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Influence of nurse's involvement on practices during end-of-life decisions within stroke units

Running title: Effect of health personnel on end-of-life decisions

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Conflict of Interest statement

No conflict of interest has been declared by the author(s).

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ABSTRACT

Objectives Decision-making processes concerning end-of-life decisions are not well understood for patients admitted into stroke units with severe stroke. To assess the influence of nurses on the medical perspectives and approaches that lead to withholding and/or withdrawing treatments related to end-of-life (EOL) decisions.

Patients and Methods: This secondary analysis nested within the TELOS French national survey was based on a physicians' self-report questionnaire and on a I-Score which was linked to nurses' involvement. Physician's responses were evaluated to assess the potential influence of nurse's involvement on physician's choices during an end-of-life decision.

Results: Among the 120 questionnaires analyzed, end-of-life decisions were more often made during a round-table discussion (58% vs. 35%, $p=0.004$) when physicians declare to involve nurses in the decision process. Neurologists involved with nurses in decision making were more likely to withhold a treatment (98% vs. 88%, $p=0.04$), to withdraw artificial feeding and hydration (59% vs. 39%, $p=0.04$), and more frequently prescribed analgesics and hypnotics at a potentially lethal dose (70% vs. 48%, $p=0.03$).

Conclusion: The involvement of nurses during end-of-life decisions for patients with acute stroke in stroke units seemed to influence neurologists' intensivist practices and behaviors. Nurses supported the physicians' decisions related to forgoing life sustaining treatment for

patients with acute stroke and may positively impact on the family's choice to participate in end-of-life decisions.

Keywords (Mesh): stroke unit, nurses, cooperative behavior, end-of-life decisions

INTRODUCTION

Stroke is a major cause of death as well as physical and cognitive disability. In the United States, almost 800,000 people experience a stroke or recurrent strokes each year. The short-term mortality rate after a stroke reaches 36% (1,2). In France, more than 75% of deaths occur in hospitals and other institutions (3), and 20% occur within specialized wards, such as intensive-care units (ICUs) or stroke units (SUs) (4–6). Among the deaths in acute-care wards, 36% are linked to end-of-life (EOL) decisions which typically affect patients admitted with severe comorbidities, such as a chronic disease, or they are elderly stroke patients (7).

Due to the severity of the pathology and/or the frequency of associated comorbidities, patients admitted in ICU or SU with an acute stroke are more likely prone to decisions regarding foregoing life-sustaining treatment (8–11).

EOL decisions are usually classified into four categories: (i) do not resuscitate (DNR) orders, (ii) withholding treatment, (iii) withdrawing treatment, and (iv) actively shortening the dying process. DNR orders are defined as instructions or decisions to not attempt cardiopulmonary resuscitation in cases of cardiac arrest during the patient's stay at hospital, and mainly concern the 13–30% of patients admitted with ischemic stroke (12,13). Active shortening of the dying process is a circumstance in which someone performs an act with the specific intention of shortening the dying process (11). Active shortening of the dying process, which is synonymous with active euthanasia, is not legal in many countries as France and participant were not asked about their opinion on this topic (14). Most of the time, these active decisions are preceded by DNR, withholding or withdrawal practices. These three types of EOL are legal in France, but are rarely clearly stated in the literature (15). Practices for withholding or

withdrawing therapy may vary according to regional and cultural differences, economic status and religions (16–18).

More generally, EOL decisions remain an ethical and legal concern in daily practice in different medical specialties, and have been discussed in many scientific articles and guidelines over the last decades. Recommendations and guidelines have been published to improve the quality of end-of-life care in all clinical areas, including strokes (19). It has been emphasized that, during palliative or the end-of-life period, patients who have been admitted for a stroke should not be excluded from acute-stroke care and should receive multidisciplinary and anticipatory care.

The implications for the patient and the participation of the family in the EOL decision-making process have been discussed and studied (20–22), but the participatory role of nurses during EOL decisions is not well understood. In this study, the term “nurses” refers to head nurses, nurses, and nurse assistants.

