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Ethical frameworks for surrogates' end-of-life planning experiences: A qualitative systematic review

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Abstract

Despite the growing body of knowledge about surrogate decision making, we know very little about the use of ethical frameworks including ethical theories, principles, and concepts to understand surrogates' day-to-day experiences in end-of-life care planning for incapacitated adults. This systematic review of 30 qualitative research papers was conducted to identify the types of ethical frameworks used to address surrogates' experiences in end-of-life care planning for incapacitated adults as well as the most common themes or patterns found in surrogate decision making research.. Seven papers explicitly identified ethical theories, principles, or concepts for their studies, such as autonomy, substituted judgment, and best interests. Themes identified about surrogate decision making included: responsibilities and goals, factors affecting surrogates' decision making, and outcomes for surrogates. In fact, an overarching theme of "wanting to do the right thing" for incapacitated adults and/or themselves was prominent. Understanding the complexity of surrogates' experiences of end-of-life care planning is beyond the scope of conventional ethical frameworks. Ethical frameworks that address individuality and contextual variations related to decision making may more appropriately guide surrogate decision making research that explores surrogates' end-of-life care planning experiences.

Keywords

Surrogate decision making; end-of-life care planning; systematic review

Introduction

A surrogate decision maker (SDM) is a person designated in a patient's advance directive (e.g., health proxy, health agent) or appointed by a court (e.g., guardian) to make necessary healthcare decisions on behalf of incapacitated individuals.¹ In most states in the United

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The Authors declare that there is no conflict of interest.

States, SDMs are also determined by state laws if designated SDMs are unable to make decisions or no one is designated or appointed in documents.² SDMs are usually family members who are asked to make a complex array of medical and other types of family-related decisions for ill family members, particularly, at end-of-life (EOL).³ These ethical decisions are difficult for many SDMs as they struggle to do what is best for their loved ones.^{4,5}

Numerous studies and guidelines suggest that SDMs should make decisions for their ill family members based on the person's advance directive, substituted judgment, or best-interest standard.^{1,6} Using the concept of substituted judgment, SDMs should make decisions based on "the patient's inferred values and preferences, as best they can be gleaned from knowledge of and experience with the patient."^{1(p52)} On the other hand, the best-interests standard is referred to as a way of making decisions that considers what would be best for the patient in given situations.¹ For this standard, the patient's current and future interests should be considered weighing the patient's previous treatment experiences, health trajectories, goals of treatment, and potential benefits and burdens of treatment as well as his/her values and beliefs.^{1,7}

However, the ethical concepts of substituted judgment and the best-interest standard generate debate among ethicists and healthcare professionals because evidence suggests that SDMs' accuracy in predicting ill family members' preferences for EOL care is poor to moderate.⁸⁻¹⁰ Others suggest that surrogate decision making, based on best interests of ill family members, is also compromised by SDMs' limited understanding of ill family members' medical information.¹ Although many studies examine these standards in relation to surrogate decision making, little information about other types of ethical frameworks exists to understand SDMs' experiences of EOL care planning.

In this paper, we conducted a systematic review of qualitative studies^{11,12} focused on SDMs' experiences as decision makers in EOL care planning for incapacitated adults and whether and what type of ethical framework was used to understand these experiences. Only qualitative studies were chosen because approaches employed in qualitative studies provide an in-depth understanding of participants' perceptions and experiences of a certain phenomenon.¹¹ Through a qualitative systematic review,^{11,12} we sought to provide an emic view of family SDMs' involvement in EOL care planning. This review also broadens our knowledge about ethical frameworks to better understand the importance of family surrogate decision making.

Methods

Search strategy

Articles published until January 31, 2015 were searched via PubMed, CINAHL, EMBASE, and Scopus using the terms "surrogate decision making," "surrogate decision makers," "family surrogates," and "decision makers," combined with "end-of-life care." With the search in PubMed, limits on language (i.e., English) and target population (i.e., adults) were applied. Articles were included if they were (a) written in English; (b) focused on qualitative research with SDMs as study participants; and (c) studied SDMs' experiences or

perspectives in EOL care planning for incapacitated adults. In contrast, we excluded articles if they were (a) reviews of the literature including systematic reviews; (b) case reports; (c) articles without abstracts; (d) research papers focused on healthcare providers or incapacitated patients as study participants; and (e) research papers without a focus on EOL care planning.

The first author initially screened articles based on titles; in other words, articles with titles that contained or meant “surrogate decision making,” “surrogate decision makers,” and/or “EOL care planning” were included for a review of abstracts. Abstracts were assessed if articles were research papers focused on SDMs (also as study participants) and EOL care planning. Full-texts of articles, filtered through the two steps, were reviewed and then included for this review if they addressed SDMs’ experiences or perspectives in the context of EOL care planning.

Appraisal strategy

The three authors reviewed and discussed the articles included in this review, focusing on study objectives, methods, and findings, and underlying ethical frameworks. We also used the Critical Appraisal Skills Programme (CASP) qualitative checklist¹³ to assess the quality of the articles included in this review but did not exclude articles based on quality. This checklist was chosen because it allows a step-by-step approach to evaluating qualitative research articles using main and sub-questions and because it “can be applied to different types of qualitative designs to assess credibility, transferability, dependability, and conformability of the studies.”^{14(p5)} This checklist contains 10 questions including items such as: (1) Was there a clear statement of the aims of the research?; (2) Is a qualitative methodology appropriate?; (3) Was the research design appropriate to address the aims of the research?; and (4) Was the recruitment strategy appropriate to the aims of the research? Under the main questions are several sub-questions for reviewers to consider in their scoring; we scored each question with a “1” if the studies met the requirement and “0” if they did not, or if it was not clear (total score: 0-9). The last question on the checklist – “How valuable is the research?” – was not included for the score.

