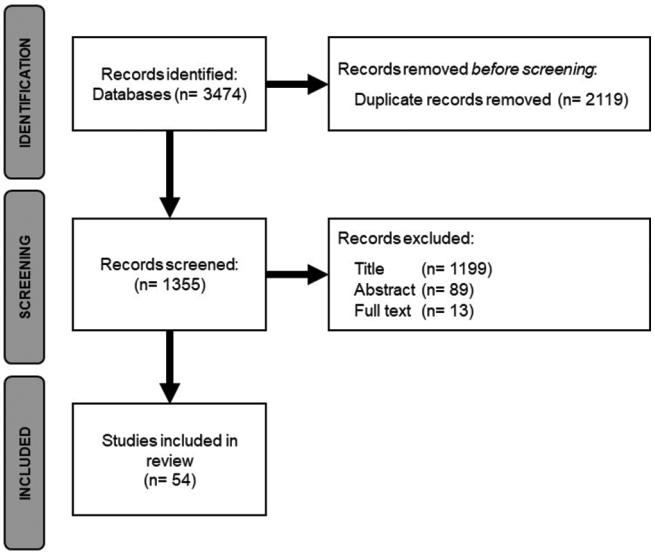

Figure 1: PRISMA[7] flow diagram. PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses.

The publication sample shows 57% of the influencing factors related to health teams, 24% to patient factors, 2% to influencing family or surrogates, and 15% to a mixed population, totaling 302 influencing factors identified in this scoping review, as follows in [Tables 1 and 2].[12-65]

After coding the factors, uniting the factors with the same meaning and categorising them into groups regarding the parts involved (health team, patient, family or surrogates, and decision environment) and also regarding the fields of influence (biological, values and quality of life or context to the decision) according to Jonsen *et al.*,[66] 89 influencing factors were defined, with the results shown in [Table 3].

The influencing factors are presented in a mosaic of factors [Figures 2 and 3], according to the involved individual and his/her category of the field of influence.

The factors found in the health team are the most prevalent in the studied literature. These factors are related to the technical aspects of the end-of-life decision, such as the characteristics of the disease, the patient's clinical status, therapeutic options, and prognoses, but also subjective and individual factors from the health professional, which include ethical, cultural and relationship values between the professional and the patient. Several influencing factors of the decision context were also found. The logistics, knowledge of the subject and communication skills in decision-making were highlighted as factors often cited.

For the patients, the influencing factors are related to the patient's current clinical condition, the prediction of prognosis, and several factors related to personal values and quality of life. There are also cultural influences on end-of-life concepts, demonstrated through religious influence and dynamics of coping with the disease.

Table 1: Characteristics of included papers - Part I.

Author	Year	Methodology	Qualsyst[10,11]	Perspective	Influencing factors
Abdullah *et al.*[12]	2020	Mixed	-	Patient; Family	8
Bandini *et al.*[13]	2017	Quantitative	100%	Patient	1
Batteux *et al.*[14]	2020	Mixed	-	Patient	5
Bopp *et al.*[15]	2018	Quantitative	100%	Health team	8
Cristina *et al.*[16]	2017	Quantitative	71%	Health team	5
Dahmen *et al.*[17]	2017	Quantitative	89%	Health team	2
Daly *et al.*[18]	2018	Quantitative	71%	Mixed	2
Derry *et al.*[19]	2019	Qualitative	75%	Patient	1
Dionne-Odom *et al.*[20]	2019	Qualitative	100%	Patient	7
Duivenbode *et al.*[21]	2019	Quantitative	100%	Health team	6
Dzeng *et al.*[22]	2018	Qualitative	95%	Mixed	9
Escher *et al.*[23]	2021	Qualitative	95%	Health team	11
Fischhoff *et al.*[24]	2019	Qualitative	65%	Patient	3
Frush *et al.*[25]	2018	Qualitative	93%	Health team	3
Geddis-Regan *et al.*[26]	2021	Qualitative	100%	Health team	3
Gerber *et al.*[27]	2021	Qualitative	100%	Patient	1
Glatzer *et al.*[28]	2020	Qualitative	70%	Health team	33
Graham[29]	2020	Qualitative	80%	Health team	3
Higginbotham *et al.*[30]	2021	Qualitative	100%	Mixed	4
Jacquier *et al.*[31]	2021	Qualitative	100%	Health team	8
Janssens *et al.*[32]	2018	Qualitative	60%	Health team	4
Kim *et al.*[33]	2017	Quantitative	82%	Health team	3

When the decision becomes the responsibility of family members or surrogates factors are alluding to the zeal in the decision, seeking greater certainty, consensus, and shared decisions, which allows for a dilution of responsibility when deciding for third parties.