A few publications have assessed the experiences and skills of nurses under the circumstances of EOL decisions: these show some discrepancies between perceptions and opinions of physicians regarding life-sustaining treatments (23,24). It has been shown that most nursing staff want to be more involved during EOL decisions and would like to help patients and their families (25). Three major roles and strategies for nurses have been identified when a life-sustaining treatment is considered: (i) they provide information, (ii) they offer support, and (iii) they act as an advocate. However, the impact of these roles and the way in which they affect a physician’s behavior, the patient's care, and a family's well-being have not been fully explored (26,27).

Aim

The aim of this study was to assess the potential influence of nurses on physician's decisions made to withhold and/or withdraw treatments for stroke patients at the end of life.

MATERIAL and METHODS

Design

This study retrospectively analyzed a one-time cross-sectional national French survey, TELOS, conducted between 2010 and 2011. TELOS was initially designed to examine and explore the practices and perceptions of physicians regarding severe-stroke patients and especially during EOL decisions. For this retrospective analysis, we hypothesized that nurse-involvement could be associated with physician's behavior during EOL decisions.

Sample/Participants

For the TELOS study, physicians were contacted using the French Neurovascular Society mailing list, which contained 224 physicians. Among these, 126 (56%) agreed to participate.

Data collection

An individual questionnaire (Q1) was mailed to head physician in charge of each SU, who provided information on the characteristics of each SU. Q1 included 20 closed or half-closed

questions, which were designed to explore the organization and performance of the SU. This questionnaire was exclusively completed by the head of the SU.

Simultaneously, a second supplementary questionnaire (Q2) was sent to all ward physicians, and anonymous responses were collected between November 2010 and May 2011. The Q2 questionnaire was sent to all senior neurologists who had agreed to participate and was composed of 80 closed and half-closed questions, and two clinical vignettes. The Q2 contained items on medical decisions and was designed to explore the physicians' decision-making processes and perceptions of disability. It covered queries on the involvement of nurses in the process of making an EOL decision. The Q2 was also constructed to provide information on the demographic characteristics of the physicians (gender, age, experience, religion).

Validity and reliability

To confirm the assumption that nurse-involvement could influence EOL decisions, we created an Implication Score (I-Score). This I-Score was based on six questions included in the Q2 questionnaire (listed in Table 1 and Supplement 2), which were selected for their ability to describe the implications and participation of nurses during EOL decisions. The six selected answers were weighted from 0–2 points, with the maximum score indicating the most effective collaboration between a physician and the nurses during an EOL decision-making process. Two questions were exclusive (Q26 and Q53 in table 1) and could only cote 1 or 2 points.

The I-Score and the different weights of the scores for each question were attributed after consensus between the ICU physicians and nurses that considered as expert and who were also involved in this study.

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A score, ranging from 0–20, was obtained by summing the weights of the six questions listed in Table 1. Then, this score was used to split the physicians into two groups according to the observed median: a first group of physicians (I-Score ≤ 10) involving a little or not at all nurses during EOL decisions ($n=64$), and a second group (I-Score >10) considering nurse's opinions during EOL decisions ($n=56$).

To identify the consequences of nurses' involvement in EOL decisions, we compared the characteristics of the two groups with regards to the responses to the Q2 questionnaire (excluding the six questions included in the I-Score).

Ethical considerations

According to local regulations, no formal ethical scrutiny was required or undertaken for this study.

Data analysis

The data are described as their frequencies and percentages for the categorical variables, and as their medians (25th–75th percentile range) for the quantitative variables. Categorical variables were compared using Fisher's exact test and quantitative variables using Wilcoxon's ranked-sum test. All tests were two-sided and statistical significance was set at the $p=0.05$ level. All analyses were performed using R software version 3.4.1 (R Foundation for Statistical Computing, Vienna, Austria).

RESULTS

Hospitals

A total of 49 distinct French SUs participated in this study among the 100 listed in the TELOS survey. The main characteristics of the participating medical units are listed in Supplement 1. Most SUs were attached to a university-teaching hospital (45%) or a general public hospital (41%), and more rarely a private institution (8%). The median number of beds in a SU was 31 (range: 28–45), including 16 (range: 12–23) dedicated to stroke management. There was an emergency department (92%), a polyvalent or medical ICU (94%), a mobile palliative care team (88%), and an ethics committee (51%) in most of the hospitals. Families were allowed to visit patients on any day of the week in all neurology wards and SUs.