Analysis strategy

To identify underlying ethical frameworks, we focused on whether and what type of ethical framework was used. In this paper, we use the term “ethical frameworks” broadly to include ethical theories (e.g., utilitarian, deontological), principles (e.g., autonomy, beneficence), and concepts (e.g., substituted judgment and best interests standard) related to surrogate decision making and used to guide research. If there was no explicit ethical framework for the study, we examined if any ethical theories or principles related to surrogate decision making were described or discussed in the introduction/background and discussion sections.

To understand SDMs’ experiences of EOL care planning, we extracted the results section from each article and analyzed it using Atlas.ti 7.¹⁵ Despite our acknowledgment of various approaches to synthesizing the findings from qualitative studies (e.g., meta-ethnography, grounded theory, thematic synthesis),¹⁶ content analysis was chosen to analyze and synthesize the findings that are already “highly organized and contextualized.”^{17(p341)}

Content analysis is used in many forms of knowledge synthesis; that is, it as “a qualitative method for systematically and rigorously integrating, interpreting, and synthesizing qualitative findings that have been extracted from multiple qualitative or mixed-method research reports.”^{17(p342)} Also, this is consistent with the purpose of this review which is to find patterns in SDMs’ experiences of EOL care planning for their ill family members, rather than developing theories or conceptual models. Among 3 different approaches of content analysis, we used conventional (or inductive) content analysis to analyze the data¹⁸ and inductively identify themes and/or categories in the results of the studies included in this review. The first author read the results repeatedly taking memos to get a general sense of the data, then open-coded the data line by line looking for key concepts or thoughts, and grouped codes into categories or sub-themes that reflected each group of clustered codes. These categories or sub-themes were then grouped into themes. The three authors discussed and refined codes, themes, and categories.^{17,18}

Findings

Study selection

The search yielded 1,152 articles after removing duplicates. We screened articles based on titles, abstracts, and full-texts, which resulted in 28 qualitative studies that satisfied the inclusion criteria. We excluded 1,124 articles because (a) titles did not indicate surrogate decision making and/or EOL care planning ($n = 720$) and (b) abstracts and/or full-texts did not indicate qualitative research focused on SDMs’ experiences or perspectives in EOL care planning for incapacitated adults ($n = 404$). As two qualitative research articles identified from reference lists were additionally included in this review, a total of 30 qualitative research articles were finally reviewed (see Figure 1).

Study characteristics

There were 25 different data sets for 30 qualitative research articles (see Table 1). Of those, 22 data sets were from North America (21 in the United States and one in Canada) and three from European countries. The number of SDMs participated in each data set ranged from 10 to 179 and study settings were hospitals ($n = 12$), long-term care facilities ($n = 5$), communities ($n = 6$), and combined settings ($n = 2$). The data also included diverse patient populations (e.g., advanced dementia, advanced cancer, traumatic brain injury).

Twelve articles reported their specific study designs (e.g., grounded theory, phenomenology) but the rest of the articles did not. Individual, semi-structured interviews were most often used in the studies included. The majority of articles reported the use of investigator triangulation and member checking during data analysis to strengthen the rigor of study findings.

Using the CASP qualitative checklist to evaluate each article included in this review, all studies satisfied at least 6 of 9 items (average=7.57). However, most of the articles did not sufficiently address two questions: “Was the research design appropriate to address the aims of the research?”; and “Has the relationship between researcher and participants been adequately considered?” As 60% of articles were not explicit about their research designs, it

was hard to decide on appropriateness of the research design. In addition, 19 articles did not report procedures about how each investigator examined his/her own role, potential positionality, and influence during recruitment, selection of study settings, and data collection. Although most of the articles reported their approaches to analyzing data in detail, a few articles ($n = 6$) did not describe specific analytic techniques including approaches to avoiding investigators' own potential biases and if data saturation was achieved.

Ethical frameworks

Ethical frameworks for research, including ethical theories, principles, and concepts, were made explicit in seven articles.^{23,26,27,31,35,44,47} These guiding ethical frameworks included traditional ethical concepts of respecting patient autonomy,^{26,35} and substituted judgment and/or best-interest standards,^{31,44,47} as well as "case-based" ethical theories (e.g., narrative ethics, casuistry).²⁷ Ethical frameworks were typically introduced in the introduction or background with research questions framed around them and points raised about the frameworks in the discussion sections.

In contrast, the majority of articles ($n = 23$) did not explicitly state ethical frameworks for their studies. Eight articles described or discussed in various sections of the papers the main points of autonomy, substituted judgment, and/or best-interest standards, including definition and limitations.^{22,24,33,37-41} However, these standards did not guide the research questions; rather, some of the research questions seem to be based on the complexity of surrogate decision making.^{24,33,37} Another 15 articles did not state ethical principles or theories related to surrogate decision making.^{19-21,25,28-30,32,34,36,42,43,45,46,48}

Overarching theme: "wanting to do the right thing"

Planning EOL care for incapacitated adults is a complex process for SDMs. However, in this process, SDMs want to do "the right thing" for their incapacitated loved ones and/or themselves in given, variable situations.³⁰ The right thing varies from person to person, even though most SDMs feel responsible for protecting, advocating, and providing care to their loved ones. Some people may pursue the persons' maximal comfort and peaceful/natural death whereas others may seek the persons' recovery or their own peace of mind. Moreover, SDMs consider various factors when deciding on the right thing, such as patients' written or verbal instructions and best interests, their own personal knowledge of their loved ones, their own preferences and best interests, family well-being and consensus, and relationship with healthcare providers. Throughout the decision-making process, most SDMs experience emotional distress due to their role obligation to do the right thing for their loved ones. Common themes about SDMs' experiences as decision makers in EOL care planning for incapacitated adults are presented in Figure 2.