Finally, all these decisions are made in an environment with a specific influencing factor, such as the society's culture and the current knowledge of medicine and policies involving the topic are constant influencers of choices.

All these influencing factors are responsible for the final decision-making, where the role of each influencing factor is modified according to the scenario involved.

DISCUSSION

End-of-life decisions are essential processes in end-of-life care. This care is built through a relationship between health professionals, the patient, and their surroundings (family members, surrogates, and environment). Regardless of the relationship model adopted, whether paternalistic, sovereign autonomy (informative model), interpretive or deliberative model,[67] there is a need for participation from the health team, patient, environment, and often the family or a designated surrogate.

The interaction of these participants, influenced by their judgments and values, associated with the search for the patient's best interests, makes end-of-life decision-making a complex procedure.[6] This complexity can be demonstrated by the wide number of found factors that influence decision-making in this environment.

Of the 89 influencing factors found in our scoping review, more than half are health team influencers, possibly reflecting the search in scientific publications in the health area. These factors were categorised according to the fields of influence, as organised by Jonsen *et al.*,[66], and also to the biological, values, and quality of life and decision context fields of influence. The discussion will present the influencing factors broken down according to the parts involved, subdividing them into the fields of influence.

Health team

We found 54 influencing factors that referred to health team professionals. Initially, we verified factors associated with the patient's profile, which includes age,[16,17,23,25,28,31,63] gender,[15,28] comorbidities,[23,28,31,63] physiological status,[23,28,61,63] the patient's degree of dependence,[31,63] the patient's ability to interact[50] and the current physical symptoms[28] that the patient is experiencing. The reason for hospitalisation,[43] the type of information that the health professional collected,[60,63] the opinion from assistant physicians who already know the patient[63] and the degree of urgency of this decision-making[28,44] are the elements that build an initial picture of which patient is being approached.

In similar reviews, some of these factors influenced up to 83% (comorbidity) of medical decisions in an emergency setting.[68]

Factors related to the disease, such as diagnosis,[15-17,28,31,43,61] prognosis,[16,18,23,28,31,61,63] current degree of the disease,[43,47,63] the potential for the investigation of the disease[60] and the type of

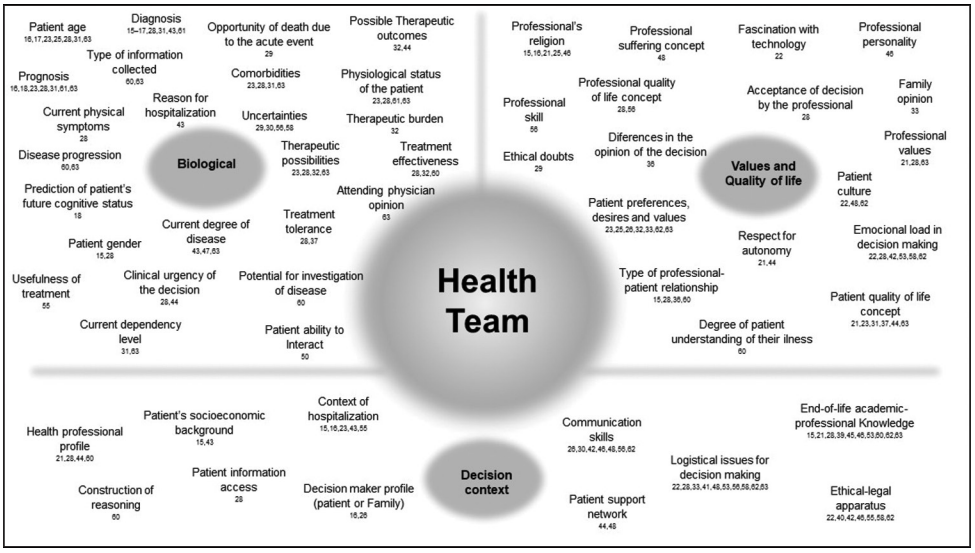

Figure 2: Influencing factors mosaic for health team.