Physicians' characteristics

Of the 126 questionnaires that were collected, a total of 120 Q2s were analyzed (6 questionnaires were excluded because the physicians did not answer one or more of questions included in the I-Score): the results are summarized in Table 2. The median age of the participating physicians was 40 (range: 34–47) years, and 44% ($n=56$) were females. Approximately 50% of the physicians reported having more than 10 years of experience in neurology and 37% in stroke management. Eighty-six percent of physicians declared that they systematically took part in the unit's “team meetings”, but only 64% took part in specific “team meetings” dedicated to EOL decisions and patients' outcomes.

The median I-Score was 10. From this, two groups of physicians were created: one with a I-Score of ≤ 10 , who considered nurses' involvement to be less important in the EOL decision-making process ($n=64$), and those with a I-Score of >10 ($n=56$) who considered that nurses should be involved in EOL decisions. Sub-item scores are given in Table 1.

We were not able to identify a dominant profile of a hospitals' care structure that specifically promoted participation of nurses in EOL decisions (Supplementary 1). In addition, the I-Score could not identify a specific profile for those physicians that involved nurses more in EOL decisions (Table 2).

Physicians' responses

The behaviors of the two groups of physicians towards the I-Score during EOL decisions are presented in Table 2. The following major differences seemed to impact the EOL decision-making process. Neurologists that more take into account nurses' opinions tended to also

withhold active treatment more often (98% vs. 88%, $p=0.04$), to withdraw nutrition and artificial hydration more often (59% vs. 39%, $p=0.04$), and to prescribe analgesics and hypnotics to potentially lethal doses more frequently (70% vs. 48%, $p=0.03$) compared to neurologists that did not confer with nurses on EOL decisions. Physicians that were more involved with nurses when making EOL decisions reported that decisions were often made during specific round-table discussions dedicated to severe-stroke patients (24% vs. 11%, $p=0.02$). This occurred more frequently during medical or unit round-table discussions (58% vs. 35%, $p=0.004$) and less often at a patient's bedside (25% vs. 49%, $p=0.02$).

The physicians' opinions relating to implications for the family also differed according to which group they were in. Physicians who were more involved with nurses during EOL decisions responded that, when DNR orders were decided upon, the “family's opinion was important” (82% vs. 64%, $p=0.047$) and that it was less often “necessary to decide” (12% vs. 30%, $p=0.047$).

These different ways of involving or consulting with the family showed that, in cases of difficult decision, a potential disagreement with the family happened more often in the physician group that seem to involve nurses (12% vs. 5%, $p=0.046$). In addition, these physicians said it was important that a physician from another unit added an external viewpoint during these meetings on EOL decisions (80% vs. 59%, $p=0.02$).

DISCUSSION

The topic of nurse–physician collaboration in the context of EOL decision-making is of concern in ICUs; our analysis seems to confirm that the participation of nurses in EOL decision-making for patients admitted into SUs could have a influence on physicians' decision making (28,29). We noted that attitudes differed during EOL decision-making according to the potential involvement of nurses in this process, despite any other influence or any specific profile of the physician or hospital. When a physician answered that nurses were involved in decision making, it seemed that the process of EOL decision making was more collegiate; in addition, these physicians valued an opinion from a physician from another department. Collaborative behavior resulted in a greater likelihood of consulting with external team members, doctors, and relatives. This was probably due to the collaboration, and because those nurses that were more involved with a physician's decisions were, consequently, more concerned and dedicated to the patients' outcomes (23,30). This increasing number of EOL decisions when nurses are involved is a key point, because lack of decision can made the team members act based on their own individual skills and because studies have highlight the role of nurses to create credible care plan during palliative care (31).

This study also highlights that effective collaboration between physicians and nurses shaped the organization of the unit and enabled effective communication among its members through meetings, including round-the-table meetings. In the ICU, the healthcare professionals involved in the decision-making process might not always assess the situation identically, challenging the interdisciplinary collaboration (17,32). Collaboration is here defined as: “ICU nurses and physicians cooperatively working together, sharing responsibility for problem solving and decision-making, to formulate and carry out plans for patient care” (33). This collaboration and more optimal organization probably provided the best-quality of EOL

decision-making by the different actors in the unit, as recommended for the management of palliative and end-of-life care of stroke patients (1,34). The importance of collaboration is required during EOL decision and particularly with stroke patient who are at high risk to experience neurological symptom (as nausea and hiccup) with a lower ratio of staff/patient than in a plaintive care ward (35).

