A PROPOSED PARADIGM SHIFT FOR
SURROGATE DECISION-MAKING IN THE ICU

by

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Abstract

Each year four million adults in North America require a surrogate to make decisions for them after being admitted to an intensive care unit (ICU). These decisions frequently involve the limitation of life-sustaining treatments. The current paradigm for making these decisions requires surrogates to rely first on any advance directives from the patient, then on the surrogate’s substituted judgment, and finally on best interests as judged by a reasonable person. Since this paradigm emerged 40 years ago, hundreds of research studies have revealed conceptual and operational deficiencies with it and have documented the harms it may cause to patients, surrogates, and medical professionals. The accumulated weight of these studies motivates the central research question of my dissertation: What shifts to the current paradigm for surrogate decision-making might alleviate its clinical and ethical deficiencies?

I address this question as an interdisciplinary neuroethics scholar relying on the research methods of interpretive description and qualitative metasynthesis to organize the accumulated evidence into pragmatic recommendations. This work required three separate but linked studies. In Study #1 I mined research on surrogates’ experiences to identify factors that influence their decision-making. In Study #2 I synthesized research on surrogate-professional relationships to identify gaps and conflicts between the decision factors from Study #1 and surrogate-professional interactions. In Study #3 I analyzed all seven editions of Beauchamp and Childress’ Principles of Biomedical Ethics (1979 to 2013), charting the evolution of bioethical thought regarding incompetent patients, and linking these changes to the results of studies #1 and #2.

The findings from these studies informed three changes I propose to the paradigm and practice of surrogate decision-making in ICU. My proposal integrates the decision standard of individual best interests, a standardized values portrait capturing the critical values underlying each patient’s individual best interests, and an interest-specific/time-limited decision protocol. Future work will be needed to test the validity and effectiveness of these changes individually and as an integrated solution. Ultimately, the changes I propose are designed to enhance the consistency, continuity, and coordination of care for decisionally incapacitated ICU patients and to yield substantial benefits to surrogate decision-makers and medical professionals.
Lay summary

Each year four million adults in Canada and the U.S. are admitted to an intensive care unit (ICU) and have to rely on their families to make decisions for them. These are often life-or-death decisions to start or continue life-sustaining treatments. The way these decisions are made today often results in patients receiving more or less treatment than they would ideally prefer, and frequently leaves some of their family with clinically significant depression or Post Traumatic Stress Disorder (PTSD). In this dissertation I systematically reviewed hundreds of research studies which examined how families and physicians make these decisions. Based on the evidence from this research, I propose three changes to the way families and physicians make decisions for ICU patients. My proposed changes are aimed at enhancing the quality of care for ICU patients and relieving families of some of the burdens of making these very difficult decisions.
Preface

This dissertation is original, unpublished, independent work by the author, Adrian C. Byram.
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<th>Description</th>
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<td>American College of Critical Care Medicine</td>
</tr>
<tr>
<td>ANH</td>
<td>Artificial Nutrition and Hydration: also referred to as MN&amp;H</td>
</tr>
<tr>
<td>ATS</td>
<td>American Thoracic Society</td>
</tr>
<tr>
<td>CMAJ</td>
<td>Canadian Medical Association Journal</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardio-Pulmonary Resuscitation</td>
</tr>
<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record</td>
</tr>
<tr>
<td>EoL</td>
<td>End-of-Life: particularly in the context of making decisions to withhold or withdraw LST</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit: a specialized hospital ward capable of providing LST</td>
</tr>
<tr>
<td>IS/TL</td>
<td>Interest-Specific/Time-Limited decision protocol</td>
</tr>
<tr>
<td>JAMA</td>
<td>Journal of the American Medical Association</td>
</tr>
</tbody>
</table>
| LST          | Life-Sustaining Treatment: typically includes one or both of:  
- mechanical ventilation to assist or replace breathing; and  
- nasogastric or gastric intubation to provide ANH |
| MAID         | Medical Assistance In Dying |
| MeSH         | Medical Search Headings: a vocabulary thesaurus for indexing PubMed articles |
| MN&H         | Medically assisted Nutrition & Hydration: also referred to as ANH |
| MOST         | Medical Orders for Scope of Treatment |
| POLST        | Physician’s Orders for Life-Sustaining Treatment |
| PRISMA       | Preferred Reporting Items for Systematic Reviews and Meta-Analyses  
(Moher, Liberati, Tetzlaff, & Altman, 2009) |
| PTSD         | Post Traumatic Stress Disorder |
| QoL          | Quality of Life |
| RDE          | Rule of Double Effect |
| SAMMS        | Similar Articles Matching Multiple Seeds:  
a method to search the PubMed literature, described in Section 3.1.1 |
| SDM          | Surrogate Decision-Maker |
| SE           | Surrogate Experience |
| SPR          | Surrogate-Professional Relationship |
| TLT          | Time-Limited Trial |
Glossary

**Advance directive:** an oral or written expression of treatment preferences for future medical care, provided by a currently competent person in case he or she loses decision-making capacity in the future.

**Bounded rationality:** a theory of human decision-making originally proposed by Simon (1955, 1956, 1957, 1972) that takes into account constraints such as limited computational capability, limited access to information, and limited time.

**Ecological rationality:** a theory of human decision-making originally proposed by Gigerenzer and colleagues (Gigerenzer & Selten, 2001b; Todd & Gigerenzer, 2012) that builds upon bounded rationality and heuristics.

**Moral distress:** a form of stress that occurs when a clinician “feels certain of the ethical course of action but is constrained from taking that action” (Hamric & Blackhall, 2007, p. 423).

**Prima facie:** a duty, obligation, or ethical principle that may be overruled in a particular situation by another more pressing duty, obligation, or ethical principle (Ross, 1930).

**Principal:** the person for whom a surrogate is acting; in this context a decisionally incapacitated or incompetent patient.

**Substituted judgment:** inference of a decisionally incapacitated patient’s treatment preferences by a surrogate decision-maker based on the surrogate’s knowledge and experience of the patient.

**Surrogate decision-maker:** a person, typically a family member, with the responsibility of making medical decisions, including EoL decisions, for a decisionally incapacitated patient—his or her principal—in ICU or other settings.

**Withdrawal aversion:** “a nonrational preference for withholding treatment over withdrawal of treatment” (Wilkinson, Butcherine, & Savulescu, 2019, p. 22).
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And, most importantly, to my wife, Carol. Thank you for your steadfast encouragement and commitment to completing this lengthy project. You are wise in ways that I will never be; I could not have written this without you.
To the dedicated physicians and nurses who spend every day caring for people balanced on the edge of life.
1 Introduction

1.1 Prevalence and importance of surrogate decision-making in ICU

Each year about 6 million adults in North America are admitted to an intensive care unit (ICU) (Barrett, Smith, Elixhauser, Honigman, & Pines, 2014; CIHI, 2016; Society of Critical Care Medicine, 2016). Adult patients are admitted to an ICU from a hospital’s general wards (18%), emergency department (58%), and after surgical procedures (23%), with primary diagnostic categories of cardiac issues (45%), respiratory insufficiency (20%), neurologic issues (19%), and other disorders (16%) (Wunsch, Angus, Harrison, Linde-Zwirble, & Rowan, 2011 Table 1).

ICUs have the “ability to support temporarily and, in some cases, replace the function of multiple-organ systems in the face of critical illness and injury” (Kelly, Fong, Hirsch, & Nolan, 2014, p. 377). In other words, the function of the ICU is to keep the patient alive until he or she recovers sufficiently from the underlying injury or disease to survive without external life support. This goal is achieved by specialist medical staff using intensive monitoring, drugs to control pain, wakefulness, blood pressure, and other somatic functions, as well as one or more life-sustaining interventions such as mechanical ventilation, artificial nutrition and hydration (ANH), inotropic support, and hemodialysis. These interventions are implemented as needed in response to the patient’s changing status during the hours and days of the patient’s stay in ICU, the length of which is highly variable (median 1.9 days, IQR 1-3.8 days, mean 3.5 days, standard deviation 5.2 days, Wunsch et al. 2011 Table 2).

More than 4 million of these 6 million patients are decisionally incompetent and require a surrogate to decide whether to begin each of these interventions and whether an intervention, once started, should later be stopped (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007).

10% to 30% of all ICU patients do not survive to discharge (Angus et al., 2004; Luce & Prendergast, 2001; Society of Critical Care Medicine, 2016). Withholding or withdrawing of life-sustaining treatment immediately precedes death for 50% to 70% of these non-survivors (Lobo et al., 2017; Prendergast & Luce, 1997; Smedira et al., 1990). However, the rate of withholding or withdrawing can be highly variable even between trauma centers within a single health care system.

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1 These proportions vary substantially by country: e.g., admission rates from the emergency department are significantly lower in both the UK (Wunsch et al., 2011) and Australia (Hillman et al., 2002); respiratory failure is the leading reason for ICU admission in those countries, not cardiac issues as in the U.S.
(Turgeon et al., 2011). On the one hand, surrogates’ decisions to limit life-sustaining treatment sometimes result in the death of a patient who would otherwise have survived, albeit with functional or cognitive deficits likely (Azoulay et al., 2003). On the other hand, decisions to limit life-sustaining treatment do not inevitably lead to the patient’s death: about 30% of ICU patients whose life-sustaining treatment was withheld or withdrawn are discharged alive (Lobo et al., 2017).

Surrogates’ decisions are truly consequential, but are fraught with uncertainty.

1.2 My engagement with and approach to surrogate decision-making in ICU

Like many adults over 50, I have had personal experience with this topic. I was the surrogate decision-maker for my mother and was involved as my wife and her sister made surrogate decisions for their mother. I also live with the unsettling realization that there is a high likelihood that I will have to act as a surrogate again—this time for my wife—and that she or someone else will have to act for me.

What triggered my intellectual interest in the topic, however, was not just personal experience. Kaufman’s ... and a time to die: How American hospitals shape the end of life (2005) alerted me to the scope and human cost of the problem. Fagerlin and Schneider’s “Enough: The failure of the living will” (2004) led me to understand that the current paradigm for solving this problem may be flawed.

As I pursued my interest, I found the lens of neuroethics—“the ethics of neuroscience and the neuroscience of ethics” (Roskies, 2002, p. 21)—to be particularly apposite for this topic. The ethics of neuroscience matter because the choices faced by surrogates frequently must be evaluated in terms of uncertain neuroscientific knowledge—what impact will the injury or disease and the proposed interventions have on the patient’s cognitive capabilities and personal identity? The neuroscience of ethics is relevant because findings from cognitive neuroscience about bounded rationality, biases, and heuristic decision-making (Gigerenzer, 2010; Kahneman & Tversky, 1984; Simon, 1957) point to constraints in the decision-making capabilities of both surrogates and medical professionals (e.g., Turpin 2019).

Unlike most authors who publish on this topic, I am neither a clinician nor a moral philosopher. I approach the topic as an interdisciplinary neuroethics scholar, relying on qualitative metasynthesis to gather evidence from research studies conducted by clinicians and from ethics frameworks developed by moral philosophers. I conduct this work from a pragmatic perspective in which “the eye of neuroethics is on the wellbeing of people and society ... [and focused on shaping] strategies for translation of results into effective and culturally attuned treatments” (Illes, 2010, p. 1295).
1.3 The current paradigm for surrogate decision-making

All Canadian provinces and U.S. states follow essentially the same paradigm for surrogate decision-making, relying on the following three hierarchical criteria (Berlinger, Jennings, & Wolf, 2013, p. 52):

i) the surrogate first relies on any clear written or oral *advance directive* from the patient;

ii) if there is no advance directive or if it is not relevant to the situation, then the surrogate uses *substituted judgment* based on their knowledge of what the patient would want in the situation;

iii) if neither of these criteria are applicable, the surrogate decides based on the patient’s *best interests*, defined as what a reasonable person in the patient’s circumstances would want.

The surrogate may be formally appointed by the patient via a durable power-of-attorney for health care, or may be drawn from the family in a legislatively-determined priority sequence; if there is no formally appointed surrogate and no family, then a court-appointed guardian acts as the surrogate decision-maker (Pope, 2012). An alternative form of directive, the Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Scope of Treatment (MOST)\(^2\), is relevant for patients in hospice or nursing homes, but is “not designed to accommodate … context-specific decision-making” (Moore, Rubin, & Halpern, 2016, p. 260). Yet it is context-specific decision-making that is needed for surrogate decision-making in ICU.

The current paradigm for surrogate decision-making was established piecemeal in the late 1970s, codified in 1983, and completed in the 1990s. The California state legislature created the advance directive by establishing the “right of an adult person to make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition” (State of California, 1976, p. 6478). In *Quinlan* (1976) the Supreme Court of New Jersey established that the principle of substituted judgment should be applied if no clear advance directive was available. In *Saikewicz* (1977) the Supreme Judicial Court of Massachusetts concluded that the patient’s best interests should be the criterion if there was no advance directive and substituted judgment was not feasible. In their report *Deciding to forego life-sustaining treatment*:

\(^2\) In 1991 the state of Oregon developed Physician Orders for Life-Sustaining Treatment (POLST); these are also known as Medical Orders for Scope of Treatment (MOST) (Meier & Beresford, 2009). These standardized two-page forms provide a very limited set of choices for prospective patients: typically, if found with no pulse or respiration, does the patient want CPR or DNR? and, if found unconscious but with pulse and respiration, does the patient want full, selective, or comfort-focused treatment?
*Ethical, medical, and legal issues in treatment decisions*, the President's Commission (1983) codified the paradigm emerging from these statutes and precedents as a recommended standard, justifying it within an autonomy and nonmaleficence-centered ethical framework. After the U.S. Supreme Court found in *Cruzan* (1990) that a state is not constitutionally required to accepted the judgment of a patient's surrogates, U.S. state and Canadian provincial legislatures enabled their citizens to appoint surrogates with legally enforceable powers-of-attorney for health care (Emanuel & Emanuel, 1992b; Province of British Columbia, 1996; Province of Ontario, 1996).

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3 The President's Commission uses the terms “self-determination” and “well-being” (1983, p. 26) respectively instead of the now more common autonomy and welfare, where welfare itself is usually separated into nonmaleficence and beneficence.
1.4 Deficiencies in the current paradigm

Starting immediately after the *Quinlan* and *Saikewicz* decisions and continuing to the present, hundreds of academic papers (e.g., Annas, 1979) raised conceptual issues with the current paradigm, documented its operational problems, and identified negative impacts on patients, surrogates, medical professionals, and health care systems.

1.4.1 Conceptual issues

**Substituted judgment is a fiction.**

Even though legal fictions are recognized as an effective means “to meet ... very powerful social needs and values” (Sabatino & Basinger, 2000, p. 120), a number of commentators have decried the idea of substituted judgment as a fiction (Childress, 1990; Dresser & Robertson, 1989; R Burt 1979 “Taking care of strangers” cited by Rhoden, 1988), or see it as only as a legal standard to be applied by a court, not as a criterion to be used by a physician or surrogate (Annas, 1979).

**Best interests is not an objective criterion.**

The current paradigm’s default criterion of best interests can be difficult to interpret because there is no objective standard of best interests that applies to everyone (Berg, Appelbaum, Lidz, & Parker, 2001). The alternative of relying on a community best interests standard—i.e., what a reasonable person from this community would supposedly decide under the circumstance—opens the question of how should the appropriate community for a patient be determined—by disease, ethnicity, religion, geography (Smucker et al., 2000)? The result is that “best interests all too frequently may be reduced to objective medical interests alone” (Diekema, 2004, p. 247).

**The preferences expressed by a person while competent should not necessarily control what happens to them after becoming incompetent.**

Dresser (1986), adopting Parfit’s “Complex View” of personhood (1982, p. 227), argues that, although the formerly-competent person who originally created the advance directive and the now-incompetent patient are legally the same person, they are psychologically and ethically two different persons, especially in the case of dementia where the “psychological continuity of memory, character, intention, and the like” (Parfit, 1971, p. 227) that constitutes the self has been destroyed by the disease. Dresser therefore claims that the formerly-competent person should not be allowed to make decisions for the now-incompetent one. Dworkin disagrees with this position, claiming that a person’s “critical interests” (1993, p. 201) persist, and therefore an advance directive
or substituted judgment that expresses those long-held critical interests should prevail. The current paradigm, which privileges any advance directive, adopts Dworkin’s position and rejects Dresser’s\(^4\).

1.4.2 Operational problems

**Most people do not prepare an advance directive or formally appoint a surrogate.**

An American Association of Retired People (AARP) poll of 1013 U.S. residents aged \(\geq 35\) years found the overwhelming majority of respondents (92%) were familiar with the concept of an advance directive, but overall, only 37% had prepared one (AARP, 2008). These U.S. numbers have been confirmed by other individual studies (House & Lach, 2014; Shapiro, 2015) and systematic reviews (Yadav et al., 2017). Two recent studies in Canada—one national (Bravo et al., 2011) and one in Nova Scotia (Digout, Lawson, MacKenzie, & Burge, 2019)—found higher rates (46% and 56% respectively with written directives) among the older adults in their samples (mean ages 75.2 and 79.1 respectively); Bravo et al. also surveyed members of research ethics boards (mean age 50.7) and found that only 42% of these respondents had prepared an advance directive.

**Advance directives are rarely entered into hospital charts, and if not entered, are ignored.**

Studies in a major urban teaching hospital and much smaller suburban hospital found that while about 35% of patients claimed to have an advance directive upon admission, only 10%-14% of the patients’ charts included a directive (House & Lach, 2014; Shapiro, 2012). Another study of adults over 65 years (\(n=1083\)) admitted to medical ICU found “only 7.4% had a living will documented in the medical record” (Torke et al., 2014, p. 373). A recent study in Quebec found “advance directives and powers of attorney were both rarely found in the charts” (Frenette, Saint-Arnaud, & Serri, 2017, p. 233). If the directive was not in the chart, families and physicians were “significantly less likely to talk about wishes expressed in these documents than patients for whom the directives are in hand” (Shapiro, 2015, p. 501). An observational study of the effect of creating a special Electronic Medical Records (EMR) tab to contain advance directives and POLST forms showed no increase in the rate of filing an advance directive but a small increase in filing a POLST (from 2.0% to 4.2% of 23,107 unique inpatient encounters) (Turley, Wang, Meng, Kanter, & Garrido, 2016).

\(^4\) The potential discrepancy between previous critical interests and current best interests may generate unique ethical dilemmas in situations where a now decisionally-incapacitated person had previously sought Medical Assistance in Dying (MAID) (Parliament of Canada, 2016). In this dissertation I am considering only surrogate decision-making, and excluding any consideration of what might be appropriate if the patient had previously sought MAID.
**Advance directives are often too vague or too absolute to be useful.**

Advance directives often contain vague terms such as “no extraordinary (or heroic) measures”, “viable”, or “ability to function”, none of which have medically specific definitions (Shapiro, 2015, p. 501). Directives also often contain highly specific commands, such as “no intubation”, which may not be what the patient would want if a complete recovery is likely (Wood & Arnold, 2012). However, some more recent advance directive forms are adopting a goals-of-care approach (e.g., Caring Info, 2017), or eliciting the patient’s values (e.g., British Columbia Ministry of Health, 2011), but not in a structured or comprehensive manner.

1.4.3 Negative impacts

1.4.3.1 Negative impacts on patients

**Advance directives address only medical interventions, not other aspects of care.**

Non-medical aspects of care, such as how one wishes one’s impending death to be supported by family and friends, are essential to preservation of human dignity (Cook & Rocker, 2014; Kuhl, Stanbrook, & Hébert, 2010). The current paradigm focuses solely on medical decisions and is silent about expressing preferences concerning the non-medical aspects of dying.

**Neither surrogates nor physicians can accurately predict patients’ preferences.**

Repeated studies of surrogate decision-making have shown that surrogates are very poor at predicting patient’s treatment preferences—even though the surrogate was a spouse or adult child who had known the subject for 40 years or more, and even when the subject had discussed his or her treatment preferences with the surrogate in the days before the study (Bravo, Sene, & Arcand, 2017; Ditto et al., 2001; Seckler, Meier, Mulvihill, & Cammer Paris, 1991; Shalowitz, Garrett-Mayer, & Wendler, 2006; Sulmasy et al., 1998; Uhlmann, Pearlman, & Cain, 1988). This research has also shown that family physicians, even after listening to the patient, were unable to predict the patient’s treatment preferences more accurately than pure chance (Ditto et al., 2001; Ouslander, Tymchuk, & Rahbar, 1989).

1.4.3.2 Negative impacts on surrogates

**The decision-making process is traumatic for surrogates and often results in clinically significant psychological distress for months afterwards.**

Surrogate decision-makers describe the process as “‘intense’, ‘painful’, ‘overwhelming’, ‘devastating,’ and ‘traumatic’” (Tilden, Tolle, Nelson, Thompson, & Eggman, 1999, p. 435), and that
“‘It was the hardest thing I have ever done in my life,’ and ‘I wouldn’t wish this on my worst enemy’” (Tilden, Tolle, Nelson, & Fields, 2001, p. 111). Residual guilt is a common theme in almost all studies of surrogate decision-makers (Hayes, 2003; Limerick, 2007; Lind, 2017; Meeker & Jezewski, 2005; Radwany et al., 2009), although recent work claims that surrogates choosing comfort care experience less grief and guilt than those prioritizing the longevity of their patients’ lives (Lovell, Smith, & Kannis-Dymand, 2015).

Smith (2016) found high-threshold symptoms of post-traumatic stress disorder, anxiety disorder, and depressive disorder in, respectively, 50%, 32% and 16% of 176 surrogate decision-makers when measured in the first 6 weeks after patient discharge. These findings of psychological distress have been corroborated by numerous other studies (Azoulay et al., 2009; Gries et al., 2010; Sood, Fisher, & Sulmasy, 2006; Tilden et al., 1999; Wendler & Rid, 2011).

Surrogates’ different interpretations of advance directives often lead to intra-family conflict.

Shapiro (2015) reports that “It is surprising how little the circle of significant others that surround the patient differ about the patient’s expressed, perceived, inferred, or overall wishes … [but] … it was not unusual to see [family members] bristle, quarrel, or clash over how to implement or act on a patient’s wishes—for example, whether it is appropriate to continue or stop aggressive treatments” (p. 509). However, the reasons for intra-family conflict may be more complex that just differing interpretations about advance directives (Kramer & Boelk, 2015).

The momentum of institutional health care overwhelms surrogates and obscures long-term outcomes.

Kaufman, after interviewing hundreds of families with ICU patients, concluded “Patients and families are given choices but only among the options made available by hospital norms and regulations and within the framework of the almost unstoppable march of treatment” (2005, p. 28). Similarly, Kruser et al. describe how “Clinical momentum builds over time with the accrual of multiple interventions … [and] obscure[s] the ability of patients, families, and physicians to consider the long-term outcomes” (2017, p. 430).
1.4.3.3 Negative impacts on medical professionals

Critical care medical professionals, especially nurses and other allied health professionals, experience high levels of moral distress.5

Using the MDS-R instrument (Hamric, Borchers, & Epstein, 2012), Dodek et al. (2016) measured the moral distress experienced by nurses, other health professionals, and physicians working in the ICUs of 13 tertiary and community hospitals. They found that nurses and other health professionals had similar scores (interquartile ranges of 55-119 and 48-115 respectively), while physicians were not immune to moral distress but generally experienced it at far lower levels (interquartile range of 45-70). “Over 80% of critical care nurses report medium to high levels of moral distress” (Corley, 2002, p. 639). Mealer & Moss ascribe nurses’ higher propensity to moral distress to their “perceived inability to make decisions and their feeling of being ‘voiceless’ during morally complex conversations” (2016, p. 1615). Nurses’ moral distress is also inversely correlated with the quality of the ethical environment in the ICU (Corley, Minick, Elswick, & Jacobs, 2005; Hamric et al., 2012; Pauly, Varcoe, Storch, & Newton, 2009). Moral distress not only has a human impact on the affected individuals, but also is “associated with staff conflict, staff attrition, and likely patient safety” (Rodney, Kadyschuk, et al., 2013, p. 168).

The current paradigm has little space for the unique contributions of nurses.

Families often perceive that nurses are more knowledgeable about the patient and are more approachable than physicians (Anderson et al., 2015). Families report trusting nurses in different ways than they trust physicians (Hutchison et al., 2016). But “nurses frequently feel caught between the family and friends and the physician’s need to preserve a patient’s life” (Storch, Starzomski, & Rodney, 2013, p. 334). However, the legislative basis of the current paradigm is written only in terms of the surrogate-physician interaction, and the President’s Commission report (1983) touches on the nurse’s role only peripherally.

1.4.3.4 Negative impacts on health care delivery systems:

ICU costs are high and increasing disproportionately.

Admissions to ICU in Canada increased 5% faster than overall hospital admissions during the years from 2008 to 2014 (CIHI, 2016). Similarly, admissions to ICU in the last month of life by U.S.

5 “Moral distress occurs when the practitioner feels certain of the ethical course of action but is constrained from taking that action” (Hamric & Blackhall, 2007, p. 423).
Medicare beneficiaries aged >65 years have increased from 24.4% in 2000 to 29.2% in 2009, and mean ICU days have increased from 1.5 to 1.8 (Teno et al., 2013, p. 470). Curtis et al. conclude that “Reducing unwanted and unwarranted ICU admission may present an important, long-term opportunity for minimizing growth in [ICU] costs” (2012, p. 588), and suggest one way to accomplish this would be if patients with chronic life-limiting illnesses and their surrogates could be helped to decide about desired treatments and acceptable burdens prior to ICU admission.
1.5 Dissertation overview – accumulating evidence for a paradigm shift

Remarkable advances in life-sustaining treatment during the 1960s and 1970s led to iconic cases such as *Quinlan* (1976) and to heightened media coverage and public awareness. The current paradigm for surrogate decision-making emerged from the various legislative acts and appeals court decisions of that time about 40 years ago. In reaction to the medical paternalism of that era, the paradigm’s ethical underpinnings were heavily influenced by the principle of respect for the patient’s autonomy held in an unresolved tension with the principle of nonmaleficence. As detailed in Section 1.4 above, researchers have documented many deficiencies in the current paradigm:

- it has unresolved problems in its conceptual roots;
- its reliance on advance directives denies its benefits to most decisionally incompetent patients;
- it often does not deliver the care that decisionally incompetent patients really want;
- it leaves many surrogates with lasting psychological harm;
- it denies some medical professionals a voice in the decision-making process; and
- it leads to increasing utilization of costly ICU resources without corresponding benefit.

Over the past 40 years researchers have also created an extensive empirical literature on how surrogates make these decisions and how surrogates and medical professionals interact in ICUs. Ethicists have explored the issues involved in choosing for incompetent patients in far greater detail and have evolved the understanding of how bioethical principles should be applied to these questions. Nonetheless, the challenges are far from resolved.

In this dissertation I first aim to develop new knowledge on surrogate decision-making from empirical and normative sources by conducting three metasynthetic studies:

- **Study #1:** What factors influence surrogates’ decision-making for adult ICU patients?
- **Study #2:** What gaps and conflicts exist between surrogates’ expressed decision factors and the attitudes and behaviors of ICU professionals?
- **Study #3:** How has bioethical thought about surrogate decision-making evolved over the past 40 years?

I then apply that knowledge as evidence to answer my overarching research question:

*What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?*
Following this introduction, in Chapter 2 I outline the overall methodological approach that unifies the three studies. I also provide an overview of the two different metasynthetic methods used in the studies.

In Chapter 3 (Study #1), I determine which factors surrogates report as important influences on their decision-making by conducting a metasynthesis of empirical research on surrogates for adult patients in North American ICUs. To find research papers to include in this metasynthesis, I extended an existing systematic search method to create a new Similar Articles Matching Multiple Seeds (SAMMS) search method used here for the first time.

In Chapter 4 (Study #2), I analyze the gaps and conflicts between the decision factors surrogates consider important (from Study #1) and the interactions between surrogates and medical professionals. This is also a metasynthesis of qualitative empirical research across North American ICUs. I use the same SAMMS method as in Study #1 for the systematic search.

In Chapter 5 (Study #3), I examine the evolution of bioethical thought as manifested by the seven editions of Beauchamp and Childress Principles of Biomedical Ethics from 1979 to 2013. This longitudinal series provides a unique data resource to explore the normative changes that might affect the paradigm for surrogate decision-making that was originally framed simply in terms of tension between respect for autonomy versus nonmaleficence.

In Chapter 6, I propose a shift in the paradigm for surrogate decision-making for adult patients in ICU. I describe how the evidence from studies #1, #2, and #3 supports this proposal, and how this proposal might alleviate the deficiencies of the current paradigm. I describe what I believe to be my original contributions and discuss how my proposal relates to the work of other authors. In closing, I describe how my proposal might be tested in future, and summarize the entire dissertation.
2 Methodological Overview

2.1 Methodological approach

Research into topics such as surrogate decision-making requires investigating complex interactions between people dealing with once-in-a-lifetime situations under conditions of extreme emotional stress. For ethical and practical reasons, these are not settings where competing scientific hypotheses can readily be tested under controlled conditions. Nonetheless, because of the harm being done to patients, surrogates, and medical professionals, there is an imperative to improve practice. Green and Britten’s insight about the epistemological value of qualitative research points the way toward a practical methodological approach:

Qualitative research can investigate practitioners’ and patients’ attitudes, beliefs, and preferences, and the whole question of how evidence is turned into practice. The value of qualitative methods lies in their ability to pursue systematically the kinds of research questions that are not easily answerable by experimental methods. (Green & Britten, 1998, p. 1230)

Within the spectrum of qualitative research methodologies, interpretive description, first described by Thorne et al. (1997), and now widely deployed in diverse health care studies, is an inductive approach ideally suited to my research question and purpose:

Interpretive description is a qualitative research approach that requires an integrity of purpose deriving from two sources: (1) an actual practice goal, and (2) an understanding of what we do and don’t know on the basis of the available empirical evidence (from all sources). (Thorne, 2016, p. 35)

In particular, the product of an interpretative description is a “coherent conceptual description” that would make sense to a clinician and would provide “a backdrop for assessment, planning and interventional strategies in keeping with recognized nursing standards of evidence, logic and ethics” (Thorne, Kirkham, & O’Flynn-Magee, 2004, p. 4). The intent is not to provide an “Interpretive Explanation” but rather a “tentative truth claim about what is common within a clinical phenomenon” (Thorne, Kirkham, et al., 2004, p. 4).

Because of the emphasis on integrating the available evidence from all sources, interpretive description research studies frequently rely on qualitative metasynthesis methods (Sandelowski, Docherty, & Emden, 1997) to incorporate qualitative and quantitative primary research. I follow this approach to integrate the large body of existing empirical research on surrogate decision-making into findings that could inform an actual practice goal.
2.2 Metasynthetic methods for interpretive description

Interpretive description has typically been described using examples that rely on the metasynthesis of qualitative primary research (e.g., Thorne, 2016). However, this should not be seen as a limitation:

interpretative description shamelessly encourages borrowing from the full universe of available design technique as appropriate to the nature of the research question at hand. But instead of forcing an overall design logic that had often proved a very poor fit with the questions applied researchers wanted to ask, it invites researchers to move beyond rule structures imposed by any disciplinary worldviews or standpoints that need not apply, and replace them instead with more relevant and meaningful disciplinary logic. (Thorne, 2016, p. 39)

Relying on this methodological license, I have combined the following two methods to address my overall research goal. These are more fully described in the methods section of each study.

i) Thematic synthesis

Studies #1 and #2 are based on the many empirical studies on surrogate decision-making. However, none of these studies (primary research) addressed my research questions directly. Thematic synthesis, developed by Thomas & Harden (2008), enables me to overcome this limitation.

Thematic synthesis is a two-stage process, starting with a metasynthesis of qualitative and quantitative primary research, then applying qualitative thematic analysis methods to answer a research question that was not asked directly by the primary research. Metasynthesis was originally developed by Noblit & Hare (1988) to address the problem of analyzing a growing number of ethnographic qualitative studies, and was first applied to health research by Jensen & Allen (1994, 1996). Metasynthesis has subsequently been complemented by formal methods to assess the quality of each work included in a synthesis (e.g., Kmet, Lee, & Cook, 2004).

ii) Intertextual analysis

My analysis of the ethics of surrogate decision-making seeks to understand the changes in bioethical thought between the time the current paradigm for surrogate decision-making was established (the late 1970s) and the present. In other words, while this analysis is focused on normative truths, it is actually an analysis of a series of historical documents about ethics. To find the relevant ethical precepts that have changed during this 40-year interval, I conducted an intertextual analysis (Coffey, 2014), which relies on close comparison of successive documents to generate an audit trail of changes.
I acknowledge that these methods are interpretive and constructionist, and as such, are subject to the limitations identified by Paterson et al.:

... no singular objective reality will be found and ... multiple, coexisting, and even sometimes incongruous realities related to the phenomenon will be found instead. Therefore, prescriptions for practice, research, or theory development that are derived from [this] research cannot be regarded as the only possible findings that could be drawn from the body of available research, but rather as those findings constructed by specific meta-synthesists at a given point in time and in accordance with their own range of interpretative skills. (Paterson, Thorne, Canam, & Jillings, 2001, p. 7)

In summary, I rely on interpretive description as my overall methodological approach. In particular, I use thematic synthesis and intertextual analysis to link normative and empirical truths into a coherent conceptual understanding of how the current paradigm and practice of surrogate decision-making in ICU could best be updated. I recognize that because these methods are interpretive and constructionist, they can yield only a tentative truth claim to suggest changes in clinical practice. Nonetheless, given the long-standing and pervasive challenges in addressing surrogate decision-making in ICUs and other practice contexts, I believe that my work provides a salient step forward.
3 Study #1: Decision Factors from the Surrogate Experience

I begin investigating my overall research question—*What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?*—by analyzing the decision-making experience of surrogates in clinical settings. In this study I conduct a metasynthesis of the extensive primary research on surrogates' experiences, seeking to answer the specific research question, 

*What factors influence surrogates' decision-making for adult ICU patients?*

**Figure 3-1: Thematic synthesis flowchart**

Identifying the decision factors from the peer-reviewed academic literature requires thematic synthesis—a method developed by Thomas and Harden (2008) for the explicit purpose of identifying themes emerging from studies that do not directly address the research question. Note that while thematic synthesis is itself a qualitative method and generates qualitative results, the studies being synthesized may themselves utilize qualitative, quantitative, or mixed methods.

The thematic synthesis process breaks down into three distinct stages as depicted in Figure 3-1, each with its own detailed method. The results from each stage served as the raw data for the next.

The methods used are detailed in Section 3.1. The results of the systematic search, thematic analysis, and strength-of-evidence assessment are presented in Section 3.2. This study's primary findings—the decision factors influencing surrogates making decisions for adult ICU patients—are presented in Section 3.3. These findings are discussed in Section 3.4, limitations examined in Section 3.5, and conclusions drawn in Section 3.6.
3.1 Methods

3.1.1 Systematic search method

3.1.1.1 Inclusion/exclusion criteria

In order for a primary research paper to be included it had to meet all of the following inclusion criteria and not match any of the exclusion criteria.

Inclusion:

- original empirical research focused on surrogates’ experiences while making EoL decisions for adult ICU patients; and
- studies conducted in ICUs located in North American hospitals; and
- published in English in the peer-reviewed academic literature.

Exclusion:

- no abstract (such articles cannot be assessed by the search strategy employed); or
- not based on validated empirical research involving EoL decision-making, e.g., reviews, case studies, practice guides, editorials; or
- focused on how specific cultural, ethnic, or religious groups approach EoL decision-making, e.g., a paper on the Buddhist perspective on surrogate decision-making would be excluded, but a paper examining the effect of intensity of religious feelings on surrogate decision-making would be included. I excluded specifically ethno-cultural studies because my research question was seeking factors common to all surrogates; including studies of particular ethno-cultural groups would have produced results with a different focus.

3.1.1.2 Search strategy

Unlike a traditional statistical Cochrane-style meta-analysis (Higgins & Green, 2011), a thematic synthesis does not require that all relevant studies be included because:

the results of a conceptual synthesis will not change if ten rather than five studies contain the same concept, but will depend on the range of concepts found in the studies, their context, and whether they are in agreement or not. Thus, principles such as aiming for ‘conceptual saturation’ might be more appropriate ... [and] aiming for maximum variability ... instead of achieving the homogeneity that is often the aim in statistical meta-analyses. (Thomas & Harden, 2008, p. 2)

In order to achieve these objectives of conceptual saturation and heterogeneity, I extended the systematic search method described by Chang et al. (2006). I refer to my extended method as the SAMMS (Similar Articles Matching Multiple Seeds) search method; its details follow.
Chang et al. (2006) describe a search method that utilizes the *Similar articles* search feature in PubMed (US National Library of Medicine, 2015), shown circled in red in Figure 3-2. This feature, originally called the PubMed Related Citations (PRC) tool, measures the “probability that a user would want to examine a particular document given known interest in another” (Lin & Wilbur, 2007, p. 423). The tool uses a probabilistic measure (Salton & Buckley, 1991) to compare all PRC terms in the target document to all PRC terms in the reference document. To enable this capability, the technical staff at the U.S. National Library of Medicine have identified about 2 million distinct PRC terms (words or phrases in the title, abstract, and MeSH keywords) and indexed over 26 million entries in PubMed for these PRC terms (National Center for Biotechnology Information, 2017).

**Figure 3-2: PubMed Similar articles search**

Chang et al. searched for articles similar to a single “key” or seed article selected to be archetypical of their topic of interest. Because of the need for heterogeneity and conceptual saturation in a thematic synthesis as noted by Thomas and Harden (2008), I extended the Chang et al. method by using multiple seed articles.

From my collection of several hundred papers on surrogate decision-making, I selected 16 that: i) met the stated inclusion/exclusion criteria, and ii) clearly reported findings relevant to my research question. These articles are listed in Table A-1.

My decision to use 16 seed articles in the search was informed by three proof-of-concept trials: the first trial with a single seed article returned 101 similar articles; the second trial with 12 seed articles returned 2167 unique similar articles. A third trial with 16 seed articles returned only 317...
more unique similar articles than the second trial. These results confirmed that while multiple seeds were highly beneficial in finding more candidate articles, the rate of increase in the number of unique candidates plateaued beyond 12 seeds. Thus, the decision to use 16 seeds reflected a balance between the total number of candidate articles to be found and the power of each incremental seed article to increase the number of unique candidate articles.

I captured the lists of similar articles obtained from PubMed for each of the 16 seed articles into an Excel spreadsheet (Microsoft Corporation). Using the filtering tools in Excel I removed all duplicates to create a list of unique candidate articles. I counted the number of seed articles “matched” by each candidate article. This process is described in detail in Appendix A2: Capturing similar articles from PubMed.

I assessed whether a candidate article met the inclusion/exclusion criteria by reading its title and abstract. I assessed all candidate articles matching three or more seeds. I also assessed a randomly selected sample of 100 candidate articles matching two seeds and another randomly selected sample of 100 articles matching one seed.

3.1.2 Thematic synthesis method

I followed the method developed by Thomas and Harden (Harden & Thomas, 2005; Thomas & Harden, 2008). This is a two-stage method, rooted in grounded theory (Glaser & Strauss, 1967), in which the primary research papers are first read to identify “descriptive themes”. These descriptive themes then form the basis for inductively inferred “analytical themes”. These stages are broadly analogous to the open coding and axial coding stages of a grounded theory qualitative analysis (Charmaz, 2006; Flick, 2014).

3.1.2.1 Stage 1: Identification of descriptive themes

I analyzed the candidate articles in sequence of decreasing number of seeds matched, i.e., starting with the papers matching 12 seeds, then continuing to the candidates matching 11 seeds, and so on. For each candidate, I first checked whether its stated research question, when examined in detail, truly met the inclusion criterion of being focused on surrogates’ experiences while making EoL decisions for ICU patients. I then open coded each candidate’s results line-by-line, identifying individual findings describing influences on surrogates’ decision-making. This process was conducted in two iterations, coding and recoding the candidates as the list of codes was refined. I stopped analyzing more candidate articles after theoretical saturation (Corbin & Strauss, 2014, p. 134) was
firmly established. Following Saldana’s recommendations for a solo coder, my supervisor reviewed my coded data at all stages and served as a “rigorous examiner and auditor of my analysis” (Saldana, 2016, p. 37). I used NVivo 12 (QSR International Pty Ltd.) qualitative research software to assist with data management and analysis.

For convenience, I refer to the articles remaining after coding was complete as the Surrogate Experience Papers (SE Papers).

3.1.2.2 Stage 2: Inference of analytic themes

Starting from the Stage 1 descriptive themes and a careful re-reading of the SE Papers, I inferred a set of analytic themes that met the following criteria:

i) direct influences on surrogates’ decisions;

ii) at a consistent level of abstraction; and

iii) capable of being grouped into larger thematic categories.

I then re-coded each of the SE Papers using these analytic themes. I iterated this process until the set of analytic themes I found was stable.

3.1.2.3 Incorporating surrogate response intensity

The SE Papers I analyzed reported thematic results in one of three different ways:

i) a cardinal measure (e.g., “120 of 279 subjects stated ...”, “82% said ...”);

ii) an ordinal measure (e.g., “Most surrogates reported ...”, “A few implied ...”);

 iii) a non-quantitative assertion (e.g., “Participants expressed ...”).

The first two provide a measure of the response intensity; information complementary to the mere presence of the analytic theme. This quantitative information adds value to the results of a thematic synthesis (Thomas et al., 2004). I transcribed the response intensities reported by each SE Paper for each analytic theme into a spreadsheet.

3.1.3 Strength-of-evidence assessment method

In this stage, I calculated a numeric measure of the strength-of-evidence for each SE Paper. I then used these numeric measures as weights to determine a ranking of the decision factors that incorporates the strength-of-evidence of the research behind each decision factor.