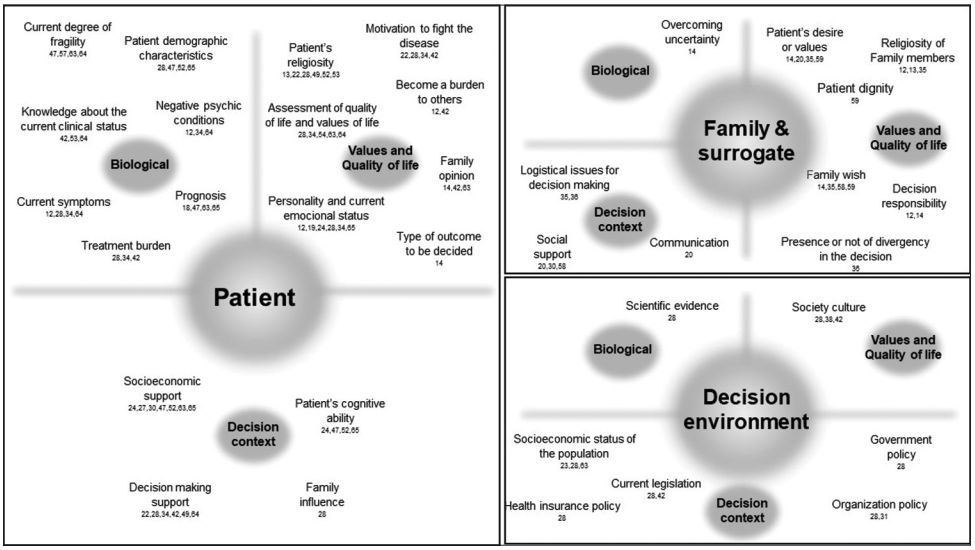

Figure 3: Influencing factors mosaic for patient, family, surrogate and decision environment.

disease progression[60,63] are widely cited. Of these, one of the most frequent factors was the assessment of prognosis, which represents a challenge in many areas of health. Mainly because there is a lot of uncertainty in the estimates.[29] This uncertainty appears as an influencing factor in the review.[29,30,56,58] It also influences the concept of therapeutic futility, since therapeutic futility is a decision based on prognostic estimates, which are subject to uncertainties,[55,63] associated with severe ethical consequences.[69]

The pace of disease progression[60,63] influences decision-making. Different profiles of disease evolution create different expectations and challenges in end-of-life care, requiring changes in approaches and points of concern in care.[70]

Influencing factors related to therapeutic options were also found, such as the possibilities,[23,28,32,63] effectiveness[28,32,60] and usefulness of treatments,[55] as well as the capacity for tolerance[28,37] and the burden[32] that the intervention will result in.

The expectation of therapeutic outcomes[32,44] and the clinical condition after treatment, such as the prediction of the patient's future cognitive status,[18] must be adjusted to the inherent uncertainties of this information. In addition, the possible loss of the opportunity of death due to the acute phase of the disease must be considered. This concept defends the idea that there is a 'window of opportunity' in the acute phase of the event where the patient is physiologically