The differences between nurses' and physicians' perceptions of EOL decisions can be identified as a strength and to improve the quality of decision-making. Nurses should be more involved in recommendations for withholding or withdrawing a therapy, and this study shows that a decision should ideally be multidisciplinary to improve patient care and to reduce job strain.

We also noted that physicians more involved with nurses in decision making thought that the family's opinion was "important", whereas the other group thought that the family's opinion was "necessary" when making a decision. Although this was a minimal difference, this is a crucial point in the way that families are involved. A previous study has shown that only 47% of family members expressed a desire to participate in the EOL decisions (21). The group that involved nurses said that it was "important" to allow a family to decide, but it was not necessary for them to be involved in the actual decision. This point seems to more respect the family's involvement, as these decisions can be a source of stress and discomfort for the family, and for the patients (36,37). The involvement of families on a non-voluntary basis can also expose the team to a greater risk of conflict with families or a difficult decision (12% vs. 5%, $p=0.04$). This difference is probably due to the fact that nurses are more often closely involved with the patient and family than physicians.

Limitations

In this retrospective analysis of a one-time cross-sectional national survey, we emphasize that nurses were not directly consulted in this vignette national prospective study: thus, the nurse's involvement could be under- or over-estimated by the physicians' viewpoints. Nevertheless, we considered that the TELOS study was a unique opportunity to investigate this field. A similar study is being conducted among French nurses to provide information on nurses' involvement in EOL decisions. Future research on nurse–physician collaboration during EOL decisions should be conducted in various countries and in different types of hospital wards to improve external validity. **Moreover, our study lacks precise information on religion and economic status and this aspect should be more investigated.** For a more complete picture of this phenomenon, nurses and allied health personal should be directly consulted to determine their attitudes and perceptions, and geographical distribution of the centers should be studied. Another limitation is that participants were not asked about their opinion on euthanasia due to the French legal framework of palliative care which does not allow euthanasia. Finally, even with the participation of 49 distinct French SUs, we cannot affirm that our study is fully representative of the French setting. Despite these limitations, our results provide some substantial information concerning nurse–physician collaboration during critical care.

Conclusion

The practice and behavior of stroke physicians seemed to be impacted by the nurses' inputs during EOL decision-making regarding patients hospitalized within acute SUs. Involvement

of nurses may aid physicians when making decisions of whether to forgo a life-sustaining therapy or to prescribe an analgesic or hypnotic medication to these patients. This is probably because making a collective decision provides a greater perspective on the meaning of care and/or because interdisciplinary EOL decisions and group discussions help to support any decision. Involvement of nurses seemed to improve the way that the family's choice was taken into account during decisions on whether to sustain or cease a therapy. Further studies are needed to confirm our findings and to identify a profile and the socio-demographic characteristics of nurses who were more involved in EOL decisions, and to determine the role of nurses in other ICUs.

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TABLE 1. Weighting of answers and descriptions of the I-Score, *n* (%). Items were extracted from the Q2 Ward Questionnaire.

Table 2. Epidemiologic characteristics of physicians according to two levels of the I-Score, *n* (%).

Supplement 1. Characteristics of the neurology wards included in the study: *n* (%). Data are given as numbers and percentages, *n* (%); * median and [1st; 3rd quartile].

TABLE 1. Weighting of answers and descriptions of the I-Score, n (%). Items were extracted from the Q2 Ward Questionnaire.