Responsibilities include protecting, advocating, and caregiving

SDMs mainly function as protectors by keeping loved ones from threats that potentially increase their suffering (e.g., life-sustaining treatment).^{27,32,38} For example, SDMs decided to withhold life-sustaining treatments from their loved ones based on perceptions of suffering intensity and futility.²⁷ One SDM said:

I said, “you tell him that I absolutely refuse for them to do anything with my father. Unless a doctor calls and tells me that I have to do something, it’s gonna stay the way it is now.” And I said, “If he doesn’t like it, and he thinks he’s gonna cause you trouble, you tell him that I’m gonna go get me a lawyer.” ^{27(p256)}

Advocating—SDMs advocate for their ill family members in various ways. This advocacy is usually demonstrated by respecting the person’s wishes, preferences and goals with healthcare providers and systems of care.^{38,39} In a study by Meeker³⁸, SDMs reported on respecting their family members’ wishes in the following way: “That’s just about what we did [followed through on earlier decisions made by or with the ill family member]. We all had agreed on this.”^{38(p216)}

Caregiving—SDMs are unique caregivers; they consistently provide for the care needs of their ill family member(s) based on ongoing assessments of the situation.^{32,38,39} For example, one daughter reported that she had to spend more time with her ill mother and older father to address their needs as her mother’s illness progressed³⁹:

I wasn’t involved that much but maybe make sure that I went there once a week and then as she got sicker, I would make sure I would go a couple of times a week but I realized now that I have to really go every day because there is always some kind of mini crisis.^{39(p112)}

SDMs’ goals in EOL care planning

SDMs share several common goals in EOL care planning for their family members, including maximal comfort, a peaceful and natural death, recovery if possible, and surrogates’ peace of mind.^{29,30,35,40,46} **Maximizing the person’s comfort** is a dominant goal for SDMs.^{30,34,35} This is also described as reducing suffering and avoiding harm. SDMs primarily want their ill family members to be comfortable at EOL.³⁰ However, SDMs’ perceptions about comfort may differ from person to person; for instance, although some SDMs viewed artificial nutrition and hydration (e.g., tube feeding and intravenous fluid) as a source of suffering, others thought that such therapy could reduce suffering.³⁵ One SDM said:

Many family members discontinue nutrition now; they stop the nutrition, and only provide fluids. That takes about 2–3 months, but I mean no! I couldn’t do something like that. ... I think it’s inhumane. Because, I don’t know, I still don’t know if he is able to perceive things. And he already had problems with his stomach and still for me it is starvation. So I wouldn’t do it.^{35(p334)}

Peaceful and natural death—SDMs often do not want to prolong the dying process of their family members,^{29,30,46} as shown in the following statement:

We have all this machinery ... which keeps us going a lot longer, but is this what we really want as a human being? ... I think sometimes we give up our rights as a human being to make choices.^{30(p279)}

However, SDMs often experience difficulty defining a natural death. For instance, some SDMs of individuals with advanced dementia did not perceive that a process of a natural death for this population includes pneumonia and swallowing problems.²⁹ As a result, they often want their family members who reside in nursing homes to be transferred to hospitals and to receive aggressive treatments.

Expectation of patient recovery—Many SDMs maintain hope that their loved ones will recover from life-threatening illnesses and continue to live longer, thus deciding to provide life-sustaining treatments despite the questionable benefits of such treatments when near death.^{34,40,46} One SDM said:

You want to give her a chance. And that's it, that's all. And that's why even now you ... they talk about the trach and dialysis and things and you think, well, I'm not sure if she'd want that trach thing going on, but ... why not give her a shot at it, a chance. ... I don't know. That's what I struggle with; that's the struggle.^{40(p1660)}

Surrogates' own peace of mind—Another important goal for SDMs in EOL care planning is their own peace of mind.^{26,29,30,40} SDMs often want to feel they have done everything possible within their reach, but the situation was beyond their ability to have an impact.²⁹ The decisions of the SDM can also leave potential scars, especially if the SDM believes that his or her decisions lead to the death of their loved one as shown in the following statement: "I didn't want it to be because I would have always lived with the 'what if's. What if? Did I make the right decision?"^{40(p1660)} Accordingly, many SDMs choose life-sustaining treatments for their family members.

SDMs may have several goals simultaneously that are somewhat contradictory. They have ambivalent views on their family members' death, such as a "blessing" and "tragedy" or "accepted" and "forbidden."^{29(p254)} Although SDMs want their family members to die naturally and peacefully, they may also decide to use life-sustaining treatments to initiate a chance of recovery.³⁰

Various factors that influence SDMs' decisions

Patients' written or verbal instructions—Many SDMs gain knowledge of their family member's wishes or preferences through prior conversations or written documents, such as advance directives.^{22,35,37,40,44,47} SDMs often feel confident and comfortable making decisions on behalf of their ill family members when they know the person's wishes.⁴² Several SDMs said, "Making the decision to stop treatment was easy, I firmly knew her wishes!" and "My mom's living will made it clear what she wanted."^{22(p268)} However, in a recent study including ethnically diverse SDMs, many adult children reported lack of knowledge regarding their parents' EOL wishes/preferences due to lack of discussions.⁴¹ Death was often considered a topic to be avoided.⁴¹

Patients' best-interests—SDMs may deliberate what would be best for their ill family members based on the persons' past, present, and future health status and quality of life.^{24,31-33,36,37,40} Quality of life is an important concept to consider that changes as diseases progress.^{24,42} At EOL, when there is thought to be little quality of life for the ill

person, a primary focus on comfort care may be best for the person.²⁴ One SDM said about consideration of the ill person's quality of life when making EOL care decisions³⁶:

Well, I know her quality of life is terrible, you know. [Life-sustaining measures] can go on and on forever until something happens and she doesn't make it. And at that point, that was when I said, "No, I just don't want that."^{36(p334)}

When making decisions using this best-interest standard, SDMs often perceive their decision-making experience to be positive.^{24,42} However, lack of SDMs' understanding of the ill persons' health status, diseases, and treatment options, tends to impede their use of this best-interest standard.