In order to assess both qualitative and quantitative papers on a common strength-of-evidence scale, I used QualSyst, a pragmatic systematic review tool (Kmet et al., 2004), which combines
quantitative instruments (Cho & Bero, 1994; Timmer, Sutherland, & Hilsden, 2003) and qualitative instruments (Mays & Pope, 2000; Popay, Rogers, & Williams, 1998).

The tool employs two scales, one with 14 items for quantitative research, and a second with 10 items for qualitative research, as summarized in Table 3-1 (full detail shown in A4: QualSyst instrument). Each item is scored as Yes, Partially, or No depending on its presence in the research. If an item does not apply it is marked as N/A; however, some items are mandatory, e.g., “Question/objective clearly described?”. After all items are scored, the Yeses are assigned a weight of 1, the Partials a weight of 1/2, the Noes a weight of 0, and the N/As are not included in the scoring totals; the weights are summed, and the sum is divided by the number of items that were scored, yielding a strength-of-evidence score between 0 and 1.
<table>
<thead>
<tr>
<th>Item</th>
<th>Allowed answers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quantitative research</strong></td>
<td></td>
</tr>
<tr>
<td>1. Question or objective sufficiently described?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>2. Design evident and appropriate to answer study question? (If the study question is not given, infer from the conclusions).</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>3. Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.</td>
<td>Y, N, P, N/A</td>
</tr>
<tr>
<td>4. Subject (and comparison group, if applicable) characteristics or input variables/information sufficiently described?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>5. If random allocation to treatment group was possible, is it described?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>6. If interventional and blinding of investigators to intervention was possible, is it reported?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>7. If interventional and blinding of subjects to intervention was possible, is it reported?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>9. Sample size appropriate?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>10. Analysis described and appropriate?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>12. Controlled for confounding?</td>
<td>Y, P, N, N/A</td>
</tr>
<tr>
<td>13. Results reported in sufficient detail?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>14. Do the results support the conclusions?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td><strong>Qualitative research</strong></td>
<td></td>
</tr>
<tr>
<td>1. Question / objective clearly described?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>2. Design evident and appropriate to answer study question? (If question not clearly identified, infer appropriateness from conclusions.)</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>3. Context for the study is clear?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>4. Connection to a theoretical framework / wider body of knowledge?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>5. Sampling strategy described, relevant and justified?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>6. Data collection methods clearly described and systematic?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>7. Data analysis clearly described, complete and systematic?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>8. Use of verification procedure(s) to establish credibility of the study?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>9. Conclusions supported by the results?</td>
<td>Y, P, N</td>
</tr>
<tr>
<td>10. Reflexivity of the account?</td>
<td>Y, P, N</td>
</tr>
</tbody>
</table>
3.2 Data analysis

3.2.1 Data analysis: Systematic search

A total of 4836 candidate articles, including duplicates and non-English articles, matched one or more of the 16 seed articles. As shown in the PRISMA diagram (Moher et al., 2009) in Figure 3-3, 2484 unique candidate articles remained after duplicates and non-English articles were removed. 622 of these candidate articles were assessed against the inclusion criteria; 61 met those criteria. These 61 candidate articles became the input to the thematic synthesis stage of this study (Section 3.2.2). Not all of these 61 were analyzed: 11 were rejected after reading the full-text because no decision factors were found; 24 were not analyzed because theoretical saturation had been reached (as described in detail in Section 3.2.2.1 below).

**Figure 3-3: Study #1 PRISMA flow of information through stages of systematic review**

- **Identification**: 4836 articles identified from SAMMS search → 2484 unique candidate articles → 16 seed articles from other sources → 1862 matching ≤ 2 seeds not assessed
- **Screening**: 622 abstracts assessed against inclusion criteria → 561 excluded
- **Eligibility**: 61 candidate articles → 24 matching ≤ 5 seeds not analyzed
- **Included**: 37 full-texts analyzed for decision factors → 11 excluded because no decision factors
- **The SE Papers**: 26 papers analyzed for content and for strength-of-evidence
Table 3-2 shows that i) the number of candidate articles found was inversely proportional to the number of seed articles matched, and ii) the likelihood of a candidate article meeting the inclusion criteria increased with the number of seed articles matched. No candidate article matched more than 12 of the seed articles, and the number of candidate articles increased from 5 candidate articles each matching 12 seeds to 1745 candidates each matching one seed. Candidate articles matching the most seed articles meet the inclusion criteria at the highest rates: 60% of those matching 12 seeds, and 44% of those matching 11 seeds. The results from Table 3-2 are shown graphically in Figure 3-4.

**Table 3-2: Study #1 candidate articles found, included, excluded, and not assessed by number of seed articles matched**

<table>
<thead>
<tr>
<th>Seed articles matched:</th>
<th>16</th>
<th>15</th>
<th>14</th>
<th>13</th>
<th>12</th>
<th>11</th>
<th>10</th>
<th>9</th>
<th>8</th>
<th>7</th>
<th>6</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candidate articles:</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>16</td>
<td>28</td>
<td>22</td>
<td>22</td>
<td>37</td>
<td>36</td>
<td>52</td>
<td>83</td>
<td>121</td>
<td>317</td>
<td>1745</td>
<td></td>
</tr>
<tr>
<td>% of total</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.2%</td>
<td>0.6%</td>
<td>1.1%</td>
<td>0.9%</td>
<td>0.9%</td>
<td>1.5%</td>
<td>1.4%</td>
<td>2.1%</td>
<td>3.3%</td>
<td>4.9%</td>
<td>12.8%</td>
<td>70.2%</td>
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</tr>
<tr>
<td>Included/excluded by inclusion/exclusion criteria</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Included:</td>
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<td>0</td>
<td>0</td>
<td>3</td>
<td>7</td>
<td>8</td>
<td>7</td>
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<td>44%</td>
<td>29%</td>
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<td>11%</td>
<td>6%</td>
<td>12%</td>
<td>6%</td>
<td>7%</td>
<td>3%</td>
<td>1%</td>
<td>10%</td>
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<tr>
<td>Excluded:</td>
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<td>0</td>
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<td>16</td>
<td>33</td>
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<td>46</td>
<td>78</td>
<td>112</td>
<td>97</td>
<td>99</td>
<td>561</td>
</tr>
<tr>
<td>% of assessed</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40%</td>
<td>56%</td>
<td>71%</td>
<td>68%</td>
<td>73%</td>
<td>89%</td>
<td>94%</td>
<td>88%</td>
<td>94%</td>
<td>93%</td>
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<td>90%</td>
</tr>
<tr>
<td>Total assessed:</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>16</td>
<td>28</td>
<td>22</td>
<td>22</td>
<td>37</td>
<td>36</td>
<td>52</td>
<td>83</td>
<td>121</td>
<td>100</td>
<td>100</td>
<td>622</td>
</tr>
<tr>
<td>% of total</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>32%</td>
<td>6%</td>
<td>25%</td>
</tr>
<tr>
<td>Not assessed:</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>217</td>
<td>1645</td>
</tr>
<tr>
<td>% of total</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
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<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>68%</td>
<td>94%</td>
</tr>
</tbody>
</table>
Figure 3-4: Study #1 inclusion rates for candidate articles by number of seed articles matched

The green bars in Figure 3-4 show the number of candidate articles versus the number of seed articles matched. The figure shows that no candidate article matched more than 12 seed articles. It also shows that the number of candidate articles increased exponentially as the number of matches decreased below six seed articles.

The orange line in Figure 3-4 shows the relationship between the rate of candidate articles meeting the inclusion criteria and the number of seed articles matched by the candidate articles; the dotted line indicates where results were estimated from two samples of 100 articles each. The figure shows that as the number of matches decreases, there is an almost linear drop in the probability of a candidate article meeting the inclusion criteria.
3.2.2 Data analysis: Thematic synthesis

3.2.2.1 Decision factor statistics

37 candidate articles matching six or more seed articles were analyzed for decision factors. A total of 27 decision factors (analytic themes) were found in 26 of these articles. These 26 articles, hereafter referred to as the SE Papers, are listed in Table A-2, which also lists the number of decision factors and QualSyst score associated with each paper. Of the 26 SE Papers, 23 are purely qualitative studies, 2 are purely quantitative, and 1 is mixed.

Figure 3-5: Decision factors found by number of candidate articles analyzed

Figure 3-5 presents the sequence in which the candidate articles were examined for decision factors, starting with candidates 1, 2, and 3, each of which matched 12 seed articles, and continuing through candidates 36 and 37, each of which matched 6 seed articles. The orange column shows the number of decision factors coded for the first time in that paper; the cream columns show the number of previously coded decision factors in that paper. For example, candidate article 7 has a total of eight decision factors; one new one and seven that were already coded at least once in candidates 1 through 6.
The orange line in Figure 3-5 shows the cumulative number of decision factors found. This line climbs rapidly with the first 10 candidates analyzed, then plateaus after 20 candidates, graphically illustrating the occurrence of theoretical saturation, which led me to stop further analysis after 37 candidates.

The green line in Figure 3-5 (to be read against the right-hand vertical axis) shows the percentage of candidate articles that contain decision factors. This green line is complementary to the orange line: the cumulative fraction of candidate articles containing decision factors decreases as more candidates are analyzed.

The number of decision factors found per SE Paper ranged from a maximum of 18 (one paper) to a minimum of 2 (three papers), with a median of 6 and an average of 6.2 decision factors per SE Paper.

3.2.2.2 Demographics

All the 26 SE Papers reported some demographic information about their subjects, i.e., the surrogates who participated in the research. The categories of demographic information reported were not always consistent, but gender, race/ethnicity, and relationship of surrogate to patient were reported for 88% of all papers.

Across all SE Papers a total of 1915 surrogates were reported as being research subjects

The demographic characteristics for all SE Papers are summarized in Table 3-3. The subjects of all the SE papers were from the U.S. The surrogates in the SE Papers are older and more female than the general U.S. population: 54.8 years vs 38.2 years, 70% vs 50.8% female. The racial distribution is less Hispanic than the general population: 66% vs 60.7% white, 20% vs 13.4% black, 11% vs 18.1% Hispanic, 7% vs 7.3% other. The religious distribution is similar to the general population: 47% vs 47% Protestant, 25% vs 21% Catholic, 3% vs 1.9% Jewish, 16% vs 22.8% none, 9% vs 7% other.

---

6 General population data on age, gender and race from U.S. Census Bureau

7 General population data on religious affiliation from Pew Research Center, www.pewforum.org/religious-landscape-study/, retrieved 2019-06-06
Table 3-3: Demographic characteristics of surrogate subjects in SE Papers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>% of SE Papers reporting</th>
<th>Average</th>
<th>Minimum</th>
<th>Median</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of subjects</td>
<td>100%</td>
<td>74</td>
<td>10</td>
<td>49</td>
<td>246</td>
</tr>
<tr>
<td>Gender (% Female)</td>
<td>88%</td>
<td>70%</td>
<td>42%</td>
<td>70%</td>
<td>90%</td>
</tr>
<tr>
<td>Mean Age</td>
<td>62%</td>
<td>54.8</td>
<td>46.5</td>
<td>54.5</td>
<td>63.0</td>
</tr>
<tr>
<td>Mean age standard deviation</td>
<td>38%</td>
<td>13.0</td>
<td>11.0</td>
<td>13.0</td>
<td>14.6</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>33%</td>
<td>6%</td>
<td>30%</td>
<td>68%</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>35%</td>
<td>0%</td>
<td>37%</td>
<td>74%</td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>11%</td>
<td>3%</td>
<td>10%</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>13%</td>
<td>8%</td>
<td>13%</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
<td>3%</td>
<td>14%</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>66%</td>
<td>40%</td>
<td>61%</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>20%</td>
<td>0%</td>
<td>13%</td>
<td>51%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>11%</td>
<td>0%</td>
<td>12%</td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
<td>0%</td>
<td>3%</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td><strong>Religious affiliation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>47%</td>
<td>10%</td>
<td>53%</td>
<td>83%</td>
<td></td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>25%</td>
<td>9%</td>
<td>26%</td>
<td>60%</td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>3%</td>
<td>0%</td>
<td>3%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>16%</td>
<td>0%</td>
<td>16%</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
<td>3%</td>
<td>8%</td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td><strong>Importance of religious belief</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very important</td>
<td>49%</td>
<td>38%</td>
<td>48%</td>
<td>63%</td>
<td></td>
</tr>
<tr>
<td>Fairly important</td>
<td>27%</td>
<td>21%</td>
<td>27%</td>
<td>34%</td>
<td></td>
</tr>
<tr>
<td>Not too important</td>
<td>14%</td>
<td>7%</td>
<td>15%</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Not at all important</td>
<td>5%</td>
<td>3%</td>
<td>5%</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>No response</td>
<td>7%</td>
<td>3%</td>
<td>7%</td>
<td>10%</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>32%</td>
<td>4%</td>
<td>30%</td>
<td>57%</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>29%</td>
<td>13%</td>
<td>32%</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>24%</td>
<td>10%</td>
<td>21%</td>
<td>54%</td>
<td></td>
</tr>
<tr>
<td>Post-graduate</td>
<td>20%</td>
<td>0%</td>
<td>21%</td>
<td>34%</td>
<td></td>
</tr>
</tbody>
</table>
3.2.2.3 Decision factors found

Table 3-4 presents all 27 decision factors grouped into six major categories. The number of SE Papers in which each factor was found is shown, together with illustrative quotations from the original papers. The quotations were chosen to highlight how each decision factor motivated the surrogates’ decisions.

Table 3-4: Decision factors found with illustrative quotations

<table>
<thead>
<tr>
<th>Decision factors</th>
<th>SE Papers with this factor</th>
<th>Illustrative quotations from the SE Papers (NB: the entire text of each bullet point is a direct quotation from the cited paper)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consequential factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of loss</td>
<td>2</td>
<td>• Another surrogate eloquently described the sentiment that drove the decisions. “And even though my mother was in that kind of shape, I didn’t really want to give her up—selfishly, I did not.” (Limerick, 2007, p. 334)</td>
</tr>
<tr>
<td>Impact on surrogate's interests</td>
<td>2</td>
<td>• The surrogate’s interests included considerations of how decisions might affect the surrogate’s lifestyle and the impact of a decision or outcome on the surrogate and/or family. (Fritsch, Petronio, Helft, &amp; Torke, 2013, p. 130)</td>
</tr>
<tr>
<td>Patient’s post-discharge QoL</td>
<td>4</td>
<td>• For some, “satisfactory” recovery meant a return of the person’s health to a certain desirable quality of life. For example, several SDMs based their level of acceptable recovery on whether or not the person would be able to become independent or whether their daily existence would be “stuck in a nursing home”. (Dionne-Odom, Willis, Bakitas, Crandall, &amp; Grace, 2015, p. 333)</td>
</tr>
<tr>
<td><strong>Contextual factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathy with patient’s pain or loss of dignity</td>
<td>5</td>
<td>• All surrogates reported that they perceived that the patient was suffering and/or reported their own empathic suffering witnessing the patient’s bodily state. (Nunez et al., 2015, p. 2389) • In describing the process of signing a DNR order, many subjects describe the realization that the patient was suffering as an important factor in the decision-making process (Handy, Sulmasy, Merkel, &amp; Ury, 2008, p. 17)</td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>3</td>
<td>• The belief that one’s presence and support could improve the patient’s prognosis was discussed by 13% (24 of 179) of surrogates. Through their own positive thinking and support, these surrogates believed that they could improve the patient’s prognosis (Boyd et al., 2010, p. 1273)</td>
</tr>
<tr>
<td>Patient’s history</td>
<td>6</td>
<td>• Many surrogates relied on their personal knowledge of unique attributes of the patient to inform their prognostic estimates (51 of 179; 28%), such as the patient’s history of illness and previous survival in the face of severe illness. (Boyd et al., 2010, p. 1273) • One surrogate described the patient, “She’s told me she’s ready to go. She’s ready to leave this life, that she’s tired and she doesn’t feel well .... She kept saying that she was ready, this was no life.” (Handy et al., 2008, p. 17)</td>
</tr>
<tr>
<td>Decision factors</td>
<td>SE Papers with this factor</td>
<td>Illustrative quotations from the SE Papers</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>----------------------------</td>
<td>-------------------------------------------</td>
</tr>
</tbody>
</table>
| Patient's intrinsic qualities            | 6                          | • Many referred to unique attributes of their loved one that would allow this patient to overcome poor odds. Characterization of the patient as “a fighter” throughout life and against the illness, with unusual strength and “will to live,” was most common (Nelson et al., 2017, p. 868)  
• Belief that patients’ fortitude will lead to better-than-predicted outcomes (Zier, Sottile, Hong, Weissfield, & White, 2012, p. 363) |
| Familial factors                         |                            |                                          |
| Decisional stress                        | 10                         | • They also struggled with a sense that their decisions, rather than the underlying critical illness, would primarily determine the patient’s outcome. Thus, some surrogates characterized a decision to limit life support as an affirmative action on their part to “kill”, “starve,” or otherwise harm the patient, even though the medical team advised that the patient was deteriorating despite this therapy. (Nelson et al., 2017, p. 869)  
• Many surrogates described emotional discomfort with making ‘life or death’ decisions as an important source of tension that sometimes made it difficult to act according to a loved one’s values. (Schenker, Crowley-Matoka, et al., 2012, p. 1661) |
| Family conflict                          | 2                          | • Some worried about being blamed for the patient’s death by family members who might disagree with a decision to withdraw life support. (Schenker, Crowley-Matoka, et al., 2012, p. 1661) |
| Need for family consensus                | 8                          | • It was also apparent across cases that SDMs who were sensitive to meeting the needs of family members were compelled to gain some degree of “consensus” and “agreement” about their decisions before expressing those decisions to the health care team. (Dionne-Odom et al., 2015, p. 337)  
• Surrogates often felt compelled to reach family consensus on decisions or have the support of their family behind the decisions they made. (Fritsch et al., 2013, p. 131) |
| Need time to prepare                     | 10                         | • Many surrogates felt that, although imperfect, physicians’ prognostic estimates would provide them a “rough ballpark” or a “warning ... for what could happen.” Prognostications allowed surrogates to begin the emotional work of preparing for a potentially bad outcome. (Evans et al., 2009, p. 50)  
• She described how making the decision that she knew was the right one became easier after she realized that the opposition from her brother and other family members to her decision to discontinue ventilator support was not because they thought it was the wrong decision but because they were not ready for their loved one to die. (Vig et al., 2007, p. 1277) |
<table>
<thead>
<tr>
<th>Decision factors</th>
<th>SE Papers with this factor</th>
<th>Illustrative quotations from the SE Papers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Institutional factors</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Established trust in physicians | 9 | • Surrogates reported that they valued a clinician’s opinion because they trusted the clinician to place the patient’s best interest first and foremost. However, surrogates seemed to only consider the clinician’s advice when they trusted the clinician. (Fritsch et al., 2013, p. 130)  
• The relationships eventually culminated in trust of members of the healthcare team, which ultimately assisted surrogates in moving forward in the decision-making process. (Limerick, 2007, p. 335) |
| Mistrust of institutions | 5 | • A small number of surrogates expressed or implied distrust of the ICU team, including a concern that clinicians sought to limit treatment to reduce use of costly intensive therapies, or a suggestion that the team itself was to blame for the poor prognosis. (Nelson et al., 2017, p. 867) |
| Too many physicians | 7 | • Two major contributors to the surrogates’ perceptions of an inability to establish personal relationships were frequent changes in the clinicians caring for the patient and the large number of clinicians involved in the patient’s care. (Torke et al., 2012, p. 1403)  
• ... receiving discrepant prognostic estimates from different physicians (8 of 50). (Zier et al., 2008, p. 2343) |
| **Normative factors** | | |
| Leave decision to God | 9 | • Some surrogates spoke of a more passive role, deferring authority over the decision-making to God. (Nelson et al., 2017, p. 870)  
• Based on religious grounds, roughly one third of surrogates doubted physicians’ ability to predict futility. These individuals believed that God was capable of miraculously healing patients regardless of the severity of their illness. (Zier et al., 2009, p. 114) |
| Make all possible efforts | 6 | • ... they generally would not choose to limit treatment if there remained hope that the patient would survive. Many surrogates approached decision-making with the belief that small chances of success are acceptable when the only other option is death. (Zier et al., 2008, p. 2344)  
• ... it was common for surrogates to consider even general discussion of expected outcomes to be premature. As some put it, surrogates thought it was “too soon to give up” (Nelson et al., 2017, p. 867) |
<p>| Patient’s best interests | 4 | • Many SDMs reported thinking that keeping someone in an undesirable state, such as in pain or comatose, was wrong when the circumstances of the patient were no longer thought of as “temporary” but rather indefinitely. (Dionne-Odom et al., 2015, p. 337) |</p>
<table>
<thead>
<tr>
<th>Decision factors</th>
<th>SE Papers with this factor</th>
<th>Illustrative quotations from the SE Papers</th>
</tr>
</thead>
</table>
| **Patient’s preferences**                            | 13                        | • Thirty (63%) family members reported having had previous conversations with their hospitalized loved one about end-of-life treatment preferences. These conversations helped to rationalize and lessen the burden of the decision to withdraw or withhold life-sustaining treatment for these family members. (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001, p. 199)  
• Most surrogates described a turning point leading to the decision to withdraw life support, often associated with a discussion with the clinical team about prognosis in relation to the patient’s values. (Nunez et al., 2015, p. 2390)  
• As noted above, most of the surrogates reported having had discussions with their loved ones, yet only 66% of them (n = 33) planned to use those conversations and the knowledge they gained of their loved ones’ preferences as the basis for decision-making. (Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006, p. 1690) |
| **Physician’s recommendation**                       | 3                         | • ... surrogates appreciated when clinicians made treatment recommendations. (Vig et al., 2007, p. 1277)                                                                                                                                 |
| **Surrogate’s preferences**                          | 2                         | • In addition to patient-centered considerations, surrogates often relied on their own wishes, or what they themselves would want if they were the patient. (Fritsch et al., 2013, p. 130)                                |
| **Decision-making control** (surrogate only, physician only, or surrogate-physician shared) | 5                         | • The majority of surrogates (55%, 127/230; 95% confidence interval, 49–62%) preferred to have final control over the value-sensitive life support decision. (Johnson, Bautista, Hong, Weissfeld, & White, 2011, p. 916)  
• Most (75%) wanted to share the decision with the physician. (Lewis et al., 2006, p. 249)  
• 5% (12/230) wanted the physician to have final control. (Johnson et al., 2011, p. 916) |
| **Prognostic factors**                               |                           | • Three percent (6 of 179) of surrogates felt that physicians should withhold prognostic information to maintain surrogates’ hope. (Apatira et al., 2008, p. 865)                                                
• When asked whether it would be helpful to hear information about clinicians’ expectations for the future course of the patient’s illness, a small number of surrogates openly stated a preference not to receive such information, or shifted the discussion to another topic. (Nelson et al., 2017, p. 868) |
<table>
<thead>
<tr>
<th>Decision factors</th>
<th>SE Papers with this factor</th>
<th>Illustrative quotations from the SE Papers (NB: the entire text of each bullet point is a direct quotation from the cited paper)</th>
</tr>
</thead>
</table>
| Need for clear and frank prognosis     | 14                        | • Overall, 87% (155/179) of surrogates wanted physicians to discuss prognosis even in the face of uncertainty. (Evans et al., 2009, p. 49)  
|                                        |                           | • Participants were clear that they desired informational support to make higher quality decisions. (Hickman, Daly, Clochesy, O’Brien, & Leuchtag, 2016, p. 88)  
|                                        |                           | • Although closely related to clinicians’ communication techniques, receiving accurate, truthful information from physicians was clearly distinguished from other communication-related themes. (Hutchison et al., 2016, p. 2211)  
|                                        |                           | • All participants reported wanting more information about their loved ones’ treatments or prognoses. Many surrogates described this information as critically important to their decision making. (Schenker, White, et al., 2013, p. 244)  |
| Prognosis confirmation from multiple sources | 5                        | • Most participants described seeking prognostic information from sources beyond the ICU clinical team, including online references, other physicians, and family or friends with medical backgrounds or similar experiences. (Schenker, White, et al., 2013, p. 245)  |
| Prognosis confirmation with own eyes    | 8                        | • Surrogates often evaluated patients’ conditions by watching for physical signs of decline. Through the process of observation, surrogates came to a new understanding or belief about the patients’ ability to survive or to live meaningful lives. (Limerick, 2007, p. 336)  
|                                        |                           | • Some surrogates (n = 12) described how their own observations of the patient would allow them to determine whether further medical intervention would be futile. (Zier et al., 2009, p. 114)  |
| Prognostic limitations of physicians   | 7                        | • Many surrogates’ first and strongest statements addressed their belief that uncertainty is inevitable when trying to predict an individual patient’s outcome. (Evans et al., 2009, p. 50)  
|                                        |                           | • The most common concern raised by surrogates (n = 20) was that predicting the future with the certainty required for a futility judgment is beyond physicians’ capabilities. (Zier et al., 2009, p. 113)  |
| Surrogate's intuition                  | 3                        | • For these surrogates, instinct, intuition, and even emotion seemed to deserve greater weight than science and logic in predicting the patient’s outcome and shaping appropriate goals of treatment. (Nelson et al., 2017, p. 868)  |
3.2.3 Data analysis: Strength-of-evidence assessment

The QualSyst scores for the 26 SE Papers analyzed in the previous section ranged from a maximum of 0.91 to a minimum of 0.23, with a median of 0.77 and an average of 0.75. The individual scores for each paper are reported in Table A-2; a histogram of the scores is shown in Figure 3-6.

**Figure 3-6: Histogram of QualSyst scores**

Table 3-5 shows the effect of weighting the decision factors by the QualSyst scores. The raw count column shows the number of SE Papers containing each decision factor. The weighted count is calculated by summing the QualSyst score of each paper containing that decision factor. For example, the “Empathy with patient’s pain or loss of dignity” decision factor appears in two papers—the first with a score of 0.91, the second with a score of 0.68—the weighted count is the sum of those two, i.e., 1.6 when rounded.
Table 3-5: Decision factors reported by SE Papers – raw and strength-of-evidence adjusted counts

<table>
<thead>
<tr>
<th>Decision factor</th>
<th>Raw count</th>
<th>QualSyst adjusted count</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consequential factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of loss</td>
<td>2</td>
<td>1.4</td>
</tr>
<tr>
<td>Impact on surrogate's interests</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Patient's post-discharge QoL</td>
<td>4</td>
<td>3.0</td>
</tr>
<tr>
<td><strong>Contextual factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathy with patient's pain or loss of dignity</td>
<td>5</td>
<td>3.8</td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>Patient's history</td>
<td>6</td>
<td>4.5</td>
</tr>
<tr>
<td>Patient's intrinsic qualities</td>
<td>6</td>
<td>4.9</td>
</tr>
<tr>
<td><strong>Familial factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisional stress</td>
<td>10</td>
<td>7.0</td>
</tr>
<tr>
<td>Family conflict</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Need for family consensus</td>
<td>8</td>
<td>6.0</td>
</tr>
<tr>
<td>Need time to prepare</td>
<td>10</td>
<td>7.0</td>
</tr>
<tr>
<td><strong>Institutional factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established trust in physicians</td>
<td>9</td>
<td>6.7</td>
</tr>
<tr>
<td>Mistrust of institutions</td>
<td>5</td>
<td>3.7</td>
</tr>
<tr>
<td>Too many physicians</td>
<td>7</td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Normative factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leave decision to God</td>
<td>9</td>
<td>7.2</td>
</tr>
<tr>
<td>Make all possible efforts</td>
<td>6</td>
<td>4.6</td>
</tr>
<tr>
<td>Patient’s best interests</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Patient’s preferences</td>
<td>13</td>
<td>9.2</td>
</tr>
<tr>
<td>Physician’s recommendation</td>
<td>3</td>
<td>2.4</td>
</tr>
<tr>
<td>Surrogate's preferences</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Decision-making control</td>
<td>5</td>
<td>3.8</td>
</tr>
<tr>
<td><strong>Prognostic factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding bad or uncertain prognosis</td>
<td>4</td>
<td>3.3</td>
</tr>
<tr>
<td>Need for clear and frank prognosis</td>
<td>14</td>
<td>10.3</td>
</tr>
<tr>
<td>Prognosis confirmation from multiple sources</td>
<td>5</td>
<td>3.4</td>
</tr>
<tr>
<td>Prognosis confirmation with own eyes</td>
<td>8</td>
<td>6.3</td>
</tr>
<tr>
<td>Prognostic limitations of physicians</td>
<td>7</td>
<td>5.7</td>
</tr>
<tr>
<td>Surrogate's intuition</td>
<td>3</td>
<td>2.5</td>
</tr>
</tbody>
</table>
3.2.4 Data analysis: Response intensity assessment

20 (77%) of the 26 SE Papers also reported a quantitative measure of the intensity of their subjects’ responses for each decision factor:

- 9 (35%) reported cardinal measures, e.g., “Overall, 87% (155/179) of surrogates wanted physicians to discuss prognosis” (Evans et al., 2009, p. 49); or
- 11 (42%) reported ordinal measures, e.g., “Most surrogates described a turning point leading to the decision” (Nunez et al., 2015, p. 2390);
- 6 (23%) stated themes without any quantitative data, e.g., “surrogates appreciated when clinicians made treatment recommendations” (Vig et al., 2007, p. 1277).

For reporting purposes, I pooled the response intensities into the four categories shown in Table 3-6.

**Table 3-6: Surrogates’ response intensity categories**

<table>
<thead>
<tr>
<th>Intensity category</th>
<th>Cardinal Measure</th>
<th>Ordinal measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>High response intensity</td>
<td>≥ 75%</td>
<td>All, almost all, most, many</td>
</tr>
<tr>
<td>Medium response intensity</td>
<td>Between 40% and 75%</td>
<td>Common, half, majority, often, typically</td>
</tr>
<tr>
<td>Low response intensity</td>
<td>≤ 40%</td>
<td>Few, minority, one-third, others, several, small, some</td>
</tr>
<tr>
<td>No quantitative data</td>
<td></td>
<td>If no cardinal or ordinal measure is specified</td>
</tr>
</tbody>
</table>

Table 3-7 shows how many SE Papers reported each level of response intensity for each decision factor. For example, the decision factor *decisional stress* was found in 10 of the SE Papers: 4 of those 10 papers reported that more than 75% or many of their research subjects reported feeling decisional stress; 1 paper reported that between 40% and 75% or half or a majority of their subjects reported feeling decisional stress; 1 paper reported that less than 40% or only a few of their subjects reported feeling decisional stress; and 4 of the 10 papers did not provide any quantitative data on response intensity. I did not adjust the response intensity counts for strength-of-evidence of the individual papers; doing so would imply a level of precision that is unwarranted by the underlying data.
Table 3-7: Response intensity counts in SE Papers

<table>
<thead>
<tr>
<th>Decision factor</th>
<th>Raw count</th>
<th>Response intensity count</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>High</td>
</tr>
<tr>
<td><strong>Consequential factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of loss</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Impact on surrogate’s interests</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Patient's post-discharge QoL</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Contextual factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathy with patient’s pain or loss of dignity</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Patient's history</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Patient's intrinsic qualities</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td><strong>Familial factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisional stress</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Family conflict</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Need for family consensus</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Need time to prepare</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td><strong>Institutional factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established trust in physicians</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Mistrust of institutions</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Too many physicians</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td><strong>Normative factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leave decision to God</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Make all possible efforts</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Patient’s best interests</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Patient’s preferences</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Physician’s recommendation</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Surrogate’s preferences</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Decision-making control</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Prognostic factors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding bad or uncertain prognosis</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Need for clear and frank prognosis</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Prognosis confirmation from multiple sources</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Prognosis confirmation with own eyes</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Prognostic limitations of physicians</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Surrogate’s intuition</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>
3.3 Results: Decision factors and their response intensities

The research question of this study was:

*What factors influence surrogates’ decision-making for adult ICU patients?*

From my analysis of the papers exploring surrogates’ experiences, I was able to identify 27 distinct factors influencing surrogates’ decision-making. These decision factors and their prevalence across the 26 SE Papers, adjusted for the strength-of-evidence of each paper, are shown in Table 3-8.

In addition to the overall prevalence of each decision factor, Table 3-8 also shows the distribution of response intensities for each decision factor. These combined results are shown graphically in Figure 3-7, which ranks the decision factors by overall prevalence, and in Figure 3-8, which ranks the decision factors by prevalence of high response intensity (i.e., decision factors reported by >75%, “most” or “all” surrogates). Ranking the decision factors by prevalence is of value in Study #2 where I look for gaps and conflicts between these decision factors and what actually transpires during the interactions between surrogates and clinicians.
Table 3-8: Decision factor prevalence adjusted for strength-of-evidence and surrogates’ response intensities

<table>
<thead>
<tr>
<th>Decision factor</th>
<th>Overall prevalence adjusted for strength-of-evidence</th>
<th>High response intensity</th>
<th>Medium response intensity</th>
<th>Low response intensity</th>
<th>No quantitative data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Consequential factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of loss</td>
<td>7%</td>
<td>0%</td>
<td>0%</td>
<td>7%</td>
<td>0%</td>
</tr>
<tr>
<td>Impact on surrogate’s interests</td>
<td>8%</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Patient’s post-discharge QoL</td>
<td>15%</td>
<td>8%</td>
<td>0%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Contextual factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathy with patient’s pain or loss of dignity</td>
<td>19%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>12%</td>
<td>0%</td>
<td>0%</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>Patient's history</td>
<td>23%</td>
<td>4%</td>
<td>4%</td>
<td>11%</td>
<td>4%</td>
</tr>
<tr>
<td>Patient’s intrinsic qualities</td>
<td>25%</td>
<td>8%</td>
<td>0%</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Familial factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisional stress</td>
<td>36%</td>
<td>14%</td>
<td>4%</td>
<td>4%</td>
<td>14%</td>
</tr>
<tr>
<td>Family conflict</td>
<td>8%</td>
<td>0%</td>
<td>0%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>Need for family consensus</td>
<td>31%</td>
<td>15%</td>
<td>4%</td>
<td>4%</td>
<td>8%</td>
</tr>
<tr>
<td>Need time to prepare</td>
<td>36%</td>
<td>7%</td>
<td>7%</td>
<td>7%</td>
<td>15%</td>
</tr>
<tr>
<td><strong>Institutional factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established trust in physicians</td>
<td>35%</td>
<td>4%</td>
<td>4%</td>
<td>8%</td>
<td>19%</td>
</tr>
<tr>
<td>Mistrust of institutions</td>
<td>19%</td>
<td>0%</td>
<td>0%</td>
<td>15%</td>
<td>4%</td>
</tr>
<tr>
<td>Too many physicians</td>
<td>26%</td>
<td>4%</td>
<td>0%</td>
<td>11%</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Normative factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leave decision to God</td>
<td>37%</td>
<td>0%</td>
<td>8%</td>
<td>29%</td>
<td>0%</td>
</tr>
<tr>
<td>Make all possible efforts</td>
<td>24%</td>
<td>4%</td>
<td>8%</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>Patient’s best interests</td>
<td>16%</td>
<td>4%</td>
<td>8%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>Patient’s preferences</td>
<td>47%</td>
<td>11%</td>
<td>11%</td>
<td>11%</td>
<td>15%</td>
</tr>
<tr>
<td>Physician’s recommendation</td>
<td>12%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Surrogate's preferences</td>
<td>8%</td>
<td>0%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>Decision-making control</td>
<td>20%</td>
<td>16%</td>
<td>0%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Prognostic factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding bad or uncertain prognosis</td>
<td>17%</td>
<td>4%</td>
<td>4%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Need for clear and frank prognosis</td>
<td>53%</td>
<td>26%</td>
<td>0%</td>
<td>8%</td>
<td>19%</td>
</tr>
<tr>
<td>Prognosis confirmation from multiple sources</td>
<td>17%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>7%</td>
</tr>
<tr>
<td>Prognosis confirmation with own eyes</td>
<td>32%</td>
<td>8%</td>
<td>4%</td>
<td>8%</td>
<td>12%</td>
</tr>
<tr>
<td>Prognostic limitations of physicians</td>
<td>29%</td>
<td>8%</td>
<td>4%</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td>Surrogate's intuition</td>
<td>13%</td>
<td>0%</td>
<td>0%</td>
<td>13%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Figure 3-7: Decision factors ranked by overall prevalence, grouped in quartiles

- Need for clear and frank prognosis
- Patient's preferences
- Leave decision to God
- Need time to prepare
- Decisional stress
- Established trust in physicians
- Prognosis confirmation with own eyes
- Need for family consensus
- Prognostic limitations of physicians
- Too many physicians
- Patient's intrinsic qualities
- Make all possible efforts
- Patient's history
- Decision-making control
- Empathy with patient's pain or loss of dignity
- Mistrust of institutions
- Prognosis confirmation from multiple sources
- Avoiding bad or uncertain prognosis
- Patient's best interests
- Patient's post-discharge QoL
- Surrogate's intuition
- Optimism affects outcome
- Physician's recommendation
- Family conflict
- Impact on surrogate's interests
- Surrogate's preferences
- Fear of loss

% of SE Papers
adjusted for strength-of-evidence

- High response intensity
- Medium response intensity
- Low response intensity
- No quantitative data
Figure 3-8: Decision factors ranked by prevalence of high response intensity, grouped in quartiles

- Need for clear and frank prognosis
- Decision-making control
- Need for family consensus
- Decisional stress
- Patient's preferences
- Prognostic limitations of physicians
- Patient's intrinsic qualities
- Patient's post-discharge QoL
- Need time to prepare
- Prognosis confirmation with own eyes
- Make all possible efforts
- Patient's best interests
- Patient's history
- Avoiding bad or uncertain prognosis
- Established trust in physicians
- Physician's recommendation
- Empathy with patient's pain or loss of dignity
- Prognosis confirmation from multiple sources
- Too many physicians
- Leave decision to God
- Surrogate's preferences
- Impact on surrogate's interests
- Mistrust of institutions
- Surrogate's intuition
- Optimism affects outcome
- Fear of loss
- Family conflict

% of SE Papers adjusted for strength-of-evidence

- High response intensity
- Medium response intensity
- Low response intensity
- No quantitative data

Percentage distribution as follows:

- Need for clear and frank prognosis: High response intensity
- Decision-making control: Medium response intensity
- Need for family consensus: Low response intensity
- Decisional stress: No quantitative data
3.4 Discussion

3.4.1 Discussion of findings

Each of the primary research papers included in this metasynthesis had its own research question and probed a different facet of the surrogate experience. As shown in Table 3-9, two of the decision factors identified in this metasynthesis were found in half of the SE Papers, and an additional six decision factors were found in one-third. The emergence of these decision factors across a broad spectrum of papers lends weight to their importance in the surrogate experience.

The overall prevalence of a decision factor, however, is not the only criterion of its importance. The method I used enabled me to capture information about the response intensity – the number of research participants responding to each decision factor (see Table 3-6 for details). This additional information adds substantial nuance to the relative importance of the decision factors.

For example, the decision factors “Decisional stress” and “Leave decision to God” both appeared in about 36% of the SE Papers, implying these two factors may be of similar importance. However, “all” or “most” surrogates (high response intensity) reported “Decisional stress” in 71% of the papers reporting this factor, while “few” or “some” surrogates (low response intensity) reported “Leave decision to God” in 78% of the papers reporting this factor. In other words, the response intensity data shows that “Decisional stress” is a consistent factor for most surrogates, but “Leave decision to God” is of significance only to a minority.

Taking both prevalence and response intensity into account (see Figure 3-8), the top four decision factors are:

- need for clear and frank prognosis;
- need for family consensus;
- decisional stress; and
- patient’s preferences.

Table 3-9: Most common decision factors

| Decision factors found in half of all SE Papers | • Need for clear and frank prognosis  
| • Patient’s preferences |
| Decision factors found in a third of all SE Papers | • Leave decision to God  
| • Need time to prepare  
| • Decisional stress  
| • Established trust in physicians  
| • Prognosis confirmation with own eyes  
| • Need for family consensus |

8 The decision factor “Decision-making control” might appear to also belong to this group, but that is an artifact of the ranking methodology. This factor was the explicit focus of 4 articles, and so it had a response intensity of 100%, i.e. all participants in these studies responded to this question. This decision factor did not appear in less specifically focused studies.
The data underlying these decision factors paints a picture of a complex decision-making process that is not reducible to a utility-maximization model. Similarly, except for the minority willing to “Leave the decision to God”, the normative principles guiding surrogates’ decisions appear to be equally complex.

3.4.1.1 Need for clear and frank prognosis

While seen as a requirement for high quality decisions (Apatira et al., 2008; Hickman et al., 2016; Nelson et al., 2017; Schenker, White, et al., 2013; Zier et al., 2008), the need for a clear and frank prognosis also affects:

- having time for surrogates and family to prepare for a decision to withdraw life-sustaining treatment (Apatira et al., 2008); and
- the process of building trust with the physician(s) (Evans et al., 2009);

Surrogates are well aware of the limits of physicians’ abilities to prognosticate (Evans et al., 2009; White, Evans, Bautista, Luce, & Lo, 2009; Zier et al., 2008). For the most part they do not want to be shielded from the truth and are wary of the risk of false hope (Apatira et al., 2008; Hutchison et al., 2016; Vig et al., 2007). But a small number are concerned that a poor prognosis will blunt hope (Apatira et al., 2008; Evans et al., 2009; Nelson et al., 2017; Schenker, White, et al., 2013), and that the family’s hope and optimism plays a role in a good outcome for the patient (Apatira et al., 2008; Boyd et al., 2010).