Question no.	Question: N=6	Response	Weight	Total: (N=120)	I-Score ≤10 (N=64)	I-Score >10 (N= 56)
Q2-22	EOLD was made by: (MC)	Physician in charge of the unit	0	66 (55%)	38 (59%)	28 (50%)
		Junior physician alone	0	0	0	0
		Senior physician of the ward	0	66 (55%)	41 (64%)	25 (45%)
		Physician who was available at the EOL decision	0	58 (48%)	33 (52%)	25 (45%)
		Maximum no. of physicians in collegial discussions that included nurses	2	96 (80%)	44 (69%)	52 (93%)
Q2-26	During EOLD, most of the time nurses were: (SC):	Consulted during discussions	2	82 (68%)	32 (50%)	50 (89%)
		Informed when decisions were made	1	32 (27%)	27 (42%)	5 (9%)
		Not asked for their opinions	0	2 (2%)	2 (3%)	0
Q2-29	When EOLDs were made, the following people were usually present: (MC):	Unit manager	0	29 (24%)	19 (30%)	10 (18%)
		Senior physician of the ward	0	50 (42%)	20 (31%)	30 (54%)
		Senior physician in charge of the patient	0	111 (93%)	61 (95%)	50 (89%)
		Other physicians in the ward	0	25 (21%)	9 (14%)	16 (29%)
		Junior physician	0	90 (75%)	45 (70%)	45 (80%)
		Physician from another unit	0	13 (11%)	4 (6%)	9 (16%)
		Head nurse	1	51 (43%)	15 (23%)	36 (64%)
		Nurse	2	80 (67%)	29 (45%)	51 (91%)
		Nurse helper	2	34 (28%)	2 (3%)	32 (57%)
		Physiotherapist	0	20 (17%)	6 (9%)	14 (25%)
		Speech therapist	0	14 (12%)	5 (8%)	9 (16%)
		Psychologist	0	14 (12%)	3 (5%)	11 (20%)
Q2-34	In your unit EOLDs were: (SC)	Frequently taken by the unit manager	0	20 (17%)	17 (27%)	3 (5%)
		Taken by the unit manager after everybody had given their opinion	0	24 (20%)	11 (17%)	13 (23%)
		Were collegial	1	71 (59%)	32 (50%)	39 (70%)
Q2-38	During EOLDs, disagreement can come from the nursing team because: (MC)	They disagreed with the EOLD	2	18 (15%)	6 (9%)	12 (21%)
		Disagreed with the execution of the EOLD	2	57 (48%)	20 (31%)	37 (66%)
		Disagreed with the way the family were managed	2	10 (8%)	2 (3%)	8 (14%)
		Found the execution of EOLD too long	2	47 (39%)	18 (28%)	29 (52%)
		Never disagreed	0	29 (24%)	25 (39%)	4 (7%)
Q2-53	Ideally, according to you, nurses should: (SC)	Be informed of EOLD	1	30 (25%)	18 (28%)	12 (21%)
		Be consulted about EOLD	2	81 (68%)	39 (61%)	43 (77%)
		Not give their opinions	0	1 (1%)	1 (2%)	0
		Only give their opinions on some occasions	0	6 (5%)	1 (8%)	5 (2%)
Total			0-20	10 [8; 13]	8 [6; 9]	13 [12; 14]

Abbreviations: SC: simple choice; MC: multiple choice; EOLD: end-of-life decisions.

Table 2. Epidemiologic characteristics of physicians according to two levels of I-Score, n (%).