Surrogates' personal knowledge of the person—When a patient's written or verbal instructions are unavailable, a SDM's own knowledge of the person, such as values, character, and personality, affects their decision making on EOL care.^{27,29,40} SDMs gain this knowledge from their lived experience with the person: "I have to make [decisions] from my heart, knowing the kind of person that she is."^{40(p1659)} Also, this knowledge supports the incapacitated person's autonomy.^{27,40}

Surrogates' own beliefs, values, preferences, and best interests—Some SDMs make decisions based on their own beliefs, values, preferences, and best interests rather than the incapacitated adult's wishes or best interests.^{26,27,33,35,39,44,45} SDMs often report that their strength or hope comes from faith or religion^{20,32,37,40} and final outcomes are in God's hands.³² Moreover, some SDMs choose what they prefer: "And even though my mother was in that kind of shape, I didn't really want to give her up—selfishly, I did not."^{36(p334)} SDMs' financial situation, own health status, and other responsibilities including taking care of their own family may also influence their decision making.⁴⁵ Interestingly, their own definitions of life-sustaining treatments, that may vary based on their prior experiences, often affect their decisions.^{26,35} In a study by Kuehlmeier, Borasio³⁵ for example, artificial nutrition and hydration was not considered to be life-sustaining treatment by a surrogate; therefore, the surrogate's wife continued to receive artificial nutrition and hydration. The husband stated that "because healthy people would also be nourished, artificial nutrition and hydration was neither artificial nor invasive. To him it was not a treatment measure at all."^{23(p334)}

Family well-being and consensus—Other family members' needs are an important consideration when SDMs make decisions for incapacitated adults.^{31,36,40,45} Family needs may bring about conflict with the ill person's expressed wishes or known values. In one study by Schenker, Crowley-Matoka⁴⁰ an SDM reported difficulty balancing between best interests for the ill person and for other family members:

Just trying to deal with the pain that everybody's [feeling] ... with ... what [the patient] would feel if we kept her alive ... because I know she's not going to be happy. What my dad feels, if we let her go, 'cause I know he's not going to be happy. And my brother's not going to be happy, and um ... just trying ... to keep a happy medium, but it's such a hard situation, that there really isn't one (p. 1661).

In addition, SDMs want to discuss with other family members EOL care to reach consensus on what is best for the ill person.^{40,41,45} A reason for this is that they do not want to feel solely responsible or be blamed for their loved ones' EOL care.⁴⁰ Moreover, family conflict around what would be best for their loved one makes surrogates' decision making more difficult and stressful.⁴⁵ Family conflict can be reduced through early and ongoing discussions about each family member's role in decision making and care for loved ones.⁴¹

Relationship with healthcare providers—Healthcare providers play important roles in the process of surrogates' decision making. They provide SDMs with information about patients' health status, prognosis, and treatment options, recommendations regarding treatments, and often reassurance about decisions.^{25,30-33,36,43,45-47} An SDM described her experience of interacting with healthcare providers when deciding to withdraw ventilator support from her husband⁴⁵:

I talked to the doctors, and they all were very helpful in giving me the proper information, and telling me that he probably wouldn't come out of it because his cancer had spread and plus he had pneumonia on top of it (p. 1277).

SDMs prefer healthcare providers' open communication about their ill family members' prognosis even though the prognosis is uncertain.^{19,20,28} They understand that predicting the future involves uncertainty and may believe the future is under God's control.⁴⁸ Moreover, open discussion about an uncertain prognosis helps SDMs realize their ill family member's serious health status, prepares them for the person's death, and often contributes to increased trust in providers.^{28,36}

Often, SDMs rely on healthcare providers for decision making on EOL care for their family members.³² In a study by Jeffers³² a husband who lacked medical knowledge reported he needed to rely on healthcare providers when making decisions for his wife because he perceived that "the way he could best assist with his wife's recovery was to give the 'go ahead' to the physicians for the medical treatment that was suggested" (p. 360). Also, he thought "his lack of medical background interfered with his ability to make decisions regarding his wife's treatment" (p. 360).

Although SDMs continually seek help and information about their ill family member's health status, prognosis, and treatment options from healthcare providers, many SDMs report limited contact and discussions with healthcare providers.^{25,30,32,36-38,42,45,46} They struggle to get clinical information about their family member from healthcare providers.^{23,43} Some SDMs in one study had to "chase" doctors to get information about their family member.³⁶ The quality of SDMs' interaction with healthcare providers is also suboptimal. Some SDMs reported healthcare providers' use of too much jargon, which interfered with their understanding of the information provided.⁴³ In addition, SDMs want to be reassured by healthcare providers about their decisions made for their ill family members.^{25,45}

Outcomes related to the decision-making process

SDMs frequently report emotional distress throughout the decision-making process for their incapacitated family members.^{21,22,29,30,32,38,40,42} They express their feelings using terms

like burden, guilt, stress, shock, and regret.^{29,30,38} Also, they perceive their experience of decision making to be devastating, hardest, and saddest.²² SDMs said about their emotional distress,³⁰ “it’s a painful thing to sit there and sign all of the papers”; “it’s totally on my shoulders ... it just weighs me down so much”; and “we have guilt. You don’t rest well. You don’t eat sleep well. You don’t eat well. ... You feel guilty” (p. 276–277).

There are many reasons for SDMs’ emotional distress: SDMs’ lack of preparedness as a decision maker^{22,24}; continuous observation on their loved ones’ deterioration and suffering^{22,29}; family conflict during the decision-making process^{21,24,27,38,40,45}; feelings of being alone^{21,32,36,41}; and memories about the decision-making experience even after the person’s death.³⁸ In one study, these feelings are not resolved despite SDMs’ knowledge of the ill family member’s wishes or preferences about EOL care.³² In this respect, healthcare providers’ emotional support for SDMs during the decision-making process is necessary. This emotional support includes providing information and frequently contacting SDMs.⁴³

Other outcomes for SDMs as they participate in EOL care planning include SDMs’ acceptance of their loved one’s death and dying and the futility of life-sustaining treatments^{36,42,46}; learning from their experience as a decision maker³⁸; and satisfaction or dissatisfaction.^{24,38} Through shared decision making with healthcare providers, SDMs tend to feel more satisfied with their decisions for their loved ones.²⁴