Table 2: Characteristics of included papers - Part II

Author	Year	Methodology	Qualsyst[10,11]	Perspective	Influencing factors
King *et al.*[34]	2018	Qualitative	100%	Patient	6
Lamahewa *et al.*[35]	2018	Qualitative	100%	Mixed	4
Laryionava *et al.*[36]	2021	Qualitative	100%	Health team	6
Latcha[37]	2019	Qualitative	70%	Health team	2
Lee[38]	2020	Qualitative	90%	Patient	1
Leibold *et al.*[39]	2018	Qualitative	100%	Health team	2
Lesieur *et al.*[40]	2018	Quantitative	100%	Health team	1
Lin *et al.*[41]	2019	Quantitative	79%	Health team	4
Lin *et al.*[42]	2019	Qualitative	100%	Mixed	13
Lobo *et al.*[43]	2017	Quantitative	100%	Health team	6
Ludlow *et al.*[44]	2021	Qualitative	100%	Health team	7
Mitropoulos *et al.*[45]	2019	Quantitative	89%	Health team	2
Ntantana *et al.*[46]	2017	Quantitative	93%	Health team	4
Orlovic *et al.*[47]	2021	Qualitative	100%	Patient	8
Radhakrishnan *et al.*[48]	2017	Qualitative	95%	Health team	6
Rego *et al.*[49]	2020	Mixed	-	Health team	2
Robijn *et al.*[50]	2018	Qualitative	100%	Mixed	2
Robijn *et al.*[51]	2020	Qualitative	95%	Health team	5
Sanders *et al.*[52]	2019	Quantitative	89%	Patient	4
Scholten *et al.*[53]	2018	Mixed	-	Mixed	6
Siddiqui *et al.*[54]	2018	Qualitative	70%	Health team	1
Simon *et al.*[55]	2017	Qualitative	75%	Health team	3
Stalnikowicz *et al.*[56]	2020	Qualitative	80%	Health team	6
Subramaniam *et al.*[57]	2021	Quantitative	100%	Patient	1
Syed *et al.*[58]	2017	Quantitative	93%	Health team	9
Tanaka *et al.*[59]	2021	Qualitative	100%	Relatives	6
Taylor *et al.*[60]	2017	Qualitative	100%	Health team	9
Van Heerden *et al.*[61]	2020	Qualitative	75%	Health team	2
Vanderhaeghen *et al.*[62]	2019	Qualitative	100%	Health team	10
Walzl *et al.*[63]	2019	Qualitative	100%	Mixed	23
Wen *et al.*[64]	2019	Quantitative	89%	Patient	5
Wu *et al.*[65]	2020	Qualitative	100%	Patient	6

Table 3: Influencing factors by classes.

Parts involved	Fields of influence			Total
	Biological	Values and quality of life	Decision context	
Health team	25	18	11	54
Patient	7	7	4	18
Family and surrogates	1	6	3	10
Decision environment	1	1	5	7
				89

unstable and the withholding or withdrawing therapies at this moment would result in his death, avoiding a progression to a chronic pathological condition, with an indefinite period, which would generate more suffering for the patient.[29]

As far as values go, we found an inconsistency between the health team's values and the values of the patients, family, or surrogates. This inconsistency is expressed by the influencing factors of the professional's religion,[15,16,21,25,46] his personal values,[21,28,63] his concepts of suffering[48] and quality of life,[28,56] his feelings of discomfort in the face of death and professional failure,[42,58] in addition to the professional's personality[46] and respect for the patient's autonomy.[21,44] On the other hand, there is a need for appreciation of the wishes of the patients or their surrogates,[23,25,26,32,33,62,63] characterised here as valuing the patient's culture[22,48,62] and their concept of quality of life.[21,23,31,37,44,63]

This inconsistency is balanced through the dynamics of the relationship between professionals and patients or

surrogates.[15,28,36,60] This relationship is full of influencing factors, such as the professional's ability to listen,[56] his emotional charge in this scenario[22,28,42,53,58,62] and whether or not there are differences between the opinions of those involved,[36] which often puts to the test the acceptance of the final decision of the deliberation,[28] influencing the dynamics of the decision.