3.4.1.2 Need for family consensus

Surrogate decision-making rarely appears to be an individual responsibility, but exactly how the responsibility is shared varies with each family. In some cases, surrogates feel “compelled” to create a family consensus (Dionne-Odom et al., 2015, p. 337); as one surrogate said, “We either all make the decision or none make the decision” (Fritsch et al., 2013, p. 131). In other cases, consensus-seeking is perceived as burden sharing by multiple family members (Abbott et al., 2001) or as a way to ease “surrogates’ fears about being later blamed for a patient’s death or disability” (Schenker, Crowley-Matoka, et al., 2012, p. 1662).

3.4.1.3 Decisional stress

Decisional stress is a constant factor for almost all surrogates. Stress comes from multiple sources, each of which influences the decision-making process in a different way:

- the emotional magnitude and guilt inherent in the decision (Buckey & Molina, 2012; Handy et al., 2008; Nelson et al., 2017);
the lack of certainty (Bute, Petronio, & Torke, 2016; Dionne-Odom et al., 2015; Nunez et al., 2015);
the burden and weariness from having to make a rapid series of many difficult treatment decisions (Hickman et al., 2016; Nelson et al., 2017); and
competing demands on the surrogate’s time and attention (Vig et al., 2007).

3.4.1.4 Patient’s preferences

Knowledge of the patient was clearly the most important normative factor for the surrogates, whether from remembered conversations with the patient or a presumed knowledge of the patient’s values (Abbott et al., 2001; Buckey & Molina, 2012; Bute et al., 2016; Dionne-Odom et al., 2015; Handy et al., 2008; Nunez et al., 2015). Reference was made to a written advance directive in only a few cases, consistent with findings that < 35% of ICU patients have prepared an advance directive, and even fewer brought it to the hospital (Shapiro, 2012). Some surrogates also found themselves in conflict with the expressed wishes of the patient, either because of emotional conflict (Schenker, Crowley-Matoka, et al., 2012) or because, in spite of this knowledge, they based their judgments on their own assessment of the patient’s likely quality of life (Dionne-Odom et al., 2015; Fritsch et al., 2013; Vig et al., 2006). Knowledge of the patient’s past history—whether positive, e.g., surviving against the odds in a prior illness, or negative, e.g., being on a downward health spiral—was also frequently reported as an influence (Boyd et al., 2010; Buckey & Molina, 2012; Limerick, 2007; Zier et al., 2009).

3.4.2 Discussion of SAMMS method

The findings reported in this chapter demonstrate the efficacy and efficiency of the SAMMS (Similar Articles Matching Multiple Seeds) systematic search method, which I developed and applied here for the first time.

The usual systematic search methods depend on subject-based queries, e.g., using Medical Search Headings (MeSH) terms. These queries typically generate hundreds or thousands of candidates. Because the candidates are unranked, those meeting the inclusion/exclusion criteria are randomly distributed throughout the result set, and the investigators have to assess all of the candidates. The SAMMS method also generates thousands of candidates, but because the candidates are ranked by the number of seeds matched, the inclusion/exclusion criteria assessment process is far more efficient. The investigators need to assess only the top-ranked candidates, typically 10-20% of the total, to find 80-90% of the articles that meet the criteria.
Similar efficiencies were found in the thematic synthesis portion of the work, which required identifying analytic themes from the results of the systematic search. The articles that matched the most seeds were more likely to contain analytic themes. 21 (78%) of the analytic themes eventually found appeared in the first 10 (27%) articles, each of which matched 11 or 12 seeds. The remaining 6 analytic themes were found in the next 10 articles, each of which matched 9 or 10 seeds. The remaining 17 (46%) articles contained no new analytic themes, but did contain many confirming instances of the themes already found. This rapid convergence to theoretical saturation not only enhances the efficiency of performing a theoretical synthesis, but increases confidence in the completeness of the result.
3.5 Limitations

3.5.1 Limitations of findings

As Thomas and Harden write, the thematic synthesis method requires “... a stage of interpretation whereby the reviewers 'go beyond' the primary research to generate new interpretive constructs, explanations or hypotheses” (2008, p. 1). They acknowledge that “This stage of a qualitative synthesis is the most difficult to describe and is, potentially, the most controversial, since it is dependent on the judgement and insights of the reviewers” (2008, p. 7). Thus, my synthesis of the empirical findings into decision factors may not be without bias. However, my findings triangulate well with other studies such as those conducted by Shapiro (2015) and Kaufman (2005) which investigated other aspects of end-of-life treatment and decision-making in the ICU.

The SAMMS method is based on an index of the literature within PubMed. My systematic search thus excludes literature not in PubMed. Given the inclusion criteria, this limitation appears not to have been a problem: before starting the searches, I investigated the results from different databases including PsychINFO (www.ebsco.com) when using subject terms such as “surrogate decision-making”. PsychINFO did not return any results from journals that were not also indexed in PubMed.

The strength-of-evidence analysis does change the ranked order of the decision factors, but such changes are minor. This may be attributed to the fact that 11 of the 26 SE Papers analyzed come from one group of researchers: Douglas White and colleagues (e.g., Schenker, Crowley-Matoka, et al., 2012; Zier et al., 2012). All of these papers have a strong and consistent methodology: average QualSyst score 0.82, minimum 0.73. Two other groups—Annette Torke (e.g., Torke et al., 2012) and Elizabeth Vig (e.g., Vig et al., 2007)—account for an additional five papers, again with strong methodology: average QualSyst score 0.74, minimum 0.59.

The concentration of evidence—16 papers from only three research groups—may have led to a bias in the results because of the consistency of their methods or the geographic concentration of their samples. However, these three are the only groups in North America that have conducted extensive empirical research on surrogate decision-makers. The evidence from the other 10 papers, although not as strong (average QualSyst score 0.67, minimum 0.23), shows that 17 of the 27 decision factors are found in both groups of papers, and only one decision factor (“Fear of loss”) is unique to the group of 10 papers. In other words, the results from the smaller group do not contradict the 16 papers from White, Torke, Vig and colleagues.
3.5.2 Limitations of SAMMS method

No formal calibration study has yet been performed on the SAMMS method. However, my search coincidentally found one review article (H. Kim, Deatrick, & Ulrich, 2017) that used a conventional subject-term search strategy to investigate surrogate decision-making. Their subject-terms were congruent with the MeSH terms of my 16 seed articles. Thus, I would anticipate the number of raw results returned by their search to be similar to the number of raw results from the SAMMS search. The initial search by Kim et al. found 1152 unique articles, i.e., about half the number (2484) found by the SAMMS method. In this one instance, therefore, the SAMMS method was more inclusive than a conventional subject-term search.

Another informal calibration point comes from Vig et al. (2007), one of the 26 SE Papers. In their literature review, Vig et al. (2007) cite five other papers that also identify some of the same decision factors they report. All five of these papers were indexed in PubMed. Three of the papers were included in my SAMMS results (Abbott et al., 2001; Jacob, 1998; Tilden et al., 2001). Of the two that were not included, one (Chambers-Evans & Carnevale, 2005) had no abstract and so would have not met my inclusion criteria. Only one paper (Russ & Kaufman, 2005) was not found in the SAMMS search.

Before the SAMMS method could be more widely used for systematic searches of the PubMed literature, it would have to be rigorously compared to the conventional MeSH term query method, and the sensitivity of the method to the number of seed articles would have to be investigated further. That work is beyond the scope of this dissertation, and because such calibrations have not been completed, it is possible that the papers selected for content analysis were biased in some unknown manner, or that papers that should have been included were excluded. The favorable comparisons with the results in Kim et al. (2017) and Vig et al. (2007), however, provide some reassurance that the SAMMS results here do not suffer from these limitations.
3.6 Conclusions

In response to the research question for this study—*What factors influence surrogates’ decision-making for adult ICU patients?*—my analysis revealed 27 different decision factors. Of these, the following four decision factors were reported in many of the primary research papers and identified by many subjects as being important:

- need for clear and frank prognosis;
- need for family consensus;
- decisional stress; and
- patient's preferences.

A fifth decision factor—"leave the decision to God"—was not so widely reported, but was identified as being very important to those subjects who did report it.

The existence of these decision factors and their importance to surrogate decision-makers should be confirmed by empirical research specifically designed for that purpose in the future. Nonetheless, they provide a framework that may serve as a guide to researchers and clinicians seeking to understand surrogates’ decision-making behavior.
4 Study #2: Decision Factors and Surrogate-Professional Relationships

I continue to investigate my overall research question—*What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?*—by exploring whether the decision factors found in Study #1 are reflected in the interactions between surrogates and ICU professionals. In this study I conduct a metasynthesis of the primary research focused on the surrogate-professional relationship (SPR), seeking to answer the research question:

*What gaps and conflicts exist between surrogates’ expressed decision factors and the attitudes and behaviors of ICU professionals?*

The gaps and conflicts found in this study may illuminate some of the causes underlying the clinical deficiencies in the current paradigm for surrogate decision-making.

**Figure 4-1: Metasynthesis flowchart**

This metasynthesis relies on three distinct methods: systematic search, thematic analysis, and directed content analysis. The directed content analysis method has two phases. These methods and phases are applied to the data sequentially, i.e., the results from each stage of analysis serve as the raw data for the next. This sequence is depicted in Figure 4-1.

The methods are detailed in Section 4.1. The data analyzed in the systematic search, thematic analysis, and directed content analysis are reported in Section 4.2. The findings of this study—the gaps and conflicts between the decision factors from Study #1 and the SPR Papers—are presented in Section 4.3. These findings are discussed in Section 4.4. Limitations to this study are examined in Section 4.5, and conclusions are drawn in Section 4.6.
4.1 Methods

4.1.1 Systematic search method

4.1.1.1 Inclusion/exclusion criteria

For a paper to be included it had to meet all of the following inclusion criteria and not match any of the exclusion criteria.

Inclusion:

- Original empirical research on the relationship between surrogates and ICU professionals in the context of EoL decision-making for adult ICU patients; and
- Conducted in ICUs located in North American hospitals; and
- Published in English in the peer-reviewed academic literature.

Exclusion:

- Included in Study #1; or
- No abstract (such papers could not be assessed by the search strategy employed); or
- Not based on validated empirical research involving EoL decision-making, e.g., reviews, case studies, practice guides, editorials; or
- Focused on how specific cultural, ethnic, or religious groups interact with medical professionals, e.g., a paper on Korean-American surrogates would be excluded, but a paper that examined how religious topics were handled in surrogate-physician conferences would be included. I excluded these ethno-cultural specific studies because my research question was seeking gaps and conflicts common to all surrogate-physician relationships; including studies of particular cultural, ethnic, or religious groups would have produced results with a different focus.

4.1.1.2 Search strategy

I used the SAMMS systematic search method described in Section 3.1.1.2 to search the PubMed database for articles similar to one or more seed articles. To begin this search process, I selected 16 seed articles (listed in Table B-1) that met the stated inclusion/exclusion criteria; these articles were selected from my database of hundreds of papers on EoL decision-making. My decision to use 16 seed articles in the search was informed by the same arguments described in Section 3.1.1.2.

I captured the lists of similar articles obtained from PubMed for each of the 16 seed articles into an Excel spreadsheet (Microsoft Corporation). Using the filtering and counting functions in Excel, I
removed all duplicates to create a list of unique candidate articles, and established the number of seed articles matched by each candidate article.

I then assessed whether each candidate article matching three or more seeds met the inclusion/exclusion criteria by reading its title and abstract. Following the same strategy as Study #1 (Section 3.1.1.2) I also assessed a randomly selected sample of 29 (10%) of the candidate articles matching two seeds and another randomly selected sample of 23 (1%) articles matching one seed.

For convenience, hereafter I refer to the articles remaining after the inclusion assessment process as the Surrogate-Professional Relationship Papers (SPR Papers).

4.1.2 Thematic analysis method

Following the methods of Flick (2014 Chapter 26) I conducted a thematic analysis of the research objective stated in each paper’s abstract to identify and categorize the primary research topics of the SPR Papers. This analysis was conducted in three stages. In the first stage, I identified a list of potential topics by reading each abstract. In the second, I refined that list to a set of distinct topics. Third, I associated each paper with a single topic.

4.1.3 Directed content analysis method

The goal of directed content analysis is “to validate or extend conceptually a theoretical framework or theory” (Hsieh & Shannon, 2005, p. 1281). I conducted a two-phase directed content analysis (Hsieh & Shannon, 2005) to extend my understanding of the findings from Study #1:

i) Phase A: requires coding the SPR Papers using an initial coding scheme based on the theoretical framework from prior research. My theoretical framework was my findings from Study #1, and the 27 decision factors from Study #1 were the initial codes. The result of this phase is a list of SPR Papers associated with each decision factor.

ii) Phase B: extends the understanding of the initial codes by examining how the SPR Papers associated with each of the original decision factors answers the research question of this study, i.e., is there a gap or conflict between the surrogates’ decision factor and what the SPR literature reports about the interactions between the surrogate and the professional.

I used NVivo 12 (QSR International Pty Ltd) qualitative research software to assist with data management and analysis for both the thematic and directed content analysis. Following Saldaña’s recommendations for solo coding, my supervisor reviewed my coded data and served as a “rigorous examiner and auditor of my analysis” (Saldana, 2016, p. 37).
4.2 Data analysis

4.2.1 Data analysis: Systematic search

A total of 3766 articles, including duplicates and non-English articles, matched one or more of the 16 seed articles. As shown in the PRISMA diagram (Moher et al., 2009)(Figure 4-2), 2700 unique candidate articles remained after I removed duplicates and non-English articles using the filtering tools in Excel. I assessed 240 of these candidate articles against the inclusion criteria and found 52 that met those criteria (the SPR Papers). All 52 SPR Papers were analyzed for content.

The search results are detailed in Table 4-1 and graphed in Figure 4-3.

Table 4-1: Study #2 candidate articles found, included, excluded, and not assessed

<table>
<thead>
<tr>
<th>Seed articles matched:</th>
<th>16</th>
<th>15</th>
<th>14</th>
<th>13</th>
<th>12</th>
<th>11</th>
<th>10</th>
<th>9</th>
<th>8</th>
<th>7</th>
<th>6</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candidate articles:</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>9</td>
<td>9</td>
<td>16</td>
<td>25</td>
<td>35</td>
<td>88</td>
<td>287</td>
<td>2225</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of total</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.3%</td>
<td>0.3%</td>
<td>0.6%</td>
<td>0.9%</td>
<td>1.3%</td>
<td>3.3%</td>
<td>10.6%</td>
<td>82.4%</td>
<td>100%</td>
<td></td>
</tr>
<tr>
<td>Included</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>3</td>
<td>8</td>
<td>10</td>
<td>10</td>
<td>14</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>52</td>
<td></td>
</tr>
<tr>
<td>% of assessed</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0%</td>
<td>0%</td>
<td>78%</td>
<td>33%</td>
<td>50%</td>
<td>40%</td>
<td>29%</td>
<td>16%</td>
<td>0%</td>
<td>0%</td>
<td>22%</td>
</tr>
<tr>
<td>Excluded</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>8</td>
<td>15</td>
<td>25</td>
<td>74</td>
<td>29</td>
<td>23</td>
<td>188</td>
<td></td>
</tr>
<tr>
<td>% of assessed</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100%</td>
<td>100%</td>
<td>22%</td>
<td>67%</td>
<td>50%</td>
<td>60%</td>
<td>71%</td>
<td>84%</td>
<td>100%</td>
<td>100%</td>
<td>78%</td>
</tr>
<tr>
<td>Total assessed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>9</td>
<td>9</td>
<td>16</td>
<td>25</td>
<td>35</td>
<td>88</td>
<td>29</td>
<td>23</td>
<td>240</td>
<td></td>
</tr>
<tr>
<td>% of total</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>10%</td>
<td>1%</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>Not assessed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>258</td>
<td>2202</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of total</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>90%</td>
<td>99%</td>
<td>91%</td>
<td></td>
</tr>
</tbody>
</table>
Table 4-1 shows that no candidate article matched more than 10 of the seed articles. It also shows that the number of candidate articles increased rapidly as fewer seeds were matched. All six of the articles that matched 9 or 10 seeds were included in Study #1 and thus did not meet the inclusion/exclusion criteria (Section 4.1.1.1). Table 4-1 also shows that the candidate articles matching the most seed articles meet the inclusion criteria at the highest rates: 78% of those matching 8 seeds, and 33% of those matching 7 seeds. The results from Table 4-1 are shown graphically in Figure 4-3.

**Figure 4-3: Study #2 inclusion rates for candidate articles by number of seed articles matched**

The green bars in Figure 4-3 show the number of candidate articles versus the number of seed articles matched. The orange line in Figure 4-3 shows the relationship between the rate of candidate articles meeting the inclusion criteria and the number of seed articles matched by the candidate articles; the dotted line indicates where results were estimated from randomly selected samples. As also seen in Study #1, the number of candidate articles increases exponentially as the number of seeds matched decreases, and the probability of a candidate article meeting the inclusion criteria is almost linearly correlated with the number of matches.
4.2.2 Data analysis: Demographic and other characteristics of the SPR Papers

The majority of the SPR papers are quite recent: 50% were published within the last seven years. The oldest was published in 1995 and the latest in 2018. The distribution by year of publication is shown in Figure 4-4.

**Figure 4-4: Distribution of SPR Papers by year of publication**

![Distribution of SPR Papers by year of publication](image)

Demographic data was not reported consistently across all the SPR Papers. The reported data was summarized and is presented in Table 4-2\(^9\).

**Table 4-2: Demographic characteristics of subjects in the SPR Papers**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>% of SPR Papers reporting</th>
<th>Patients</th>
<th>Surrogates</th>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of subjects</td>
<td>100%</td>
<td>1591</td>
<td>3179</td>
<td>5345</td>
</tr>
<tr>
<td>Gender (% Female)</td>
<td>81%</td>
<td>45%</td>
<td>66%</td>
<td>41%</td>
</tr>
<tr>
<td>Mean Age</td>
<td>65%</td>
<td>54</td>
<td>50</td>
<td>38</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>65%</td>
<td>70%</td>
<td>72%</td>
<td>71%</td>
</tr>
<tr>
<td>African-American</td>
<td>16%</td>
<td>11%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13%</td>
<td>15%</td>
<td>25%</td>
<td></td>
</tr>
</tbody>
</table>

---

\(^9\) Some of the SPR Papers shared the same set of family-physician conference data, recoding the same transcriptions to address different research questions, e.g. Selph et al. (2008), (2007), Hsieh et al. (2006), West et al. (2005), and Curtis et al. (2005). I removed these duplicate counts from the totals, so that the numbers of subjects reported in Tables 4-2 and 4-3 represents numbers of unique individuals.
Each of the SPR papers relied on one of the four following research methods:

i) qualitative analysis of family-physician conferences;

ii) qualitative interviews with surrogates or clinicians;

iii) quantitative survey of surrogates or clinicians; or

iv) a trial of some proposed intervention directed at either surrogates or physicians.

The number of papers using each research method is shown in Table 4-3, along with the total number of research subjects reported by the authors.

**Table 4-3: Research methods and numbers of subjects in the SPR Papers**

<table>
<thead>
<tr>
<th>Research method</th>
<th>Number of SPR Papers</th>
<th>Total number of subjects reported</th>
<th>Other Medical Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Patients</td>
<td>Surrogates</td>
</tr>
<tr>
<td>Family-physician conferences</td>
<td>19</td>
<td>674</td>
<td>1192</td>
</tr>
<tr>
<td>Qualitative interviews with:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>surrogates</td>
<td>3</td>
<td>196</td>
<td>228</td>
</tr>
<tr>
<td>clinicians</td>
<td>13</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>surrogates and clinicians</td>
<td>3</td>
<td>44</td>
<td>110</td>
</tr>
<tr>
<td>Quantitative surveys with:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>surrogates</td>
<td>1</td>
<td>0</td>
<td>96</td>
</tr>
<tr>
<td>clinicians</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Intervention trials directed at:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>surrogates</td>
<td>7</td>
<td>310</td>
<td>1186</td>
</tr>
<tr>
<td>clinicians</td>
<td>2</td>
<td>367</td>
<td>367</td>
</tr>
<tr>
<td>Total</td>
<td>52</td>
<td>1591</td>
<td>3179</td>
</tr>
</tbody>
</table>
4.2.3 Thematic data analysis: Research topics found in the SPR Papers

From the thematic analysis I found that the 52 SPR Papers focused on 14 different primary research topics. These topics and their prevalences are listed in Table 4-4.

Table 4-4: Topics in the SPR Papers ranked by prevalence

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description of research focus</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective communication</td>
<td>Modes and process of professional-to-surrogate communication</td>
<td>10 (19%)</td>
</tr>
<tr>
<td>Conflicts</td>
<td>Nature, frequency, and causes of ICU conflict, usually between surrogates and physicians, but also intra-medical team and intra-family</td>
<td>8 (15%)</td>
</tr>
<tr>
<td>Prognostic uncertainty</td>
<td>How prognostic uncertainty is understood, communicated, or dealt with</td>
<td>8 (15%)</td>
</tr>
<tr>
<td>Family support</td>
<td>How professionals’ behaviors can assist or impede families in coping with the ICU and decision-making</td>
<td>4 (7.7%)</td>
</tr>
<tr>
<td>Goals of care</td>
<td>The process of setting goals of care, or of determining appropriate goals of care</td>
<td>4 (7.7%)</td>
</tr>
<tr>
<td>Physician’s role</td>
<td>The roles physicians take in their relationships with surrogates: e.g., collaborative, facilitative, directive, informational</td>
<td>4 (7.7%)</td>
</tr>
<tr>
<td>Patient’s preferences and EoL</td>
<td>Whether patient’s preferences and/or future EoL were discussed by surrogates and professionals as part of the decision-making process</td>
<td>3 (5.8%)</td>
</tr>
<tr>
<td>Physician variability</td>
<td>Factors that contribute to variability in physicians’ beliefs, recommendations, or actions</td>
<td>3 (5.8%)</td>
</tr>
<tr>
<td>Prognostic accuracy</td>
<td>The correlation between actual outcomes and physicians’ and/or surrogates’ predictions at the time of decision-making</td>
<td>2 (3.8%)</td>
</tr>
<tr>
<td>Surrogate’s role</td>
<td>The nature of the surrogate’s role and of the physician’s role in guiding the surrogate, especially towards decision-making based on substituted judgment and patient’s best interests</td>
<td>2 (3.8%)</td>
</tr>
<tr>
<td>Moral distress</td>
<td>The medical staff’s distress when surrogates’ choices or indecision lead to treatment past the point of futility</td>
<td>1 (1.9%)</td>
</tr>
<tr>
<td>Recommendations by physicians</td>
<td>Whether physicians should or are willing to provide recommendations on EoL decisions to surrogates</td>
<td>1 (1.9%)</td>
</tr>
<tr>
<td>Religion</td>
<td>Professionals’ interactions with family and surrogates on religious or spiritual issues</td>
<td>1 (1.9%)</td>
</tr>
<tr>
<td>Responsible physician</td>
<td>Which physician is responsible for the care of the patient, and who do surrogates turn to for information and recommendations</td>
<td>1 (1.9%)</td>
</tr>
</tbody>
</table>

The first three topics account for 50% of the 52 SPR Papers analyzed, with an average 8.7 studies per topic. The other 11 topics have an average of only 2.4 studies per topic.
4.2.4 Content data analysis: Decision factors from Study #1 found in the SPR Papers

Each of the 52 SPR Papers contained content related to one or more decision factors, and, conversely, 26 of the 27 decision factors appeared in at least one SPR Paper. The distribution of decision factors was skewed: four factors were referenced in 20% or more of all studies, while 14 decision factors were referenced in less than 10% of all studies.

Table 4-5 graphically depicts the uneven distribution of the 27 decision factors across the SPR Papers. This heatmap shows the number of SPR Papers referencing each decision factor for each SPR topic. For example, seven studies in Table 4-5 had both Prognostic uncertainty as a topic and Need for clear and frank prognosis as a decision factor.

Table 4-5: Number of SPR Papers by SPR topic referencing each decision factor

<table>
<thead>
<tr>
<th>Decision factors</th>
<th>Prognostic uncertainty</th>
<th>Conflicts</th>
<th>Effective communication</th>
<th>Family support</th>
<th>Physician variability</th>
<th>Goals of care</th>
<th>Physician's role</th>
<th>Prognostic accuracy</th>
<th>Moral distress</th>
<th>Patient preferences and QoL</th>
<th>Surrogate's role</th>
<th>Recommendations by physicians</th>
<th>Religion</th>
<th>Responsible physician</th>
<th>SPR Papers referencing factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient preferences</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>14</td>
<td>27%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for clear and frank prognosis</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>12</td>
<td>23%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisional stress</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>11</td>
<td>21%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision-making control</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>11</td>
<td>21%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s post-discharge QoL</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>9</td>
<td>17%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient best interests</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>15%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician’s recommendation</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>13%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prognostic limitations of physicians</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>12%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too many physicians</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>6</td>
<td>12%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoiding bad or uncertain prognosis</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Established trust in physicians</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need time to prepare</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surrogate’s preferences</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>10%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family conflict</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leave decision to God</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make all possible efforts</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Empathy with patient’s pain or loss of dignity</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact on surrogate’s interests</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for family consensus</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prognosis confirmation from multiple sources</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mistrust of institutions</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s history</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s intrinsic qualities</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of loss</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prognosis confirmation with own eyes</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surrogate’s intuition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td>0%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Number of different decision factors referenced by SPR Papers: 26 | Total SPR Papers: 52
The bottom rows of Table 4-5 show the number of different decision factors referenced by the SPR Papers in that topic (both as a count and a percentage of the 27 decision factors), and the total number of SPR Papers in that topic. For example, for the topic of Prognostic uncertainty, the 10 SPR Papers in this topic referenced 16 different decision factors. The rightmost columns show the total number of SPR Papers containing a reference to each decision factor, both as a count and a percentage of the total number of papers. For example, the decision factor Patient’s preferences was referenced in 14 (27%) of the SPR Papers.

Another way of viewing the difference between the SE Papers of Study #1 and the SPR Papers of Study #2 is by comparing the ranking of the decision factors between the two. As Thorne (2008, p. 156) cautions, prevalence or rank should not be interpreted as necessarily implying importance or relevance. Here rank is construed strictly as a measure of how many papers in each group contained one or more references to each decision factor.
Table 4-6: Comparison of decision factor prevalence rankings between the SE and SPR Papers

<table>
<thead>
<tr>
<th>Decision factor (from Study #1)</th>
<th>SE prevalence rank</th>
<th>SPR prevalence rank</th>
<th>SE vs SPR rank difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for clear and frank prognosis</td>
<td>1</td>
<td>2</td>
<td>+1</td>
</tr>
<tr>
<td>Patient’s preferences</td>
<td>2</td>
<td>1</td>
<td>-1</td>
</tr>
<tr>
<td>Leave decision to God</td>
<td>3</td>
<td>14</td>
<td>+11</td>
</tr>
<tr>
<td>Decisional stress</td>
<td>4</td>
<td>3</td>
<td>-1</td>
</tr>
<tr>
<td>Need time to prepare</td>
<td>5</td>
<td>10</td>
<td>+5</td>
</tr>
<tr>
<td>Established trust in physicians</td>
<td>6</td>
<td>10</td>
<td>+4</td>
</tr>
<tr>
<td>Need for family consensus</td>
<td>7</td>
<td>18</td>
<td>+11</td>
</tr>
<tr>
<td>Prognosis confirmation with own eyes</td>
<td>8</td>
<td>25</td>
<td>+17</td>
</tr>
<tr>
<td>Prognostic limitations of physicians</td>
<td>9</td>
<td>8</td>
<td>-1</td>
</tr>
<tr>
<td>Patient's intrinsic qualities</td>
<td>10</td>
<td>22</td>
<td>+12</td>
</tr>
<tr>
<td>Make all possible efforts</td>
<td>11</td>
<td>14</td>
<td>+3</td>
</tr>
<tr>
<td>Too many physicians</td>
<td>12</td>
<td>8</td>
<td>-4</td>
</tr>
<tr>
<td>Patient's history</td>
<td>13</td>
<td>22</td>
<td>+9</td>
</tr>
<tr>
<td>Decision-making control</td>
<td>14</td>
<td>3</td>
<td>-11</td>
</tr>
<tr>
<td>Empathy with patient's pain or loss of dignity</td>
<td>15</td>
<td>18</td>
<td>+3</td>
</tr>
<tr>
<td>Prognosis confirmation from multiple sources</td>
<td>16</td>
<td>18</td>
<td>+2</td>
</tr>
<tr>
<td>Avoiding bad or uncertain prognosis</td>
<td>17</td>
<td>10</td>
<td>-7</td>
</tr>
<tr>
<td>Patient’s best interests</td>
<td>18</td>
<td>6</td>
<td>-12</td>
</tr>
<tr>
<td>Mistrust of institutions</td>
<td>18</td>
<td>22</td>
<td>+4</td>
</tr>
<tr>
<td>Patient’s post-discharge QoL</td>
<td>20</td>
<td>5</td>
<td>-15</td>
</tr>
<tr>
<td>Surrogate’s intuition</td>
<td>21</td>
<td>27</td>
<td>+6</td>
</tr>
<tr>
<td>Optimism affects outcome</td>
<td>22</td>
<td>14</td>
<td>-8</td>
</tr>
<tr>
<td>Physician’s recommendation</td>
<td>23</td>
<td>7</td>
<td>-16</td>
</tr>
<tr>
<td>Family conflict</td>
<td>24</td>
<td>14</td>
<td>-10</td>
</tr>
<tr>
<td>Impact on surrogate’s interests</td>
<td>25</td>
<td>18</td>
<td>-7</td>
</tr>
<tr>
<td>Surrogate’s preferences</td>
<td>26</td>
<td>10</td>
<td>-16</td>
</tr>
<tr>
<td>Fear of loss</td>
<td>27</td>
<td>25</td>
<td>-2</td>
</tr>
</tbody>
</table>

Table 4-6 compares the rank of each decision factor based on its prevalence from Study #1 (Table 3-8) and its prevalence among the 52 SPR Papers (taken from Table 4-6). It also shows the SE vs SPR rank difference calculated by subtracting the SE rank from the SPR rank. This subtraction strategy is a straightforward way to highlight factors with the greatest differences, i.e., those factors most likely to have a gap or conflict between the surrogates’ experiences and the surrogate-professional interactions. The rank differences from Table 4-6 are shown graphically in Figure 4-5.
Green bars in Figure 4-5 designate factors that are referenced more or less equally in both groups of studies, i.e., where the rankings differ by a rank difference of less than 5.2 positions, which is one sample standard deviation. The purple and orange bars identify decision factors with a rank difference greater than one sample standard deviation.
4.3 Results: Gaps and conflicts between the decision factors and the SPR Papers

This section reports the results from Phase B of the directed content analysis method (Section 4.2.4), in which the understanding of each decision factor from Study #1 is extended by analysis of the SPR Papers that also reference that factor. In particular, this analysis focuses on whether there are conflicts or gaps between the surrogates’ decision factors and professionals’ attitudes and behaviors.

The results are summarized in Table 4-7 and presented in detail in Sections 4.3.1 through 4.3.27.

Table 4-7: Summary of SPR Papers’ content by decision factor

<table>
<thead>
<tr>
<th>Decision factor (in SE rank order)</th>
<th>Summary of SPR Papers’ content relevant to this decision factor</th>
</tr>
</thead>
</table>
| 1. Need for clear and frank prognosis | • Conflicting reports on whether prognoses are routinely or infrequently discussed with families.  
• Prognoses may be presented more frequently to better educated families and by white physicians.  
• Surrogates often misinterpret prognostic statements and are highly biased to more optimistic interpretations.  
• Surrogates prefer to receive prognoses as quantitative estimates, but physicians prefer to deliver them in qualitative terms. |
| 2. Patient’s preferences | • Often not discussed by surrogate and physician nor the basis for actual decision-making.  
• What discussion of preferences and values that does occur is often perfunctory and focused on instrumental values such as survival and pain as opposed to more existential values such as autonomy, physical and cognitive functioning, and emotional wellbeing. |
| 3. Leave decision to God | • 77% of surrogates claim their religious beliefs are very important or fairly important yet only one SPR Paper examined the place of religious beliefs in surrogate-physician discussions and it reported that these beliefs were discussed in only 16% of surrogate-physician conferences.  
• Optimism discordant with physician’s prognosis was often grounded in religious beliefs. |
| 4. Decisional stress | • Exacerbated by a difference in perception of the meaning of limitation of life-sustaining treatment: some surrogates perceive it to be a deliberate act of killing, but physicians uniformly perceive it as allowing a natural death to proceed.  
• Physicians may express greater prognostic certainty than they actually believe or may avoid discussing palliative care in order to reduce surrogates’ and families’ decisional stress.  
• Physicians can relieve some of this stress with empathetic statements, but these opportunities are often missed.  
• Statements by physicians that push decisional responsibility onto the family can be interpreted by the family as abandonment by the physician.  
• Decisional stress reduces surrogates’ ability to understand clinicians’ statements and to reflect on patient’s preferences and values. |
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<th>Decision factor (in SE rank order)</th>
<th>Summary of SPR Papers’ content relevant to this decision factor</th>
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<tr>
<td>5. Need time to prepare</td>
<td>• This need is confirmed by the SPR Papers.</td>
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<td>• Physicians and nurses are well aware of this need and act to satisfy it.</td>
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<td>6. Established trust in physicians</td>
<td>• Physicians are well aware of the need and take active steps in order to establish trust.</td>
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<td>• Nurses play an important role in the process of establishing trust.</td>
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<td>7. Need for family consensus</td>
<td>• Physicians recognize this can be used to clarify patient’s preferences.</td>
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<td>• Physicians sometimes use this need to encourage agreement with recommendations resisted by the surrogates.</td>
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<td>8. Prognosis confirmation with own eyes</td>
<td>• Only one SPR Paper even acknowledges that surrogates may form their own prognostic opinions.</td>
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<td>• No SPR Paper addresses how physicians should interact with skeptical surrogates.</td>
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<td>9. Prognostic limitations of physicians</td>
<td>• Lack of research on ICU survivor outcomes and lack of contact with post-discharge patients both contribute to intensivists' prognostic limitations.</td>
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<td>• Complex ethical questions are raised when physicians, as is common, do not disclose their own uncertainty.</td>
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<td>10. Patient’s intrinsic qualities</td>
<td>• Surrogates’ belief in such qualities is a substantial contributor to surrogates’ discordant optimism about patient outcomes.</td>
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<td>• Physicians who have experienced surprising recoveries are more concerned about tailoring their decision-making to each patient as a unique individual.</td>
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<td>11. Make all possible efforts</td>
<td>• There is conflicting evidence as to whether it is staff or family that is most often the proponent of continuing aggressive treatment when there is disagreement about limiting life-sustaining treatment.</td>
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<td>• Comfort care is often not introduced by physicians as an option in family-physician conferences; the only option discussed is continuation of full intensive care.</td>
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<td>12. Too many physicians</td>
<td>• This issue has been frequently remarked upon in the SPR Papers, but only one paper has proposed any solutions.</td>
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<td>• Too many so-called attending physicians confuse the medical staff.</td>
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<td>• Emotional stress for family members, interference with reevaluation of the goals of care, and delay in decision-making all result from too many physicians.</td>
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<td>13. Patient’s history</td>
<td>• Patient’s prior QoL or other history not discussed in the SPR Papers.</td>
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<td>14. Decision-making control</td>
<td>• Physicians perceive themselves as being more active in decision-making than surrogates claim they want physicians to be.</td>
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<td>• Physicians become more directive if there is a divergence between the surrogate’s choice and their own.</td>
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<td>• Physicians may indirectly make decisions by omitting options during family conferences.</td>
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<td>15. Empathy with patient's pain or loss of dignity</td>
<td>• Physicians explicitly use empathetic suffering as a strategy to encourage limitation of life-sustaining treatment.</td>
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<td>• Empathetic suffering may assist families in transitioning from a perspective of death-as-a-burden to one of death-as-a-benefit.</td>
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<td>16. Prognosis confirmation from multiple sources</td>
<td>• Surrogates’ seeking of external confirmation is confirmed, but may be perceived as a distraction by ICU professionals.</td>
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<tr>
<td>Decision factor (in SE rank order)</td>
<td>Summary of SPR Papers’ content relevant to this decision factor</td>
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| 17. Avoiding bad or uncertain prognosis | • Unwillingness to accept a poor prognosis is the greatest impediment to fruitful discussions about goals of care.  
• The process of disclosing a poor prognosis needs to be carefully managed by the physician.  
• If the prognosis is extremely poor, some physicians overstate the certainty of their prognosis.  
• Physicians personally invested in a good surgical outcome are themselves more unwilling to accept a poor prognosis and thus less likely to discuss limitation of life-sustaining treatment. |
| 18. Patient’s best interests | • Physicians are willing to use “artful strategies” (Mehter, McCannon, Clark, & Wiener, 2018, p. 247) to persuade surrogates who are proposing limitation decisions that the physicians perceive are not in the patient’s best interests.  
• The topic of patient’s best interests is very rarely discussed in family conferences. |
| 19. Mistrust of institutions | • Not explicitly addressed in the SPR Papers except once as another reason for discordance between the physician’s prognosis and the surrogate’s. |
| 20. Patient’s post-discharge QoL | • Surrogates rarely introduce the topic of post-discharge QoL, and it is discussed at less than 50% of family conferences.  
• Clinicians often sidestep questions about QoL, answering instead with technical and physiological details. This may be due to their uncertainty about actual outcomes.  
• Physicians do recognize that discussion of post-discharge QoL is an effective way of making patient’s preferences and values more concrete. |
| 21. Surrogate’s intuition | • This factor was not mentioned in any of the 52 SPR Papers. |
| 22. Optimism affects outcome | • The SPR Papers confirm that some surrogates believe their optimism affects the patient’s outcome. |
| 23. Physician’s recommendation | • Physicians vary widely in their practice of providing a recommendation concerning limitation of life-sustaining treatment: most provide such a recommendation always or often, but about 10% never do. |
| 24. Family conflict | • Reported as infrequent. |
| 25. Impact on surrogate’s interests | • No discussion about long term impacts.  
• Limited recognition of surrogate’s immediate responsibilities outside ICU. |
| 26. Surrogate’s preferences | • Surrogates’ preferences are often dominant in limitation of life-sustaining treatment decisions.  
• When surrogate’s preferences seem dominant, physicians are often motivated to engage in coaching and persuasion to return to a substituted judgment standard or to accept the physicians’ best interests judgment. |
| 27. Fear of loss | • Physicians infrequently expressed empathy for the impending loss. |
4.3.1 Need for clear and frank prognosis

The SPR Papers confirm that surrogates actively seek prognostic information. For example, as Tilden et al. described, “Although they appreciated, on the whole, that clinicians are understandably reluctant to give information prematurely that may later change, many subjects [surrogates] appealed for early and direct talk” (Tilden, Tolle, Garlan, & Nelson, 1995, p. 637). This need for prognosis was particularly acute in out-of-hospital cardiac arrest (OHCA) cases (Dale, Sinuff, Morrison, Golan, & Scales, 2016) and cardiopulmonary ICU settings, with 60% of surrogates wanting updates twice a day during the first few days after their patients’ admission (LeClaire, Oakes, & Weinert, 2005).

However, the SPR Papers reveal three significant gaps between surrogates’ need for clear and frank prognoses and physicians’ capabilities and preferences. First, there are conflicting results as to whether surrogates actually receive the prognostic information they seek. While White et al. report “There was at least one physician statement about prognosis in 50 of 51 conferences (98%)” (2007, p. 444), the same paper also found that the number of prognostic statements in each conference was positively correlated with the degree of conflict between family and physician about limiting treatment, the educational level of the family, and the physician’s race being white. Of these factors, the most important was educational level, especially if one of the family members had attended graduate school. Cox et al. found that only 26% of surrogates reported that their physicians “discussed their loved one’s prognosis for survival, functional limitations, quality of life, or expected caregiving needs,” which led 35% of surrogates to feel that “attending physicians were not the primary source of information about tracheostomy and PMV [prolonged mechanical ventilation]” (2009, p. 2891).

Second, multiple studies report substantial gaps between surrogates’ interpretations of prognoses and physicians’ intended meaning. Surrogates’ interpretations are generally more optimistic than physicians. For example, Leiter et al. (2018) report that 73% of surrogates’ interpretations were more optimistic, while White et al. (2016) report that 43% were more optimistic and 10% more pessimistic.

Third, 82% of surrogates prefer to receive quantitative estimates, while 75% of physicians prefer to give qualitative estimates (Quinn et al., 2017). Even though surrogates and physicians prefer different ways of expressing the prognosis, Lee et al. report that this choice does not affect surrogates’ understanding of physicians’ intent (Lee Char, Evans, Malvar, & White, 2010, p. 906).
4.3.2 Patient’s preferences

As seen in Study #1, surrogates report that patient’s preferences and values constitute one of the most important factors affecting their decisions. However, patient’s preferences and values do not always enter into the decision. For example, 40% of surrogates made decisions based not on patient’s preferences and values, but on “what the whole family wanted (28%), what the subject wanted for the patient (6%), or what the subject wanted for him/herself (2%)” (LeClaire et al., 2005, p. 1733). Multiple studies have found that the attending physician can mitigate this discrepancy but often misses the opportunity to do so (Brush, Brown, & Alexander, 2012; Curtis et al., 2002, 2005; LeClaire et al., 2005; Pecanac, 2017; Pecanac & Brown, 2017). Pecanac reported that by starting a decision-making discussion with a question about patient’s preferences, the physician “orients the surrogates to consider the preferences of the patient (instead of the clinicians or the surrogates)” (2017, p. 1269).