Discussion

A review of 30 qualitative studies revealed several common themes about SDMs’ experiences as decision makers in EOL care planning for incapacitated adults but with the limited guidance from ethical frameworks. First, SDMs want to do ‘the right thing’ for their ill family members and/or for themselves. Knowing what the ‘right thing’ to do, however, is often complicated by individual differences among SDMs. Each SDM may have a different priority in goals of care for their loved one as well as the factors that contribute to that priority. Although final decisions on goals of care are made by SDMs for incapacitated individuals, SDMs and their family members are dependent on each other and do not hold equal power in the decision-making process. This can create conflict and unease within families because SDMs’ own interests are often considered over their ill family members’ expressed wishes or interests and vice versa. Additionally, SDMs and healthcare providers are interconnected; they are often dependent on each other when making decisions for incapacitated adults in critical situations.⁴⁹ This, too, can create discomfort amongst all stakeholders. Consequently, SDMs experience emotional distress throughout and even after EOL care planning. Our findings well support that surrogate decision making is “far more complex, dynamic, and nuanced than is generally understood.”^{50(p. 49)}

Second, most of the studies we reviewed did not explicitly state the use of theoretical frameworks (including ethics-related frameworks) to guide research questions on surrogate decision making. We found that thirteen articles discussed the traditional ethical principles of respecting patient autonomy and ethical concepts such as substituted judgment, and/or best-interest standards. However, this was often part of the background or discussion sections of the articles; an explicit framework from which the research questions were

derived was not present in eight of the studies we examined. Yet, surrogates' engagement in the decision making process regarding their ill family members' EOL care cannot be fully understood using a single ethical principle or concept.⁵⁰

Understanding the complexity of SDMs' experiences of EOL care planning is beyond the scope of these ethical frameworks and involves considering a number of other ethical concepts. These concepts may include 'non-maleficence,' 'sanctity of life doctrine,' 'acts/omissions distinction,' and 'doctrine of double effect,' which are frequently discussed in healthcare fields.⁵¹ Non-maleficence indicates that people should make decisions that do not harm others.⁵¹ This was rarely discussed as an ethical framework in the studies reviewed but frequently nuanced by SDMs participants as they wanted to protect their ill family members from suffering. Sanctity of life doctrine means that all human beings' life is valuable, so discontinuing the life is wrong no matter how reasonable the decision is.⁵¹ Many family SDMs accept that their ill family members might have very poor quality of life and prognosis, but they still tend not to consider withdrawing and withholding life-sustaining treatments to be potentially a right thing to do for the patients and part of the reasons may be related to this doctrine.

Act-omissions distinction indicates that doing actions to stop someone's life is different from doing nothing for someone who is dying, even though the results are same, someone's death. Based on this distinction, withholding life-sustaining treatment is often permissible.⁵¹ Another concept, doctrine of double effect, explains that actions performed to achieve favorable outcomes can be considered acceptable even though they result in expected but unintended, unfavorable outcomes.^{51,52} Although we did not see these concepts clearly in the studies reviewed, it is worth it to think about if family members consider act and omissions to be different when planning EOL care for their ill family members and how the doctrine of double effect manifests in family surrogate decision making.

As the ethical theories, principles, and concepts mentioned above are deployed differently depending on cultures and countries,^{53,54} SDMs' experiences in EOL care planning are likely to differ. Moreover, as these traditional ethical frameworks do not explain fully about SDMs' experiences of EOL care planning, there has been a shift toward discussing 'case-based ethics' including narrative ethics and casuistry, as described in one of the studies reviewed.²⁷ These case-based ethical theories may better address contextual variations related to surrogate decision making in EOL care planning for their ill family members. Despite the cross-cultural differences in the meaning of ethical concepts, all healthcare providers are committed to EOL goals that support patients and their families.

Limitations and recommendations

Several limitations need discussion. First, because the studies were initially screened by title, some research relevant to this topic may have been excluded from this review. Second, the data we used in this review are the findings of individual qualitative studies, which are already organized and abstracted at various levels, as the level of interpretation and abstraction differs from qualitative description to phenomenology. Moreover, the styles of presenting the findings differ across the studies, from succinct description to highly detailed description. Therefore, analyzing and synthesizing the findings across the studies was

challenging and we may have potentially missed important information. For example, in our review, qualitative codes that were less frequently manifested in the studies reviewed were dropped during the process of categorizing given the volume of information. These minor codes may have valuable information in understanding SDMs' experiences in EOL care planning. Third, targeted patient populations (e.g., cancer, dementia) and study sites (e.g., hospitals, nursing homes) vary in this review. As this review explored common themes and categories in relation to SDMs' experiences in EOL care planning, unique experiences of each group of SDMs were not identified. However, the findings of this review still contribute to expanding current knowledge regarding the complexity of surrogate decision making. Fourth, the majority of SDMs who participated in the studies reviewed were white and from the United States and Europe. Few studies explored minority surrogates' experiences.^{21,41} Studies that explore experiences of other racial/ethnic SDMs, or those in other countries, may broaden our insight into surrogate decision making. Finally, most studies employed individual or focus-group interviews to understand SDMs' experiences when engaging in EOL care planning. Few studies observed the interactions of SDMs and healthcare providers in healthcare settings for EOL care planning. Future research should examine these interactions using participant observational methods.

Many studies that explore surrogates' experiences of EOL care planning do not explicitly use ethical frameworks and also indicate the limitations of dominant, conventional approaches (e.g., ethical principles and ethical concepts of substituted judgment and best-interest standards) on understanding SDMs' experiences. Research that examines other modes of ethical guidance is necessary. For example, the role of the doctrine of double effect, narrative ethics, and casuistry, have rarely been used or explored in research about family surrogate decision making. Studies that examine core features of these ethical frameworks in relation to surrogates' EOL care planning are needed to advance the current state of the science and support healthcare providers, especially nurses, to communicate efficiently with SDMs. As nurses generally spend more time with patients and their family members at the bedside,⁵ they may have more opportunities to explore and understand SDMs' perceptions of EOL care decisions as well as their values, beliefs, and goals.