In relationships that adopt a shared decision model, healthcare professionals and patients or family members work together to reach a mutual consensus on the best course of action. This consensus should include two sources of knowledge, the health professional with technical knowledge and the patient and family nucleus with knowledge of values and preferences, both with equal importance in the final decision.[71] This deliberation should not allow the imposition of values, but a bond in which the final benefit will be achieved based on trust between the parties and the concept of the broader patient's good, emphasised by Pellegrino and Thomasma.[72] These mentioned authors describe that beneficence is not restricted to the biomedical (technical) good, possibly influenced by a fascination with technology by professionals.[22] Decision-making in this model seeks an integral vision, which includes the values of the patient as a human being with the ability to choose, with individual desires for the specific imposed situation, and with transcendental values, expressed through an ultimate, non-negotiable desire.[72]

Deliberations for decision-making must have prudence as a principle, which seeks an opening in dialogue, with the permission of the intellectual approximation of those involved. Recognising that everyone has something to teach, with the possibility of opening new perspectives capable of making changes, revisions, enrichments, or additions of their points of view.[73] In this deliberating environment, influencing factors of ethical doubts,[29] the family member's opinions[33], and the patient's or surrogates' degree of ability to understand the disease[60] are dealt with.

In the decision context, a frequently mentioned theme was the lack of time available for the end-of-life approach. This research showed it through the mentioning work overload of the health team and the need to reevaluate the policies of relationship followed by the health team when approaching patients.[22,41] This same theme was mentioning by other logistical issues, such as the structure and the need for administrative tools to facilitate this approach.[22,28,33,41,48,53,56,58,62,63]

The technical training of health professionals in the area of end-of-life care,[15,21,28,39,45,46,53,60,62,63] which includes experience in this area of expertise, technical knowledge of symptom control and the knowledge of the ethical-legal aspect of the proposed conduct,[39,62] appears as a negative influence on decision-making due to a deficit in this learning, which shows a fragility in the formation and dissemination of this theme, especially in the practical aspect. The communication skill[26,30,42,46,48,56,62] mainly mentioned in relation to the training in this type of scenario is a strong influencing factor in decision-making.

Other factors of a more pragmatic aspect permeate the decision context, such as the availability of access to patient information,[28] the characteristics of hospitalisation,[15,16,23,43,55] in addition to the profiles of the professional[21,28,44,60] in relation to their responsibility for this decision-making and the decision-maker's profile, whether he is choosing for himself or a third party (Surrogate).[16,26]

The decision is also made up of surrounding components, which include the support network for practical assistance in the care process[44,48] and the patient's socioeconomic context,[15,43] indirectly reflecting the help capacity that this patient will be able to find.

Finally, the way in which the reasoning[60] is constructed for this decision-making generates a difference in the choices. The formation of analytical, critical, and more rational reasoning is different from intuitive, spontaneous, and emotion-loaded decisions, which generate more insecurity or biases, especially in the past form of decisions.[74] Intuitive and quick reasoning, commonly observed in clinical routine,[4] uses mental shortcuts for faster conclusions. However, these shortcuts or, also known as heuristics, make reasoning more susceptible to failure.[75] Failures in this reasoning construction process result in heterogeneity of decisions, making them imprecise and unreliable.[76]

Patients

The patients were the second most referenced group in the studies listed in this scoping review, which represents about a quarter of the articles. Despite appearing in second place in terms of frequency of influencing factors, this character is considered to be the most important in decision-making, with the patient's wishes, advance directives of will, or discussion about autonomy always being mentioned in other topics.

As an influencer in the decision of their end-of-life care, personal characteristics such as age, ethnicity and gender are often cited, which demonstrates that experiences, cultures and the way, in which they deal with life are factors that strongly influence the decision.[28,47,52,65]

On the other hand, the aspects of the disease are also important for the choice of options, especially for the prognosis,[18,47,63,65] including the severity of the clinical condition,[65] its reversibility and the remaining lifetime.[47] In this aspect, disease development[63] is a decision-modifying factor, influencing in a different way depending on the context experienced at the time. Diseases show different ways of reaching the outcome of death and in each subtype of clinical evolution, there are different challenges in the care.[77] The condition of this disease progression brings several influencing factors, such as physical, psychological,[12,34,64] social and spiritual symptoms[12,28,34,64]

and the degree of functionality or independence at the time of the decision[47,57,63,64] as elements of this decision-making. The expectation of suffering in the end-of-life process is demonstrated by citing the burden of the treatment,[28,34,42] something that indirectly expresses other influencing factors in the field of values and quality of life.