The discussion of patient’s preferences and values is often perfunctory and focused solely on instrumental values such as survival, bodily integrity, or freedom from pain. Scheunemann et al. (2015) reported that both patient’s preferences and values were discussed in only 37% of family-physician conferences, and:

When clinicians and surrogates discussed patients’ values, they focused on longevity (32%), bodily integrity (17%), and symptom palliation (17%). In more than 88% of conferences, there was no conversation about the patient’s values regarding autonomy and independence, emotional wellbeing and relationships, physical function, cognitive function, or spirituality. (Scheunemann et al., 2015, p. 761)

These findings reinforce earlier findings:

Whereas the majority of physicians elicited patient preferences or values (88%), the overwhelming majority did so narrowly (82%). (Uy, White, Mohan, Arnold, & Barnato, 2013, p. 1514)

... these physicians made efforts to bring the patient’s values and preferences to the fore by asking questions such as, “has she ever talked about whether she would accept being on a breathing machine long-term?” and “if she could sit up in bed, what would she say about this decision?” (White, Malvar, Karr, Lo, & Curtis, 2010, p. 5)

4.3.3 Leave decision to God

Only one of the SPR Papers explicitly focused on religious and spiritual issues during discussions between surrogates and physicians (Ernecoff, Curlin, Buddhadaumaruk, & White, 2015). This paper found that religious or spiritual considerations were raised in only one of every six family conferences, and that physicians rarely responded to religious or spiritual language in similar terms:

Religious or spiritual considerations were raised in 40 of 249 (16.1%) family meetings. Surrogates were the first to voice a religious or spiritual concept in 26 meetings (10.4%); health care professionals were the first in 14 meetings (5.6%)
... Health care professionals most commonly responded to surrogates’ religious or spiritual statements by speaking about the medical plan for treatment or goals of care, including terminal event planning and implications for care (15 of 40 meetings).

... physician responses rarely directly addressed surrogates' spiritual or religious language. (Ernecoff et al., 2015, pp. 1665–1666)

The impact of strong religious beliefs was observed to affect concordance with the physician’s prognosis by both White et al. (2016) and Leiter et al.: “Surrogates who designated religion as ‘very important,’... had lower numeracy scores and were less concordant” (2018, p. 266). Further, experiences with strongly religious families have caused some physicians to recognize their own prognostic limitations and alter their mode of interaction in these situations:

There was a patient with acute leukemia (in the ICU) for longer than a month on a ventilator with multiple organ failure. (The patient’s wife) had a very strong and fervent belief (in divine intervention) that the patient was going to survive. I felt compelled to take the opposite position. So, I went so far in multiple family discussions to actually pull articles from the literature... and highlight where it would say things like “survival is unprecedented.” I rotated off service... About 6 months later, there was a knock on my office door. (The patient) was standing there with his wife... He gave me a big hug and said, “I forgive you.” And I mean, who could forget that? So every patient, thereafter, that I have ever been faced with where there was not necessarily ambiguity about what the patient is going to be, but ambiguity with family members and I don’t press that. I work through the pace with the families and where they can go. And there are some of them that are very unreasonable. (Wilson et al., 2013, p. 1012)

4.3.4 Decisional stress

The SPR Papers illuminate a difference in perception between some surrogates and most physicians that often exacerbates decisional stress. Limitation of life-support can be perceived as either allowing a natural death to proceed or as a deliberate act of killing:

The issue of whether withdrawing life support is synonymous to killing was raised only by family members ... When the topic of killing was raised, the discussions tended to be emotional and poignant. Family members became distressed, often crying, and indicated that they knew the patient was going to die but emphasized the importance of not killing. ... The clinicians in these conferences were in opposition to the possibility of the act of withdrawal being interpreted as killing. Withdrawing or withholding life support was uniformly perceived by clinicians as allowing the patient to die. (Hsieh, Shannon, & Curtis, 2006, p. 298)

Empathetic statements by the physician can often alleviate some of this decisional stress (Selph, Shiang, Engelberg, Curtis, & White, 2008) but these opportunities are often missed (Curtis et al., 2005). On the other hand, a statement by the physician suggesting that a decision limiting life-support is the family’s sole responsibility may be construed by the family as “abandonment by the clinician” and add to their stress (West, Engelberg, Wenrich, & Curtis, 2005, p. 801).

Physicians may act in ways that they believe will reduce stress for families. For example, they may express greater certainty than they “actually believe ... to decrease the burden of decision-
making on the family” (Schuster, Hong, Arnold, & White, 2012, p. 133). Alternatively, Schenker, Tiver et al. speculate that “failure to mention the option of comfort care represents a conscious attempt by physicians to protect families from the emotional difficulty of thinking about the possibility of a loved one’s death” (2012, p. 1613).

Stress can also impact the ability of surrogates to effectively understand clinicians’ statements and to fully reflect on patient’s preferences and values:

surrogates were perceived to “hear every third or fourth word” spoken by clinicians (RN12, staff nurse). The inability of substitute decision makers to fully understand and integrate information intensified the work of clinicians to carefully elicit patient values and preferences and to effectively but empathically engage surrogates in shared decision making. (Dale et al., 2016, p. 1117)

Families’ distress concerning decisions to limit treatment is “a significant cause of distress for the nurses and physicians” (Workman, McKeever, Harvey, & Singer, 2003, p. 19).

4.3.5 Need time to prepare

The SPR Papers confirm that surrogates and families need time to prepare for these decisions. They also show that both physicians and nurses are well aware of this need:

Physicians recognized that surrogates often changed their decisions over time as they were able to assimilate what was happening and “come to terms with things.” (Brush, Brown, et al., 2012, p. 1082)

Many physicians believed that families need time to come to terms with their loved one’s prognosis and that allowing time often softened the family’s resistance to de-escalating care. These physicians allowed families time to process their loved one’s condition over a series of meetings while carefully modulating their approach to minimize adversarial encounters. (Mehter et al., 2018, p. 244)

Subjects said that both physicians and nurses usually eased the family gradually toward this understanding through tentative and cautionary statements that laid the ground work for the patient’s death. (Tilden et al., 1995, p. 634)

4.3.6 Established trust in physicians

Physicians appear to be well aware of the importance trust plays for surrogates, take active steps to build trust, and even delay decision-making until trust is established:

Many physicians built trust by communicating more frequently, honestly, and sincerely with surrogates and by attempting to present a unified message to the surrogate. Many physicians also said it was helpful to recruit practitioners who had formed trusting relationships with patients and surrogates such as the patient’s long-standing physician to join negotiations. A few physicians reported delaying negotiations, and even initial discussions, until they had gained the surrogate’s trust. (Brush, Brown, et al., 2012, p. 1082)
Clinicians other than physicians also have a significant role in developing trust:

The presence in prognostic discussions of clinicians such as nurses who spent a lot of time at the bedside helped families to trust information presented. These clinicians could talk with families after discussions, to translate and reinforce information. Such interactions were often less stressful than family meetings or discussions with physicians ... (Anderson et al., 2015, p. 147)

Failure to build trust impacts the surrogate’s decision-making capability, and worsens the surrogates’ bias towards prognostic optimism:

... surrogates were likely to reject even factual information from physicians they mistrusted. (Brush, Brown, et al., 2012, p. 1081)

... surrogates’ personal estimates of the patient’s prognosis were significantly more optimistic than their understanding of the physician’s prognostication. This discordance was greater among surrogates with less trust in physicians. (Lee Char et al., 2010, p. 907)

4.3.7 Need for family consensus

Physicians recognize that this need can help to clarify patient’s preferences (Burns et al., 2003). Some physicians also use it as a tool to encourage agreement with a recommendation to limit life-sustaining treatment:

Some physicians perceived that guilt felt by surrogates sometimes prevented them from agreeing with physicians to limit a patient’s life support. Physicians said they tried to alleviate this guilt by ... encouraging the involvement of other family members in decision making. (Brush, Brown, et al., 2012, p. 1082)

4.3.8 Prognosis confirmation with own eyes

In Study #1 this decision factor was reported in 32% of the studies (quality-adjusted) and was ranked 8th of 27. However, only one SPR Paper acknowledges that surrogates may form their own opinions, quoting a surrogate, “Seeing those graphic pictures [radiographs] was helpful. Then I can look at it and form my own opinion” (Anderson et al., 2015, p. 146). None of the 52 SPR Papers address how surrogates’ own opinions may affect decision-making, or how physicians should interact with surrogates whose own eyes do not confirm the physicians’ prognoses.

4.3.9 Prognostic limitations of physicians

Intensivists reported that lack of reliable outcome data (Dale et al., 2016) and lack of contact with ICU survivors were primary factors contributing to their prognostic uncertainty. One physician explained:

As critical care physicians we’re seeing them for a short window of acute illness and then boom, we’re shipping them off to the hospital or we’re shipping them off to rehab. I only see them acutely in the ICU and I don’t work at long-term rehab, so I don’t see the downstream effect. (Turnbull, Davis, Needham, White, & Eakin, 2016, p. 1548)
Further, Schuster et al. found that physicians often did not disclose their uncertainty and that this raises “complex ethical questions” by creating “the false impression that decisions are simply technical medical judgments, rather than complex value judgments” (2012, p. 8).

4.3.10 Patient’s intrinsic qualities

Surrogates’ beliefs about their patients’ unique intrinsic qualities contribute significantly (24 of 71 subjects) to why surrogates hold discordantly optimistic expectations (White et al., 2016).

Experienced physicians reported having had at least one surprising outcome, where a patient who they had given up on recovered fully. These occurrences influenced the physicians to place more focus on the patient as a unique person. As one physician expressed:

Things looked about as futile as they could get and there was a positive outcome which makes me very much convinced that we never know 100%. As you get more and more experience you realize you have to tailor everything to the patient. (Wilson et al., 2013, p. 1012)

4.3.11 Make all possible efforts

Families are often not the ones advocating for all possible efforts. Breen et al. reported that in cases with family-staff conflicts, 76% of the time it was staff who were wanting to continue aggressive treatment (Breen, Abernethy, Abbott, & Tulsky, 2001, p. 286). However, these findings were not replicated by Studdert et al. (2003), who found that in most cases it was the family wanting more aggressive treatment. More recently, Schenker, Tiver et al. found similar results to Breen et al.: “comfort care was not presented as an option in 32 of 72 family-physician conferences, and in 25 of these conferences only unlimited intensive care was discussed” (2012, p. 1609).

4.3.12 Too many physicians

The challenge of multiple physicians is a frequent topic in the SPR Papers and is clearly confusing to the medical staff in the hospital:

An intensivist, asked to identify “the attending” referred to “the admitting attending, the operating attending, and the consulting attendings.” A nurse manager was asked if the “attending of record for the patient, making the decisions, is different than the ICU attending” and responded, “It could be both, but we always have to go back to the attending physician.” A SICU nurse reflected, “It seems funny to have two attendings, and they are both talking to the family, and they’re not talking to each other.” (Baggs et al., 2012, pp. 58–59)
Several authors noted that the involvement of too many physicians resulted in emotional stress for family members, interference with reevaluation of the goals of care, and delay in decision-making:

The very fast paced environment and constantly changing nurse and physician providers, pressures to ensure the ICU is operating efficiently, and the emotional stresses on family members all could interfere with both conscious appraisals of one’s values, as well as opportunities to discuss and reevaluate goals of care. (Daly et al., 2016, p. 6)

One common discrepancy is when one team of providers or specialists fails to communicate with others, and patient care is consequently compromised by delays, misinformation, or other disagreements regarding a care plan. (Ellis, Gergen, Wohlgemuth, Nolan, & Aslakson, 2016, p. 12)

Physician shift changes delayed addressing life support decisions by disrupting continuity of care (Wilson et al., 2013, p. 1011)

Only one SPR Paper described interventions that had been proposed or tested to alleviate this challenge, but found “the study of outcomes has been limited to measures such as hospital and ICU mortality, length of stay, intensivist burnout, job distress, and work-home life imbalance, but the work has not focused on the consequences of these changes for families” (Baggs et al., 2012, p. 61).

4.3.13 Patient’s history

No direct consideration of the patient’s history or prior quality of life was evidenced in the SPR Papers. Only one paper (Breen et al., 2001) touched on the subject, noting that the age of the patient was likely to impact how the physician would choose to interpret a surrogate’s choices for that patient.

4.3.14 Decision-making control

In Study #1, I found that about 50% of all surrogates want to share decisions to limit life-sustaining treatment with the physician, about 50% want to make the decision themselves, and a very few (5%) want the physician to make the decision (Johnson et al., 2011; Lewis et al., 2006; Nunez et al., 2015). However, these studies are vague about exactly what level of information, counsel, and involvement the surrogate expects from the physician.

The SPR Papers examine the physician’s role in much finer detail. Some studies delineate the various possible physician roles (Mehter et al., 2018; Uy et al., 2013; White et al., 2010); others describe how physicians react when surrogates’ decisions deviate from the physicians’ view of patients’ best interests (Brush, Brown, et al., 2012; Combs, Rasinski, Yoon, & Curlin, 2013).
paper examines in depth whether decision-making is really shared (White, Braddock III, Bereknyei, & Curtis, 2007).

Collectively these studies reveal that compared to what surrogates claim to want:

i) physicians perceive themselves as playing a more active role in the decision-making process; and

ii) evidence from family conferences confirms physicians are more directive than might be appropriate in an ideal shared decision-making model.

This is especially true when there is a divergence between the physician’s and the surrogates’ treatment choice, or if the physician has strong beliefs about the limitation of life-sustaining treatment. For example:

Although physicians commonly stressed that the surrogates had the “final word,” many viewed it as their role to guide or try to alter surrogates’ decisions, especially if they felt surrogates were making decisions that were not in patients’ best interests. (Brush, Brown, et al., 2012, p. 1081)

Despite coaching on the meaning of substituted judgment and apparent sincerity in attempting to exercise it, physicians perceived that families commonly experienced difficulty separating their own preferences from those of the patient—a circumstance that made physicians more likely to engage in persuasion. (Mehter et al., 2018, p. 244)

In bivariate analyses, the strength of the physicians’ belief that life support should be withdrawn was the only variable associated with presentation of comfort care.

... Our finding that clinicians frequently did not inform surrogates about the option of comfort care after on average nearly 2 weeks of intensive care is surprising and may pose a threat to the quality of shared decision making in ICUs. (Schenker, Tiver, et al., 2012, pp. 1609–1610)

4.3.15 Empathy with patient’s pain or loss of dignity

Physicians may use surrogates’ empathetic suffering, which the medical team may also share, to encourage “a shared mandate to pursue patient well-being” (Workman et al., 2003, p. 19), especially if there is disagreement about limitation of life-sustaining treatment:

Physicians described several ways of redirecting conversations to convince families to change their minds. Strategies included ... discussing patient suffering. (Mehter et al., 2018, p. 244)

Physicians may also rely on empathetic suffering to help families navigate the gulf from death-as-a-burden to death-as-a-benefit:

Death was viewed as a benefit, often from the perspective of the patient, if it offered the opportunity to honor the patient’s wishes, end suffering, prevent lingering, end a life without quality, permit a peaceful or natural death, or allow the patient to join deceased family members. On the other hand, death could be viewed as a burden or harm from the viewpoint of the patient, surviving family members, or clinicians. (Hsieh et al., 2006, p. 298).
4.3.16 Prognosis confirmation from multiple sources

The SPR Papers confirmed this behavior by surrogates and families. Anderson et al. (2015), Dale et al. (2016), and Tilden et al. (1995) all discussed how surrogates and families sought additional materials and used the Internet to better understand both the patient’s situation and what they were being told by physicians.

However, such information seeking is seen as an unhelpful distraction by ICU professionals:

Further evidence of this struggle was noted in surrogates’ frequent use of the Internet to navigate unfamiliar terms and treatments:

*Everyone just kind of looks up everything online, and then they just kind of come in with a whole bunch of new questions that may not be related to the patient at all (RNS, staff nurse).*

Several intensivists explained how this phenomenon required continuous translation of critical care terminology and other information during family–team meetings. (Dale et al., 2016, p. 1119)

4.3.17 Avoiding bad or uncertain prognosis

Physicians see unwillingness to accept a poor prognosis as the greatest impediment to fruitful discussions about goals of care (You et al., 2015). Physicians recognize this phenomenon and recommend that it be managed actively:

Many participants (n = 84, 71%) recommended that clinicians should not simply provide a prognostic estimate but should also educate families and help them to understand how they arrived at their estimate. To come to an understanding and acceptance of a poor prognosis, families needed to understand the disease processes causing a poor prognosis. (Anderson et al., 2015, p. 144)

However, when the prognosis is extremely poor, “… some physicians may not acknowledge prognostic uncertainty, opting instead to imply certainty or respond ambiguously to questions about whether death is the certain outcome” (Schuster et al., 2012, p. 8). Nor are physicians themselves immune from this phenomenon:

Surgeon and non-surgeon intensivists, as well as nurses, observed that when a physician was personally invested in a good surgical outcome, there was less inclination for that surgeon to address life support decisions, limit life support, or recognize a poor prognosis. (Wilson et al., 2013, p. 1013)
4.3.18 Patient’s best interests

If the surrogate’s choice about limiting life-sustaining treatment conflicts with what the physician believes is the patient’s best interest, multiple studies report that physicians are then willing to use “artful strategies to size up, engage, and shape families’ views” (Mehter et al., 2018, p. 247):

Our participants invoked a variety of reasons for trying to change surrogates’ decisions about withholding or withdrawing life support. Most commonly, physicians perceived the surrogates were making decisions that were not in the patients’ best interest. Although a best interest standard was commonly invoked, a few physicians who used it noted that such a standard could be quite difficult to discern. (Brush, Brown, et al., 2012, p. 1084)

Alternatively, a physician may [communicate prognostic certainty] to influence surrogates’ decisions toward the treatment course the physician believes to be in the best interest of the patient, the physician, or society. (Schuster et al., 2012, p. 9)

In spite of the tendency for physicians to resort to their perception of patient’s best interests, the nature of the patient’s best interests is rarely discussed at family conferences. In the 142 family conferences observed in total by Cunningham, Scheunemann, Arnold & White (2018) and Scheunemann et al. (2015), no discussions were framed in terms of the patient’s best interests.

4.3.19 Mistrust of institutions

The issue of mistrust of institutions was addressed directly in only one SPR Paper (Lee Char et al., 2010), where it was proposed as another reason for discordance between the physician’s and the surrogate’s prognoses. The effect of socio-economic status on institutional mistrust was noted in one of the SE Papers:

... one surrogate recounted his belief that his mother’s pain was not adequately treated because of her Medicaid status: “They have the pain medicine here. It’s just a shame that they’re reluctant to give it to her because they didn’t think they were gonna get their money for it, so she had to lay here and suffer the whole time.” (Torke et al., 2012, p. 1404)

Other causes (e.g., race) of mistrust in health care institutions have been documented in several studies not included in the SPR Papers (e.g., Boulware, Lisa A Cooper, Ratner, LaVeist, & Powe, 2003; Lang et al., 2013). The impact of institutional mistrust on surrogate-physician interactions does not appear to be well documented.

4.3.20 Patient's post-discharge QoL

In Study #1 surrogates rarely reported concern about post-discharge QoL (ranked 20th of 27 decision factors). The SPR Papers support the finding that surrogates do not consider QoL to be important. Turnbull et al. reported that “families rarely ask any questions about functional recovery”
Even when it was discussed, the topic was most often introduced by an Advanced Practice Nurse (60% of the time), but only 17% of the time by the surrogate or family (Douglas, Daly, & Lipson, 2012).

Studies of family conferences reported that patient’s post-discharge QoL was discussed in less than half of family meetings (26% in Cox et al., 2009; 45% in Douglas et al., 2012). When the topic is introduced, clinicians often answer with physiological or technical information thereby missing the opportunity to provide a direct answer to the surrogate’s question about effect on QoL (Curtis et al., 2005, p. 846). This reluctance may result from intensivist’s lack of contact with ICU survivors, creating “tension between a perceived professional obligation to discuss post-discharge outcomes with surrogates and uncertainty in their ability to accurately predict those outcomes” (Turnbull et al., 2016, p. 1549).

On the other hand, many physicians recognize that discussion of post-discharge QoL is a good way of making the prognosis more concrete (Anderson et al., 2015) and easing into a decision based on patient’s preferences (Pecanac, 2017).

4.3.21 Surrogate’s intuition

This factor was not mentioned in any of the 52 SPR Papers.

4.3.22 Optimism affects outcome

The SPR Papers frequently characterize surrogates as expecting more optimistic prognoses than physicians: e.g., 71 of 156 (45%) (White et al., 2016, p. 2089). Some of the SPR Papers confirm the finding from Study #1 that some surrogates believe that their optimism has a direct effect on the outcome (Lee Char et al., 2010; White et al., 2016).

4.3.23 Physician's recommendation

Study #1 found that surrogates generally prefer receiving a recommendation from the attending physician (Vig et al., 2007). The SPR Papers report that most of the time most intensivists and other ICU physicians do make life-sustaining treatment recommendations to surrogates and families. However, there is a wide variation in their behavior, for example in one study when ICU physicians were asked how often they made specific recommendations about whether to continue or limit life support, the answers ranged from always (21%), through often (38%) and sometimes (29%), to
rarely or never (12%) (Brush, Rasinski, Hall, & Alexander, 2012, p. 635). Similar variations in providing recommendations were also reported by Uy et al. (2013).

4.3.24 Family conflict

Conflict in general is the second most frequent topic among the SPR Papers, but family conflict was ranked 24th of 27 decision factors by surrogates.

On closer inspection this apparent discrepancy is resolved in the SPR Papers. Collectively, they show that family conflict is quite infrequent: Breen et al. (2001) report that it occurs in less than 25% of all conflicts; Studdert et al. (2003) place the rate even lower at 12%; and Tilden et al. note that when conflict occurs it is unsettling for both family members and clinicians but is “infrequent” (1995, p. 637).

4.3.25 Impact on surrogates’ interests

The SPR Papers have almost no discussion of long-term impact on surrogates:

Only 33 surrogates (26%) reported that physicians discussed their loved one’s prognosis for ... expected caregiving needs. (Cox et al., 2009, p. 2891)

... predominately fewer physicians (38%) reported explaining what they would do if they were a family member, using vivid imagery (28%) or discussing the economic impact of continued life support (1%). (Shah, Rasinski, & Alexander, 2015, p. 281)

In one study, only the nurses recognized that surrogates’ “involvement [in ICU] must be balanced with other commitments such as caring for other family members who remained at home” (Ellis et al., 2016, p. 12).

4.3.26 Surrogates’ preferences

Surrogates make very few references to their preferences as a decision factor (ranked 26th of 27 decision factors), but the SPR Papers report that surrogates’ or families’ preferences are often dominant:

Others [surrogates] made decisions based on what the whole family wanted (28%), what the [surrogate] wanted for the patient (6%), or what the [surrogate] wanted for him/herself (2%). (LeClaire et al., 2005, p. 1733)

Discussions that centered on honoring the patient’s wishes versus following family members’ wishes in decision making were raised in 44 of the 51 conferences ... The most common presentation was that the patient would wish to limit life support, whereas family members’ preferences were to not limit life support. However, in one conference, the family wished to limit life support against the wishes of the patient. (Hsieh et al., 2006, p. 298)
These and other SPR Papers characterize these situations as requiring intervention by the physicians to return to a substituted-judgment norm:

Despite coaching on the meaning of substituted judgment and apparent sincerity in attempting to exercise it, physicians perceived that families commonly experienced difficulty separating their own preferences from those of the patient—a circumstance that made physicians more likely to engage in persuasion. (Mehter et al., 2018, p. 244)

In this example, the physician missed the opportunity to correctly explain surrogate decision making and, as a result, the family member made a decision that may have gone against the wishes of the patient, by the family member’s own admission. (Curtis et al., 2005, p. 847)

4.3.27 Fear of loss

Physicians’ empathy for the fear of loss and difficulty of watching the death of the loved one was expressed only infrequently:

This type of empathic statement occurred in 28% (14/51) of conferences and included empathic statements related to the process of accepting the impending loss of a loved one, being helpless in face of the disease, coping with the dying process, and general emotional reactions to anticipated loss. (Selph et al., 2008)
4.4 Discussion

The immediate objective of Study #2 was to identify gaps and conflicts between surrogates’ decision factors from Study #1 and the attitudes and behaviors of ICU professionals. The overall objective of studies #1 and #2 together was to understand how any such gaps or conflicts might contribute to the clinical deficiencies in the current paradigm for surrogate decision-making.

This discussion is organized into five subsections corresponding to the following categories of gaps and conflicts. Table 4-8 shows the linkages between the decision factors and these categories:

1. gaps in communication;
2. conflicts about decisional authority;
3. conflicts in interpretation of patient’s preferences;
4. gap and conflicts concerning prognosis; and
5. minimal gaps and conflicts.

Table 4-8: Linkages between decision factors and categories of gaps and conflicts

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<td>3. Leave decision to God</td>
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<td>4. Decisional stress</td>
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<td>5. Need time to prepare</td>
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<td>7. Need for family consensus</td>
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<td>15. Empathy with patient’s pain or loss of dignity</td>
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<td>17. Avoiding bad or uncertain prognosis</td>
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<td>18. Patient’s best interests</td>
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<td>20. Patient’s post-discharge QoL</td>
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<td>21. Surrogate’s intuition</td>
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<td>22. Optimism affects outcome</td>
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<td>23. Physician’s recommendation</td>
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<td>24. Family conflict</td>
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<td>26. Surrogate’s preferences</td>
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<td>27. Fear of loss</td>
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4.4.1 Gaps in communication

Perhaps the most glaring gap in communication concerns consideration of surrogates’ religious and spiritual beliefs by physicians. Nine of the SE Papers in Study #1 contained the decision factor *Leave decision to God*; averaged across these studies, 77% of the respondents claimed their religious beliefs were either very important or fairly important. This finding is broadly in line with other studies about the importance and prevalence of religious belief in North America, e.g., 66% of religiously affiliated U.S. adults say religion very important to them (Pew Research Center, 2014).

However, families’ religious and spiritual considerations were not addressed in the SPR Papers —only 1 of 52 studies (Ernecoff et al., 2015) addressed the topic, even peripherally. Ernecoff et al.’s findings highlight a major disconnect between the claimed importance of religion to surrogates and the way the topic is handled in family-physician conferences. The topic is raised in only 1 in 6 conferences, and when it is raised the physicians rarely engage in religious or spiritual terms, retreating instead to medical and technical language.

This apparent reluctance to engage in communication about non-medical topics extends beyond religious topics. Physicians infrequently acknowledge the surrogate’s fear of impending loss and grief (Selph et al., 2008). Curtis et al. (2005) note that many such opportunities to display empathy and reduce the stress on the surrogates and family are missed.

Surrogates generally look to physicians for recommendations regarding limitation of life-sustaining treatment (Johnson et al., 2011; Vig et al., 2007; White et al., 2009), however only 60% of physicians report making recommendations always or often (Brush, Rasinski, et al., 2012; Uy et al., 2013); the other 40% miss opportunities to leverage a recommendation into a broader discussion about patient’s preferences and values.

Many of the communication gaps noted above may be attributable to the issue of too many physicians being involved in the care of ICU patients (Baggs et al., 2012; Daly et al., 2016; Ellis et al., 2016; Wilson et al., 2013).

4.4.2 Conflicts about decisional authority

White et al. (2010) identify four different roles physicians may take during surrogate decision-making: informative, facilitative, collaborative, and directive. In only 1 (2%) of the 63 decisions studied did the physician take a directive role; in 55 (87%) of the decisions the physicians took the
facilitative or collaborative role. Thus it would appear that physicians are complying with the overwhelming majority of surrogates who claim to want to retain a controlling or shared decisional authority for themselves (Johnson et al., 2011; Lewis et al., 2006; Nunez et al., 2015).

However, numerous other studies show that physicians routinely take a more directive stance if the surrogate’s choice regarding limitation of life-sustaining treatment differs from theirs. Several different strategies are employed by physicians. One is to simply not present a treatment option the physician believes is inappropriate (Schenker, Tiver, et al., 2012). Another is to express an uncertain prognosis with far greater certainty than the physician actually believes in order to remove doubt from the surrogate (Schuster et al., 2012). A third is to leverage the family’s desire for consensus, or their empathetic suffering, or simply the passage of time to encourage a decision that accords with the physician’s own judgment (Brush, Brown, et al., 2012; Mehter et al., 2018; Tilden et al., 1995).

When physicians do take a more directive stance, they claim to do so in pursuit of what they believe are the patient’s best interests (Mehter et al., 2018). However, best interests “must take into account quality-of-life judgments” (Buchanan & Brock, 1990, p. 124 original italics), a norm that persists to the current day (Beauchamp & Childress, 2013, p. 228). Furthermore, post-treatment quality-of-life is one of the four topics constituting “the essential ethical structure of every clinical encounter” (Jonsen, Siegler, & Winslade, 2015, p. 2).

Yet the findings in this study show that:

i) the patient’s best interests are rarely if ever discussed with the surrogates (Cunningham et al., 2018; Scheunemann et al., 2015); and

ii) neither surrogates nor physicians appear to discuss quality-of-life or functional recovery in most conferences (Cox et al., 2009; Douglas et al., 2012; Turnbull et al., 2016).

This may imply that physicians are reducing the best interests criterion to “objective medical interests alone” (Diekema, 2004, p. 247). However, by replacing the surrogates’ judgments with their own they are failing to comply with the professional norm of shared decision-making in the ICU (Kon, Davidson, Morrison, Danis, & White, 2016a).

4.4.3 Conflicts in interpretation of patient’s preferences

Knowledge of the patient’s preferences and values is the touchstone of substituted decision-making (Buchanan & Brock, 1990, p. 119). Surrogates appear to recognize its importance: in Study
#1 it was ranked 2nd of 27 decision factors. However, the patient’s preferences and values are discussed in only 37% surrogate-physician conferences (Scheunemann et al., 2015; Uy et al., 2013).

Even when the patient’s preferences and values are discussed, the focus is on instrumental values—longevity, bodily integrity, pain—associated with the patient’s immediate medical condition. Values that matter to the person’s identity—autonomy, emotional well-being, relationships, cognitive and physical functioning, i.e., what Dworkin (1993) terms their critical interests—are not discussed (Scheunemann et al., 2015; Uy et al., 2013; White et al., 2010). The “normative expectation that critical care units must promote survival” (Daly et al., 2016, p. 6), may override such long-term interests.

Family and surrogate preferences are reported to play a substantial role in 40% of decisions (Hsieh et al., 2006; LeClaire et al., 2005), in contradiction to the findings of Study #1 in which surrogates ranked their own preferences as 26 of 27 decision factors.

4.4.4 Gaps and conflicts concerning prognosis

The most significant gap in prognosis is the family’s and surrogate’s greater optimism, which in turn often leads to a sense of conflict between the physician and surrogate. This optimism surfaces in a majority of surrogates (Leiter et al., 2018), and is variously reported to stem from intimate knowledge of the patient’s unique qualities, trust in religion (White et al., 2016), or belief that their optimism affects the patient’s outcome (Lee Char et al., 2010). Some more experienced physicians claim to have seen enough cases warranting the surrogates’ optimism that their prognoses are now far less absolute and allow for more uncertainty (Wilson et al., 2013).

Although prognostic statements by physicians were reported to be almost universal in family conferences (50 of 51 conferences observed: White, Engelberg, et al., 2007), 74% of surrogates felt that relevant prognostic topics such as “functional limitations, quality-of-life, or expected care-giving needs” were not discussed (Cox et al., 2009, p. 2891). In some cases, families and surrogates are very unwilling to accept a poor prognosis, leading to a substantial impediment in discussing the goals of care (You et al., 2015). Surrogates are more likely to doubt if the physician characterizes treatment as futile (Zier et al., 2009). Taking the time to educate the family about the disease processes leading to the poor prognosis may aid in overcoming this gap (Anderson et al., 2015).

Several other factors contribute to gaps and conflict surrounding prognosis. Perhaps most important is the stress on surrogates, which so overwhelms them that they only “hear every third or
fourth word spoken by clinicians” (Dale et al., 2016, p. 1117). Overcoming surrogates’ stress intensifies the workload on the attending clinicians. A complicating factor is that critical care physicians have little experience with the long-term outcomes of their patients who survive to discharge (Dale et al., 2016; Turnbull et al., 2016; Wilson et al., 2013). This lack of direct experience limits their confidence in their prognoses.

Surrogates also rely on other sources, particularly the Internet, for prognostic information (Anderson et al., 2015; Boyd et al., 2010; Dale et al., 2016; Tilden et al., 1995). Further, surrogates form their own opinions from their own observations (Anderson et al., 2015), and have their own intuitions (Schenker, White, et al., 2013). However, clinicians often find this information-gathering distracting (Dale et al., 2016). No SPR Papers addressed how physicians should interact with surrogates’ own opinions and intuitions.

A number of ways to overcome these gaps and reduce the conflicts have been proposed:

- Nelson et al. (2017) found that individual surrogates responded to prognostic information in one of six characteristic ways. They suggest that tailoring the presentation to match each surrogate’s characteristic response may help clinicians to communicate prognosis more effectively.

- Gutierrez (2013) found that prognoses were communicated to the family at a time driven by the physician, based on his or her level of prognostic certainty and perception of the urgency to make decisions, rather than by the family’s need for early prognostic information. Gutierrez suggests that by separating prognostic discussions from decision-making families will have more time to adapt to a prognosis, reducing conflict about the EoL decisions that may later be necessary. Similar findings were reported earlier by Apatira et al. (2008).

- Russ and Kaufman (2005) point to the vagueness of most prognoses contrasted with the specificity and detail of intervention plans as a major source of frustration and confusion for families and surrogates. They suggest this confusion can be alleviated by presenting both prognoses and interventions at similar and appropriate level of detail.

- Hutchison et al. (2016) found that surrogates trust nurses along different dimensions than they trust physicians. They suggest that regularly including nurses in family-physician meetings may broaden trust.
4.4.5 Minimal gaps or conflicts

Surrogates in Study #1 frequently reported established trust in physicians as an important decision factor. The SPR Papers show that physicians recognize the necessity of actively building trust (Brush, Brown, et al., 2012) and of involving other clinicians—particularly nurses—who have a big role in contributing to overall trust (Anderson et al., 2015).

Another area of consensus is that families and surrogates need time to process a poor prognosis and prepare to make EoL decisions (Brush, Brown, et al., 2012; Mehter et al., 2018; Tilden et al., 1995). This factor is ranked 4th of 27 by surrogates in Study #1.

Family conflict is rarely reported as a significant decision factor by surrogates (24 of 27 decision factors in Study #1). Conflict is the second most frequent topic found in the SPR Papers, but it is most often conflict between physicians, or physicians and administrators, or physicians and surrogates, not intra-family conflict.
4.5 Limitations

Each of the 52 SPR Papers examined in this study had its own set of research objectives, none of which were explicitly surrogate-professional relationships. The directed content analysis method I used here is effective at finding areas where there are gaps in the existing research. It is also effective at raising questions about misalignments between surrogates’ expressed decision factors and the attitudes and behaviors of ICU professionals. This method points toward areas where more research may be fruitful; it does not provide definitive answers to these questions.

Unlike the grounded theory method which has the well-defined stopping criterion of theoretical saturation, there is no such well-defined criterion for the directed content analysis method. I analyzed every one of the 52 studies found in the systematic review process, but other relevant studies almost certainly exist. If these had been analyzed they might contain additional insights into one or more of the decision factors. Thus, I cannot be certain that this analysis represents a complete set of insights into the gaps and conflicts between surrogates’ expressed decision factors and the behaviors and attitudes of ICU professionals when interacting with surrogates.

Thorne et al. warn that in performing qualitative analysis “there are (at least) two levels of variation that must be explained: those within the phenomenon under study and those across reports from different analysts writing in different places and times” (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004, p. 1355). My analysis of these variations shows:

- **Temporal variation:** probably not important because 36 (70%) of the SPR Papers were published between 2010 and 2019 and only 2 (4%) papers before 2000.
- **Geographical variation:** By design of the inclusion/exclusion criteria, all the primary research in this study was conducted within a single geographical area—North America. However, within this large and heterogenous region, more than one third of the studies were conducted in just two cities, San Francisco (18%) and Seattle (18%), and by one large group of collaborators typically involving researchers at one or both of the University of Washington (UW) and the University of California San Francisco (UCSF). Nonetheless, the most prevalent gaps and conflicts found in the UW and UCSF research are similarly prevalent in research from other groups.

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10 4 (8%) of the 52 SPR Papers involve Canadian subjects in Canadian ICU settings; the remainder are US. This proportionality is roughly consistent with the 1:9 population ratio between the two countries.
4.6 Conclusions

In response to the research question for this study—*What gaps and conflicts exist between surrogates’ expressed decision factors and the attitudes and behaviors of ICU professionals?*—my analysis has shown that there are indeed significant gaps and conflicts:

- gaps in communication between surrogates and physicians, especially regarding religious considerations and emotional expressions of support;
- conflicts in decisional authority, particularly resulting from passive paternalism and replacing a quality-of-life best interests standard by a medical best interests standard;
- conflicts between patients’ and surrogates’ preferences, especially since patient’s preferences are rarely explicitly discussed by physicians and surrogates together; and
- conflicts resulting from the gap in prognostic optimism often observed between families and physicians.

Due to the limitations of the methods I employed, the existence of these gaps and conflicts should be confirmed by purpose-specific empirical studies in the future.
5 Study #3: Evolution of Bioethical Thought on Surrogate Decision-making

In this last study of my thesis, I remain focused on my overall research question—*What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?*—but I turn my attention from the clinical to the ethical deficiencies of the current paradigm.

The current paradigm for surrogate decision-making was established in the early 1980s (President’s Commission, 1983), shortly after the publication of the first texts codifying modern North American bioethics—the *Belmont Report* (National Commission, 1978) and the first edition of *Principles of Biomedical Ethics* (Beauchamp & Childress, 1979). The normative basis of the current paradigm was framed by the tension between two of the newly codified bioethical principles—respect for autonomy and nonmaleficence. These principles emerged from both Kantianism and utilitarianism (Beauchamp & Childress, 1979), the two theories then dominant in moral philosophy (Hursthouse, 1999).

Since that time almost 40 years ago, scholarly thought about moral philosophy in general and bioethics in particular has evolved considerably. For example, in her examination of the turn to virtue ethics in the philosophical and applied ethics literature of the last half of the 20th century, Hursthouse asserted: “Beauchamp and Childress, whose *Principles of Biomedical Ethics*, from being initially dismissive, has become increasingly friendly to virtue ethics in its successive editions” (1999, p. 41).

Testing Hursthouse’s assertion led me to make a preliminary comparison between Beauchamp and Childress’ seven editions (1979, 1983, 1989, 1994, 2001, 2009, 2013). In the first edition I found little mention of virtue ethics—only 23 pages listed in the index—and no mention of surrogate decision-making. However, by the seventh edition, the index listed 195 pages on virtue ethics, and 29 pages on surrogate decision-making. Figure 5-1 confirms a turn to virtue ethics in *Principles*, in addition to decreases in pages associated with deontology and utilitarianism.

This turn to virtue ethics led me ask whether this and other changes in bioethics since 1979 would argue for a shift in the paradigm for surrogate decision-making. Answering this larger question required me to first answer the specific research question of this third study:

*How has bioethical thought about surrogate decision-making evolved over the past 40 years?*
5.1 Data sources

Beauchamp and Childress are the only authors to have published multiple editions of a landmark comprehensive bioethics textbook spanning the interval from the publication of *The Belmont Report* (1978) until the present. The first edition of *Principles of Biomedical Ethics*, written while Beauchamp was also writing the final version of *The Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978), was specifically intended to fulfill “the need for a systematic analysis of the principles that should govern a wide range of decisions affecting biomedicine” (Beauchamp & Childress, 1979, p. xi original emphasis). The seven editions of *Principles* have been cited about 25,000 times\(^{11}\), and the latest edition continues to be one of the most popular bioethical textbooks\(^{12}\).

I acknowledge that Beauchamp and Childress’ principlist approach has critics (e.g., Clouser & Gert, 1990; Gert, Culver, & Clouser, 2006; Jonsen, 1995). I also acknowledge that it is insufficient to provide guidance in “complex sociopolitical climates in which health care is delivered and in which resources for health are embedded” (Rodney, Burgess, Phillips, McPherson, & Brown, 2013, p. 71). However, the principles enunciated in *The Belmont Report* (1978) “found their way into the general literature of the field, and … grew … into the basic principles of bioethics” (Jonsen, 1998, p. 104), at least in North America (Häyry, 2003). Beauchamp and Childress’ principlist approach forms the basis for bioethics curricula from secondary schools (Chowning et al., 2012) to post-graduate clinical ethics courses at major universities (University of Texas, n.d.). The four principles have become “the reference tetrad *par excellence* that physicians and ethicists use to resolve ethical dilemmas and define the right conduct of physicians and patients” (Pellegrino & Thomasma, 1993, p. 52 original italics) and “the most common ethical currency in North American and British biomedical ethics” (Kaldjian, Weir, & Duffy, 2005, p. 308).

Thus, in spite of their limitations, the seven successive editions of *Principles* provide an unparalleled data source to answer my research question of how bioethical thought has evolved since the current paradigm for decision-making was established 40 years ago.