Conclusions

This systematic review presents common themes manifested in existing qualitative literature on SDMs' engagement in EOL care planning for ill family members. It also discusses individual differences in how SDMs assist loved ones in EOL care planning. Furthermore, the limited use of ethical frameworks (beyond the concepts of "substituted judgment and the best interest") to guide research questions surrounding surrogate decision making calls on renewed efforts to broaden our theoretical thinking in how ethical frameworks might deepen our understanding of the relationship between and among SDMs, patients, and the healthcare system.

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Figure 1.
Flow Diagram

Figure 2.
Surrogates' experiences as decision makers during EOL care planning

Table 1

Summary of Qualitative Studies about SDMs’ Experiences of EOL Care Planning

Author	Objectives	Ethical framework	Design/data collection/analysis	Subjects	Settings	Rigor	Summary of the results	CASP score ^a
Apatira, Boyd ¹⁹	Explore SDMs’ perceptions about discussing uncertain prognoses	NR	<ul style="list-style-type: none">• Unspecified• Individual interviews• Constant comparison	179 SDMs	ICUs USA	<ul style="list-style-type: none">• Investigator triangulation• Member check	Open discussions about uncertain prognosis were preferred with the following reasons: (a) preparing for the future, (b) supporting the patient and family, (c) aversion to false hope, (d) physicians’ obligation to discuss prognosis, and (e) hope not coming from physicians.	7
Boyd, Lo ²⁰	Describe SDMs’ perceptions of prognosis and affecting factors	NR	<ul style="list-style-type: none">• Unspecified• Individual interviews• Inductive analytic approach	179 SDMs	ICUs USA	<ul style="list-style-type: none">• Investigator triangulation• Member check	SDMs estimated patients’ prognostication based on (a) patient characteristics, (b) their own understanding of patients’ physical conditions and histories of illness or recovery, (c) their experiences at the bedside, and (d) “ <i>optimism, intuition, and faith-based beliefs</i> ” (p. 1270).	6
Braun, Beyth ²¹	Describe SDMs’ experiences of making EOL decisions for others	NR	<ul style="list-style-type: none">• Unspecified• Focus-group interviews• Inductive content analysis	44 SDMs	Hospital USA	<ul style="list-style-type: none">• Investigator triangulation	Burden was described in three domains: (a) personal: psychosocial (e.g., guilt), financial, caregiving, and physical; (b) family: feeling alone and family conflict; and (c) clinical: uncertainty and forceful decision making. Poor communication with providers increased burden.	6
Buckey and Molina ²²	Explore SDMs’ experiences of decision making	NR	<ul style="list-style-type: none">• Unspecified• Written statement• Grounded-theory approach	59 SDMs	Hospital, hospices, other agencies USA	NR	SDMs were not emotionally or legally prepared for decision making on behalf of their family members. It was stressful for them to watch their family members declining. Spirituality and availability of advance directives contributed to SDMs’ positive experiences during the decision-making process.	6
Bute, Petronio ²³	Identify challenges SDMs face when communicating with clinicians	Communication privacy management theory	<ul style="list-style-type: none">• Unspecified• Individual interview• Strauss and Corbin’s (1990) process	35 SDMs	ICUs USA	<ul style="list-style-type: none">• Investigator triangulation	SDMs had trouble obtaining timely, accurate information from providers and conveying patients’ information to (multiple) providers (often not knowing the patient’s wishes). Hospital policies and rules also influenced exchanging information.	6
Caron, Griffith ²⁴	Explore SDMs’ perceptions about the decision-making process	Limitations of autonomy, beneficence, nonmaleficence, justice	<ul style="list-style-type: none">• Grounded theory• Individual interview• Constant comparison/dimensional analysis	24 SDMs Advanced dementia	LTCFs Canada	<ul style="list-style-type: none">• Investigator triangulation	Decision-making process involves multiple factors related to patients, caregivers, healthcare providers, family context, and characteristics of treatments. Family surrogates had little information about their roles, but most wanted to participate in decision making. QOL was a main consideration and contributed to the level of treatments.	8
Caron, Griffith ²⁵	Explore SDMs’ perspectives about interactions with	NR	<ul style="list-style-type: none">• Grounded theory• Individual interview	24 SDMs Advanced dementia	LTCFs Canada	<ul style="list-style-type: none">• Investigator triangulation	Four main themes were identified: (a) lack of personalized relationship; (b) lack of contact or consistent meetings	8