Question	Total: (N=120)	I-Score ≤10 (N=64)	I-Score >10 (N= 56)	p-value
Age (years)	40 [34 ; 47]	39 [35 ; 45]	42 [34; 47]	0.4
Gender (F)	56 (44%)	29 (47%)	27 (49%)	0.9
Neurologist physician	120 (95%)	62 (98%)	55 (98%)	1
Experience (years)				
<1	1 (1%)	0	1 (2%)	0.5
1–5	29 (24%)	14 (22%)	15 (27%)	
6–10	29 (24%)	18 (29%)	11 (20%)	
>10	59 (49%)	31 (49%)	28 (51%)	
Proportion of stroke patients				
<1/3	16 (13%)	7 (11%)	9 (16%)	0.5
1/3–2/3	43 (36%)	24 (38%)	19 (34%)	
2/3– 100%	47 (39%)	23 (37%)	24 (43%)	
100%	13 (11%)	9 (14%)	4 (7%)	
Experience in the unit (years)				
<1	12 (10%)	7 (11%)	5 (9%)	0.9
1–5	42 (35%)	22 (35%)	20 (36%)	
6–10	21 (17%)	12 (19%)	9 (16%)	
>10	44 (37%)	22 (35%)	22 (39%)	
In the management of severe stroke patient, have you ever: (MC)				
Withheld an active treatment?	111 (93%)	56 (88%)	55 (98%)	0.04
Withdrawn nutrition or artificial hydration?	58 (48%)	25 (39%)	33 (59%)	0.04
Prescribed analgesics and/or hypnotics at a potentially lethal dose?	70 (58%)	31 (48%)	39 (70%)	0.03
Are there round-the-table meetings in your unit, and do you join in? (SC)				
Yes, systematically	103 (86%)	57 (89%)	46 (82%)	0.3
Yes, occasionally	7 (6%)	3 (5%)	4 (7%)	
No	2 (2%)	1 (2%)	1 (2%)	
Are there medical round-the-table meetings in your unit to talk about patients, and do you join in? (SC)				
Yes, systematically	99 (83%)	57 (89%)	42 (79%)	0.3
Yes, occasionally	16 (13%)	6 (9%)	10 (19%)	
No	0	0	0	
Are there team round-the-table meetings of physicians and AHPs in your unit to talk about patients' outcomes, and do you join in? (SC)				
Yes, systematically	77 (64%)	41 (64%)	36 (67%)	0.6
Yes, occasionally	26 (22%)	15 (23%)	11 (20%)	
No	4 (3%)	1 (1%)	3 (6%)	
Decided to withdraw or continue a life-sustaining treatment for severe stroke at a bedside meeting?: (SC)				
never	6 (5%)	2 (3%)	4 (7%)	0.02
sometimes	53 (44%)	26 (41%)	27 (49%)	
often	45 (38%)	31 (49%)	14 (25%)	
Decided to withdraw or continue a life-sustaining treatment for severe stroke during a medical or unit team meeting?: (SC)				
never	16 (13%)	14 (22%)	2 (4%)	0.004
sometimes	44 (37%)	26 (41%)	18 (34%)	
often	53 (44%)	22 (35%)	31 (58%)	
Decided to withdraw or continue a life-sustaining treatment for severe stroke during a specific meeting dedicated to the situation?: (SC)				
never	56 (47%)	37 (60%)	19 (35%)	0.02
sometimes	34 (28%)	17 (27%)	17 (31%)	
often	20 (16%)	7 (11%)	13 (24%)	
Is there complementary ongoing medical education and/or do you frequently work with specialists in: (MC)				
ethics	17 (14%)	9 (14%)	8 (14%)	1

palliative care	29 (23%)	18 (28%)	11 (20%)	0.3
none	79 (63%)	42 (66%)	37 (66%)	1
In cases of a difficult decision, were the difficulties linked?:				
	Potential disagreement with family			
never	8 (7%)	7 (12%)	1 (2%)	0.046
sometimes	97 (81%)	49 (82%)	48 (86%)	
often	10 (8%)	3 (5%)	7 (12%)	
always	1 (1%)	1 (2%)	0	
	Psychosocial situation of the patient			
never	48 (40%)	30 (52%)	18 (35%)	0.04
sometimes	60 (50%)	26 (45%)	34 (65%)	
often	2 (2%)	2 (3%)	0	
always	0	0	0	
For DNR orders, do you think that the family's opinion is: (SC)				
Necessary to make a decision?	26 (22%)	19 (30%)	7 (12%)	0.047
Important to make a decision	87 (73%)	41 (64%)	46 (82%)	
Is not necessary: the family does not need to be involved	6 (5%)	4 (6%)	2 (4%)	
Do you find it important that a physician from another unit, or the palliative-care team are present during an EOLD: (SC)				
Yes	83 (69%)	38 (59%)	45 (80%)	0.017
No	37 (31%)	26 (14%)	11 (20%)	
In cases with an uncertain outcome, would you say that you are: (SC)				
Pessimistic	42 (35%)	16 (33%)	26 (58%)	0.023
Optimistic	51 (43%)	32 (67%)	19 (42%)	
Religion (SC)				
Buddhist	0	0	0	0.9
Catholic	52 (43%)	27 (44%)	25 (47%)	
Jewish	0	0	1 (2%)	
Muslim	4 (3%)	3 (5%)	1 (2%)	
Protestant	1 (1%)	1 (2%)	0	
None	43 (36%)	23 (37%)	20 (38%)	
Other	5 (4%)	3 (5%)	2 (4%)	
Importance of religion (SC)				
Important	30 (26%)	18 (27%)	12 (24%)	0.7
Not important	67 (56%)	33 (57%)	34 (62%)	

Abbreviations: SC: simple choice; MC: multiple choice; ELD: end-of-life decisions.