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\(^{11}\) scholar.google.ca/scholar?cluster=17129316548341959408&hl=en&as_sdt=0,5 accessed 2019-01-21

\(^{12}\) According to Amazon.com on 2019-01-14, *Principles* was the second best-selling bioethics textbook (at #10 in Medical Ethics). Vaughn’s *Bioethics* (2016), first edition in 2010, was at #2. These detailed rankings change frequently but consistently show these two as the best-selling bioethical texts. www.amazon.com/Best-Sellers-Books-Medical-Ethics/zgbs/books/227668/ref=zg_bs_nav_b_3_265542
5.1.1 Structural changes in *Principles of Biomedical Ethics*: 1st edition to 7th edition

The structure of *Principles of Biomedical Ethics* has evolved from the first edition in 1979 to the 7th edition in 2013: chapters were retitled, the sequence of chapters was altered, totally new chapters were added. These changes are shown in Table 5-1.

**Table 5-1: Structural evolution of chapters in *Principles of Biomedical Ethics***

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<td>Types of Ethical Theory</td>
<td>Moral Character</td>
<td>Moral Character</td>
<td>Moral Character</td>
</tr>
<tr>
<td>4</td>
<td>The Principle of Nonmaleficence</td>
<td>The Principle of Nonmaleficence</td>
<td>The Principle of Nonmaleficence</td>
<td>Nonmaleficence</td>
<td>Nonmaleficence</td>
<td>Respect for Autonomy</td>
<td>Respect for Autonomy</td>
</tr>
<tr>
<td>5</td>
<td>The Principle of Beneficece</td>
<td>The Principle of Beneficece</td>
<td>The Principle of Beneficece</td>
<td>Beneficece</td>
<td>Beneficece</td>
<td>Nonmaleficence</td>
<td>Nonmaleficence</td>
</tr>
<tr>
<td>6</td>
<td>The Principle of Justice</td>
<td>The Principle of Justice</td>
<td>The Principle of Justice</td>
<td>Justice</td>
<td>Justice</td>
<td>Beneficece</td>
<td>Beneficece</td>
</tr>
<tr>
<td>7</td>
<td>The Professional and Patient Relationship</td>
<td>Professional/Patien t Relationships</td>
<td>Professional-Patient Relationships</td>
<td>Professional-Patient Relationships</td>
<td>Professional-Patient Relationships</td>
<td>Justice</td>
<td>Justice</td>
</tr>
<tr>
<td>8</td>
<td>Ideals, Virtues, &amp; Integrity</td>
<td>Ideals, Virtues, &amp; Conscientious Actions</td>
<td>Ideals, Virtues, &amp; Conscientiousness</td>
<td>Virtues &amp; Ideals in Professional Life</td>
<td>Moral Theories</td>
<td>Professional-Patient Relationships</td>
<td>Professional-Patient Relationships</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Method &amp; Moral Justification</td>
<td>Professional-Patient Relationships</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Method &amp; Moral Justification</td>
<td>Method &amp; Moral Justification</td>
<td></td>
</tr>
</tbody>
</table>

The first major structural change came in 5th edition (2001) when the topics addressed in Chapter 8 in all previous editions were moved to Chapter 2 and retitled “Moral Character”. The topics of Chapter 2 “Types of Ethical Theory” were moved to Chapter 8, and a new chapter titled “Method & Moral Justification” was added as Chapter 9.

A second significant structural change was introduced in 6th edition (2009) when an entirely new Chapter 3 “Moral Status” was inserted after Chapter 2 “Moral Character”. Beauchamp and Childress also divided the book into three major parts:

- Part I Moral Foundations: Chapters 1, 2, and 3
- Part II Moral Principles: Chapters 4, 5, 6, 7, and 8
5.2 Methods

To conduct a longitudinal analysis of the seven editions of Beauchamp and Childress, I followed a three-step process for the analysis of documentary data (Coffey, 2014):

i) comparing and annotating new and changed topics, chapter-by-chapter, edition-to-edition;
ii) applying qualitative analysis to the topic annotations emerging from step i) to identify major themes in the evolution of bioethical thought about surrogate decision-making; and
iii) using the methods of intertextual analysis to convert the discourse around each of the themes (from step ii) themes into a series of continuous narratives detailing the 1979-2013 evolution of highly specific bioethical topics associated with surrogate decision-making.

The methods involved in these three steps are described in detail in the following subsections.

5.2.1 Comparison and annotation method

I scanned all pages of each chapter in each edition into separate portable document files (PDFs) and made the scanned images searchable using the text recognition software in Acrobat XI (Adobe Corp.). To compare the contents of two editions, I scrolled through the PDFs in a synchronized manner as shown in Figure 5-2.

**Figure 5-2: Screen capture showing method of side-side edition comparison**

This example shows the Respect for Autonomy chapter from 4th edition on the left and 5th edition on the right. The marks and notes on the images are previous readers’ marginalia in the library’s books.
As I compared the text of each subsequent edition against the prior edition, I annotated new or changed topics in each chapter by extensive note-taking, recording the annotations in a longitudinal format using OneNote software (Microsoft Corporation), as shown in Figure 5-3. Each annotation was marked by a bullet in the left-most column; additional details (if any) were indented under the annotation.

**Figure 5-3: Screen capture of a topic annotations fragment showing typical annotation detail**

This example shows some of the topic annotations in the Respect for Autonomy chapter. Blue headings are the section and subsection headings used by Beauchamp and Childress. These typically map to the topics that are my units of analysis. Numbers in [] are page references. Underlined phrases are hyperlinks to more detailed notes.

My unit of analysis for annotation was a topic. Each topic was typically a chapter section or subsection identified with its own heading; occasionally it was a sub-group of one or more paragraphs. My annotation method involved first briefly describing a new topic or materially changed content within a topic, and then documenting the authors’ apparent rationale by capturing either key quotations or citations. Changes such as the introduction or removal of clarifying sentences or examples were not annotated if they did not materially change the sense of the topic. Substantial reductions in the amount of text without changing the thrust of the argument were annotated as “tightening”. Topics that were completely deleted were annotated by a reference to the nature of the now-deleted topic and its page numbers in the prior edition.
Because of the focus of my research question I only annotated changes nominally related to clinical decision-making, e.g., changes related to patient autonomy were annotated, but changes related to randomized control trials or public health policy were not included. However, I did read all the text of every chapter to ensure that if a topic touched on clinical decision-making it was annotated.

The eight chapters of the 1st edition, and Chapter 3 “Moral Status” of the 6th edition may appear to be special cases because there were no equivalent prior chapters to compare them against. However, they were annotated in exactly the same way as any of the subsequent editions with an annotation created for each new topic. For example, in Figure 5-3 above, the topic “The Triumph or Failure of Autonomy” is an entirely new topic introduced for the first time in 5th edition. Each of the topics annotated in 1st edition is methodologically equivalent to this example.

Because the intertextual analysis method requires returning to the original text, the brevity or level of detail in these annotations does not affect the ultimate analysis. The level of detail in these annotations was chosen to facilitate scanning multiple columns of annotations in the following analysis.

I recorded a total of 532 annotations of new, changed, or deleted topics across the seven editions. These annotations were distributed among the different chapters and editions of Principles as shown in Table 5-2.

Table 5-2: Count of new, changed, and deleted topic annotations by chapter and edition of Principles of Biomedical Ethics

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Moral Norms</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>10</td>
<td>6</td>
<td>4</td>
<td>8</td>
<td>30</td>
</tr>
<tr>
<td>Moral Theories</td>
<td>25</td>
<td>0</td>
<td>2</td>
<td>15</td>
<td>6</td>
<td>7</td>
<td>16</td>
<td>71</td>
</tr>
<tr>
<td>Respect for Autonomy</td>
<td>12</td>
<td>6</td>
<td>14</td>
<td>25</td>
<td>8</td>
<td>3</td>
<td>10</td>
<td>78</td>
</tr>
<tr>
<td>Nonmaleficence</td>
<td>20</td>
<td>11</td>
<td>16</td>
<td>8</td>
<td>1</td>
<td>2</td>
<td>10</td>
<td>68</td>
</tr>
<tr>
<td>Beneficence</td>
<td>15</td>
<td>4</td>
<td>7</td>
<td>13</td>
<td>0</td>
<td>4</td>
<td>7</td>
<td>50</td>
</tr>
<tr>
<td>Justice</td>
<td>20</td>
<td>6</td>
<td>12</td>
<td>15</td>
<td>6</td>
<td>10</td>
<td>10</td>
<td>79</td>
</tr>
<tr>
<td>Professional-Patient Relationships</td>
<td>11</td>
<td>7</td>
<td>10</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>43</td>
</tr>
<tr>
<td>Moral Character</td>
<td>5</td>
<td>7</td>
<td>9</td>
<td>7</td>
<td>4</td>
<td>12</td>
<td>8</td>
<td>52</td>
</tr>
<tr>
<td>Moral Status</td>
<td>18</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>22</td>
</tr>
<tr>
<td>Method and Moral Justification</td>
<td>33</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>39</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>109</td>
<td>41</td>
<td>71</td>
<td>101</td>
<td>34</td>
<td>94</td>
<td>82</td>
<td>532</td>
</tr>
</tbody>
</table>
Interpretations of the counts above are subject to notable limitations:

- any change in a topic increased the count by one, but so did the introduction or deletion of an entire topic;
- a single topic may have had multiple changes in a new edition thereby generating multiple annotations;
- chapters with many pages and many topics (such as Nonmaleficence) have had many more changes than chapters with few pages (such as Moral Norms);
- only topics associated with clinical decision-making were recorded (which was why Moral Norms in 1st edition has a count of 1); and
- the number of counts should not be interpreted as a measure of importance.

Even with these caveats, the most changes associated with the ethics of clinical decision-making are observed in 4th and 6th editions.

5.2.2 Thematic coding method

The topic annotations themselves form a textual data set which, in turn, can be qualitatively analyzed to identify major themes in the evolution of bioethical thought in surrogate decision-making. Following Flick (2014), I conducted an initial coding pass of the topic annotations followed by two rounds of axial coding to refine the categories of bioethical evolution related to surrogate decision-making.

I used NVivo 12 (QSR International Pty Ltd) qualitative research software to assist with data management and analysis. Following Saldaña’s recommendations for solo coding, my supervisor reviewed my coded data and served as a “rigorous examiner and auditor of my analysis” (Saldana, 2016, p. 37).

I identified a total of 455 references to 84 initial codes in 12 categories within the 532 topic annotations. After two iterations, I refined these initial codes to a set of five themes: three specific to surrogate decision-making and two related to medical decision-making more generally although still highly salient to surrogate decision-making. These themes, their descriptions, and number of topic annotations referenced are shown in Table 5-3. These themes were then used to drive the intertextual analysis, as described in Section 5.2.3.
Table 5-3: Themes found in the new, changed, and deleted topic annotations between all seven editions of *Principles of Biomedical Ethics*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
<th>Number of annotations referenced</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Normative basis for surrogate decision-making</td>
<td>Ethical grounds for the use of surrogates; criteria that should be used when making decisions for incompetent patients</td>
<td>75</td>
</tr>
<tr>
<td>2. Limiting life-sustaining treatment</td>
<td>Ethical questions around starting and stopping life-sustaining treatment</td>
<td>26</td>
</tr>
<tr>
<td>3. Family-physician interactions</td>
<td>Roles and responsibilities of decisionally incapacitated patients' families and physicians</td>
<td>29</td>
</tr>
<tr>
<td>4. Role of virtue ethics in bioethics</td>
<td>The nature and application of the virtues appropriate for health care professionals</td>
<td>59</td>
</tr>
<tr>
<td>5. Bounded rationality</td>
<td>Ethical impacts on decision-making by physicians and families due to their limited capacities to process information</td>
<td>8</td>
</tr>
</tbody>
</table>

5.2.3 Intertextual analysis method

Coffey describes how intertextual analysis can be used for a variety of purposes, including determining “how texts are linked as sequences of documents, ... to understand the nature and meaning of those sequences” (2014, p. 11).

The metaphor of the *audit trail* is at the core of the intertextual method:

... we can pay attention to the intertextuality of documents: that is, their relational qualities and what these can reveal about the setting under investigation. The concept of audit is useful here. ... One of the root metaphors of an audit is that of the audit trail. Audit trails trace each document and statement ... to other documents contained in the audit file. There is an assumption that references can and should be made to other documents; indeed it is through these references and trails that decisions ... are documented and justified. (Coffey, 2014, p. 10)

These audit trails emerged from the previous thematic analysis. Each theme was associated with a subset of the topic annotations. Each such annotation subset formed a type of audit trail, highlighting the changes in the content of that axial theme from 1st to 7th edition.

Bazerman identifies a total of six levels of intertextuality “at which a text explicitly invokes another text and relies on the other text as a conscious resource” (Bazerman, 2003, pp. 86–87). The text under analysis may draw on:

i) other texts as a “source of meanings to be used at face value ... and as authoritative”;

ii) other texts to present “explicit social dramas” that frame the discussion;

iii) other texts as “background, support, and contrast”;

iv) “beliefs, issues, ideas ... likely familiar to the readers”;

92
v) “recognizable kinds of language, phrasing, and genres ... evoking particular social worlds”;

and

vi) “the available resources of language ... [including] the cultural world of the time”.

I applied this intertextual analysis method to each theme (from Table 5-3 above) separately. First, I examined the text underlying each annotation associated with the theme, looking for intertextual traces at all six levels that may illuminate the nature and meaning of the change. In other words, my intertextual analysis was not limited to just the text of Beauchamp and Childress’ seven editions, but also included work they cited, other contemporaneous papers, court cases, and books. This process was analogous to initial coding in grounded theory and resulted in a set of “fragmentary narratives” about the evolution associated with each theme.

In the next phase of intertextual analysis, I identified specific bioethical topics that grouped the fragmentary narratives, e.g., the distinction between killing and letting die, or the acceptability of passive paternalism. This phase was analogous to the axial coding phase in grounded theory. I then rearranged the fragmentary narratives from the first stage into “continuous narratives” that describe the arc of evolution for that bioethical topic from 1st edition to 7th edition. I iteratively refined each continuous narrative by reference back to original texts from Beauchamp and Childress or other authors.
5.3 Results

These results are the continuous narratives that describe the evolutionary arc of bioethical thought about each of the themes described in Table 5-3.

5.3.1 Results: Theme 1. Normative basis for surrogate decision-making

The normative basis for surrogate decision-making across the seven editions of Principles reflects the tension between the principle of respect for autonomy and the principle of nonmaleficence in situations where neither autonomy nor harm have clear meanings.

By the early 1970s there was a growing recognition that the “success of medicine [had] shifted the locus of dying to ... health care institutions, thus transferring control over treatment away from the patient and ... family to the health care provider and the state” (Montange, 1974, p. 1632). This loss of individual control was sufficient to induce the California legislature to “recognize the right of an adult person to make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition” (State of California, 1976, p. 6478). Within a year, seven more states had followed California’s lead to create natural death acts (Raible, 1977)13. The Quinlan (1976) and Saikewicz (1977) cases established the initial legal precedents that guided surrogate decision-making for years afterward.

1st edition, 1979

Because “autonomy ... is the basic justifying principle” [1st 65]14 for informed consent, Beauchamp and Childress conclude that for incompetent patients “the justification for second party15 consent derives largely and perhaps exclusively from the moral demand that ... patients be protected from harm—a demand derived from the principles of non-maleficence and beneficence” [1st 66].

13 Similar legislation was enacted somewhat later in Canada (e.g., Province of British Columbia, 1996; Province of Ontario, 1996)
14 These findings make extensive reference to the various editions of Beauchamp and Childress Principles of Biomedical Ethics. In the interests of conciseness and clarity, I cite these references as [edition page], e.g., [5th 241], rather than the standard APA style of (Beauchamp & Childress, 2001, p. 241), which is redundant, long, and leaves out the critical edition number. I continue to use the standard APA citation style for works other than the various editions of Principles.
At the time of this edition’s publication the “orthodox jurisprudential” interpretation of harm was couched in terms of interests: “A person is harmed when someone invades (blocks or thwarts) one of his interests” (Feinberg, 1977, p. 62). Interests fall into two categories:

'Welfare interests' are interests in the indispensable means to one's ulterior goals, whatever the latter may be. These include health, financial sufficiency, and the like. 'Ulterior interests' are based on stable, long-range objectives, achievements of goals valued at least partly as ends in themselves—for example producing a book, raising a family, building a dream house, advancing a cause. (Feinberg, 1977, p. 46)

While acknowledging this broader view of harm as an invasion of interests, Beauchamp and Childress adopt a narrower view of harm:

we will concentrate on physical harms, including pain and suffering, disability, and death, without denying the importance of mental harms and other injuries. In particular, we will emphasize intending, causing, permitting, and imposing the risk of death, although we will also refer to other harms along the way. [1st ed. 99]

2nd edition, 1981

The legal doctrine of “substituted judgment”—originating in 19th century laws on lunacy (Harmon, 1990)—was adapted to decision-making for incompetent patients by the Quinlan court (1976, p. 44). Beauchamp and Childress acknowledge that this decision criterion “begins with the premise that the decision properly belongs to the incompetent patient by virtue of the rights of autonomy and privacy” [2nd ed. 138]. However, they immediately disparage this criterion as “a fiction” [2nd ed. 138]. They continue by citing Annas who, having reviewed both the Quinlan and Saikewicz cases, concludes:

Therefore, while the doctrine of "substituted judgment" makes most sense from the viewpoint of protecting the right to privacy and self-determination of the incompetent, in the two cases under discussion, use of the more objective "best interests" test would have been more logical. (Annas, 1979, p. 376)

In contrast to autonomy as a fiction, Robertson argued that it is necessary to treat an incompetent patient as fictionally autonomous, otherwise he or she would be treated “in all respects as a non-thinking, non-choosing, irrational being—in short, as a non-person” (Robertson, 1976, p. 65). Beauchamp and Childress accept that the logical consequence of Robertson’s argument is that the decision-maker is free to choose treatment or non-treatment, even in “those cases in which the incompetent has not expressed a relevant preference, without feeling bound by the best interests standard or even the reasonable person standard” [2nd ed. 140].

However, Beauchamp and Childress finally conclude, “Because of these confusions and unresolved problems, it is best to rely most heavily, and perhaps exclusively, on the nonmaleficence-based, best-interests standard rather than on the allegedly autonomy-based substituted judgment
They position the best interests standard as based on “highly tangible factors—physical and financial risks, benefits and harms—[which make] use of such generalizations as ‘health is better than illness’ and ‘life is preferable to death’” [2nd 138].

Events between 2nd and 3rd editions, 1981-1989

Conroy (1985) established influential standards for decisions to limit life-sustaining treatment for incompetent patients, especially if the patients’ deaths are not foreseeably imminent. The Conroy court set forth three standards for withholding or withdrawing treatment from an incompetent patient:

i) Subjective: when it is clear that the particular patient would have refused the treatment under the circumstances involved. ... Such an intent might be embodied in a written document, or ‘living will’, [or] evidenced in an oral directive that the patient gave to a family member, friend, or health care provider, [or] consist of a durable power of attorney ... (Conroy, 1985, p. 361);

ii) Limited-objective: when there is some trustworthy evidence that the patient would have refused the treatment, and the decision-maker is satisfied that it is clear that the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him. By this we mean that the patient is suffering, and will continue to suffer throughout the expected duration of his life, unavoidable pain, and that the net burdens of his prolonged life ... markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life. This limited-objective standard permits the termination of treatment for a patient who had not unequivocally expressed his desires before becoming incompetent (Conroy, 1985, p. 365); and

iii) Pure objective: the net burdens of the patient's life with the treatment should clearly and markedly outweigh the benefits that the patient derives from life. Further, the recurring, unavoidable and severe pain of the patient's life with the treatment should be such that the effect of administering life-sustaining treatment would be inhumane. Subjective evidence that the patient would not have wanted the treatment is not necessary under this pure-objective standard. Nevertheless, even in the context of severe pain, life-sustaining treatment should not be withdrawn from an incompetent patient who had previously expressed a wish to be kept alive in spite of any pain that he might experience. (Conroy, 1985, p. 367)

3rd edition, 1989

Beauchamp and Childress introduce a distinction between “ideal” and “normal choosers”, the latter being people whose choices do not meet a rigorous standard of autonomy (such as proposed by Benn, 1975; G. Dworkin, 1988). They also introduce their own pragmatic criteria for autonomous

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16 Summary of Conroy: Guardian sought to remove nasogastric feeding tube from his ward, an elderly, bedridden woman living in a nursing home with serious and irreversible physical and mental impairments. NJ Supreme Court reversed lower court decision that a surrogate could not decide to withhold nourishment unless patient was brain dead or vegetative and death was irreversibly imminent. Instead, they held “that life-sustaining treatment may be withheld or withdrawn from an incompetent patient [by the surrogate] when it is clear that the particular patient would have refused the treatment under the circumstances involved. The standard we are enunciating is a subjective one, consistent with the notion that the right that we are seeking to effectuate is a very personal right to control one's own life. The question is not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself” (Conroy, 1985, p. 361).
actions: “normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine the action” [3rd 69]. They claim that while intentionality is binary, the other two conditions can be satisfied partially, making autonomy “a broad continuum from fully present to wholly absent” [3rd 69].

Recognizing that “in the practical world, where people’s actions are rarely, if ever, fully autonomous” they suggest a realistic goal is only that “consequential [health care] decisions be substantially autonomous” [3rd 69]. Furthermore, the “criteria of substantiality and substantial autonomy …will be treated throughout this book as a matter that is best addressed in a particular context” [3rd 69]. They may intend this pragmatic definition of autonomy to apply to their later claim that “Autonomy deserves protection even if a person’s choice would not maximize individual or social welfare” [3rd 75].

While acknowledging that Conroy “clarifies and combines the standards of best interests and substituted judgment” [3rd 173], Beauchamp and Childress express several objections to the decision standards in Conroy:

• a proxy might “selectively choose from the patient's life history those values that accord with the proxy's own values and then use only the selected values in reaching decisions”;  
• a proxy might decide “based on values of the patient that are only distantly relevant to the immediate decision”; and  
• “whether the burdens considered under the best interests standard should be limited to physical pain and suffering, as the court's language at points suggests” [3rd 176].

In summary, despite Conroy Beauchamp and Childress remain strongly in favor of a nonmaleficence-based decision criterion, except where there is very strong evidence of the patient’s prior preferences:

previously competent patients who have autonomously expressed their preference can be fairly treated under the standard of substituted judgment, although many practical problems remain in implementing the standard. For previously competent patients whose prior preferences cannot be reliably traced and for never-competent patients, it is appropriate to rely on the best interests standard, based on nonmaleficence and beneficence, rather than on the substituted judgment standard, which is based on autonomy. [3rd 176]
Nonetheless, Beauchamp and Childress continue to stress that no single principle is primary, and every decision requires judgment and balance:

According to the structure of the argument we have developed throughout this book, there is no premier and overriding authority in either the patient or the physician and no preeminent principle in biomedical ethics—*not even the admonition to act in the patient's best interest.* [3rd 211 emphasis added]

**4th edition, 1994**

Beauchamp and Childress acknowledge feminist criticism that the then-current emphasis on autonomy in ethical theory ignored familial and communal relationships. While they do not deny the importance of these relationships—“Communal life and human relationships provide the matrix for the development of the self, and no defensible theory of autonomy denies this fact” [4th 125]—they do not propose how such relationships should be incorporated into the principle of respect for autonomy or into surrogate decision-making.

Beauchamp and Childress also introduce “positive obligations” associated with the principle of respect for autonomy, specifically the physician’s obligation to help the patient to “overcome their sense of dependence and achieve as much control as possible or as they desire” [4th 127].

In 1986, Dresser, citing a theory of identity proposed by Parfit (1984), proposes that

... a legal standard based on respect for incompetent patients would exclude the notion that a past person's statements and behavior should control her future treatment and that other parties should be obliged to effectuate [sic] the formerly expressed preferences. (Dresser, 1986, p. 381)

While accepting that her proposal has “some attractiveness”, Beauchamp and Childress reject it because of the difficulty in finding “ways to mark the point of discontinuity in order to draw the line between different selves” [4th 132].

Beauchamp and Childress introduce the “pure autonomy standard” which “eliminates the ghost autonomy found in substituted judgment” [4th 173]. This standard requires that “prior, autonomous judgments should be accepted [but only if] such judgments are known, not merely conjectured, and are directly relevant to a contemplated action” [4th 174]. They also propose a utilitarian definition of the best interests standard, imposing a maximization criterion on the decision-maker:

Under the best interests standard a surrogate decisionmaker must determine the highest benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs. [4th 178]
Relying on a case involving the forcible administration of anti-psychotic medication, the 1983 President's Commission asserted that patients' best interests may be interpreted to include the family:

The impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates. (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983, p. 135)

Beauchamp and Childress disagree with this conclusion: “a patient sometimes has an interest in the family's welfare, but it is a long step from this premise to a conclusion about whose interests should be overriding” [4th 217], especially if the patient has never been competent.

5th edition, 2001

Beauchamp and Childress propose an “economy of standards” [5th 103], collapsing the advance directives/substituted judgment/best interests hierarchy into two standards, Pure Autonomy and Best Interests. If the previously autonomous patient has provided a directive, written or oral, that “supports a reasonable base of inference for a surrogate” [5th 103] then, relying on the principle of respect for autonomy, the Pure Autonomy standard should prevail. Otherwise, the Best Interests standard should prevail. In this context, they define best interests as a process that:

locates the highest net benefit ... by assessing risks and benefits of various treatments and alternative to treatment, by considering pain and suffering, and by evaluating restoration or loss of functioning. It is, therefore, inescapably a quality of life criterion. Those applying the best interest standard should consider the formerly autonomous patient’s preferences, values, and perspectives only as far as they affect interpretations of quality of life, direct benefit, and the like. [5th 102]

6th edition, 2009

Beauchamp and Childress cite the case of Margo, a 55-year-old Alzheimer’s patient who attended an art therapy class every day. Margo, according to her physician, was “one of the happiest people I have known” (Firlik, 1991, p. 201) and illustrates the debate between Dresser (Dresser, 1986, 1995; Dresser & Robertson, 1989) and Dworkin (1993) about whether a patient’s long-term critical interests, expressed through some form of advance directive, should prevail over their current experiential interests. Contrary to their earlier dismissal of Dresser’s (1986) claim [4th 132], Beauchamp and Childress now conclude that in such cases, “it seems unfair to the now happily situated incompetent person to be bound by a prior decision that may have been ill informed” [6th 139].

7th edition, 2013

Beauchamp and Childress move their discussion of surrogate decision-making from Chapter 4 “Respect for Autonomy” to Chapter 6 “Beneficence” in this edition. This change may be explained by
a change in their view of the basis for surrogate decision-making. Until this edition, they have
 treated surrogate decision-making as a problem of consent. For example, in introducing the section
titled “Framework of Standards for Surrogate Decision-making”, they state “We shift now from the
conditions of consent to problems of consent when surrogate decision makers are involved”
[6th 135]. In this edition, the section on surrogate decision-making follows a section titled
“Paternalism: Conflicts between beneficence and respect for autonomy” [7th 214], and its
introductory sentence is, “We turn now from paternalistic protections to the related domain of
surrogate decision-makers ...” [7th 226].

The Pure Autonomy and Best Interests standards are defined so that their application is
mutually exclusive [7th 228]. However, Beauchamp and Childress assert that the “best interests
standard can in some circumstances validly override advance directives executed by formerly
autonomous patients” [7th 229], for example if “the designated surrogate makes a decision that
threatens the patient’s best interests” [7th 229] or in a case such as Margo, the happy Alzheimer’s
5.3.2 Results: Theme 2. Limiting life-sustaining treatment

My analysis of limiting life-sustaining treatment (LST) across the seven editions of Principles revealed that debate is centered on three distinct dichotomies:

i) Ordinary treatment vs. extraordinary treatment: historically (e.g., Judicial Council of the AMA, 1973) an ethical distinction was drawn between a physician’s obligation to provide so-called ordinary vs. extraordinary treatments;

ii) Killing vs. letting die: as found in Study #1, surrogates often characterize a “decision to limit life support as an affirmative action on their part to ‘kill,’ ‘starve,’ or otherwise harm the patient” (Nelson et al., 2017, p. 869) and this killing is seen as morally unacceptable while letting die is morally acceptable; and

iii) Withholding vs. withdrawing: both surrogates and physicians perceive that not starting a treatment is morally more acceptable than stopping a treatment (Micetich, Steinecker, & Thomasma, 1983).

My results are presented in three subsections corresponding to these three dichotomies.

5.3.2.1 Ordinary vs. extraordinary treatment

By the early 1970s, ethicists recognized that “contemporary medicine ... can keep almost anyone alive” with the consequence that the decision to treat should now rest on “the quality of the life sustained and preserved” (McCormick, 1974, p. 174). In other words, the morally acceptable grounds for deciding to limit treatment expanded from the “cessation of the employment of extraordinary means to prolong the life of the body when there is irrefutable evidence that biological death is imminent” (Judicial Council of the AMA, 1973, p. 140) to allowing or even requiring a judgment about quality-of-life (McCormick, 1974) or a detriment-benefit analysis (Jonsen, 1977).

1st edition, 1979

Beauchamp and Childress incorporate Jonsen’s 1977 detriment-benefit analysis and other earlier work into two possible justifications17 for decisions to limit a patient’s treatment:

i) The patient’s death, while foreseeable, is not the direct and intentional consequence of the decision to limit treatment.

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17 They allude to several other justifications, such as lack of moral status, but do not develop arguments supporting these justifications.
This moral justification relies on the rule (or principle) of double effect (RDE), which is frequently used to justify giving dying patients sedatives or analgesics to relieve respiratory distress, even though the drugs may hasten or even cause death [1st 104].

ii) The need for extraordinary means to preserve life in the face of imminent death.

Beauchamp and Childress recast the traditional ordinary/extraordinary treatment dichotomy in terms of obligatory/optional treatment [1st 118]. For incompetent patients in particular, they then proposed that a treatment should be considered optional “when it offers no prospect of benefit to the patient” or “when its burdens outweigh its benefits for the patient” [1st 119-20]. Their proposed burdens-to-benefits analysis was similar to McCormick’s quality-of-life judgement or Jonsen’s detriment-benefit ratio.

Deciding when burdens outweigh benefits necessarily involves a quality-of-life judgment. This in turn creates a debate between those who resist such judgments and those who find them morally necessary. Ramsey (1977) contends that “a quality of life approach shifts from the question whether treatments are beneficial to patients to the question whether patients’ lives are beneficial to them” [1st 124 original emphasis]. On the other hand, McCormick (1978) holds that “the maintenance of physical life should not automatically be considered a benefit to the person”, and that a minimal condition for benefit is that the person retains “the capacity for experience or social interrelating” [1st 124].

4th edition, 1994

In this edition Beauchamp and Childress take a much firmer stance on the four “traditional guidelines” for decisions to limit life-sustaining treatment:

1. Withholding and withdrawing life-sustaining treatment
2. Extraordinary (or heroic) and ordinary treatment
3. Artificial feeding and life-sustaining medical technologies
4. Intended effects and merely foreseen effects

We will argue that these distinctions are all untenable. They are distinctions without a relevant difference and should be replaced by the distinction between obligatory and optional means of treatment and by an account of the benefit-burden ratio. The venerable position that these traditional distinctions occupy in many professional codes, institutional policies, and writings in biomedical ethics does not supply an adequate reason for retaining them. Indeed, some of these distinctions are morally dangerous. [4th 196]

They go on to describe how ordinary and extraordinary treatments have been defined in terms of professional practice or due care standards, have become “attached to particular technologies” [4th 200], or are distinguished by being “simple or complex, natural or artificial, noninvasive or highly invasive, inexpensive or expensive, and routine or heroic” [4th 201]. However, “All treatments that
fall into these classifications are sometimes beneficial for patients, sometimes burdensome; the principal consideration is whether a treatment is beneficial or burdensome, not its form” [4th 201].

This brings their argument back to the balance of burdens and benefits—a balance that, by the principle of respect for autonomy, can be weighed only by the patient or their surrogate. They conclude that:

... the distinction between ordinary and extraordinary treatment is morally irrelevant and should be replaced by the distinction between optional and obligatory treatment, as determined by the balance of benefits and burdens to the patient. [4th 202]

Beauchamp and Childress refine the obligatory/optional dichotomy by dividing the obligation to treat into three categories and two sub-categories:

I. Obligatory to Treat (Wrong Not to Treat)
II. Optional Whether to Treat
   A. Neutral (Neither Required nor Prohibited)
   B. Supererogatory (Surpassing Obligation)
III. Obligatory Not to Treat (Wrong to Treat) [4th 211]

The principle of nonmaleficence imposes the Category I obligation to treat, but since this is a prima facie principle it has to be balanced with other principles such as respect for autonomy and beneficence. A treatment may fall into Category II if it has no benefit to the patient, as determined by the patient or their surrogate. Finally, it may fall into Category III if the burdens far exceed the benefits, again as determined by the patient or their surrogate [4th 212].

7th edition, 2013

While their arguments are presented more succinctly (only one page instead of five in 4th edition), Beauchamp and Childress retain the same conclusion: “the distinction between ordinary and extraordinary treatment is morally irrelevant. The distinction between optional and obligatory treatment, as determined by the balance of benefits and burdens to the patient, is the pertinent distinction” [7th 163].

Beauchamp and Childress also reorder and simplify their obligatory/optional categories introduced in 4th edition:

I. Obligatory to Treat (Wrong Not to Treat)
II. Obligatory Not to Treat (Wrong to Treat)
III. Optional Whether to Treat (Neither Required nor Prohibited) [7th 169]

While there is a prima facie obligation to provide life-sustaining treatment (Category I), the burdens of treatment may so outweigh the benefits that even for an incompetent patient, there is an obligation not to treat (Category II). Treatments fall into Category III if they are morally neutral,
i.e., provide no physiological benefit \[7^{th} 170\], or the burdens outweigh the benefits as determined by the patient or surrogate \[7^{th} 171\]. In the case of incompetent patients, Beauchamp and Childress continue to place a duty on the attending physicians and other health care professionals “to safeguard the patient’s interests ... by monitoring the quality of surrogate decision-making” \[7^{th} 191\].

5.3.2.2 Killing vs. letting die

1\textsuperscript{st} edition, 1979

Beauchamp and Childress begin by acknowledging “For many people, it is important to distinguish killing and letting die and to prohibit the former while authorizing the latter—in some cases” \[1^{st} 106\]. But, “In recent years, the distinction between killing and letting die has come under frequent attack” \[1^{st} 106\]. After an extensive examination of Rachels’ \(1975\) arguments that “killing is not, in itself, worse than letting die” \[1^{st} 107\] and of contrary theological and philosophical arguments, Beauchamp and Childress conclude:

Probably no single reason by itself is sufficient to support the moral relevance of the distinction, and thus to prohibit killing while permitting some intentionally allowed deaths. But several reasons together indicate that the distinction is worth retaining ... \[1^{st} 109\]

4\textsuperscript{th} edition, 1994

Beauchamp and Childress find that “both ordinary discourse and legal concepts are as misleading as they are helpful” in understanding the moral distinctions between killing and letting die \[4^{th} 220\]. After an attempt to define these terms more sharply,

[They] conclude that the distinction between killing and letting die suffers from vagueness and confusion. It is conceptually impossible to classify many acts as instances of letting die without also classifying them as instances of killing. We have also seen that the language of killing is so confusing—causally, legally, and morally—that we should avoid it in discussions of euthanasia and assistance in dying. It is often morally and conceptually more satisfactory to discuss these issues exclusively in the language of optional and obligatory treatments, dispensing altogether with killing and letting die. \[4^{th} 225\] original emphasis

This leads them to the further conclusion that:

We need to know something about the actor’s motive (whether it is benevolent or malicious, for example), the patients’ request, and the consequences of the act. Only these additional factors will allow us to place the act on a moral map and allow us to make a normative judgment about it. All instances of killing and letting die, then, must satisfy independent criteria, such as the balance of benefits over burdens to the patient, to determine their acceptability. \[4^{th} 225\]

7\textsuperscript{th} edition, 2013

Beauchamp and Childress refine the arguments first presented in 4\textsuperscript{th} edition that the distinction between killing and letting die is morally irrelevant and that it is “The validity of the authorization—
not some independent assessment of causation—[which] determines the morality of the action [to limit life-sustaining treatment]” [7th 177].

In their analysis of the Limits of Casuistry [7th 402] Beauchamp and Childress use the case of an ALS patient who decided to discontinue ventilation (Kaufert & Koch, 2003) to demonstrate how the framing of a case—as an end-of-life decision vs a disability care issue—can change its moral diagnosis, i.e., “what is the case really about” (Arras, 1991, p. 37)? While this example is not specific to surrogate decision-making and the killing/letting die dichotomy, it reinforces the need to move toward certainty of the moral diagnosis before reaching any conclusions, particularly when making decisions to limit LST.

5.3.2.3 Withholding vs. withdrawing

1st edition, 1979

Beauchamp and Childress touch on this dichotomy only to dismiss it: “The moral grounds for withdrawing are the same as for withholding treatment” [1st 126]. Their justification for this assertion is that the “critical issue is not that of an act versus an omission” [1st 126].

3rd edition. 1989

Beauchamp and Childress cite Micetich et al. (1983) as showing that there is a psychological aspect to this question: many physicians and family members find the decision to stop a life-sustaining treatment far more difficult than to not start that treatment in the first place. This leads Beauchamp and Childress to ask: “does this psychological fact have moral significance, and should acts of withdrawing (stopping) be viewed as killing rather than letting die?” [3rd 149].

An essentially utilitarian argument had previously been advanced to answer this question:

Ironically, if there is any call to draw a moral distinction between withholding and withdrawing, it generally cuts the opposite way from the usual formulation: greater justification ought to be required to withhold than to withdraw treatment. Whether a particular treatment will have positive effects is often highly uncertain before the therapy has been tried. If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than mere surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable. (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983, p. 76)

Even though physicians may be reluctant to start a treatment because “stopping it appears to breach faithfulness and contractual obligations to the patient and family” [3rd 149], Beauchamp and Childress conclude “[patients’] wishes and interests may be violated if care-givers are afraid to
commence treatments on the grounds that it is somehow wrong to withdraw a treatment even when it has become clear that its continuation is unwarranted” [3rd 150].

Providing CPR is often seen as somehow different than other decisions to limit LST. However, there is no justification to be “found in the distinction between withholding and withdrawing treatments. The identical substantive and procedural standards should apply to CPR as to other life-sustaining treatments” [3rd 150].

5th edition, 2001

Beauchamp and Childress continue to acknowledge that “responsible health care may require proposing a trial with periodic reevaluation” [5th 122], i.e., not withholding a treatment whose burdens and benefits are uncertain and which may later need to be withdrawn. The justification for such a trial rests solely on its ability to reduce the physician’s and surrogate’s uncertainty.

Otherwise Beauchamp and Childress further strengthen the case against assigning any moral weight to the distinction between withholding and withdrawal of life-sustaining treatment:

We conclude that the distinction between withholding and withdrawing is morally untenable and can be morally dangerous. Decisions about beginning or ending treatment should be based on considerations of the patient’s rights and welfare and, therefore, on the benefits and burdens of the treatment, as judged by a patient or authorized surrogate. Moreover, if a caregiver makes decisions about treatment using this irrelevant distinction, or allows a surrogate (without efforts at dissuasion) to make such a decision, the caregiver is morally blameworthy for negative outcomes. [5th 122]

7th edition, 2013

Physicians continue to feel an ethical distinction between withholding and withdrawing, now in the context of deactivating already implanted cardiovascular implantable devices (CIEDs). Devices such as implantable cardioverter-defibrillators (ICDs), which operate only intermittently, are perceived as ethically different than CIEDs such as pacemakers, which operate continuously, because the latter’s deactivation may lead to immediate death, thereby “increasing the professional’s sense of causal and moral responsibility” [7th 161]. A consensus report by the American College of Cardiology, the American Geriatrics Society, the American Academy of Hospice and Palliative Medicine, the American Heart Association, the Hospice and Palliative Nurses Association, and the European Heart Rhythm Association concurred with Beauchamp and Childress’s earlier conclusions about a lack of moral distinction between withholding and withdrawal:

The right to refuse or request the withdrawal of a treatment is a personal right of the patient and does not depend on the characteristics of the particular treatment involved (i.e., CIEDs). Therefore, no treatment, including CIED therapies, has unique ethical or legal status. (Lampert et al., 2010, p. 1009)
Previously, although Beauchamp and Childress maintained that medically administered nutrition and hydration (MN&H) fell into the same category as other LSTs, they were equivocal, noting that their view “remains controversial” [6th 161]. In this edition, the equivocal passages have been deleted, and their claims now stand alone:

No morally relevant difference exists between the various life-sustaining technologies, and the right to refuse medical treatment for oneself or others is not contingent on the type of treatment. There is no reason to believe that MN&H is always an essential part of palliative care or that it necessarily constitutes a beneficial medical treatment. [7th 164]
5.3.3 Results: Theme 3. Family-physician interactions

Study #1 found that several of the decision factors important to surrogates concerned the relationship between the physicians and family, e.g.,

- the need for clear and frank prognosis from physicians;
- the need for trust in health care professionals by families; and
- a strong preference for decision-making to be shared between family and physician with the family having the ultimate authority.

Study #2 found considerable evidence of latent paternalism by physicians.

My analysis of the family-physician interaction across the seven editions of the *Principles* revealed corresponding ethical dimensions:

- the family’s decision-making role;
- the acceptability of passive paternalism; and
- the duties of veracity and fidelity in trust-building.

My detailed results are presented along these three ethical dimensions.