Author	Objectives	Ethical framework	Design/data collection/analysis	Subjects	Settings	Rigor	Summary of the results	CASP score ^a
	healthcare providers		<ul style="list-style-type: none">• Constant comparison/dimensional analysis				with providers; (c) importance of sharing values and beliefs; and (d) “level of trust in the relationship” (p. 241).	
Dreyer, Forde ²⁶	Describe how patient autonomy is protected, and SDM’s experiences of deciding on limiting LST	Respecting patients’ autonomy	<ul style="list-style-type: none">• Qualitative description• Individual interviews• Constant comparison	15 SDM’s	NHs Norway	<ul style="list-style-type: none">•	Some SDM’s acted on their own preferences and feelings rather than the patients’ best interests. Several just agreed to providers’ suggestion to limiting LST. Some wanted the patients to have artificial nutrition and hydration because of their concerns about the patients’ thirst.	9
Elliott, Gessert ²⁷	Understand SDM’s ethical thinking during the decision-making process	Case-based ethical theory (narrative & casuistry)	<ul style="list-style-type: none">• Unspecified• Focus-group interviews• Thematic analysis	39 SDM’s Advanced dementia	NHs USA	<ul style="list-style-type: none">•	4 themes were identified: gaining decision-making authority, making short- and long-term decisions, rationalizing the decisions and advocating the elders.	7
Evans, Boyd ²⁸	Explore SDM’s perceptions about discussing an uncertain prognosis	NR	<ul style="list-style-type: none">• Unspecified• Individual interviews• Constant comparison	179 SDM’s	ICUs USA	<ul style="list-style-type: none">••	87% preferred physicians discussing an uncertain prognosis. Open discussions allowed SDM’s to prepare for anticipated bereavement, helped them make (best) decisions, and augmented their trust in physicians.	7
Forbes, Bem-Klug ²⁹	Explore SDM’s perceptions about EOL decision-making process	NR	<ul style="list-style-type: none">• Unspecified• Focus-group interview• Content analysis	28 SDM’s Advanced dementia	NHs USA	<ul style="list-style-type: none">••	Decision-making experiences included (a) “emotional effects,” (b) “insult-to-life stories,” (c) “two faces of death,” (d) “values and goals regarding EOL treatments,” and (e) “unrecognized dying trajectory” (p. 251).	7
Gessert, Forbes ³⁰	Understand SDM’s experiences as decision makers	NR	<ul style="list-style-type: none">• Unspecified• Focus-group interviews• Content analysis	28 SDM’s Advanced dementia	NHs USA	<ul style="list-style-type: none">••	Challenges included (a) emotional stress, (b) lack of information/knowledge, (c) being uncomfortable with setting goals (strong desire to “do the right thing,” p. 279), (d) lack of experiences with death of their loved ones, and (e) inconsistent communications with providers.	7
Hirschman, Kapo ³¹	Understand standards SDM’s used in decision making	Substituted judgment Best interests	<ul style="list-style-type: none">• Unspecified• Individual interviews• Qualitative-quantitative analysis approach	30 SDM’s Advanced dementia	Community centers and LTCFs USA	NR	Decision-making standards used by SDM’s were substituted judgment (43%), best interests (57%), or both (37%). Factors related to not using substituted judgment included family consensus, high expectations on the patient, considering patient’s QOL, and providers’ impact.	8
Jeffers ³²	Understand SDM’s lived experiences during the decision-making process	NR	<ul style="list-style-type: none">• Phenomenology• Individual interviews• Interpretive analysis	11 SDM’s	Community USA	NR	SDM’s experiences included (a) considering the patient’s past, present, and future health status; (b) consenting to or refusing treatments and feeling responsible for the final decisions; (c) feeling regretful/guilty about the decisions;	8

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Author	Objectives	Ethical framework	Design/data collection/analysis	Subjects	Settings	Rigor	Summary of the results	CASP score ^a
Jox, Denke ³³	Explore SDM’s’ perceptions about their decision-making process	Limitations of substituted judgment	<ul style="list-style-type: none">Experimental, vignette studyIndividual interviewsContent analysis	16 SDMs Family	Community Germany	<ul style="list-style-type: none">	and (d) keeping them strong through faith and support from others. 25% and 31% of family SDMs wanted the placement of feeding tubes and pacemakers; making decisions in an intuitive manner considering patient’s current status; their own preferences.	9
Kaldjian, Shinkunas ³⁴	Understand SDM’s’ goals of care, foundational beliefs, and ethical values	NR	<ul style="list-style-type: none">UnspecifiedIndividual interviewsQualitative-quantitative analysis approach	20 SDMs Dementia	Inpatient/ outpatient clinic USA	NR	Goals of care were comfort (100%), maintaining mental and physical functions (75%), and prolonging life (53%). Most believed that the patient’s life still had a purpose (75%) and was worth living (65%). Almost all would allow the use of IVF (95%) or antibiotics (95%) if the treatments could be beneficial.	7
Kuehlmeier, Borasio ³⁵	Examine if the patient’s known wishes affect SDM’s’ decisions	Autonomy	<ul style="list-style-type: none">UnspecifiedIndividual interviewsContent analysis	14 SDMs Vegetable state	LTCF Germany	NR	Factors affecting surrogates’ decisions included (a) surrogates’ own interpretation of the patient’s health problems and recovery potential, (b) their own definition of LST measures, and (c) “moral obligation not to harm the patient” (p. 334).	8
Limerick ³⁶	Describe SDM’s’ perceptions about their decision-making process to withhold and withdraw LST	NR	<ul style="list-style-type: none">Grounded theoryIndividual interviewsThematic analysis	17 SDMs	ICUs USA	<ul style="list-style-type: none">	Three main domains were identified: (a) “Interacting in the personal domain” (e.g., seeking family support), (b) “Interacting in the ICU environment domain” (e.g., discussing the patient’s prognosis with a healthcare team), and (c) “Coming to the final decision in the decision domain” (e.g., developing a new belief about LST; p. 334).	8
Long, Clark ³⁷	Describe SDM’s’ perceptions about EOL decision making	NR	<ul style="list-style-type: none">Qualitative descriptiveIndividual interviewsInductive approach	10 SDMs Traumatic brain injury	Hospital USA	NR	SDMs considered various resources for decision making (e.g., prior conversation, prognosis, QOL). They were dissatisfied with physicians’ limited availability/interaction and communication skills and considered ICU nurses’ assistance to be helpful in understanding the nature of patient care.	7
Meeker ³⁸	Explore SDM’s’ perceptions about EOL decision making	NR	<ul style="list-style-type: none">Grounded theoryIndividual and focus-group interviewsConstant comparison	20 SDMs Advanced cancer	Community USA	<ul style="list-style-type: none">	A process of “seeing them through with care and respect” was described. This process consisted of categories including “learning the diagnosis,” “standing with,” “acting for,” “brokering information,” “working with family,” and “outcomes” (p. 204).	8
Meeker ³⁹	Explain SDM’s’ decision-making process	NR	<ul style="list-style-type: none">Grounded theoryIndividual longitudinal interviewsConstant comparison	40 SDMs Advanced cancer, 80 interviews	Community USA	<ul style="list-style-type: none">	The “responsive care management” process consists of three phases: (a) “monitoring” (SDMs observe and assess the patients), (b) “buffering” (interacting with patients and healthcare systems), (c) “taking over” (shielding and	8