The patient's desires,[28,34,54,63,64] cited in several studies on influencing factors, demonstrate their importance in the patient's decision-making. These values and concept of quality of life are built through the patient's profile, such as his personality traits (introverted or extroverted)[12,19,24,28,34,65] and his profile of coping with challenges[22,28,34,42] being able to delegate or assume decisions, associated with his cultural acceptance of death,[22,28,34,42] closely linked to his spirituality, presenting themselves in a positive or negative light on the influence of the decision.[13,22,28,49,52,53]

Other external factors influence these values, such as the workload brought by the disease to the patient's caregivers and the burden imposed on society,[12,42] which can modify the convictions of the choices presented, especially when the decision-making involves the possibility of an outcome of cognitive after-effect and not just the risk of death.[14] Therefore, the family members' opinion becomes one of the influencing factors for the patient's decision.[14,42,63]

As far as the burden of the treatment goes, the patient's socioeconomic capacity and degree of social and financial support to meet the required care are factors of strong influence on patients.[24,27,30,47,52,63,65] However, the support also involves the patient's relationship with the health team and family members who accompany him, expressed through the trust of this interaction, availability, and freedom to share doubts, feelings, and uncertainties.[22,28,34,42,49,64]

All these factors are moderated by the patient's ability to understand the situation,[42,53,64] influenced by his cognitive ability and degree of desire for complete knowledge of the clinical condition.

Family and surrogates

End-of-life care and palliative care have as their guiding principle, the inclusion of family members and loved ones as an integrated part of the process.[78] Therefore, the analysis of influencing factors of family members and surrogates is of paramount importance, especially when we are talking about situations in which this component is the decision maker himself, either because the patient is no longer able to express his wishes or in cases of a designation by the patient through advance directives of will.[79]

This review shows that one of the concerns of family members and surrogates as an influencing factor of the decision is overcoming uncertainty about the best decision that the patient would want.[14] It is not always easy to express the wishes for all possible scenarios and it is necessary for the family member or surrogate to decide, even if they are not completely certain. To perform this task, the family member or surrogate takes into account the wishes previously expressed by the patient,[14,20,35,59] but also uses his values and concepts,[14,35,58,59] his spirituality and his concepts of death and end of life,[12,13,35] associated with the moral quality of dignity.[59] The presence of choice divergences[36] as a decision-modifying factor shows that decisions for third parties involve a high level of responsibility,[12,14] especially when there are diversified risks such as death or physical and cognitive after-effects.

Decisions carried out by family members or surrogates are dependent on social support for the decision maker, but this interaction can also result in conflicts that result in more condescending decisions.[58]

Again, it is noted that the quality of the health team's relationship with the patient and family members is a strong factor influencing the decision. This aspect is presented through communication skills,[20] respecting the educational level and cognitive capacity of the interlocutors and the degree of trust established in this relationship.[35,36]

Decision environment

The decision environment concerns external influencers to the decision individuals (health staff, patients, family members, or surrogates). This includes the technical development of the health area, with better scientific research on topics related to end-of-life care,[28] the culture of the society in which the decision-making takes place[28,38,42], and the socioeconomic capacity of the country.[23,28,63] It also includes the distribution of the financial resources, mainly the funds destined for the promotion of health in palliative care.[28] The end-of-life care policy of health insurance, with their coverages and incentives, as well as the institutional organisation where the care is being carried out (protocols, support, and guidelines) are strong influencers of the decision.[28,31] It can also be noted that the current legislation on this subject influences the decision-making of all members.[28,42]

In view of the data presented, it appears that this scoping review achieved its initial objective, which is to map the influencing factors in end-of-life decision-making in adults and the elderly. However, it does have some limitations; initially, the review was not carried out by peers, with only one reviewer. Second, this scoping review did not delve into the grey literature, which could broaden the mapping of influencing factors. Finally, there was no clear evidence of saturation of the theme, even considering frequent repetitions of some influencing factors among the studies, with an open field for future complementary research.

CONCLUSION

The mapping of influencing factors can help support end-of-life decision-making. The recognition of influences can improve our choices, making them increasingly autonomous

and competent. There are many opportunities for future studies in the quantitative and qualitative assessment of the weight of the influence of the different factors listed in the different scenarios and decisions in the health area.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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