5.3.3.1 The family’s decision-making role

In one of the first papers to examine the nature and ethics of the patient-physician relationship in contemporary medicine, Veatch (1972) described four possible models:

i) The engineering model: the physician as applied scientist presenting “all the facts and let[ting] the patient make the choices” (p. 5);

ii) The priestly model: which “takes the locus of decision-making away from the patient and places it in the hands of the professional” (p. 6);

iii) The collegial model: in which “the physician and the patient ... see themselves as colleagues pursuing the common goal of eliminating the illness and preserving the health of the patient” (p. 7); and

iv) The contractual model: with “obligations and expected benefits limited in scope [applying] to both parties” (p.7).

Veatch notes that the priestly model, enshrining the ethical precept of “benefit and do no harm to the patient”, is the establishment view of the early 1970s. But he claims that only in the contractual model “can there be at true sharing of ethical authority and responsibility” and “a real sharing of decision-making in a way that there is realistic assurance that both patient and physician will retain their moral integrity” (Veatch, 1972, p. 7).
In 1979 Beauchamp and Childress assert “While Veatch’s ideal is admirable, it is unrealistic for much of medical practice” and claim that “the physician is thrust into a paternalistic role” [1st 162]. This view of the physician as the patient’s paternalist guardian informs the decision-making process they propose for incompetent patients:

The family’s role should be primary because of the presumed identity of interests with the patient, and intimate knowledge of his or her wishes and wants. Nevertheless, that role should not be final or ultimate, because families do not always know or seek the best interests of their members. In this unhappy event, the physician(s) should attempt to persuade the family to reach a different decision. Should their attempts fail, they should invoke institutional procedures established to resolve such conflicts, e.g., an ethics committee in the hospital, and, if appropriate, the courts. [1st 128]

By 1989 many jurisdictions in North America had passed statutes establishing the legal status of surrogate decision-making by families of adult patients. In her analysis of these statutes, Areen noted that there are few protections for patients whose “families decide on the basis of ignorance or in bad faith” (1987, p. 234). Beauchamp and Childress rely on these findings to reiterate that when making decisions for incompetent patients “the authority of the family should not be final or ultimate” [3rd 179]. They still assign a paternal guardianship role to the physician:

Physicians and other health-care professionals can and should help the family become adequate decision makers by imparting sufficient information and by imparting a proper climate for discussion. However, these health-care professionals remain moral agents with a responsibility to safeguard the patient’s interests and preferences (where known) by monitoring the quality of surrogate decision making. [3rd 180]

However, they have dropped their call for proactive paternalism present in 1st and 2nd editions that: “If families do not know or seek the best interests of their members, the physician(s) should attempt to persuade the family to reach a different decision” [2nd 141].

Events between the 3rd and 4th editions, 1990-1994

The Cruzan (1990) decision was handed down shortly after the publication of the 3rd edition. This case18 went directly to the issue of whether a family’s decision to limit LST should prevail, even

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18 Nancy Cruzan, after being severely injured in an automobile accident in 1983, was in a persistent vegetative state in a Missouri state hospital, with the state bearing the cost of her care. Her parents requested that artificial nutrition and hydration (ANH) be withdrawn, citing Cruzan’s earlier verbal expression to a housemate that she would not want to continue her life if she could not live “at least halfway normally” (Cruzan, p. 261). The hospital employees refused to honor the parents’ request without court approval. A state trial court authorized the termination of ANH. The Missouri State Supreme Court reversed that decision, on the grounds that “the State Living Will statute embodied a state policy strongly favoring the preservation of life, and that Cruzan’s statements to her housemate were unreliable for the purpose of determining her intent” (Cruzan, p. 261). Her parents appealed that decision to the U.S. Supreme Court.
if there was no explicit advance directive. The U.S. Supreme Court rejected the appeal on a variety of legal grounds, as well as:

- Requiring not only clear and convincing evidence of Cruzan’s “observations that she did not want to live life as a ‘vegetable’” (Cruzan, p. 263), but also that this evidence had to specifically address her intent to limit artificial hydration and nutrition; and
- Family relationships do not translate into a constitutional obligation for any State to abide by a family’s decision (Cruzan, p. 263).

In a separate concurring opinion, Justice O’Connor emphasized that the Court’s decision did not “preclude a future determination that the Constitution requires the States to implement the decisions of a duly appointed surrogate” (Cruzan, p. 292) and that “such a duty may well be constitutionally required to protect the patient’s liberty interest in refusing medical treatment” (Cruzan, p. 289). Her opinion was interpreted by many states to imply that formally appointed proxies with powers of attorney for health care may be constitutionally protected guardians of incompetent patients’ right to refuse unwanted treatment. By October 1991, 31 states had enacted laws enabling their citizens to establish durable powers of attorney for health care (Emanuel & Emanuel, 1992b).

In dissent, Justice Brennan, joined by Justices Marshall and Blackmun, argued that requiring a formal directive with explicit instructions about specific treatments “is unrealistic, and for all practical purposes, it precludes the right of patients to forgo life-sustaining treatment” (Cruzan, p. 324). In a separate dissent, Justice Stephens recognizing the limitations of courts and legislatures in making choices about life and death, concluded “It may be that the best we can do is to ensure that these choices are made by those who will care enough about the patient to investigate his or her interests with particularity and caution” (Cruzan, p. 354).

In direct reaction to Cruzan, Annas (1991) and Emanuel & Emanuel (1992b) argued for increased emphasis on appointing proxy decision-makers with durable powers of attorney, and decreased emphasis on advance directives and living wills, which had proved ineffective.

Other authors argued for the primacy of the family as decision-maker for incompetent patients, whether or not a health care proxy had been formally appointed. Rhoden (1988, 1990) not only proposed a “legal presumption in favor of the choice of a close family member”, but that this presumption should be so strong that “Physicians should either accept a proxy’s choice or else bear the burden of challenging the decision in court as being unreasonable” (1988, p. 437). King (one of
the Belmont Report commissioners) concurs that families should be the deciders because “By failing to allow families to decide when there is no ‘clear and convincing evidence’” (Cruzan, p. 261) of individual choices, we may deny rather than protect what many individuals would have chosen for themselves because of their relationships with their close-ones” (King, 1991, p. 77).

4th edition, 1994

In this edition, Beauchamp and Childress do not change the language describing the family’s role or physician’s role in decision-making for incompetent patients, except for one subtle deletion. All previous editions had stated:

> The family’s role should be presumptively primary because of expectable identification with the patient’s interests and intimate knowledge of his or her wishes. However, the authority of the family should not be final or ultimate. [3rd 179]

In the 4th edition, the second sentence becomes only a qualifying clause in a sentence about “demonstrably unsatisfactory” family members [4th 240]. Beauchamp and Childress also cite Rhoden’s and King’s papers about the absolute primacy of families’ decision-making authority in an adjacent footnote, but do not describe these proposals in the main text.

5th edition, 2001

Beauchamp and Childress add an explicit obligation for those health care professionals involved with a patient’s care to “seek to disqualify potential decision-makers because of their incompetence, ignorance, bad faith, or conflict of interest” [5th 156].

6th edition, 2009

Beauchamp and Childress, citing Kim & Kjervik (2005), claim that “there is evidence that many patients strongly prefer family members in interaction with physicians as the decision-making authorities” [6th 188], adding this as further support for the primacy of family decision-making.

Following Weissman (2004) Beauchamp and Childress propose that physicians also have an obligation to:

> serve both the family and the patient by helping surrogates see that rapid functional decline has set in and the time has come to shift from life-prolonging measures to palliative care centered on increased comfort and reduction of the burdens of treatments. [6th 189]

7th edition, 2013

Beauchamp and Childress cite the emotional burdens experienced by surrogates as imposing an obligation on health care professionals to “recognize and help address the burdens of decision-making on familial and other surrogates” [7th 191].
5.3.3.2 The acceptability of passive paternalism

In 1987, Blackhall initiated a broad debate about medical futility and passive paternalism by suggesting that in cases “where CPR has no potential benefit ... it is not the physician’s responsibility to offer CPR” (Blackhall, 1987, p. 1285). The question of “under what circumstances can life-sustaining interventions be limited without the informed consent of the family?” (Youngner, 1988, p. 2094 original emphasis) was the subject of four articles in the same issue of JAMA (Murphy, 1988; Schiedermayer, 1988; Taffet, Teasdale, & Luchi, 1988; Youngner, 1988).

By 1990 two distinct positions were being advanced. One claimed that if “in the last 100 cases a medical treatment has been useless ... physicians can judge a treatment to be futile and are entitled to withhold a procedure on this basis [and] need not obtain consent from patients or family members” (Schneiderman, Jecker, & Jonsen, 1990, p. 949). The other perspective recognized that “In medicine, it is difficult to predict with complete certainty that a treatment will provide no benefit to a particular patient” and claimed that “patient preferences about the goals of therapy are an essential component of the clinical determination of futility” (Lantos et al., 1989, p. 83).

4th edition, 1994

Beauchamp and Childress introduce the concept of medical futility and passive paternalism in this edition [4th 288ff]. They describe how goals can differ between physicians and patients or families. For example, the physician’s goal may be survival to discharge, while the patient’s goal may be just to survive for another day until a loved one arrives [4th 289]. They acknowledge that their position is influenced by Truog et al. “... the problem with futility is that its promise of objectivity can rarely be fulfilled” (1992, p. 1563) and thus the physician cannot act without the involvement of the patient or family. However, Beauchamp and Childress temper this position by following Youngner (1990) in asserting that passive paternalism may be justified because “It may be misleading and may diminish autonomy to provide information about a useless procedure” [4th 290].

6th edition, 2009

Reflecting the “fall of the futility movement” (Helft, Siegler, & Lantos, 2000, p. 293), Beauchamp and Childress removed much of the previous edition’s section on futility [5th 192-4]. They argue that “it is not clear that the language of futility illuminates the range of relevant ethical issues in passive paternalism, in part because of its variable and vague uses”, that the term “futility” should be replaced by “clinically nonbeneficial interventions”, and that in these situations, “physicians'
decisions often involve balancing the probable benefits and burdens to patients, a judgment that goes beyond judgments of medical futility” [6th 220].

5.3.3.3 The duties of veracity and fidelity in trust-building

Reasoning from intuition, Ross defined fidelity as “the disposition to fulfill promises and implicit promises because we have made them” (1930, p. 22 original emphasis), and placed the duty of fidelity first among his list of prima facie duties.

In his introduction to the 1969 Beecher Lectures, Ramsey identified the fundamental moral nature of covenants of loyalty “between physicians and patients”, “between the living and the dying”, “between the well and the ill”. He then places the “the Biblical norm of fidelity to covenant” (2002, p. xlv original emphasis) at the center of his framework for medical ethics.

1st edition, 1979

Beauchamp and Childress position trust as a direct consequence of a deontological duty of veracity: “At the core of such [trust] relationships is confidence in and reliance upon others to respect the principle of veracity” [1st 203]. In this edition, Beauchamp and Childress treat veracity as an “expression of the duty of fidelity” [1st 203]; they do not consider fidelity to be a separate complement to trust.

2nd edition, 1983

Beauchamp and Childress introduce a separate section on the “Rules of Fidelity”, and follow Ross and Ramsey in recognizing that the act of promise-making is not morally neutral: “In making promises, people make morally neutral acts obligatory; they impose obligations on themselves by creating expectations in others. Promising thus changes the structure of rights and obligations” [2nd 238]. They then claim that both fidelity and veracity are necessary for trust: “In both speech and promising there is an invitation to the other to trust, to make himself vulnerable; the liar and the promise-breaker then abuse that trust” (Fried, 1981, p. 16 cited at [2nd 238]).
Beauchamp and Childress use *Truman v. Thomas* (1980)\(^{19}\) to expand the duty of veracity “to any truthful and honest management of information that stands to affect a patient’s understanding or decision-making. It is not limited to situations in which informed consent is sought” [3rd 310].

In Study #1, I found that trust in physicians was a major determinant of surrogates’ ability to move forward with making decisions. Beauchamp and Childress likewise acknowledge the importance of trust—"the confident belief in and reliance upon the ability and moral character of another person” [4th 469]—especially in health care. However, in the modern health care system, trust has been eroded by “the loss of intimate contact between physicians and patients, the increased use of specialists, high charges for health care, conflicts of interest in referrals and investments in clinical centers, and the growth of large, impersonal, and bureaucratic medical institutions” [4th 470]. Thus, in settings such as an ICU, they concur with Veatch (1985) in suggesting that “when strangers interact in health care, character will generally play a less significant role than principles and rules that are backed by sanctions” [4th 470].

Beauchamp and Childress describe the empirical studies of Korean- and Mexican-Americans (Blackhall, Murphy, Frank, Michel, & Azen, 1995) and of Navajos (Carrese & Rhodes, 1995) which report that people in these cultures avoid making or even becoming aware of the need to make major medical decisions. Beauchamp and Childress note these findings are often interpreted as opposing the principle of respect for autonomy. But, as they emphasize, “Autonomous choice is a *right*, not a *duty* of patients” [5th 63 original emphasis]. Thus, the health care professional has a practical responsibility “to inform patients or their families of their right to know and to decide without compromising [or disrespecting] their systems of belief and value” [5th 63].

Beauchamp and Childress also make a subtle change in the title of a subsection in a larger section describing the duty of veracity. In the 4th edition the title is “Limited Disclosure and Deception” [4th 398], and the text describes situations in which limited disclosure or deception may not be morally justifiable.

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\(^{19}\) The California Supreme Court found that “a physician’s failure to inform a patient of the material risks of not consenting to a recommended Pap smear, so that the patient might make an informed choice, ... breached the physician’s duty of due care to his patient, who died from cancer of the cervix” (Truman v. Thomas, 1980, p. 288).
be justifiable. In this edition, the title is “Disclosing Bad News to Patients” [5th 285] and incorporates recent work on the concept of staged-disclosure (Christakis, 1999; Girgis & Sanson-Fisher, 1998; Ptacek & Eberhardt, 1996) as an ethically preferable alternative to benevolent deception.

7th edition, 2013

Beauchamp and Childress temper the duty of veracity with “the therapeutic value of hope for patients, along with the virtues of compassion, gentleness, and sensitivity, which are often morally more important than comprehensive disclosures” [7th 306]. They also warn against relying too heavily on the family’s judgment that a patient would not want to receive bad news, although doing so “need not fail to respect individual autonomy, particularly if the patient authorizes the clinician’s independent disclosure to the family” [7th 305].
5.3.4 Results: Theme 4. Role of virtue ethics in bioethics

In the middle of the 20th century “normative ethics was dominated by just two theories: deontology and utilitarianism. ... Virtue ethics was regarded not as a third approach in its own right, but as emphasizing a few points ... that deontologists and utilitarians could usefully incorporate into their approaches” (Hursthouse, 1999, pp. 1–2). This was the state of moral philosophy when Beauchamp and Childress started writing *Principles*. Indeed, they began by acknowledging that one of them was a utilitarian and the other a deontologist [1st 40].

1st edition, 1979

Beauchamp and Childress address the issue of virtues and character, but only as a subsection in the last chapter; on the other hand, all of Chapter 2 is devoted to deontology and utilitarianism. While acknowledging that “several contemporary philosophers” position virtue ethics as an alternative to utilitarian and deontological theories, they deny its equivalence:

*We do not agree with those (a) who try to drive a wedge between an ethics of duty and an ethics of virtue or between acts and agents, or (b) who try to make the ethics of virtue primary. Especially troubling is the view that if persons, such as health care professionals or researchers have good motives and are virtuous, their acts will be acceptable [1st 234]*

However, they accept an instrumental role for what MacIntyre (1967) termed the secondary virtues, such as sincerity and conscientiousness: “These secondary virtues concern *how* we act, while primary virtues concern *what* is done” [1st 243 original emphasis].

Events between 1st and 2nd editions, 1979-1984

Three influential books on virtue ethics were published in this interval: MacIntyre (1981) *After virtue*, Hauerwas (1981) *A community of character: Toward a constructive Christian social ethic*, and Pence (1980) *Ethical options in medicine*. All three of these are cited by Beauchamp and Childress, who characterize the first two as, respectively, an “influential defense of the Aristotelian perspective” and a “strong statement of the primacy of character in Christian ethics” [2nd 278].

2nd edition, 1984

Rather than being dismissive of virtue ethics as they were in 1st edition, Beauchamp and Childress acknowledge that “This position [a character needing no external rules to justify right conduct] is attractive in many respects” [2nd 262]. They cite Kass who criticized “the attempt to replace the often inarticulate yet prudent judgments of discerning physicians with explicit rules or procedures will not lead to better decisions” (Kass, 1980, p. 1811 at [2nd 263]). They also cite Pence who argued that “almost any experimenter can get around any informed consent document if he
really so desires” and therefore there is a necessity to inculcate the “right kind of desires” (Pence, 1980, p. 177 at [2nd 264]).

Nonetheless, they still conclude, “In short, none of the above arguments—or any others known to us—succeed in making judgments about persons independent of judgments about acts or in making virtue primary or sufficient for the moral life” [2nd 265]. They also assert an asymmetric complementarity between rules and virtues: “for every principle, rule, or ideal, there is a corresponding virtue” but “it may not be possible to say that for every moral virtue, there is a corresponding moral principle, rule, or ideal” [2nd 265].

3rd edition, 1989

Beauchamp and Childress begin to find that character, i.e., virtue ethics, may be necessary in their discussion of the nonmaleficence principle, noting that in cases involving the principle (or rule) of double effect:

[the] facts about the physician’s motivation and perhaps character may make a decisive moral difference. But the principle of double effect seems unable to reach this conclusion on its own. In effect, the principle has been transformed into another moral framework about motivation and character. [3rd 133]

In their conclusion to the section on virtues in chapter 8, Beauchamp and Childress now claim that

[They] have argued that there is an important and complementary role for the virtues in the moral life and also in ethical theory. ... Virtue theorists rightly point out that a virtuous person can often more readily discern what is right than can a mere rule follower. Virtues and character may therefore play a significant role in deliberation about a course of action.

... Rights and obligations simply do not always suffice to determine appropriate conduct. [3rd 385]

4th edition, 1994

In this edition’s Chapter 2 “Types of Ethical Theory”, Beauchamp and Childress expand the list of analyzed ethical theories from utilitarianism and Kantianism to virtue ethics, as well as liberal individualism, communitarianism, ethics of care, casuistry, and principle-based theories. After analyzing each theory according to eight criteria [4th 45-48], they then evaluate each theory both critically and constructively.
In their critical evaluation of virtue ethics, they conclude that “Virtue is not enough. ... In many circumstances, principles and rules are essential to guide conduct” [4th 68-9]. However, their constructive evaluation accepts that virtue ethics has a complementary role and may in some cases be more salient to moral action than principles:

When the feelings, concerns, and attitudes of others are the morally relevant matters, rules and principles are not as likely as human warmth and sensitivity to lead us to notice what should be done. Even a seldom noticed virtue, such as cheerfulness or tactfulness, can be far more significant than standard rules in some contexts. Furthermore, forms of loyalty, reliability, and commitment to other persons can, across time, be more integral to an adequate or full moral life than following principles or rules.

To look at acts without also looking at the moral appropriateness and desirability of feelings, attitudes, forms of sympathy, and the like is to miss a large area of the moral picture. We do not merely expect persons to act in certain ways. We also expect them to have certain emotions, certain forms of responsiveness, and a trustworthy character. Character ethics helps us introduce this subtlety in moral theory [4th 69]

These arguments are reiterated at the beginning [4th 462] of chapter 8, now titled “Virtues and Ideals in Professional Life” instead of “Ideals, Virtues, and Conscientiousness” as in the 2nd and 3rd editions.

Beauchamp and Childress follow MacIntyre (1981) and Emmet (1966) in asserting that “Each organized body of professional practices ... requires professionals to cultivate certain virtues ... [which dispose] a person to act in accordance with the objectives of the practices” [4th 463]. They then introduce the following four “focal” virtues which they claim “are widely acknowledged in biomedical ethics and ... help us focus on the character of health professionals” [4th 466]:

i) Compassion: “a trait combining an attitude of active regard for another's welfare with an imaginative awareness and emotional response of deep sympathy, tenderness, and discomfort at the other person's (or animal's) misfortune or suffering” [4th 466];

ii) Discernment: “the ability to make judgments and reach decisions without being unduly influenced by extraneous considerations, fears, or personal attachments” [4th 468]. This virtue, closely associated to the classical cardinal virtue of phronesis, enables its possessor “to identify what a circumstance calls for in the way of human responsiveness” [4th 468];

iii) Trustworthiness: “a confident belief in and reliance upon the ability and moral character of another person” [4th 469]; and

iv) Moral integrity: “in its most general sense ... soundness, reliability, wholeness, and integration of moral character. In a more restricted sense, and the one primarily [used by Beauchamp and Childress] ... fidelity in adherence to moral norms” [4th 471].
5th edition, 2001

In this edition Beauchamp and Childress restructure the sequence and titles of the chapters: the discussion of virtues and ideals—previously in the last chapter—is now Chapter 2 “Moral Character”. Before they introduce the four principles in Chapter 1 “Moral Norms”, they make it clear that these two chapters are of equal importance: “good moral choices often depend more on character than principles” [5th 14]. They begin the second chapter by claiming that “Often, what counts most in the moral life is not consistent adherence to principles and rules, but reliable character, good moral sense, and emotional responsiveness” [5th 26].

However, their acceptance of virtue ethics is not unequivocal:

... in contrast to radical forms of character ethics, we do not hold that the merit in an action resides in motive or character alone. The action must be appropriately gauged to bring about the desired results and must conform with relevant principles and rules. [5th 30]

Beauchamp and Childress add conscientiousness as a fifth focal virtue to the four introduced in 4th edition, i.e., compassion, discernment, trustworthiness, and moral integrity, now plus conscientiousness. They claim a person acts conscientiously “if he or she is motivated to do what is right because it is right, has tried with due diligence to determine what is right, intends to do what is right, and exerts an appropriate level of effort to do so” [5th 37].

6th edition, 2009

In their description of common morality, which Beauchamp and Childress have come to rely on as a theoretical foundation for principlism [6th 387-388], they note that it contains both standards of action (e.g., do not kill, do not steal) and standards of character (e.g., honesty, fidelity) [6th 3].

Beauchamp and Childress accept that “in irresolvable and tragic dilemmas, the virtues help direct agents to appropriate responses, including appropriate attitudes and emotions” [6th 47]. However, they immediately qualify this claim, stating that “this theory does not prove some sort of triumph of virtues over principles and rules of obligation. Rather, it shows their close connection” [6th 47].
At the beginning of their chapter on Moral Character, Beauchamp and Childress restate their claim that principles and virtues are equally necessary to ethical analysis, especially in health care:

Although principles and virtues are different and taught differently, virtues are no less important in the moral life. Indeed, the Aristotelian virtues are "valuable in large part because they are immunities from common forms of distortion in practical reasoning, arising from characteristically human desires, emotions, or feelings" (Brewer, 2009, p. 209). Moreover, the goals and structure of medicine, health care, public health, and research call for a deep appreciation of moral virtues. [7th 31]
5.3.5 Results: Theme 5. Bounded rationality and bioethics

Simon (1955, 1956, 1957) introduced the concept of bounded rationality 20 years before the Belmont Report and the 1st edition of Principles, and revisited the subject seven years before their publication (Simon, 1972). These works, and those of other authors on this topic, were primarily in the economics, psychology, decision, and organization theory literatures. I have no evidence that either Beauchamp or Childress were aware of these works or of the concept of bounded rationality prior to 2009. However, there is evidence that they were aware of human’s cognitive limitations in decision-making and that they attempted to mitigate these limitations when proposing bioethical norms.

1st edition, 1979

In their examination of utilitarianism, Beauchamp and Childress acknowledge humans’ cognitive limitations when making utilitarian calculations: “While we must always attempt to make accurate measurements of the preferences of others, this seldom can be done because of our limited knowledge and time. Often in everyday affairs we must act on severely limited knowledge of the consequences of our actions’ [1st 26].

In their analysis of patients’ comprehension of information prior to giving consent, Beauchamp and Childress touch on cognitive limitations—"comprehension is both limited and difficult" [1st 76]—but do not proffer any guidance on how to solve the problem other than to “strive harder … to foster information and to avoid undue influence” [1st 76].

Events between 1st and 3rd editions, 1979-1989

Kahneman and Tversky’s (1984; 1981) findings on perceptions of risk and framing effects became increasingly well-known outside of the economics literature where they had originally been published (1979).

3rd edition, 1989

Beauchamp and Childress claim that some theories of autonomy (e.g., G. Dworkin, 1988; Frankfurt, 1971) require such rigorous standards of understanding that few choices could be termed truly autonomous, thereby rendering the principle of respect for autonomy meaningless. They step around this objection by introducing the concept of “normal choosers”, whose levels of understanding fall on “a broad continuum from fully present to wholly absent”, and require “not full or even nearly full understanding” for an action to be considered autonomous [3rd 69]. This
flexibility allows “thresholds marking substantially autonomous decisions [to] be carefully reasoned in light of specific goals” [3rd 69].

Beauchamp and Childress explicitly raise the issue of cognitive limitations in their discussion of consent: “there are significant constraints on the amount of information that can be meaningfully processed and retained by patients” [3rd 102]. They discuss issues such as framing effects (e.g., Tversky & Kahneman, 1981), inadequate time to reflect, and inappropriate disclosure of alternatives. However, they conclude that “health care professionals frequently do not address these needs” [3rd 103].

6th edition, 2009

In their discussion of paternalism, Beauchamp and Childress use the term “bounded rationality” for first time, citing Jolls, Sunstein and Thaler (1998) [6th 211]. However, this part of the discussion is limited to whether overcoming cognitive limitations by manipulating choice architectures (Camilleri & Larrick, 2015) constitutes hard or soft paternalism. Beauchamp and Childress do not expand their general discussion of autonomy or surrogate decision-making to include considerations of bounded rationality.

7th edition, 2013

Beauchamp and Childress cite studies that show decision aids may assist in overcoming cognitive limitations faced by patients:

use of these decision aids correlates with patients' increased knowledge and more active participation in decision making. Other benefits include a reduction in patients' decisional conflict based on inadequate information or unclarity about their personal values and preferences and fewer decisions for elective procedures. [7th 135]

They also report [7th 135] an interesting side-effect of overcoming cognitive limitations—people may choose differently than medical professionals think appropriate. In one trial of a decision aid among adults with low education, consent to a colon cancer screening was reduced (59% vs. 71%, P= .001), even though informed choice was increased and decisional conflict decreased (S. K. Smith et al., 2010), leading to calls for a paternalistic intervention that the decision aid should “encourage adherence to recommendations” (Bekker, 2010).
5.4 Discussion

The immediate objective of this study was to investigate *How has bioethical thought about surrogate decision-making evolved over the past 40 years?* However, this specific question was situated within my overall research question: *What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?* In particular, my analysis in this study is focused on the ethical deficiencies of the current paradigm.

5.4.1 Discussion: Theme 1. Normative basis for surrogate decision-making

Significant evolution in bioethical thought regarding the normative basis for surrogate decision-making has occurred over the past 35 years—starting in 1979 from purely harm protection, and evolving by 2013 to reliance on either the patient’s previously-expressed directives or the patient’s best interests.

- In the 1st edition of *Principles of Biomedical Ethics*, the norm for surrogates was seen quite simply as a “moral demand that patients be protected from harm” [1st 66] because an incompetent patient could not consent.
- The 2nd edition recognized the possibility of the patient’s autonomy being expressed by substituted judgment but discounted its practicality, recommending reliance “perhaps exclusively, on the nonmaleficence-based, best-interests standard [2nd 141] which in turn should be based on “highly tangible factors” [2nd 138].
- The 3rd and 4th editions both had extensive discussions of the standards set forth in *Conroy* (1985).
- By the 5th edition, two mutually exclusive standards had been proposed: Pure Autonomy if there is a “reasonable base of inference” [5th 103] for the patient’s preferences; otherwise Best Interests defined in terms of maximizing the patient’s quality of life including not just pain and suffering but also long-term functioning [5th 102].
- By the 7th edition, the language disparaging substituted judgment as a “fiction” [2nd 138, 6th 136] had been removed. Also, the dichotomy between the standards had been recast as

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20 This discussion makes extensive reference to the various editions of Beauchamp and Childress *Principles of Biomedical Ethics*. In the interests of conciseness and clarity, I cite these references as [edition page], e.g., [5th 241], rather than the standard APA style of (Beauchamp & Childress, 2001, p. 241), which is redundant, long, and leaves out the critical edition number. I continue to use the standard APA citation style for works other than the various editions of *Principles*. 

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tension between paternalism and respect for autonomy [7th 226] rather than between nonmaleficence and respect for autonomy as it had in all prior editions.

Nonetheless, the 7th edition still accepted that “the best interests standard can in some circumstances validly override” the pure autonomy standard [7th 229], i.e., protection from harm still remains the fundamental norm.

Although this evolution now establishes a clear demarcation as to when pure autonomy should be the criterion and when best interests should prevail, some questions have not been adequately resolved, especially about what best interests really means.

At least three authors have proposed that humans have two distinct levels of interests or desires: Frankfurt’s (1971) first-order desires and second-order volitions, Feinberg’s (1977) welfare and ulterior interests, and Dworkin’s (1993) experiential and critical interests. These authors all claim that it is from the combination of these second-level interests that each human’s singular personhood emerges. This raises the question of whether physicians and surrogates should give greater weight to a patient’s known or inferable second-order interests when assessing that patient’s best interests.

Appelbaum, as early as 1983, recognized the inherent link between best interests and substituted judgment (Gutheil & Appelbaum, 1983). He returned to the subject in 2001 with different co-authors:

The difficulty with the best interests standard is not in the statement of it but in giving content to it. The substituted judgment approach is, in fact, one way of doing so. That is, a surrogate who makes a decision for an incompetent patient on the basis of that patient’s instructions—written or oral, express or implied—is seeking to implement the patient’s best interests as that patient would have defined them. (Berg et al., 2001, p. 115 original italics)

Although written for a pediatric context, Diekema’s analysis of best interests is also relevant to surrogate decision-making for adults. First, “the notion of ‘best interest’ is inherently a question of values” (Diekema, 2004, p. 246). Second, “best interests all too frequently may be reduced to objective medical interests alone” (Diekema, 2004, p. 247). Finally:

it is not clear that the best interest of the child should always be the sole or primary consideration in treatment decisions. There are few situations in which society actually requires parents to always act in a way that is optimal for their children. In seeking to optimize family welfare, parental decisions may commonly subjugate the interests of individual children, and while the state can certainly intervene when parents endanger their children, it is not justified in intervening simply because parental decisions may compromise the interests of a child in favor of those of the family. (Diekema, 2004, p. 248)
Beauchamp and Childress, however, continue to insist that, unless the patient explicitly states otherwise, “it is not proper to impute altruism or any other motive to that patient against his or her medical best interests” [7th 171 emphasis added]. Setting the best interests threshold higher for adult patients than for pediatric patients raises the question, “does bioethics value an adult’s life more highly than a child’s?”

Best interests as used in bioethical discourse appears to have two distinct interpretations. The first—medical best interests—is very much associated with survival in the short run balanced against short run pain and suffering. It is concerned only with the patient’s welfare or experiential interests. The second interpretation—call it individual best interests—is concerned with the patient’s ulterior or critical interests and with values beyond mere corporeal survival. Unfortunately, Beauchamp and Childress and many other authors writing on this topic often conflate these two interpretations, leading to a lack of clarity in whether it is the physician or the surrogate who should determine “best” for a particular patient.

5.4.2 Discussion: Theme 2. Limiting life-sustaining treatment

5.4.2.1 Extraordinary vs extraordinary treatment

In the late 1970s, two justifications were accepted for limiting life-sustaining treatment: the Rule of Double Effect, and a distinction between ordinary and extraordinary treatment. The latter was perceived as being flawed by several ethicists (Beauchamp & Childress, 1979; McCormick, 1974; Ramsey, 1977). Beauchamp and Childress proposed the obligatory/optional dichotomy as an alternative to ordinary/extraordinary, changing the judgment to one framed in terms of the patient’s welfare instead of one framed in terms of the historical vagaries of medical practice.

By the 4th edition, the justification for limitation had been simplified to “the actor's motive, the patients' request, and ... the balance of benefits over burdens to the patient” [4th 225]. This language has not changed thereafter [7th 177].

- The Rule of Double Effect continues to be one of the justifications—the decision-maker’s intent is critical. The durability of this rule—first formulated by St. Thomas Aquinas in the 13th century (Mangan, S.J., 1949)—and its deep connection to the decision-maker’s character are remarkable when considered in light of my findings about the salience of virtue ethics to medical decision-making.
• Knowledge of the patient’s desires means that there cannot be general rules about limiting or not limiting certain treatments. The limitation decision has to stem from the individual patient.

• How to judge the balance between burdens and benefits was controversial in 1979 and remains so in 2013: “These judgments require defensible criteria ... that avoid reducing quality-of-life judgments to arbitrary personal preferences or to the patient’s social worth” [7th 171]. No such generally defensible criteria appear to have yet been established.

The language of advance directives was originally couched in terms of the ordinary/extraordinary treatment distinction, e.g.,

TO MY FAMILY, TO MY PHYSICIAN --
Should the occasion arise in my lifetime when death is imminent and a decision is to be made about the nature and the extent of the care to be given to me and I am not able at that time to express my desires, let this statement serve to express my deep, sincere and considered wish and hope that my physician will administer to me, simple, ordinary medical treatment. I ask that he not administer heroic, extraordinary, expensive or useless medical care or treatment which in the final analysis will merely delay, not change, the ultimate outcome of my terminal condition. (Example directive proposed by Judicial Council of the AMA, 1973, p. 138, emphasis added)

While some contemporary advance directive forms still couch the instructions in terms of what treatments one wants or does not want, others express the decision in goal-oriented terms equivalent to the latest ethics guidance:

END-OF-LIFE DECISIONS: I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below: (Initial only one box)
[ ] (a) Choice NOT To Prolong Life
I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits,
OR
[ ] (b) Choice To Prolong Life
I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort should be provided at all times even if it hastens my death:
_____________________________ (Caring Info, 2017)

5.4.2.2 Killing vs. letting die

Originally this distinction was understood to be crucial to the justification of a decision to limit treatment. By 1994 the distinction between these terms was found to be too vague and morally confusing to be useful in ethical discourse [4th 225]. Even though these terms continue to be used to denote non-justifiable and justifiable treatment limitation decisions, especially in ordinary language
used by physicians and laypersons alike, it is the distinction between obligatory and optional treatments that is critical [7th 177].

5.4.2.3 Withholding vs. withdrawing

The ethical discomfort felt by both professionals and families when stopping treatment as opposed to never starting treatment was first described in the literature during the late 1970s (e.g., Baer, 1978). The President’s Commission (1983) concluded the decision not to start carried a greater moral burden than the decision to stop, contrary to the disposition of both physicians and families. By 1994, Beauchamp and Childress were able to unequivocally assert “the distinction between withholding and withdrawing is morally untenable and can be morally dangerous” [4th 198], an assertion they continue to make [7th 161]. But 60% of physicians continue to feel that stopping a device that is continually providing LST is ethically more fraught than choosing not to start such an intervention (Mueller, Jenkins, Bramstedt, & Hayes, 2008). This psychological concern and the intuition of many surrogates leads some ethicists to continue to question the ethical equivalence of withholding versus withdrawing (Glick & Jotkowitz, 2019; Ursin, 2019), while others continue to defend this equivalence theory against an irrational “withdrawal aversion” (Wilkinson et al., 2019).

However, as Hofmann argues, while equivalence theory is theoretically sound, “it may rarely apply in practice, and thus be less relevant than assumed in guidelines” (2019, p. 30). As the President’s Commission identified in 1983, there is an “epistemic asymmetry” (Hofmann, 2019, p. 30) between the decision to withhold and the decision to withdraw, an asymmetry that has moral valence in the decision-making process for each individual patient.

In clinical practice there is rarely a singular withholding/withdrawal decision that decides the fate of each patient; Morgan et al. found that, for 30% of the patients who died in the medical ICU of a large academic hospital, there was a practice of “no escalation of care ... the sequential withholding or withdrawing of life-sustaining interventions while often continuing others” (2014, p. 359). Relying on such a no-escalation-of-treatment strategy when the goals of care transition from cure to comfort is still controversial (Curtis & Rubenfeld, 2014; D. R. Thompson, 2014). No-escalation-of-treatment and time-limited trials (Quill & Holloway, 2011) are two recent examples of how clinicians are now seeking to navigate the ethical, psychological, and emotional challenges of withholding/withdrawing decisions.
5.4.3 Discussion: Theme 3. Family-physician interactions

5.4.3.1 The family’s decision-making role

Beauchamp and Childress have remained consistent in asserting that “the family’s role should be primary” [1st 128 and 7th 190]. However, they have moved away from requiring active paternalism by the physician “to persuade the family to reach a different decision” [2nd 141] if the physician does not believe the family is seeking the best interests of the patient. Now, they identify four aspects to the physicians’ role:

i) citing the emotional burdens placed on surrogates (Wendler & Rid, 2011), the physician “should recognize and help address the burdens of decision-making” [7th 191];

ii) “help the family become more adequate decision-makers” [7th 191];

iii) “safeguard the patient’s interests and preferences, where known, by monitoring the quality of surrogate decision-making” [7th 191]; and

iv) “helping surrogates see ... the time has come to shift from life-prolonging measures to palliative care” [7th 191].

Remarkable by their absence are any references to the shared decision-making literature that proliferated during the 1990s and 2000s (e.g., Brock, 1991; Charles, Gafni, & Whelan, 1997; Elwyn, Edwards, Gwyn, & Grol, 1999; Emanuel & Emanuel, 1992a; Veatch, 2009). In the particular context of surrogate decision-making in ICU, shared decision-making has gone from being proposed as the most appropriate model by an international consensus conference in 2003 (Carlet et al., 2004; B. T. Thompson et al., 2004) to being promulgated as their formal policy by the American College of Critical Care Medicine and the American Thoracic Society in 2016 (Kon et al., 2016a; Kon, Davidson, Morrison, Danis, & White, 2016b).

Also remarkable is Beauchamp and Childress’ lack of follow up to Brennan’s prescient 1990 dissent about advance directives in *Cruzan*: requiring formal directives “is unrealistic and ... precludes the rights of patients to forego life-sustaining treatment” (Cruzan, 1990, p. 324). Extensive empirical work, notably by Shapiro (2007, 2012, 2015) and Kaufman (2005) as well as papers in ethics journals (e.g., Fagerlin & Schneider, 2004) have shown that advance directives do not work either practically or theoretically. Given the legal and procedural reliance placed on advance directives, this gap threatens the principles of both respect for autonomy and nonmaleficence in decision-making for incompetent patients.
5.4.3.2 The acceptability of passive paternalism

The position ultimately advocated by Beauchamp and Childress is that a physician is still obligated to offer an intervention to the patient or surrogate even if it has a very low probability of physiological benefit given the patient’s current circumstances. In other words, medical futility does not give the physician a license to act as a passive paternalist. Even Schneiderman, who originally argued that physicians were entitled to withhold quantitatively futile procedures without the patient’s or family’s consent (1990), now concurs that a change in therapeutic goals occasioned by the physiological futility of further treatment “requires intensive communication between physician, patient, and patient’s family” (2013, p. 178).

While the ethicists appear to agree that passive paternalism is unacceptable, not all current-day physicians agree (the following papers are all either authored by physicians or have clinicians as subjects):

- In Study #2, I found physicians relying on paternalistic reasoning to justify an unwarranted degree of prognostic certainty, especially about the certainty of death (Schuster et al., 2012).
- Roeland et al. (2014) modify Kon’s (2010) shared decision-making continuum so that the poles are “Patient direct autonomy” and “Clinician directed paternalism” and propose that, to the extent the patient or family displays what they term “maladaptive coping”, the physician should adopt a more and more directive approach. However, they do not go so far as to suggest the physician withhold information about options.
- Long and Shuman go further, claiming that “physicians are not compelled to recommend anything they do not believe confers medical benefit or is not relevant to the decision at hand” (2016, p. 8).
- Bailoor et al. (2018) examined this question empirically, surveying 169 clinicians (faculty, residents, fellows, nurses, nurse practitioners, and physician assistants) who treat patients with intracerebral hemorrhage or neurological critical care in a single academic center. They report that 30.2% of the clinicians considered “protective paternalism” to be acceptable. Only 11.4% of a self-selected sample of non-clinicians (N=649) considered protective paternalism to be acceptable.

This evidence seems to imply that a substantial fraction of clinical practitioners takes a more pragmatic position on passive paternalism than is endorsed by the bioethics literature.
Beauchamp and Childress also take note of “libertarian paternalism” (Sunstein & Thaler, 2003), which supposedly relies on nudging to “shape and steer persons without thwarting their free choice” [6th 212]. Beauchamp and Childress recommend caution in its application to macro-scale issues such as health-related public policy. However, they do not examine its micro-scale effect or ethical consequences. There is little question that choice architecture—defaults, framing, and information structuring—all affect individual decision-making (Camilleri & Larrick, 2015). To my knowledge, there is no literature that addresses how choice architecture impacts surrogate decision-making in ICU.

5.4.3.3 The duties of veracity and fidelity in trust-building

To begin with Beauchamp and Childress accept that “Nondisclosure, deception, and even lying can sometimes be justified when veracity conflicts with other duties” [1st 204] such as beneficence, especially when breaking bad news to patients and families. By 2001, the development of the staged-disclosure process (Girgis & Sanson-Fisher, 1998) makes outright deception or non-disclosure much less ethically justifiable. But by 2013, Beauchamp and Childress offer several explicit justifications to sidestep the duty of veracity: “the therapeutic value of hope ... the virtues of compassion, gentleness and sensitivity” [7th 306].