Author	Objectives	Ethical framework	Design/data collection/analysis	Subjects	Settings	Rigor	Summary of the results	CASP score ^d
Schenker, Crowley-Matoka ⁴⁰	Explore SDMs' intrapersonal tensions during the decision-making process	NR	• Unspecified	30 SDMs	ICUs USA	•	controlling healthcare decisions; p. 107).	8
			• Individual interviews				Despite "the importance of considering their loved ones' values or acting in their interest" (p. 1659), SDMs did not	
			• Constant comparison				want to feel responsible for the patients' death, and wanted to pursue any chance of recovery and maintain their family well-being. Their coping strategies included discussing with family members and religious practices.	
Su, McMahan ⁴¹	Explore SDMs' perceptions about filial expectations and first-born roles	[Assumption] culturally different views on autonomy	• Unspecified	69 SDMs	Community USA	•	SDMs reported limited communication due to unspoken expectations that the eldest will be a primary decision maker. Avoiding conversations about death led to the firstborn's lack of knowledge about the patient. Family conflict was common. They experienced emotional stress and loneliness.	8
			• Focus-group interviews				Audit trail	
			• Thematic analysis				Investigator triangulation	
Tilden, Tolle ⁴²	Explore SDMs' perceptions about the decision-making process	NR	• Ethnographic approach	30 SDMs	Hospital USA	•	SDMs went through four phases: (a) "recognition of futility," (b) "coming to terms," (c) "shouldering the surrogate role," and (d) "facing the question" (p. 430–431). Seeking a "triangulation of certainty" was prominent	8
			• Individual interviews				6 months later, with more emphasis on the patients' best interests.	
			• Content analysis				Investigative audit	
Torke, Petronio ⁴³	Describe SDMs' experiences of communicating with healthcare providers	NR	• Unspecified	35 SDMs	Hospitals USA	•	SDMs developed relationships with a team of providers based on the providers' roles. SDMs wanted frequent communication, information, and emotional support. Communication with clinicians affected SDMs' trust and mistrust of clinicians and hospital.	8
			• Individual interviews				SDMs planned to make decisions based on (a) "conversations," (b) "written documents," (c) "shared values and life experiences with patients," (d) "surrogates' own beliefs, values, and preferences," (e) "seeking input from others in the surrogates' network" (p. 1690–1691).	
			• Grounded-theory analysis				Facilitators included prior experiences of decision making, successful stress management, support from others, family consensus, and decisions related to the patient's reduced suffering. In contrast, examples of challenges were competing responsibilities, decision making from a distance, financial situations, and family conflict.	
Vig, Taylor ⁴⁴	Explore SDMs' considerations in the decision-making process	Substituted judgment Best interests	• Descriptive study	50 SDMs	Hospital USA	•	Investigator triangulation	8
			• Individual interviews				Investigator triangulation	
			• Thematic analysis				Investigator triangulation	
Vig, Starks ⁴⁵	Describe facilitators of and challenges to decision making	NR	• Unspecified	50 SDMs	Hospital USA	•	Facilitators included prior experiences of decision making, successful stress management, support from others, family consensus, and decisions related to the patient's reduced suffering. In contrast, examples of challenges were competing responsibilities, decision making from a distance, financial situations, and family conflict.	8
			• Individual interviews				Facilitators included (a) "knowing EOL wishes," (b) "communication with healthcare providers," (c) "acceptance or acknowledgment of futility," (d) "strengthening relationships with the loved ones," (e) "pain and symptom management" (p. 249).	
			• Content analysis				Facilitators included (a) "knowing EOL wishes," (b) "communication with healthcare providers," (c) "acceptance or acknowledgment of futility," (d) "strengthening relationships with the loved ones," (e) "pain and symptom management" (p. 249).	
Wilson ⁴⁶	Identify important factors for their decision making	NR	• Phenomenology	10 SDMs	Community USA	NR	Important factors included (a) "knowing EOL wishes," (b) "communication with healthcare providers," (c) "acceptance or acknowledgment of futility," (d) "strengthening relationships with the loved ones," (e) "pain and symptom management" (p. 249).	8
			• Individual interview				Important factors included (a) "knowing EOL wishes," (b) "communication with healthcare providers," (c) "acceptance or acknowledgment of futility," (d) "strengthening relationships with the loved ones," (e) "pain and symptom management" (p. 249).	
			• Thematic analysis				Important factors included (a) "knowing EOL wishes," (b) "communication with healthcare providers," (c) "acceptance or acknowledgment of futility," (d) "strengthening relationships with the loved ones," (e) "pain and symptom management" (p. 249).	

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Author	Objectives	Ethical framework	Design/data collection/analysis	Subjects	Settings	Rigor	Summary of the results	CASP score ^a
Wittich, Williams ⁴⁷	Explore SDMs' understanding of (a) the patients' EOL wishes and (b) whether the wishes are honored	Substituted judgment	<ul style="list-style-type: none">• Unspecified• Individual interviews• Thematic analysis	78 Next of kin	Hospital USA	<ul style="list-style-type: none">•	When realizing that the patient is sick or dying, SDMs tried to understand the patient's EOL preferences through (a) hearing the patient's statement and conversation with healthcare providers, (b) seeing healthcare providers' care for the patient, and (c) interacting with healthcare providers.	7
Zier, Burack ⁴⁸	Understand SDMs' beliefs about physicians' prognostic accuracy	NR	<ul style="list-style-type: none">• Unspecified• Individual interviews• Grounded-theory analysis	50 SDMs	ICUs USA	<ul style="list-style-type: none">••	SDMs' doubt in physicians' prognostication was attributed to (a) "the influence of God," (b) "the inherent inaccuracy of predicting the future," (c) "prior experience with physicians' inaccurate prognostications," and (d) "current experiences in the intensive care unit" (p. 2342).	8

EOL = end of life; ICU = intensive care unit; IVF = intravenous fluid; LST = life-sustaining treatment; LTCF = long-term care facility; NH = nursing home; NR = not reported; QOL = quality of life; SDM = surrogate decision maker.

^aOut of 9 points.