In practice it appears that strict adherence to a duty of veracity is not the norm: “Doctors frequently censor information they give to patients about outlook on the grounds that what someone does not know cannot harm them” (Fallowfield & Jenkins, 2004, p. 313). However, a recent review article acknowledges that withholding information risks patient trust, and places the responsibility squarely on the physician: “Balancing hope with honesty is one of the most important skills of the art of medicine” (Sarafis, Tsounis, Malliarou, & Lahana, 2013, p. 134).

5.4.4 Discussion: Theme 4 - The role of virtue ethics in bioethics

The role of character in Beauchamp and Childress *Principles of Biomedical Ethics* evolved most dramatically between the 1st edition in 1979 and the 4th edition in 1994; changes thereafter were directed more at consolidating the place of character in bioethics.

In the 1st edition, only secondary virtues such as sincerity and conscientiousness—that “concern how we act” [1st 243 original emphasis]—were seen as instrumentally useful. However, by the 4th edition four “focal” virtues—compassion, discernment, trustworthiness, and moral integrity—had been identified as “widely acknowledged in biomedical ethics” [4th 466]. A fifth focal virtue—
compassion—was added in 5th edition. Also in the 5th edition, the discussion of virtue ethics was moved from the last to the second chapter, “Moral Character”, right after “Moral Norms” in which the four principles of bioethics are proposed. The need for both principles and character is summed up by the following words that have appeared in all editions after the 4th:

Our feelings and concerns for others lead us to actions that cannot be reduced to merely following rules, and morality would be a cold and uninspiring practice without appropriate sympathy, emotional responsiveness, excellence of character, and heartfelt ideals that reach beyond principles and rules. [7th 30]

A decade before the 4th edition of Principles, Pellegrino made a forceful argument for the necessity of virtue in any system of ethics:

[T]he virtuous person is someone we can trust to act habitually in a 'good' way—courageously, honestly, justly, wisely, and temperately. He is committed to being a good person and to the pursuit of perfection in his private, professional and communal life. He is someone who will act well even when there is no one to applaud, simply because to act otherwise is a violation of what it is to be a good person. No civilized society could endure without a significant number of citizens committed to this concept of virtue. Without such persons no system of general ethics could succeed, and no system of professional ethics could transcend the dangers of self-interest. That is why, even while rights, duties, obligations may be emphasized, the concept of virtue has 'hovered' so persistently over every system of ethics. (Pellegrino, 1984, p. 243)

Within medical ethics, Pellegrino claims the need for virtue is found in “those moments of clinical truth when specific decisions and actions are chosen” (1984, p. 245), which occur more often in some specialties than others:

Some branches of medicine would seem to demand a stricter and broader adherence to virtue than others. Generalists, for example, who deal with the more sensitive facets and nuances of a patient's life and humanity must exercise the virtues more diligently than technique-oriented specialists. The narrower the specialty the more easily the patient’s good can be safeguarded by rules, regulations rights and duties; the broader the specialty the more significant are the physician's character traits. (Pellegrino, 1984, p. 247)

One exception to this rule may be found in ICU; critical care physicians may be far more like generalists in their need to rely on the virtues in those moments of clinical truth.

A year before Beauchamp and Childress first proposed their four focal virtues for medical professionals, Pellegrino and Thomasma (1993) proposed a list drawn more from the classic Aristotelian-Thomist tradition, but adapted to the challenges faced by health care professionals:

- Fidelity to trust: Pellegrino and Thomasma maintain this virtue is the most critical for professional ethics, because “trust is most problematic when we are in states of special dependence” for it is then that “we are forced to trust professionals if we wish to access their knowledge and skill.” They claim the alternative is an “ethics of distrust”, which relies on contractual relationships, and is “perilous, self-defeating and ultimately impossible in practice” (1993, p. 65). Their emphasis on fidelity to trust as the virtue is subtly but
importantly different than Beauchamp and Childress, who conflate the outcome of trustworthiness with the virtue itself. [7th 40]

- Compassion: Similarly to Beauchamp and Childress [7th 37], Pellegrino and Thomasma explain compassion in terms of “co-suffering, of fellowship in the experience” and claim the physician fails to demonstrate compassion if he or she “shows disrespect, lack of concern, indifference, or disengagement from [the patient’s] way of seeing her predicament” (1993, p. 80).

- Phronesis: Pellegrino and Thomasma term this “medicine’s indispensable virtue,” (1993, p. 87) and describe it as the ability to strike the appropriate balance between the many dilemmas faced in clinical practice, e.g., between compassion and objectivity, or full disclosure and managed disclosure of information. Beauchamp and Childress call this virtue “discernment” [7th 39].

- Fortitude: as a virtue, fortitude is not just courage, but sustained courage in the face of opposition. Pellegrino and Thomasma claim fortitude is a necessary virtue for medical professionals because of the difficulty of acting in the best interests of their patients in today’s “environment of ‘corporate medicine’” (1993, p. 112). Beauchamp and Childress do not cite fortitude or courage as one of their focal virtues.

- Temperance: in the medical context, Pellegrino and Thomasma define the virtue of temperance in terms of its corresponding vices: excess—the temptation to play God—and deficiency—a “pusillanimous abandonment of patients without sufficient intervention” (1993, p. 120). Beauchamp and Childress do not include temperance among their virtues.

- Integrity: Pellegrino and Thomasma divide the concept of integrity in the medical context into “the integrity of persons” and “the person of integrity”. A physician who is a person of integrity “not only accepts respect for the autonomy of others as a principle but interprets its application in the most morally sensitive way” (1993, p. 132). Their interpretation is more focused on autonomy; Beauchamp and Childress focus more on overall fidelity to one’s moral character. [7th 40]

Pellegrino and Thomasma do not address Beauchamp and Childress’s fifth focal virtue of conscientiousness.

Neither Beauchamp and Childress nor Pellegrino and Thomasma consider how virtue ethics extend beyond individual physicians to health care practices (e.g., medicine, nursing) and institutions (e.g., hospitals, insurers). Rodney et al. (2013, p. 363) incorporate MacIntyre’s (2007)
definition of virtue and its relationship to practice as part of their examination organizational ethics in health care.

Aristotle not only defines virtue as “a mean with respect to two vices, the one vice related to excess, the other to deficiency” (2011, 1107a1), but he frequently uses the vices to bring the meaning of a virtue to life, e.g., “concerning money ... the mean is magnificence; the excess is vulgarity and crassness; the deficiency paltriness” (2011, 1107b17). Beauchamp and Childress rarely enhance the descriptions of their proposed virtues with their corresponding vices of excess and deficiency. One exception is their assertion that an excess of compassion may “cloud judgment and preclude rational and preclude rational and effective responses” [4th 467].

Some authors remain unconvinced that the role of character is equally important to principles in regulating the ethical conduct of medical professionals. Jansen first claims to have “found wanting three proposals [by Pellegrino (1984)] that purport to show how a virtue-based ethical approach to medical ethics could improve upon or supplement non-virtue-based approaches. ... the good insights in these proposals can be accommodated within non-virtue based approaches” (Jansen, 2000, p. 268). She then poses a more robust challenge:

Virtue ethics is best suited for communities that share a thick conception of the good life and where there is substantial agreement on which ideals of character are valid. ... [Thus,] an important motivation for turning away from virtue ethics and toward principle and duty-based approaches is that these latter approaches are better able to respond to the pluralism and complexity of modern societies. (Jansen, 2000, p. 272)

Beauchamp and Childress share this concern: “When strangers meet, character often plays a less significant role than principles, rules, and institutional policies” [7th 382]. Jansen (2000) claims that “it is possible for people to accept the same set of principle, duties and rules for different reasons” (p. 272) and that rules and principles are thus more suited to interacting with “patients from a variety of different cultural, ethnic and religious backgrounds” (p. 272). However, the difficulty of navigating the principle of respect for autonomy with Navajo (Carrese & Rhodes, 1995), Korean-American and Mexican-American (Blackhall et al., 1995) populations shows that principles are not immune to problems of pluralism. In response to this problem Beauchamp and Childress ask, “The practical question is whether it is possible to inform patients of their rights to know and to decide without compromising their systems of belief and values or otherwise disrespecting them” [7th 110]. The virtues of compassion and discernment appear to be critical in situations like this. It may be that—contra-Jansen—virtue ethics is actually the complement to principlism necessary to resolve problems of pluralism.
5.4.5 Discussion: Theme 5. Bounded rationality and bioethics

The cognitive limitations of humans are touched on in the various editions of *Principles*, but the discussion is never extended to include bounded rationality, i.e., how the heuristics humans use to overcome their cognitive limitations (e.g., Gigerenzer & Selten, 2001a; Hogarth & Karelaia, 2006) impact the ethics of decision-making by both patients and health care professionals. The example of the colon cancer screening decision aid and the paternalistic backlash it generated demonstrates the ethical impact of both cognitive limitations and of our attempts to ameliorate them.

The flexibility introduced by accepting that normal choosers may have different levels of understanding but still retain their autonomy creates room for the cognitive limitations of the choosers to be taken into consideration when establishing thresholds for autonomous decisions.

After acknowledging the cognitive limitations affecting utilitarianism, Beauchamp and Childress propose a solution: “What is important, morally speaking, is that one conscientiously attempts to determine the most favorable action, and then with equal seriousness attempts to perform this action” [1st 26]. It seems that this solution moves the moral weight away from the rightness of the act itself and onto how the agent reaches their decision. In other words, because the utilitarian calculation is intractable, the rightness of the act is to be judged by the conscientiousness and phronesis of the deciding agent; a virtue criterion effectively replaces the utilitarian one. This example may be interpreted as demonstrating that the virtues can be interpreted as bounded rationality heuristics.
5.5 Limitations

This study’s first and biggest limitation is its data sources. By relying solely on Beauchamp and Childress to exemplify all bioethical thought over a 40-year period I have by definition overlooked other major contributions to the discipline. I have attempted to overcome this limitation and the bias introduced by it by including other authors’ texts in my analysis as context warranted. However, these other texts were included in an ad hoc manner. To properly overcome the limitation, I would have had to perform a series of systematic reviews of the bioethics literature looking for topics such as surrogate decision-making and virtue ethics, a project beyond the scope of this dissertation.

A second limitation results from subjective aspects of the inter-textual method. The differences I found between successive editions are objective, and my annotation method allows other researchers to confirm the differences I found. However, the selection of which differences to report is subjective. My selections were influenced by my evaluation of the weight and salience of the differences, but other researchers might disagree with my judgments.
5.6 Conclusions

In response to the research question for this study—*How has bioethical thought about surrogate decision-making evolved over the past 40 years?*—my analysis has shown that bioethical thought on surrogate decision-making has evolved in the 40 years since the original edition of *Principles of Biomedical Ethics* in 1979, but not in all respects.

- The normative basis for surrogate decision-making, originally limited to nonmaleficence, now includes a criterion based on respect for the incompetent patient’s autonomy, but its application is limited.
- The criteria for limiting life-sustaining treatment have been simplified from three dichotomies—extraordinary vs. ordinary treatment, killing vs. letting die, and withholding vs withdrawing—to one, optional vs. obligatory treatment.
- The physician’s obligation in family-physician interactions has evolved from an expectation of passive paternalism to a requirement to enhance the autonomy of the patient through the family and to help the family with the burdens of decision-making and accepting the shift to palliative care.
- As Hursthouse (1999) and my preliminary analysis both suggested, there has been a major turn toward virtue ethics in bioethics, such that the health care professional’s character is now seen as co-equal to the four principles in determining ethical conduct, and specific five virtues have been proposed for physicians to embrace.
- While there has been occasional acknowledgment of humans’ cognitive limitations since the 1st edition, there has been no examination of the ethical consequences of decisions affected by these cognitive limitations or by decision-makers’ reliance on bounded rationality heuristics.

These evolutionary changes all impact the ethical dimensions of the paradigm for surrogate decision-making and inform my responses to my overall research question—*What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?*
6 Proposed Paradigm Shift in Surrogate Decision-Making

In this dissertation, I sought to answer the overall research question What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies? In studies #1 and #2 I analyzed the experience of surrogates and their interactions with ICU professionals in order to better understand some of the causes underlying the clinical deficiencies. In Study #3 I explored the evolution of bioethical thought on surrogate decision-making over the past 40 years to ascertain if there had been new insights that might impact the ethical deficiencies of the current paradigm.

In this chapter, I bring together the evidence from the three studies to deliver an answer to my overall research question. I start by briefly describing three proposed shifts to the current paradigm (Section 6.1). Using these proposed shifts as a framework, I present the clinical and ethical evidence supporting my proposal from the three studies (Section 6.2).

I continue by describing some possibilities for implementing the proposed changes (Section 6.3), and detail how my proposal may alleviate the deficiencies documented in Section 1.4 (Section 6.4). I describe my original contributions and discuss how the proposed changes relate to the work of other authors (Section 6.5). I discuss some future work that will be required to test my proposal (Section 6.6). Finally, I conclude by summarizing the results of the entire dissertation (Section 6.7).
6.1 Proposed paradigm shift

In this section I propose three changes to the current paradigm (Table 6-1):

1. collapse the hierarchy of three normative decision standards into one;
2. base decisions on a structured, objective assessment of the patient’s values; and
3. formalize a protocol for how decisions are made, documented, and communicated.

I use these proposed changes as a framework to present the supporting evidence in Section 6.2.

Table 6-1: Comparison of current and proposed paradigms and practices

<table>
<thead>
<tr>
<th>Decision standard</th>
<th>Current paradigm and practice</th>
<th>Proposed changes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Advance directive Substituted judgment Reasonable-person best interests</td>
<td>Individual best interests</td>
</tr>
<tr>
<td>Decision basis</td>
<td>Unstructured, subjective inference of patient’s treatment preferences even when an advance directive is available.</td>
<td>Structured, objective assessment of patient’s values from a values portrait</td>
</tr>
<tr>
<td>Decision protocol</td>
<td>No protocol defined</td>
<td>Formal interest-specific/time-limited (IS/TL) protocol</td>
</tr>
</tbody>
</table>

The results of the three studies I conducted suggest that this combination of changes would simplify the decision-making process for decisionally incompetent patients, and may relieve patients, surrogates and medical professionals from some of the deficiencies inherent within the current paradigm.

6.1.1 One decision standard – individual best interests

My proposal simplifies the decision-making process by employing only one normative decision-making standard—the patient’s *individual best interests*—unlike the current paradigm, which relies on a hierarchy of three standards.

Each patient’s individual best interests would be determined by combining their medical best interests with their individual values. Their individual best interests would become the touchstone for all decisions about limiting life-sustaining treatments.

Individual best interests would replace the advance directive decision standard, but still enable a person to exert their autonomy in advance. Instead of expressing autonomy by preparing an advance directive, which is an unstructured list of treatment preferences for hard-to-imagine
hypothetical situations, a person would document their concrete, current values by completing a structured questionnaire—the values portrait (described in the following subsection, 6.1.2).

Individual best interests would replace the substituted judgment decision standard with what might be termed “substituted interests” (Sulmasy & Snyder, 2010). Instead of engaging in an unstructured attempt to guess the patient’s treatment preferences, surrogates would identify their patient’s individual values by completing a structured values portrait questionnaire that has some claim to objectively reflect the patient’s individual values.

The individual best interests standard would also replace the reasonable-person best interests standard, except in those rare cases where there is no surrogate who knows the patient. The difference between these two best interests standards is that the fictitious and subjective reasonable-person is replaced with the values portrait, an objective attempt to assess the values of the actual patient.

6.1.2 Structured, objective assessment of patient’s values – the values portrait

The individual best interests standard requires that decisions be made by selecting the treatment option with the best QoL benefit-to-burden ratio. Evaluating QoL benefits and burdens requires both medical judgment from the physician and knowledge of the patient’s values.

In order to assess the patient’s values in an objective manner, I propose the development of a values portrait. The purpose of the values portrait is to bring the patient’s values and current QoL status into focus, just as the physician’s judgment brings the patient’s medical interests into focus.

I envision the values portrait as a short, standardized questionnaire tested for validity and reliability across a broad spectrum of the cultures found in North America. The values portrait is not intended to be a highly nuanced rendering of a person’s values, but an instrument designed and optimized for the single purpose of making life-sustaining treatment decisions.

A fully competent person could complete a values portrait at any time, just like an advance directive can be completed today. Alternatively, during routine hospital admissions, competent patients without a values portrait could be requested to complete one, just like they are often asked
to complete a POLST or another treatment-preference document today. If an ICU patient had not completed a values portrait, the surrogate would be asked to complete one using their knowledge of the patient’s values. The questionnaire itself would be the same, whether the values portrait is completed in advance by the principal or after ICU admission by their surrogate. To my knowledge, no such instrument has yet been developed.

6.1.3 A formal decision process — the IS/TL protocol

The proposed paradigm shift incorporates a formalized interest-specific/time-limited (IS/TL) protocol for all optional treatment decisions. The IS/TL protocol serves three major purposes. The first is to foster consideration of both medical best interests and individual values in a shared decision-making context. The second is to reduce withdrawal aversion by the surrogate and physician. The third is to improve continuity of care.

The first purpose is served by the interest-specific aspect of the protocol. The protocol obliges the physician to specify the medical interest served by the proposed treatment and to specify a physiological goal defining success. The protocol also obliges the physician to identify all other treatment options, such as palliation, and describe how each would affect the patient’s medical interests. Then, the surrogate and physician, working together in a shared decision-making mode and using the values portrait as a guide, would identify the individual values served, and assess the benefits and burdens of each treatment option before selecting the one most aligned with the patient’s individual best interests.

The time-limited aspect of the protocol is intended to reduce withdrawal aversion by both physician and surrogate. The protocol would oblige the physician to specify a time limit to reach the

21 Capturing values portraits during the routine admission process may be worthwhile because about 40% of admissions to ICU are from the general and surgical wards after originally routine admissions.

22 I adopt the obligatory/optional treatment categorization proposed by Beauchamp and Childress:
   I Obligatory to Treat – Wrong Not to Treat
   II Obligatory Not to Treat – Wrong to Treat
   III Optional Whether to Treat – Neither Required nor Prohibited (Beauchamp & Childress, 2013, p. 169)

The IS/TL protocol would apply only to decisions about category III Optional treatments

physiological goal\textsuperscript{24}. The protocol would also require that, by default, all IS/TL decisions be made with the understanding that if the goal is not met in the time limit and the surrogate does not actively dissent, the physician may withdraw the treatment without the further assent of the surrogate\textsuperscript{25}.

The third purpose of improving continuity of care is achieved by formalizing the IS/TL protocol. The medical interests and individual values served by the treatment, the physiological goal and its time limit, and the surrogate’s informed nondissent would all be documented in the patient’s chart as part of the original decision and would be visible to and incumbent upon all succeeding physicians. While the formality of the IS/TL protocol may be perceived to be an onerous increase in the workload of already time- and resource-stretched physicians and other health care providers, the increased effort to document each decision may be offset by improvement in cross-shift and cross-specialty communication.

\textsuperscript{24} There are some interventions—such as evacuating an intra-cranial blood clot—that cannot be reversed if the physiological goal of the intervention is not achieved. In these situations, there is no withdrawal decision to be made, and the protocol would not apply.

\textsuperscript{25} This concept, termed “informed nondissent” by Kon (2010), was originally proposed as a part of a shared decision-making continuum for decisionally competent patients, but subsequently extended to decisionally incompetent patients (Kon & Dudzinski, 2019).
6.2  Evidence for the proposed paradigm shift

My proposed paradigm shift is an inductive hypothesis, the type of “tentative truth claim” (Thorne, Kirkham, et al., 2004, p. 4) that emerges from an interpretive description (as described in the Methodological Overview, Section 2.1). The evidence from the three studies I conducted informs and buttresses my proposal, but does not necessarily prove it as matter of deductive logic.

To recapitulate the studies:

- Study #1: the decision factors emerging from research into surrogates’ experiences – a metasynthesis of 26 SE papers including data from 1,915 surrogates (Section 3.2.2.2);
- Study #2: gaps and conflicts between the decision factors from Study #1 and surrogates’ interactions with ICU professionals emerging from research on surrogate-professional relationships – a metasynthesis of 52 SPR papers including data from 3,179 surrogates and 5,345 clinicians (Table 4-2);
- Study #3: the evolution of bioethical thought on surrogate decision-making from the time of current paradigm’s origin (c. 1980) to the present – an intertextual analysis of the seven editions of Beauchamp and Childress *Principles of Biomedical Ethics* plus other contextually relevant material such as court cases and works cited by Beauchamp and Childress.

6.2.1  Evidence for the individual best interests decision standard

My studies demonstrate that the current decision-making standards largely lack utility and justification, and that an individual best interests standard may align better with actual clinical behavior and evolved ethical thought.

**Clinical evidence relating to decision standards**

In studies #1 and #2 I found little evidence that surrogates or physicians rely on the advance directives standard, i.e., written directives or conversations specifically about treatment preferences. Instead, surrogates described their understanding of patient preferences in terms of informal discussions about interests rather than treatment preferences, e.g., one surrogate stated, “She always told us … that she never wanted to be a burden on anybody, where … she really wasn’t productive … or couldn’t live a life” (Fritsch et al., 2013, p. 129). Advance directives were explicitly mentioned in only 5 of the 26 SE papers in Study #1, and these all noted that most patients do not have written advance directives, consistent with other studies (AARP, 2008; House & Lach, 2014; Shapiro, 2012; Yadav et al., 2017). Only 1 of the 52 SPR papers in Study #2 touched on clinicians’
interactions with surrogates regarding advance directives; clinicians rated “Patient does not have advance directive” and “Advance directive lacks sufficient detail” as among the four least important of 22 possible barriers to a goals-of-care discussion with surrogates (You et al., 2015, p. 553).

The evidence concerning the substituted judgment standard from studies #1 and #2 is primarily about problems in applying it. All discussions of substituted judgment in Study #1 concerned the difficulties separating patients’ preferences from surrogates’ preferences (Fritsch et al., 2013; Schenker, Crowley-Matoka, et al., 2012; Vig et al., 2006). In Study #2, there is some evidence that physicians respect the place of substituted judgment (Combs et al., 2013). However, most of the evidence from surrogate-physician interactions points to either a misunderstanding of substituted judgment by the families and surrogates (Curtis et al., 2002; LeClaire et al., 2005; Mehter et al., 2018), or a deliberate attempt by physicians to influence the substituted judgment decision towards the physician’s own view of patients’ best interests (Brush, Brown, et al., 2012; Mehter et al., 2018; Wilson et al., 2013).

In Study #1 there is some evidence that surrogates applied a best interests standard defined in terms of long-term benefit (Dionne-Odom et al., 2015), but the evidence also shows that surrogates have multiple different interpretations of what best interests means (Fritsch et al., 2013). The evidence from Study #2 shows a prevailing belief by physicians that their role is to “guide or try to alter surrogates’ decisions, especially if they felt surrogates were making decisions that were not in [what the physicians believed to be] the patients’ best interests” (Brush, Brown, et al., 2012, p. 1081) (also Mehter et al., 2018; Schuster et al., 2012). Some physicians also noted that best interests could be “quite difficult to discern [because] critical care physicians generally lack longstanding relationships with patients … and must rely on patients’ surrogates” (Brush, Brown, et al., 2012, p. 1084).

The most striking evidence from Study #2 was that the current paradigm’s formal decision standards are rarely invoked by physicians, even when making decisions to limit life-sustaining treatment. In 55% of 73 ICU family-physician conferences examined (Cunningham et al., 2018), the physician did not present any normative standard for making the decision; in 22%, only one of the three formal decision standards was presented; in 1%, two standards were presented; all three standards were never presented. The formal best interests standard was never explicitly presented, but informal “patient as a person” and “family-centered” standards were suggested in 14% and 8% of the conferences respectively.
Ethical evidence relating to decision standards

In Study #3 I found that the advance directive and substituted judgment standards, based on the principle of respect for autonomy, have long been ethically controversial, while the best interests standard, based on the principles of nonmaleficence and beneficence, has strengthened over the forty years since the current paradigm originally emerged.

In *Quinlan* (1976) and *Saikewicz* (1977), which established the substituted judgment standard, Annas claims the “use of the more objective ‘best interests’ tests would have been more logical” (1979, p. 376). This and other arguments led Beauchamp and Childress to conclude that its “fictional quality makes substituted judgment highly controversial” (1983, p. 139). In reaction to the *Cruzan* (1990) decision, Annas (1991) and Emanuel & Emanuel (1992b) argued for decreased emphasis on advance directives because they had proved ineffective. By 1994 Beauchamp and Childress “conclude that we should abandon substituted judgment insofar as possible in law and in ethics and substitute a pure autonomy standard” (Beauchamp & Childress, 1994, p. 173). However, their pure autonomy standard is narrow, applying “exclusively to formerly autonomous, now-incompetent patients who expressed a relevant autonomous preference” (1994, p. 173) either in writing or, if orally, directly to the surrogate. By the 7th edition, Beauchamp and Childress, having accepted Dresser’s (1986) argument that advance directives should not always control, conclude that the “best interests standard can in some circumstances validly override advance directives executed by formerly autonomous patients” (2013, p. 229). In other words, except in those cases where a patient has communicated a very clear and relevant treatment preference directly to the surrogate, Beauchamp and Childress have collapsed the normative basis for surrogate decision-making to a best interests standard.

There is, however, a significant difference between my proposal and Beauchamp and Childress. Their calculus of best interests is based on a relatively narrow view of harm—“pain and suffering, disability and death” (Beauchamp & Childress, 1979, p. 99)—while my proposal follows the more orthodox position that harm results from invading, blocking or thwarting a person’s interests (expressed or not), whether those are welfare (instrumental) interests or ulterior (extrinsic) interests (Feinberg, 1977).

I believe this difference is critical because of an ethical concern first raised by Robertson (1976), who argued it was necessary to treat an incompetent patient as fictionally autonomous otherwise they would lose the moral status of being human. If best interests are reduced to essentially
physiological interests as Beauchamp and Childress propose, then the patient’s humanity and moral status are indeed in danger. My proposal seeks to capture the patient’s extrinsic interests in the values portrait so that the individual best interests standard embodies the patient’s individual identity and moral status, thereby avoiding Robertson’s trap.

**Conclusion regarding decision standards**

The clinical evidence shows that all three of the current formal standards have limited operational utility for either surrogates or clinicians. The clinical evidence also shows that surrogates tend to rely on patient’s preferences expressed in terms of personal interests or values, and clinicians tend to rely on medical best interests. The ethical evidence refutes the advance directive and substituted judgment standards, but strengthens support for a best interests standard.

The individual best interests standard, which combines surrogates’ understanding of patient’s personal values with physicians’ judgment of medical best interests, aligns with current clinical behavior. Individual best interests as the sole decision standard also aligns with the evolution of ethical thought.

**6.2.2 Evidence for the values portrait**

My proposed shift to the individual best interests standard requires surrogates and clinicians to incorporate each patient’s values into the decision-making process. This requirement in turn generates two more requirements: i) surrogates and clinicians need to have knowledge of each patient’s values, and ii) the decision-making process in the ICU needs to foster a shared understanding of the patient’s values.

To meet these requirements for knowledge and shared understanding I have proposed the mechanism of the values portrait. The values portrait is:

- structured: requires responses for all values important to treatment limitation decisions;
- objective: tested and refined across groups with different socio-cultural backgrounds;
- accessible: incorporated into the patient’s electronic medical record; and
- consistent: a single touchstone for all decisions.

Structure is needed to provide guidance to the person filling out the values portrait questionnaire, so that the responses provide a fully rounded picture of the patient’s values. Structure is also needed to ensure that all the issues needed to determine individual best interests
are addressed in family-physician conferences. The evidence shows such structure is not currently present: the clinical evidence from Study #2 reveals that when values are discussed in family-physicians conferences today the focus is almost exclusively on short-term instrumental issues (e.g., bodily integrity, symptom palliation) rather than long-term extrinsic values (e.g., autonomy, relationships, emotional wellbeing) (Scheunemann et al., 2015; Uy et al., 2013; White et al., 2010). Recent evidence from the academic literature shows that in the 44% of family-physician conferences that even deliberated about patient values, only one instrumental value (patient’s willingness to accept invasive or burdensome treatment) dominated all discussions (Scheunemann et al., 2019). However, the ethical evidence (Study #3) associates individual values with second-level, long-term, extrinsic interests, not with first-level, short-term, instrumental interests (R. Dworkin, 1993; Feinberg, 1977; Frankfurt, 1971).

Objectivity is needed in judging the balance between benefits and burdens. The ethical evidence highlights the need for some degree of objectivity: “These judgments require defensible criteria ... that avoid reducing quality-of-life judgments to arbitrary personal preferences or to the patient’s social worth” (Beauchamp & Childress, 2013, p. 171).

Accessibility is needed to support continuity of care. In studies #1 and #2 I found both surrogates and clinicians complain about the impact of too many physicians involved in the care of each patient. Surrogates tire “of explaining the same information over and over” (Bute et al., 2016, p. 805) and are angered by ever-changing physicians’ unfamiliarity with their patient (Baggs et al., 2012). Physicians acknowledge the impact on continuity of care (Daly et al., 2016; Ellis et al., 2016; You et al., 2015), and specifically on understanding patient’s values and preferences:

The way we transfer care (during handoffs) is such that (patient preferences) get lost. (A new physician coming onto service) didn’t know the (patient’s preferences)... and without knowing that piece of the puzzle... it was impossible to (make the right decision). (Wilson et al., 2013, p. 1011)

Incorporating the values portrait into the EMR will not solve these problems entirely, but may alleviate them.

Consistency is needed to ensure that the individual best interests standard is actually applied and that all decisions for each patient are made using the same criteria. In studies #1 and #2, I found this was not so: even though surrogates identify patient’s preferences and values as critical decision factors, these preferences and values were discussed in only 37% of family-physician conferences (Scheunemann et al., 2015), functional recovery or post-discharge QoL was discussed in less than half of family-physician conferences (Cox et al., 2009; Douglas et al., 2012; Turnbull et al., 2016), and
40% of decisions were made using criteria other than patient preferences (LeClaire et al., 2005). Attending physicians can mitigate this discrepancy but they often miss the opportunity to do so (Brush, Brown, et al., 2012; Curtis et al., 2002, 2005; LeClaire et al., 2005; Pecanac & Brown, 2017).

6.2.3 Evidence for the IS/TL protocol

I present this evidence using the framework of the proposed IS/TL protocol’s three purposes:

i) foster explicit consideration of patient’s values and shared decision-making;

ii) reduce withholding aversion; and

iii) improve continuity of care.

Evidence relating to consideration of patient’s values and shared decision-making

In studies #1 and #2 I documented evidence of gaps and conflicts between surrogates’ preferred approaches to decision-making (Johnson et al., 2011; Lewis et al., 2006; Nunez et al., 2015) and physicians’ typical approaches (Brush, Brown, et al., 2012; Combs et al., 2013; Mehter et al., 2018; Uy et al., 2013; White, Braddock III, et al., 2007; White et al., 2010). These studies reveal that while surrogates claim to prefer either sharing the decision with the physician or making it themselves, physicians often resort to persuasion or even intentional omission of alternatives (Schenker, Tiver, et al., 2012) in order to guide the decision toward what they perceive to be the patient’s best interests. Other evidence from Study #2 shows that patient’s best interests are rarely if ever discussed with surrogates (Cunningham et al., 2018; Scheunemann et al., 2015) and neither surrogates nor physicians appear to discuss quality-of-life or functional recovery in most conferences (Cox et al., 2009; Douglas et al., 2012; Turnbull et al., 2016).

Since 2016, shared decision-making has been the official policy of the ACCCM and the ATS, two of the professional societies governing ICU practice in the U.S. (Kon et al., 2016a, 2016b). In the ICU context, shared decision-making is defined as:

a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values, goals, and preferences. (Kon et al., 2016b, p. 1334)

Evidence from Study #2 showed that shared decision-making in ICU was “often incomplete” (White, Braddock III, et al., 2007, p. 465). More recent evidence, published after I had completed Study #2, confirms that “ICU family conferences about goals of care appear to rarely follow recommended practices for shared decision making based on patients’ values and preferences” (Scheunemann et al., 2019, p. E8).
In direct response to this evidence, my proposal calls for explicit discussions about both individual values and medical best interests within a shared decision-making framework.

**Evidence relating to reducing withdrawal aversion**

The evidence to support a time-limited trial as a means of reducing withdrawal aversion comes from all three of my studies. The clinical evidence (studies #1 and #2) shows that withdrawal aversion is real: some surrogates perceive withdrawal of life-sustaining treatment as a deliberate act of killing (Hsieh et al., 2006; Nelson et al., 2017) and a majority of physicians find withdrawing life-sustaining treatments psychologically and ethically more fraught than withholding the same treatments (Chung, Yoon, Rasinski, & Curlin, 2016). The ethical evidence (Study #3) shows that overcoming withdrawal aversion is morally necessary and suggests a time-limited trial as a solution:

> Whether a particular treatment will have positive effects is often highly uncertain before the therapy has been tried. If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than mere surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable (President’s Commission, 1983, p. 76).

Beauchamp and Childress added the element of “periodic reevaluation” to the trial and concluded “Not to propose or allow the test at all is morally worse than not trying” (1994, p. 198). Clinical evidence shows that families need time to prepare for EoL decisions (Brush, Brown, et al., 2012; Mehter et al., 2018; Nunez et al., 2015; Tilden et al., 1995; Vig et al., 2007; White et al., 2009); the same phenomenon even applies to surgeons personally invested in good surgical outcomes (Wilson et al., 2013). The option of proposing a TLT enables physicians to give families and invested clinicians more time without extending the decision process indefinitely.

The concept of informed nondissent is relatively new (Kon, 2010) and its application to decisionally incapacitated patients is even newer (Kon & Dudzinski, 2019). I found evidence in studies #1 and #2 that there are surrogates who may benefit from being able to distance themselves from a withdrawal decision: surrogates who report “emotional difficulty with making life-or-death decisions” (Schenker, Crowley-Matoka, et al., 2012, p. 1661) or those who feel “responsible for the death” (Nunez et al., 2015, p. 2391). However, because the concept is so new, there is no clinical evidence from my studies to support incorporating informed nondissent into the IS/TL protocol, and the ethical evidence introduces a caveat. For informed nondissent to work, surrogates will have to

---

26 While the ethical value of a periodically reevaluated trial was introduced in 1994, the clinical value of this approach was not widely recognized in the critical care medicine literature until a seminal paper in *JAMA* introduced the term *time-limited trial* (TLT) (Quill & Holloway, 2011).
place great trust in physicians, but as Beauchamp and Childress acknowledge, “a true climate of trust is endangered in contemporary health institutions” (2013, p. 40).

The clinical and ethical evidence strongly support my proposal of incorporating time-limited trials into the same protocol used to encourage shared decision-making. Evidence to support the inclusion of an informed nondissent default to the protocol is weaker and mixed.

**Evidence relating to improving continuity of care**

The clinical evidence from studies #1 and #2 shows that given the variety of medical professionals involved and the inevitable shift changes, continuity of care is a real challenge in contemporary ICUs (Baggs et al., 2012; Daly et al., 2016; Wilson et al., 2013). Communication is of particular importance for relational, informational, and management continuity (Haggerty et al., 2003), but is often disrupted:

One common discrepancy is when one team of providers or specialists fails to communicate with others, and patient care is consequently compromised by delays, misinformation, or other disagreements regarding a care plan. (Ellis et al., 2016, p. 12)

These communication failures directly impact the surrogates and families, often to the detriment of the patient (Bute et al., 2016; Nelson et al., 2017; Torke et al., 2012; Vig et al., 2007). Surrogates’ trust in clinicians is particularly vulnerable: as one surrogate said “I didn’t feel like I could trust any one of [the physicians] because they weren’t communicating with one another” (Limerick, 2007, p. 335). Communication failures are also a major source of moral distress among ICU clinicians: “Watching patient care suffer due to lack of continuity and poor communication were the highest-ranked sources of moral distress”. (Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2015, p. 117)

The benefit of formal protocols and standardization for patient care quality is well supported by research separate from my three studies. Standardization has been widely accepted by health care institutions as an integral part of evidence-based medicine (Timmermans & Epstein, 2010), and formal protocols are key to achieving consistency, continuity, and coordination (March, 2006). Protocols for clinical procedures, such as ventilator weaning, have long been known to be effective tools in ICU (Wall, Dittus, & Ely, 2001).

My proposal to create a formal IS/TL protocol responds to the evidence that continuity of care, especially inter-physician communication, is impaired in contemporary ICUs. My solution is supported by the evidence that formal protocols are key to improving continuity of care.
6.3 Hypothetical implementation possibilities

In an ICU that has adopted my proposed paradigm shift, the individual best interests decision standard and the role of the values portrait would be outlined to the patient (if competent at the time) and surrogate as soon as possible after the patient was admitted to the ICU. The surrogate would be requested to review any existing values portrait or to complete one for the patient, and then to assent to using the values portrait as the basis for decision-making.

Ideally the values portrait would be incorporated into the patient’s EMR, would be accessible to all medical professionals involved in the patient’s care, and would be discussed at daily rounds by the medical team\textsuperscript{27}. If the surrogate had assented to using the values portrait as the basis for decision-making, every family-physician conference would begin by reviewing the patient’s values portrait and every decision would be justified in terms of individual best interests as determined by a combination of the patient’s values from the values portrait and the physician’s assessment of the patient’s medical best interests.

My proposal to start all decision-making conferences with a review of the values portrait follows Pecanac’s finding, who reported that by starting a conference with a question about patient’s preferences, the physician “orients the surrogates to consider the preferences of the patient (instead of the clinicians or the surrogates)” (2017, p. 1269).

My proposal calls for formalizing the IS/TL protocol and standardizing its use within an ICU. The formalized protocol would oblige clinicians to document the rationale for each decision including the goals and time limits for any trials. Other physicians providing care for the patient would be obliged to consider preceding decisions before suggesting any treatment changes, and to present the proposed changes to the surrogates within the context established by previous rationales.

\textsuperscript{27} Thanks to Dr. Patrick McDonald for suggesting the values portrait be discussed at daily rounds.
6.4 How the proposed shift alleviates deficiencies in the current paradigm

In Section 1.4 I detailed many of the deficiencies in the current paradigm. In this section I describe how my proposed paradigm shift may alleviate each of these deficiencies.

6.4.1 Conceptual deficiencies

Substituted judgment is a fiction.

This deficiency is eliminated because the paradigm no longer depends on substituted judgment as a decision standard.

Best interests is not an objective standard.

On the one hand, the proposed shift acknowledges the subjectivity of best interests and places this subjectivity at the core of the decision-making process. On the other hand, the proposed shift introduces an objective aspect to the best interests judgment process by incorporating a standardized instrument—the values portrait.

The preferences expressed by a person while competent should not necessarily control what happens to them after becoming incompetent.

Dresser’s (1986) concern about this has been largely ignored by advance directive statutes (e.g. Province of British Columbia, 1996 Provision 19.8), but, as Beauchamp and Childress acknowledge, there are cases where “it seems unfair to the now happily situated incompetent person to be bound by a prior decision that may have been ill informed” (2009, p. 139). The proposed paradigm shift resolves this issue by eliminating the straitjacket of the advance directive and replacing it with a more flexible individual best interests standard.

Replacement of the advance directive does not come at the cost of Dworkin’s integrity view of autonomy, the “right to a life structured by [one’s] values” (1993, p. 224). Indeed, the values portrait provides an instrument for the competent person to document his or her critical interests in advance, and in a manner that is far more likely to later result in life-sustaining treatment decisions compliant with those interests.

6.4.2 Operational deficiencies

Most people do not prepare an advance directive or formally appoint a surrogate.

Two recent survey and review papers (Carr & Luth, 2017; Yadav et al., 2017) both noted that while there is substantial research on the socio-demographic characteristics of people who
complete an advance directive, there was little research on why people do not do so. While not definitive, two older studies (Beck, Brown, Boles, & Barrett, 2002; Srinivasan, 2005) suggest that discomfort with difficult-to-visualize, hypothetical situations and discomfort with thoughts of death and dying are at least two of the reasons why people do not complete advance directives. These studies also reinforce the preconception that most people are comfortable with letting their families decide.

More people may fill out a values portrait than an advance directive because the values portrait is couched in positive and concrete terms—what is important to a person in the present—rather than hypothetical terms about a subject most people know little about and would rather avoid. The values portrait is also a structured questionnaire, making it much easier to complete than a freeform advance directive. Furthermore, the values portrait’s purpose aligns with helping people’s families decide, which is what most people really want to happen in such a situation. Because the values portrait is intended to be a short questionnaire, it can also be easily filled out as part of the admission process by those patients entering hospital for a non-emergency procedure.

**Advance directives are rarely entered into hospital charts, and if not entered, are ignored.**

As a standardized instrument, the structure of the values portrait can easily be merged into any electronic medical record system and become a standard part of each hospital’s patient charts.

**Advance directives are often too vague or too absolute to be useful.**

Advance directives are often too vague or too absolute because, to be effective, they must be very specific and relevant to the patient’s actual diagnosis and treatment options. The values portrait, however, is a guide created for the specific purpose of assessing the benefit-burden ratios of treatment options, no matter what the diagnosis or options available.

### 6.4.3 Negative impacts

#### 6.4.3.1 Negative impacts on patients

**Advance directives address only medical interventions, not other aspects of care.**

Surrogates and medical professionals may be able to use the values portrait to discern non-medical aspects of care that are of significance to the patient.

**Neither surrogates nor physicians can accurately predict patients’ preferences.**

Almost 30 years ago, Buchanan and Brock described four asymmetries (1990, p. 153) that render any such preferences essentially unknowable in principle, let alone in practice. For this
reason, my proposed paradigm shift explicitly rejects the concept of predicting the patient’s treatment preferences and replaces it with a rigorous process to assess the patient’s individual best interests.

6.4.3.2 Negative impacts on surrogates

The decision-making process is traumatic for surrogates and often results in clinically significant psychological distress for months afterwards.

Eliminating all psychological distress for surrogates by changing the decision-making paradigm is impossible, if only because it is difficult to disentangle the psychological effects of decisional stress from those of anticipatory grieving. However, any reductions in decisional stress would almost surely be beneficial.

Grounding the decision-making in the values portrait—which brings what the patient believes to be important into focus—may help the surrogate see how their decision aligns with the patient’s values, thereby reducing the surrogate’s perceived burden of responsibility.

The IS/TL protocol is designed to reduce decisional stress. Instead of being pressured into a decision where withholding or treating are the only two options, the time limitation provides an interval during which surrogates can psychologically prepare for a transition to palliative care if the treatment is unsuccessful. Additionally, by relying on the informed nondissent element of the protocol, the ultimate decisional stress of actually withdrawing treatment can be transferred from the surrogate to the physician.

Surrogates’ different interpretations of advance directives often lead to intra-family conflict.

Removing advance directives will remove this cause of conflict, but may introduce differing interpretations of the values portrait as a new source of conflict. In some cases, the specificity and standardization of the various elements of the values portrait may enable conflicting family members to understand the cause of their conflict more clearly and so negotiate a settlement.

The momentum of institutional health care overwhelms surrogates and obscures long-term outcomes.

The IS/TL protocol is designed to break the momentum of institutional care by requiring a clear time-limited goal for each new intervention. Because the goal has to be stated in terms of the patient’s individual best interests—not just their medical, short-term survival interests—attention to long-term outcomes is encouraged in each successive intervention. Furthermore, the
standardization of the protocol ensures that as different physicians take over the patient’s care, the original goals and time limits are not arbitrarily changed.

6.4.3.3 Negative impacts on medical professionals

Critical care medical professionals, especially nurses and other allied health professionals, experience high levels of moral distress.

One of the requirements for the proposed paradigm shift to be effective is that all medical professionals involved in a patient’s care have access to the patient’s values portrait and to the goals and time limits of each intervention decided under the IS/TL protocol. This enables them to confirm for themselves that each patient’s treatments are aligned with that patient’s individual best interests.

The current paradigm has little space for the unique contributions of nurses.

Family conferences should include the nurses involved in a patient’s care, especially those the family has come to trust. Because the assessment of the benefit-burden ratio is not in purely physiological terms but requires judgments based on the values portrait—visible to all participants—nurses and other allied professionals are equally well situated to contribute.

6.4.3.4 Negative impacts on health care delivery systems

ICU costs are high and increasing disproportionately

If a values portrait can be created before transfer from a surgical or medical ward to ICU, it may be possible to reduce the number of ultimately inappropriate transfers into ICU, which, as Curtis et al. (2012) concluded, is one of the few ways to reduce growth in ICU costs.

The time-limitation element of the IS/TL protocol may reduce the duration of some treatments; it may also encourage the choice of time-limited withdrawal rather than immediate withholding, and thereby increase costs.
6.5 Original contributions

My proposed paradigm shift contains three major changes, which together form an integrated whole:

i) individual best interests as the only decision standard;
ii) the values portrait, a structured, objective basis for decision-making; and
iii) the IS/TL protocol to formalize the decision process.

I believe I have made two original contributions: the first is the concept of the values portrait, and the second is the integration of all three changes. Many other authors have written about eliminating the advance directive or substituted judgment standards. Components of the IS/TL protocol have been suggested previously, although, to my knowledge, no one has unified the components into a single protocol.

6.5.1 Individual best interests as the sole decision standard

In choosing to rely solely on individual best interests I am following a well-trodden ethical and philosophical path. Since the earliest days of bioethics the patient’s interests have been held as paramount, the only question being whether those interests should be interpreted in terms of quality-of-life (McCormick, 1974) or the inherent respect due to a person (Ramsey, 1970). After 35 years of examining all the alternatives, Beauchamp and Childress (2013) conclude that in almost all situations the best interests standard is the only valid standard.

But what about the advance directive and substituted judgment standards that have been embedded in legislation and practice for decades? The evidence from my three studies shows that these standards largely lack utility in practice. Other authors have long argued that they should be eliminated on a variety of grounds.

The advance directive standard was created explicitly “in the interest of protecting individual autonomy” (State of California, 1976, p. 6479). In effect, it was an attempt to project a patient’s consent from a time when they were autonomous to a later time when they were no longer autonomous. But, the very concept of the advance directive fails in this task, as Fagerlin and Schneider so vividly convey:

The conventional—legal and ethical wisdom—insists that candidates for even a flu shot give “informed consent.” And that wisdom has increasingly raised the standards for disclosure. If we applied those standards to the information patients have before making the astonishing catalog of momentous choices living wills can embody, the conventional wisdom would be left shivering with indignation. (Fagerlin & Schneider, 2004, p. 33)
Given the inherent failure of the advance directive standard to provide informed consent, and its operational failure to actually guide decision-making in more than 5% of actual situations (Shapiro, 2012), my proposal to eliminate it as a decision standard is both logically necessary and empirically valid.

The substituted judgment standard requires “the decision should be that which would be made by the incompetent person” (Saikewicz, 1977, p. 753), in other words, that the surrogate decide by guessing what would have been the patient’s preferences. However, the empirical data showing that surrogates cannot accurately guess their principals’ preferences is overwhelming (Bravo et al., 2017; Ditto et al., 2001; Seckler et al., 1991; Shalowitz et al., 2006; Sulmasy et al., 1998; Uhlmann et al., 1988). Furthermore, its ethical basis is highly questionable:

we should be cautious of any legal fiction that involves impersonation, of any device that allows one human being to inhabit the shell of another. … With the doctrine of substituted judgment, the raw truth is: the [surrogate] and the [patient] do not stand on equal footing; they are not both rational, autonomous human beings. Beneath the façade of equality is total power in the wielder of the words, and no power in his victim (Harmon, 1990, pp. 70–71).

My proposal to also eliminate the substituted judgment standard is justified by its demonstrated inability to achieve its stated purpose and its ethical danger.

I am not alone in concluding that a values-centric best interests standard should replace the advance directive and substituted judgment standards:

Given the data on its inherent flaws and its apparent inconsistency with the very principle of autonomy that it was designed to embody, it is time to let go of substituted judgment as the predominant model of decision making for the seriously ill. (Torke, Alexander, & Lantos, 2008, p. 1516)

Sulmasy and Snyder (2010) propose replacing substituted judgment with “substituted interests”:

This model emphasizes authenticity … rather than the autonomy the patient cannot exercise, asking surrogates to provide knowledge of patients’ authentic values and interests (“substituted interests”) rather than guessing what the patient would have decided. A “best judgment” about what decision advances the good of each patient as a unique individual follows. (p. 1946)

The substituted interests proposal was endorsed by Cook & Rocker (2014) in their New England Journal of Medicine review of best ICU practices.

6.5.2 Eliciting patient’s values – the values portrait

Creating a tool to elicit patient’s values was perhaps first addressed by Doukas and McCollough (1991) who proposed that physicians assist competent patients in preparing a “Values History” as a complement to an advance directive. More recently, Scheunemann, Arnold and White (2012)
proposed a framework for the physician to elicit an incompetent patient’s values from the
surrogate, as a “conversation, rather than a pen and paper exercise” (p. 480).

However, almost 30 years after Doukas and McCullough, the most prolific group of researchers
in this field28 are still calling for tools “to better prepare surrogates to represent patients’ values and
preferences in ICU family conferences” (Scheunemann et al., 2019, p. E8).

My proposed values portrait has two features that differentiate it from previous proposals to
elicit patients’ values. First, it is a standardized instrument. Second, the same instrument is used to
elicit values whether in advance by the person themself or after ICU admission by the person’s
surrogate. I believe these features lead to several important advantages:

i) because it is a closed-ended questionnaire, the quality of the results does not depend on an
interlocutor’s or interpreter’s skill or time available;

ii) because the same instrument is used by the principal or their surrogate, systematic biases
between principals and surrogates can be studied in research settings and then allowed for
in clinical situations;

iii) because the results are standardized, they are easy to capture in EMRs and, as health care
professionals become used to reading the results, they can readily incorporate this
knowledge of patients’ individual values in their interactions with patients and families; and

iv) because it is standardized and objective, different versions of the values portrait instrument
can be subjected to controlled trials and improved over time.

6.5.3 Time-limited trials and informed nondissent

My proposal for an IS/TL decision protocol draws on several threads: the ethical and clinical
value of time-limited trials, the clinical experience of time-limited trials, and the incorporation of
informed nondissent into time-limited trials.

The ethical value of time-limited trials is detailed above in Section 6.2.3.

28 The various members of this group have published well over 100 papers on surrogate decision-making and
related topics since their first paper (White, Curtis, Lo, & Luce, 2006).
The clinical value of the time-limited trial (TLT) was introduced in a seminal paper in *JAMA* by Quill and Holloway, who identified both the benefits of TLTs:

TLTs help establish mutual expectations, guidance, and a regular structured dialogue about how the patient is progressing, lessening the chance of conflict among treatment teams and the patient or family. TLTs also may provide a way of finding a middle ground with patients who want “everything” done vs unilaterally trying to limit treatment. (Quill & Holloway, 2011, p. 1484)

and the limitations of TLTs:

If clinical deterioration is rapidly unfolding, there may not be sufficient time to formally initiate a TLT. Furthermore, in today’s fragmented health care environment, the risk of health care professionals disagreeing with one another and thereby undermining the trial is substantial. (p. 1484)

Several other authors have also described clinical benefits possible from TLTs (Curtis et al., 2012; Schenker, Tiver, Hong, & White, 2013; Shapiro, 2012; A. K. Smith, Lo, & Sudore, 2013). In addition, Downar et al. (2014) describe how trials with properly documented rationales would help resolve subsequent disputes or evaluations by ethics review boards.

The clinical experience of TLTs is mixed. In a study of 72 family conferences Schenker, Tiver et al. (2013) found TLTs were offered in only 9 (13%) cases and in none of those cases were all the options discussed. They also found that the goals of the trials were always physiological, “but little information was given about what would count as improvement or how these milestones would be interpreted to evaluate whether a trial was successful” (Schenker, Tiver, et al., 2013, p. 865). Even though Schenker, Tiver et al. speculated that physicians did not offer more TLTs because of their discomfort in describing trials to the families, they found “no evidence” that families shared these concerns and indeed a “minority of families suggested a trial themselves” (p. 868). In a qualitative study of ICU professionals, Bruce et al. found the most important factor in successfully completing a TLT is taking ownership, that “the physicians-of-record are responsible” (2015, p. 2538).

The proposed IS/TL protocol is designed to gain the clinical benefits while addressing the limitations and experience described by these authors. Two key aspects of the protocol are first that it is a protocol, i.e., a standardized process, and second, that adherence to the protocol is mandatory for all physicians within an ICU. The protocol specifies not only what has to be considered in making a treatment decision, but how to document both the rationale for the decision and the decision itself. My intention is both to improve communication between the multiple physicians involved in a single patient’s care, and to prevent disagreements among physicians from affecting the best interests of the patient.
In 2010, Kon introduced the concept of “informed nondissent” as a way for “the physician to bear the major burden of the decision making” in a shared decision-making environment:

With informed nondissent decision making, the physician, guided by the patient’s values, determines the best course of action and fully informs the patient. The patient may either remain silent, thereby allowing the physician’s decision to stand, or veto the decision. In this approach the patient must understand all pertinent information (as he/she would in any method of decision making). Furthermore, the patient must appreciate that silence will be construed as tacit agreement. (Kon, 2010, p. 903)

Wilkinson and Savulescu (2014) appear to have adapted the informed nondissent model to surrogate decision-making and TLTs, calling for the “expectation that at the end of that time treatment would be withdrawn unless the patient had shown a definite response to treatment” (p. 136). My proposed IS/TL protocol includes informed nondissent for the same reason Kon originally proposed—to move the major burden of an emotionally-fraught withdrawal decision from the surrogate to the physician.
6.6 Future work

My proposal hangs on the question of whether an effective values portrait questionnaire can be constructed. In order to be effective, the values portrait has to:

• provide guidance to typical surrogates and physicians on whether to limit or not limit life-sustaining treatment in the majority of clinical situations encountered in each of the various types of ICU;
• provide the same guidance whether the values portrait was completed by the principal or their designated surrogate;
• provide appropriate guidance for all major socio-economic-cultural groups in the population; and
• be stable and robust.

My future work will be primarily empirical: understanding the nature and frequency of the actual clinical situations requiring these types of decisions; developing candidate questionnaires that would enable surrogates and physicians to discriminate between decisions to treat or not to treat; and testing whether these candidate values portraits generated the same results if completed by principals or surrogates. After these steps are taken, testing in the general population and across longer time frames will be needed.
6.7 Conclusion

My review of the literature revealed many deficiencies with the current paradigm for making decisions for incompetent patients. My first two studies showed that there are many gaps and conflicts between the factors surrogates consider in decision-making and what is actually discussed in their interactions with ICU professionals. My third study showed that ethical thought about making decisions for incompetent patients has evolved somewhat since the current paradigm was established in the 1970s and early 1980s, but that several aspects of the current paradigm always were and still are ethically dubious.

My goal in conducting this research was to influence practice by answering the question: *What shifts to the current paradigm for surrogate decision-making in ICU might alleviate its clinical and ethical deficiencies?* Interpretive description, the methodological approach I selected, seeks to provide “a backdrop for assessment, planning and interventional strategies” in pursuit of a practice goal (Thorne, Kirkham, et al., 2004, p. 4).

In keeping with this practice goal and methodological approach, and based on the evidence from my three studies, I have proposed three changes to the paradigm and practice of surrogate decision-making in the ICU:

i) the adoption of individual best interests as the sole normative standard for making decisions for incompetent patients;

ii) a standardized, objective values portrait that captures the critical values informing each patient’s individual best interests;

iii) an interest-specific/time-limited protocol for making all optional treatment decisions.

My original contributions are i) the standardized, objective values portrait; ii) the use of the same values portrait either by a person as a form of advance directive or by their surrogate after admission to ICU; and iii) integration of the changes into a single standardized solution to enhance the consistency, continuity, and coordination of care for incompetent patients.

My proposal needs to be critically examined by health care professionals, ethicists, and lawyers. The validity of the values portrait concept then needs to be empirically tested and benefits demonstrated.
Bibliography


CIHI. (2016). *Care in Canadian ICUs*. Ottawa, Canada: Canadian Institute for Health Information.


Corley, M. C. (2002). Nurse moral distress: A proposed theory and research agenda. *Nursing Ethics,* 165


Gutierrez, K. M. (2013). Prognostic categories and timing of negative prognostic communication


Kass, L. R. (1980). Ethical dilemmas in the care of the ill. I What is the physician’s service. JAMA, 244(16), 1811–1816.


Rubenfeld (Eds.), *Managing death in the ICU: The transition from cure to comfort.* (pp. 19–29). Oxford: Oxford University Press.


https://doi.org/10.1111/j.1540-8159.2008.00879.x


Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research, 8*(3), 341–351.


Thomas, J., Harden, A., Oakley, A., Oliver, S., Sutcliffe, K., Rees, R., ... Kavanagh, J. (2004). Integrating qualitative research with trials in systematic reviews. *BMJ, 328*, 1010–1012. https://doi.org/10.1109/METRIC.2004.1357885


A: Appendix – Study #1 Details

A1: Study #1 seed articles

Table A-1: Seed articles for Study #1 and number of similar articles matching each seed article

<table>
<thead>
<tr>
<th>Seed paper citation</th>
<th>Similar articles</th>
</tr>
</thead>
</table>
A2: Capturing similar articles from PubMed

The step-by-step process I used to collect the similar articles from PubMed and transfer them to a spreadsheet is pictured below as a series of screen captures from the PubMed website (https://www.ncbi.nlm.nih.gov/pubmed/).

The following steps were repeated for each seed article:

- Find the seed article in PubMed
- Click on the “See all …” hyperlink as shown in the screenshot below circled in orange

A list of all the similar articles is displayed, such as shown below
• The similar articles can then be directly copied from the web browser and pasted into the spreadsheet. Alternatively, the “Send to” hyperlink, circled in orange as shown below, can be clicked and the similar articles can then be directed to an intermediate, more convenient destination, and then copied into the spreadsheet.

• I chose to have the results emailed to me, thereby:
  i) preserving the hyperlinks, making the inclusion criteria assessment much easier; and
  ii) capturing the results in a date-stamped third-party record.

The Send to File option would also be effective, but does not preserve the hyperlinks nor create the date-stamped record.
A3: SE Papers analyzed in Study #1

The following 26 SE Papers met the inclusion/exclusion criteria of Section 3.1.1.1 and contained decision factors. The third column shows the number of decision factors found during the thematic synthesis described in Section 3.2.2. The right-most column shows the QualSyst score, a measure of each paper’s strength-of-evidence as determined in Section 3.2.3.

Note that the titles and authors are hyperlinks copied unchanged from the similar articles results in PubMed, i.e., this is the raw data and has not been reformatted into APA citations. Clicking on any one of these will cause the full citation and abstract of the paper to be displayed in a separate Web browser window.

Table A-2: SE Papers analyzed in Study #1, numbers of decision factors and QualSyst scores

<table>
<thead>
<tr>
<th>SE Paper title and authors</th>
<th>Seeds Matched</th>
<th>Number of Decision Factors</th>
<th>QualSyst Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acutely Bereaved Surrogates' Stories About the Decision to Limit Life Support in the ICU.; Nunez ER, Schenker Y, Joel ID, Reynolds CF 3rd, Dew MA, Arnold RM, Barnato AE.</td>
<td>12</td>
<td>6</td>
<td>0.82</td>
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<td>I don't want to be the one saying ‘we should just let him die’: intrapersonal tensions experienced ; Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB.</td>
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<td>Leveraging the lived experience of surrogate decision makers of the seriously ill to develop a dec.; Hickman RL Jr, Daly BJ, Clochesy JM, O'Brien J, Leuchtag M.</td>
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<td>Communicating with clinicians: the experiences of surrogate decision-makers for hospitalized older; Torke AM, Petronio S, Purnell CE, Sachs GA, Helft PR, Callahan CM.</td>
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<td>Decision conflict and regret among surrogate decision makers in the medical intensive care unit.; Miller JJ, Morris P, Files DC, Gower E, Young M.</td>
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<td>Doubt and belief in physicians' ability to prognosticate during critical illness: the perspective o; Zier LS, Burack JH, Micco G, Chipman AK, Frank JÁ, Luce JM, White DB.</td>
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<td>Making decisions for hospitalized older adults: ethical factors considered by family surrogates.; Fritsch J, Petronio S, Helft PR, Torke AM.</td>
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<td>Surviving surrogate decision-making: what helps and hampers the experience of making medical decisi; Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K.</td>
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<td>An empirical study of surrogates' preferred level of control over value-laden life support decision; Johnson SK, Bautista CA, Hong SY, Weissfeld L, White DB.</td>
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<td>Are physicians' recommendations to limit life support beneficial or burdensome? Bringing empirical evidence to clinical practice; White DB, Evans LR, Bautista CA, Luce JM, Lo B.</td>
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<td>Beyond substituted judgment: How surrogates navigate end-of-life decision-making; Vig EK, Taylor JS, Starks H, Hopley KE, Fryer-Edwards K.</td>
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<td>Conceptualizing surrogate decision making at end of life in the intensive care unit using cognitive dissonance theory; Dionne-Odom JN, Willis DG, Bakitas M, Crandall B, Grace PJ.</td>
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<td>Dimensions and Role-Specific Mediators of Surrogate Trust in the ICU.; Hutchison PJ, McLaughlin K, Corbridge T, Michelson KN, Emanuel L, Sporn PH, Crowley-Matoka M.</td>
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<td>The Voice of Surrogate Decision Makers: Family Responses to Prognostic Information in Chronic Critical Illness.; Nelson JE, Hanson LC, Keller KL, Caron SS, Cox CE, Tulsby JA, White DB, Chai EJ, Weiss SP, Danis M.</td>
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<td>Hope, truth, and preparing for death: perspectives of surrogate decision makers.; Apatira L, Boyd EA, Malvar G, Evans LR, Luce JM, Lo B, White DB.</td>
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<td>Surrogate decision makers and proxy ownership: challenges of privacy management in health care decision making.; Bute JJ, Petronio S, Torke AM.</td>
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<td>Surrogate decision makers' responses to physicians' predictions of medical futility.; Zier LS, Burack JH, Micco G, Chipman AK, Frank JA, White DB.</td>
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<td>Surrogates' perceptions about feeding tube placement decisions.; Lewis CL, Hanson LC, Golin C, Garrett JM, Cox CE, Jackman A, Phifer N, Carey TS.</td>
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<td>The process used by surrogate decision makers to withhold and withdraw life-sustaining measures in the ICU.; Limerick MH.</td>
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<td>Honoring patient care preferences: surrogates speak.; Buckey JW, Molina O.</td>
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<td>It's not just what the doctor tells me: factors that influence surrogate decision-makers' perception of medical futility.; Boyd EA, Lo B, Evans LR, Malvar G, Apatira L, Luce JM, White DB.</td>
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<td>Surrogate decision makers' interpretation of prognostic information: a mixed-methods study.; Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB.</td>
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<td><strong>It hurts to know... and it helps: exploring how surrogates in the ICU cope with prognostic inform:</strong> Schenker Y, White DB, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM.</td>
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<td><strong>Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty:</strong> Evans LR, Boyd EA, Malvar G, Apatira L, Luce JM, Lo B, White DB.</td>
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<td><strong>The surrogate's experience in authorizing a do not resuscitate order:</strong> Handy CM, Sulmasy DP, Merkel CK, Ury WA.</td>
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<td><strong>Families looking back: one year after discussion of withdrawal or withholding of life-sustaining su:</strong> Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA.</td>
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</table>
A4: QualSyst instrument

From Kmet et al. (2004)

Quantitative research instrument

1. Question or objective sufficiently described?
   
   **Yes**: Is easily identified in the introductory section (or first paragraph of methods). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific intervention(s) /association(s) /descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is not considered sufficiently described.

   **Partial**: Vaguely/incompletely reported (e.g. “describe the effect of” or “examine the role of” or “assess opinion on many issues” or “explore the general attitudes”...); or some information has to be gathered from parts of the paper other than the introduction/background/objective section.

   **No**: Question or objective is not reported, or is incomprehensible.

   **N/A**: Should not be checked for this question.

2. Design evident and appropriate to answer study question? (If the study question is not given, infer from the conclusions).
   
   **Yes**: Design is easily identified and is appropriate to address the study question / objective.

   **Partial**: Design and/or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question.

   **No**: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified.

   **N/A**: Should not be checked for this question.

3. Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.
   
   **Yes**: Described and appropriate. Selection strategy designed (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., “cancer” -- ICD code or equivalent should be provided). Studies of volunteers: methods and setting of recruitment reported. Surveys: sampling frame/strategy clearly described and appropriate.

   **Partial**: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as “volunteers” or “healthy volunteers”. Surveys: target population mentioned but sampling strategy unclear.

   **No**: No information provided. Or obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). Or presence of
selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study).

N/A: Descriptive case series/reports.

4. Subject (and comparison group, if applicable) characteristics or input variables/information sufficiently described?
   Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). Decision analyses: baseline estimates for input variables are clearly specified.

   Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). Or incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). Decision analyses: incomplete reporting of baseline estimates for input variables.

   No: No baseline / demographic information provided. Decision analyses: baseline estimates of input variables not given.

   N/A: Should not be checked for this question.

5. If random allocation to treatment group was possible, is it described?
   Yes: True randomization done - requires a description of the method used (e.g., use of random numbers).

   Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).

   No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).


6. If interventional and blinding of investigators to intervention was possible, is it reported?
   Yes: Blinding reported.

   Partial: Blinding reported but it is not clear who was blinded.

   No: Blinding would have been possible (and was possibly done) but is not reported.


7. If interventional and blinding of subjects to intervention was possible, is it reported?
   Yes: Blinding reported.

   Partial: Blinding reported but it is not clear who was blinded.

   No: Blinding would have been possible (and was possibly done) but is not reported.

8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?

Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, “objective” criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. Surveys: clear description (or reference to clear description) of questionnaire/interview content and response options. Decision analyses: sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, or not sure (i.e., not reported in detail, but probably acceptable). Or precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. Or instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). Surveys: description of questionnaire/interview content incomplete; response options unclear. Decision analyses: sources of uncertainty are defined only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. Or measures employ only ill-defined, subjective assessments, e.g. “anxiety” or “pain.” Or obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). Surveys: no description of questionnaire/interview content or response options. Decision analyses: sources of uncertainty are not defined for input variables.

N/A: Descriptive case series / reports

9. Sample size appropriate?

Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > 1⁄2 effect size) and/or problems with multiple testing are evident. Decision analyses: size of modeled cohort / number of iterations specified and justified.

Partial: Insufficient data to assess sample size (e.g., sample seems “small” and there is no mention of power/sample size/ effect size of interest and/or variance estimates aren’t provided). Or some statistically significant results with standard errors > 1⁄2 effect size (i.e., imprecise results). Or some statistically significant results in the absence of variance estimates. Decision analyses: incomplete description or justification of size of modeled cohort / number of iterations.

No: Obviously inadequate (e.g., statistically non-significant results and standard errors > 1⁄2 effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). Decision analyses: size of modeled cohort / number of iterations not specified.

N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. Analysis described and appropriate?

Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”) and appropriate.

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. Or minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). Or multiple testing problems not addressed.
No: Analysis methods not described and cannot be determined. Or obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). Or a study with a descriptive goal / objective is over-analyzed.

N/A: Descriptive case series / reports

11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/ objective upon which the conclusions are based)?

Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model.

Partial: Undefined “+/-” expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model.

No: No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis.

N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.

12. Controlled for confounding?

Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc.). Decision analyses: dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. Or control of confounding reportedly done but not completely described. Or randomized study without report of comparability of baseline characteristics. Or confounding not considered, but not likely to have seriously distorted the results. Decision analyses: incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. Decision analyses: dependencies between variables not considered.

N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. Results reported in sufficient detail?

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. Or difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or “n” changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data
14. Do the results support the conclusions?

**Yes:** All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren’t based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in addition to rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., “suggesting,” “possibly”).

**Partial:** Some of the major conclusions are supported by the data, some are not. Or speculative interpretations are not indicated as such. Or low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

**No:** None or a very small minority of the major conclusions are supported by the data. Or negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. Or conclusions are missing. Or extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

**N/A:** Should not be checked for this question.

---

**Qualitative research instrument**

Note: the N/A response is not allowed for any of the qualitative questions.

1. **Question / objective clearly described?**

   **Yes:** Research question or objective is clear by the end of the research process (if not at the outset).

   **Partial:** Research question or objective is vaguely/incompletely reported.

   **No:** Question or objective is not reported, or is incomprehensible.

2. **Design evident and appropriate to answer study question? (If question not clearly identified, infer appropriateness from conclusions.)**

   **Yes:** Design is easily identified and is appropriate to address the study question.

   **Partial:** Design is not clearly identified, but gross inappropriateness is not evident; or design is easily identified but a different method would have been more appropriate.

   **No:** Design used is not appropriate to the study question (e.g. a causal hypothesis is tested using qualitative methods); or design cannot be identified.

3. **Context for the study is clear?**

   **Yes:** The context/setting is adequately described, permitting the reader to relate the findings to other settings. Also is there evidence of the adaption and responsiveness of the research to the circumstances and issues of real-life social settings.

   **Partial:** The context/setting is partially described.

   **No:** The context/setting is not described.
4. Connection to a theoretical framework / wider body of knowledge?
   **Yes:** The theoretical framework/wider body of knowledge informing the study and the methods used is sufficiently described and justified.

   **Partial:** The theoretical framework/wider body of knowledge is not well described or justified; link to the study methods is not clear.

   **No:** Theoretical framework/wider body of knowledge is not discussed.

5. Sampling strategy described, relevant and justified?
   **Yes:** The sampling strategy is clearly described and justified. The sample includes the full range of relevant, possible cases/settings (i.e., more than simple convenience sampling), permitting conceptual (rather than statistical) generalizations.

   **Partial:** The sampling strategy is not completely described, or is not fully justified. Or the sample does not include the full range of relevant, possible cases/settings (i.e., includes a convenience sample only).

   **No:** Sampling strategy is not described.

6. Data collection methods clearly described and systematic?
   **Yes:** The data collection procedures are systematic, and clearly described, permitting an “audit trail” such that the procedures could be replicated.

   **Partial:** Data collection procedures are not clearly described; difficult to determine if systematic or replicable.

   **No:** Data collection procedures are not described.

7. Data analysis clearly described, complete and systematic?
   **Yes:** Systematic analytic methods are clearly described, permitting an “audit trail” such that the procedures could be replicated. The iteration between the data and the explanations for the data (i.e., the theory) is clear – it is apparent how early, simple classifications evolved into more sophisticated coding structures which then evolved into clearly defined concepts/explanations for the data). Sufficient data is provided to allow the reader to judge whether the interpretation offered is adequately supported by the data.

   **Partial:** Analytic methods are not fully described. Or the iterative link between data and theory is not clear.

   **No:** The analytic methods are not described. Or it is not apparent that a link to theory informs the analysis.

8. Use of verification procedure(s) to establish credibility of the study?
   **Yes:** One or more verification procedures were used to help establish credibility/ trustworthiness of the study (e.g., prolonged engagement in the field, triangulation, peer review or debriefing, negative case analysis, member checks, external audits/inter-rater reliability, “batch” analysis).

   **No:** Verification procedure(s) not evident.

9. Conclusions supported by the results?
   **Yes:** Sufficient original evidence supports the conclusions. A link to theory informs any claims of generalizability.

   **Partial:** The conclusions are only partly supported by the data. Or claims of generalizability are not supported.
No: The conclusions are not supported by the data. Or conclusions are absent.

10. Reflexivity of the account?

Yes: The researcher explicitly assessed the likely impact of their own personal characteristics (such as age, sex and professional status) and the methods used on the data obtained.

Partial: Possible sources of influence on the data obtained were mentioned, but the likely impact of the influence or influences was not discussed.

No: No evidence of reflexivity in the study report.
### B: Appendix – Study #2 Details

#### B1: Study #2 seed articles

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<thead>
<tr>
<th>Seed article citation</th>
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<tr>
<td>Cypress BS (2010). The intensive care unit: Experiences of patients, families, and their nurses. <em>Dimensions in Critical Care Nursing</em>, 29, 94–101</td>
<td>438</td>
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<tr>
<td>Scheunemann LP, Cunningham TV, ... White DB (2015). How clinicians discuss critically ill patients’ preferences and values with surrogates. <em>Critical Care Medicine</em>, 43(4), 757–764.</td>
<td>304</td>
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</table>
B2: SPR Papers analyzed in Study #2.

The following 52 SPR Papers met the inclusion/exclusion criteria of Section 4.1.1.1.

Note that the titles and authors are hyperlinks copied unchanged from the similar articles results in PubMed, i.e., this is the raw data and has not been reformatted into APA citations; PubMed also truncates both the title and the list of authors if either exceeds 99 characters. Clicking on any one of these will cause the full citation and abstract of the paper to be displayed in a separate Web browser window.

Table B-2: SPR Papers analyzed in Study #2

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<tr>
<td>A randomized trial of two methods to disclose prognosis to surrogate decision makers in intensive c; Lee Char SJ, Evans LR, Malvar GL, White DB.</td>
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<tr>
<td>Expanding the paradigm of the physician’s role in surrogate decision-making: an empirically derived; White DB, Malvar G, Karr J, Lo B, Curtis JR.</td>
<td>8</td>
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<tr>
<td>Health Care Professionals’ Responses to Religious or Spiritual Statements by Surrogate Decision Mak; Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB.</td>
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<tr>
<td>How clinicians discuss critically ill patients’ preferences and values with surrogates: an empirica; Scheunemann LP, Cunningham TV, Arnold RM, Buddadhumaruk P, White DB.</td>
<td>8</td>
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<tr>
<td>Investigating conflict in ICUs-is the clinicians’ perspective enough?; Schuster RA, Hong SY, Arnold RM, White DB.</td>
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<tr>
<td>Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate D; White DB, Ernecoff N, Buddadhumaruk P, Hong S, Weissfeld L, Curtis JR, Luce JM, Lo B.</td>
<td>8</td>
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<tr>
<td>Quality of communication in the ICU and surrogate’s understanding of prognosis.; Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB.</td>
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<tr>
<td>Critical care physicians’ approaches to negotiating with surrogate decision makers: a qualitative s; Brush DR, Brown CE, Alexander GC.</td>
<td>7</td>
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<tr>
<td>Factors that contribute to physician variability in decisions to limit life support in the ICU: a q; Wilson ME, Rhudy LM, Ballinger BA, Tescher AN, Pickering BW, Gajic O.</td>
<td>7</td>
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<tr>
<td>What Families Need and Physicians Deliver: Contrasting Communication Preferences Between Surrogate ; Quinn T, Moskowitz J, Khan MW, Shutter L, Goldberg R, Col N, Mazor KM, Muehlschlegel S.</td>
<td>7</td>
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<tr>
<td>A multicenter study of key stakeholders’ perspectives on communicating with surrogates about prognosis; Anderson WG, Cimino JW, Ernecoff NC, Ungar A, Shotsberger KJ, Pollice LA, Buddadhumaruk P, Carson S.</td>
<td>6</td>
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<tr>
<td>Communication of prognostic information for critically ill patients.; LeClaire MM, Oakes JM, Weinert CR.</td>
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<tr>
<td>How do clinicians prepare family members for the role of surrogate decision-maker?; Cunningham TV, Scheunemann LP, Arnold RM, White D.</td>
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<tr>
<td>Physician Approaches to Conflict with Families Surrounding End-of-Life Decision-making in the Inten; Mehter HM, McCannon JB, Clark JA, Wiener RS.</td>
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<tr>
<td>Recommendations to limit life support: a national survey of critical care physicians.; Brush DR, Rasinski KA, Hall JB, Alexander GC.</td>
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<tr>
<td>The Influence of Surrogate Decision Makers on Clinical Decision Making for Critically Ill Adults.; Shah RD, Rasinski KA, Alexander GC.</td>
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<tr>
<td>Withholding and withdrawing of life support from patients with severe head injury.; O'Callahan JG, Fink C, Pitts LH, Luce JM.</td>
<td>6</td>
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<tr>
<td>Conflict Management Strategies in the ICU Differ Between Palliative Care Specialists and Intensivists; Chiarchiaro J, White DB, Ernecoff NC, Buddadhumaruk P, Schuster RA, Arnold RM.</td>
<td>5</td>
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<tr>
<td>Decision proposals in the family conference.; Pecanac KE, Brown RL.</td>
<td>5</td>
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<tr>
<td>Do physicians disclose uncertainty when discussing prognosis in grave critical illness?; Schuster RA, Hong SY, Arnold RM, White DB.</td>
<td>5</td>
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<tr>
<td>Empathy and life support decisions in intensive care units.; Selph RB, Shiang J, Engelberg R, Curtis JR, White DB.</td>
<td>5</td>
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<tr>
<td>Finding common ground to achieve a &quot;good death&quot;: family physicians working with substitute decision; Tan A, Manca D.</td>
<td>5</td>
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<td>Numeracy and Interpretation of Prognostic Estimates in Intracerebral Hemorrhage Among Surrogate Decision Makers; Leiter N, Motta M, Reed RM, Adeyeye T, Wiegand DL, Shah NG, Verceles AC, Netzer G.</td>
<td>5</td>
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<td>Physicians' decision-making roles for an acutely unstable critically and terminally ill patient.; Uy J, White DB, Mohan D, Arnold RM, Barnato AE.</td>
<td>5</td>
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<td>Prognostication during physician-family discussions about limiting life support in intensive care unit.; White DB, Engelberg RA, Wenrich MD, Lo B, Curtis JR.</td>
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<td>The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment; Barnato AE, Arnold RM.</td>
<td>5</td>
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<td>Understanding Goals of Care Statements and Preferences among Patients and Their Surrogates in the Medical Intensive Care Unit.; Brandt DS, Shinkunas LA, Gehlbach TG, Kaldjian LC.</td>
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<tr>
<td>Association between physicians' beliefs and the option of comfort care for critically ill patients.; Schenker Y, Tiver GA, Hong SY, White DB.</td>
<td>4</td>
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<tr>
<td>Communicating Delicately: Introducing the Need to Make a Decision About the Use of Life-Sustaining Care.; Pecanac KE.</td>
<td>4</td>
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<tr>
<td>Complexity Analysis of Decision-Making in the Critically Ill.; Daly BJ, Douglas SL, O'Toole E, Rowbottom J, Hoffer A, Lipson AR, Burant C.</td>
<td>4</td>
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<tr>
<td>Conflict associated with decisions to limit life-sustaining treatment in intensive care units.; Breen CM, Abernethy AP, Abbott KH, Tulsky JA.</td>
<td>4</td>
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<td>Contradictions and communication strategies during end-of-life decision making in the intensive care unit.; Hsieh HF, Shannon SE, Curtis JR.</td>
<td>4</td>
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<tr>
<td>Expressions of nonabandonment during the intensive care unit family conference.; West HF, Engelberg RA, Wenrich MD, Curtis JR.</td>
<td>4</td>
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<tr>
<td>Identifying family members who may struggle in the role of surrogate decision maker.; Majesko A, Hong SY, Weissfeld L, White DB.</td>
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<td>SPR Paper title and authors</td>
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<td>Intensivist-reported Facilitators and Barriers to Discussing Post-Discharge Outcomes with</td>
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<td>Intensive; Turnbull AE, Davis WE, Needham DM, White DB, Eakin MN.</td>
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<td>Missed opportunities during family conferences about end-of-life care in the intensive care</td>
<td>4</td>
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<tr>
<td>unit.; Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD.</td>
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<tr>
<td>Understanding Early Decisions to Withdraw Life-Sustaining Therapy in Cardiac Arrest Survivors.</td>
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<td>AQu; Dale CM, Sinuff T, Morrison LJ, Golan E, Scales DC.</td>
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<td>Barriers to goals of care discussions with seriously ill hospitalized patients and their</td>
<td>3</td>
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<td>families: You JJ, Downar J, Fowler RA, Lamontagne F, Ma IW, Jayaraman D, Kryworuchko J,</td>
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<td>Strachan PH, Ilan R.</td>
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<tr>
<td>Changing the culture around end-of-life care in the trauma intensive care unit.; Mosenthal</td>
<td>3</td>
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<tr>
<td>AC, Murphy PA, Barker LK, Lavery R, Retano A, Livingston DH.</td>
<td></td>
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<tr>
<td>Conflict in the care of patients with prolonged stay in the ICU: types, sources, and</td>
<td>3</td>
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<tr>
<td>predictors.; Studdert DM, Mello MM, Burns JP, Puopolo AL, Galper BZ, Truog RD, Brennan TA.</td>
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<tr>
<td>Decisions about life-sustaining treatment. Impact of physicians' behaviors on the family.;</td>
<td>3</td>
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<td>Tilden VP, Tolle SW, Garland MJ, Nelson CA.</td>
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<td>Empowering the &quot;Cheerers&quot;: Role of Surgical Intensive Care Unit Nurses in Enhancing Family</td>
<td>3</td>
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<td>Resilience; Ellis L, Gergen J, Wohlæmuth L, Nolan MT, Aslaksen R.</td>
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<tr>
<td>Expectations and outcomes of prolonged mechanical ventilation.; Cox CE, Martinu T, Sathy SJ,</td>
<td>3</td>
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<td>Clay AS, Chia J, Gray AL, Olsen MK, Govert JA, Carson SS, Tulsky JA.</td>
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<tr>
<td>Intensive care nurses' and physicians' experiences with demands for treatment: some</td>
<td>3</td>
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<td>implications for; Workman S, McKeever P, Harvey W, Singer PA.</td>
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<tr>
<td>Neglect of quality-of-life considerations in intensive care unit family meetings for long-stay</td>
<td>3</td>
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<td>inte; Douglas SL, Daly BJ, Lipson AR.</td>
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<td>Resident physician interactions with surrogate decision-makers: the resident experience.;</td>
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<td>Reckrey JM, McKee MD, Sanders JJ, Lipman HI.</td>
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<tr>
<td>Results of a clinical trial on care improvement for the critically ill.; Burns JP, Mello MM,</td>
<td>3</td>
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<tr>
<td>Studdert DM, Puopolo AL, Truog RD, Brennan TA.</td>
<td></td>
</tr>
<tr>
<td>Substituted judgment in principle and practice: a national physician survey.; Combs MP,</td>
<td>3</td>
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<td>Rasinski KA, Yoon JD, Curlin FA.</td>
<td></td>
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<tr>
<td>The Family Navigator: A Pilot Intervention to Support Intensive Care Unit Family Surrogates.;</td>
<td>3</td>
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<td>Torke AM, Wocial LD, Johns SA, Sachs GA, Callahan CM, Bosslet GT, Slaven JE, Perkins SM,</td>
<td></td>
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<td>Hickman SE.</td>
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<td>Toward shared decision making at the end of life in intensive care units: opportunities for</td>
<td>3</td>
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<td>improve; White DB, Braddock CH 3rd, Bereknyei S, Curtis JR.</td>
<td></td>
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<tr>
<td>Who is attending? End-of-life decision making in the intensive care unit.; Baggs JG, Schmitt</td>
<td>3</td>
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<td>MH, Prendergast TJ, Norton SA, Sellers CR, Quinn JR, Press N.</td>
<td></td>
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