Practices to Reduce Physician-Family Conflict during Surrogate Decision Making

by
Katherine Paige Polte

A THESIS

submitted to

Oregon State University

Honors College

in partial fulfillment of
the requirements for the
degree of

Honors Baccalaureate of Science in Biology
(Honors Scholar)

Presented May 25, 2022
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AN ABSTRACT OF THE THESIS OF

Katherine Paige Polte for the degree of Honors Baccalaureate of Science in Biology presented on May 25, 2022. Title: Practices to Reduce Physician-Family Conflict during Surrogate Decision Making.

Abstract approved:_

Courtney Campbell

This thesis aims to investigate the reasons for discordance in the physician-family relationship, to explore how to improve that relationship, and to develop a set of practices to help prevent conflicts. The research was done by analyzing research on surrogate decision making, conflicts surrounding end of life, and case studies. I found that communication is extremely important to reducing conflicts, as is respect and use of appropriate communication strategies. Two sets of practices were developed, one for writing advance directives, and one for preventing conflicts. The set of practices for writing advance directives is; 1) begin end of life planning early, 2) include surrogate(s), physicians, and anyone else who will be participating in decision making in the planning process, and 3) advance directives should include how strictly the surrogate(s) are to follow them. The set of practices for reducing conflicts is; 1) be respectful of the family and their choices, 2) communication with the family should begin early and happen often, and 3) ensure communication strategies are appropriate for the situation. The research though thorough, would have been much improved by interviewing physicians and families and determining their perspectives on such situations.

Keywords: physician, family, conflict, communication, end of life

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Honors Baccalaureate of Science in Biology project of Katherine Paige Polte presented on May 25, 2022.

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

Katherine Paige Polte, Author

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Chapter 1: Introduction

A family joins hands around an ICU bed and prays as the machines beep steadily in the background, they hold the hands of the woman lying there, but she gives no indication she knows they are there. After suffering a cardiac arrest on the way to the hospital Selena can no longer speak, or even open her eyes; she is entirely reliant on the machines to keep her alive. Selena's physicians do not expect her to "wake up from this in a meaningful way", but her family has not given up hope. Wearing her large dark sunglasses like a shield, Selena's daughter says to her mother's physician, "Even though my mom is in this situation it would feel like murder to pull her life support". When the physician asks her what her mother would have wanted in this situation she says, "My mom already made her decision and that's how come her heart is still beating. She can go at any time, but she knows to stay here because she loves me. If I were to pull that life support, there would be no me". However, Selena's physician, Dr. Zitter has a difficult time supporting any further interventions in Selena's case. In a meeting with Selena's brothers, in response to a question about what else could be done she says, "Everyday people with very poor neurological prognosis are attached permanently to machines and, unfortunately, it's very hard, emotionally, for us physicians when we feel that we're taking a body and we're just, we're keeping it alive when it's not really the person". Later while talking another physician Dr. Zitter expresses fears that any further interventions would only cause Selena more suffering without any benefit (Krauss).

Selena's case is explored in the Netflix documentary *Extremis*. Selena and her family are in a situation that many people may face. As medical technology gets better, it has become able to support people who would have otherwise died, forcing families to decide if they want to let the patient die or continue living attached to machines (Hsieh et al., p.294). Her case is also a good example of how the relationship between a patient’s family and their physician can become fraught when the patient can no longer communicate. Any decision making in regard to patient care becomes more difficult when the patient cannot advocate for themselves. In situations like these the patient’s family, or another surrogate, and the patient’s physicians must work together to ensure the patient receives the best and most appropriate care. However, as illustrated by Selena’s case, there are many situations in which the patient's family and the patient’s physician fundamentally disagree on what decision to make, which can make the appropriate course of action unclear.

Significance

I have experienced this from both the perspective of a healthcare worker and a family member. In my time working in a dementia care facility, I had the chance to work with a gentleman with pain from bone spurs in his legs whose family refused to seek hospice care, which meant that our nurse could not give him certain pain medications. Seeing him in such pain that he could not stand, pain so severe that even helping him get his legs up into bed could be bad enough to trigger hallucinations was truly awful. Not being able to do anything was torture. But I have also seen the other side. At the end of my grandpa’s life, he collapsed and ended up in the ICU while physicians tried to determine if he would be able to recover. This was during spring 2021 so due to the COVID-19 pandemic no one could visit him or discuss his prognosis with his physicians in person. This led to extremely poor communication between my family and his physicians, causing some animosity toward the physicians from my family, and adding unnecessary stress.

The relationship between a patient’s physician and their family is often overlooked, but it is becoming increasingly important. Many people die in ICUs, and the majority of them are unable to communicate, and as medical technology improves this will only become more common (Hseih et al., p.294). In these situations, the relationship between the family and the physician becomes the most important in order to ensure the patient is cared for appropriately. However, navigating end of life decision making is complicated and can often result in conflicts. A study by Breen et al., found that as many as 48% of cases where reduction of care is considered result in conflicts between the patient's family and their physician (p. 283). These conflicts only make an already upsetting time for the family more challenging. Establishing a good physician-family relationship is important to minimize stress for all involved, and to maintain a strong line of communication so that any decision making can be dealt with appropriately. In this thesis I will look to find a set of practices that can be applied to end of life surrogate decision making to ease the decision making process and prevent conflict between the physician and their patient's family.

Expected Results

The aim of this thesis is to investigate the reasons for discordance in the physician-family relationship, and to explore how to improve the relationship so that the patient can receive the best quality of care. In researching this subject, I expect to find that better communication and a closer relationship between a patient's family and physician will help to prevent conflict and make decision making easier. I also expect to find that respect for the family's decisions, even when the physicians disagree with them, will help to strengthen the relationship. I anticipate learning that one of the best ways to prevent conflicts in end of life decision making is to discuss with the patient in advance what they want at the end of life, and to document it either in the form of an advance directive or some other form of end of life planning. However, I also expect to find that there are significant barriers to these conversations and will look for strategies both physicians and families can employ to begin these conversations.

Methodology

I will approach research into this subject by analyzing the currently available literature on end of life decision making and conflicts between families and physicians, as well as by looking at case studies of end of life decision making from the American Medical Association (AMA) *Journal of Ethics* and various documentaries. In the second chapter of this thesis, I will look at research on communication in the ICU, sources of conflict and resolution strategies, cultural and religious differences and how they can contribute to conflicts, decision making standards, and advance directives. I will find research on these topics by looking at paper recommended by my mentor Dr. Campbell, or by simply entering phrases like, "physician-family relationship", "physician-family conflict", and "physician-family communication" into the Google Scholar search engine and looking at the first few articles that come up. I will also include a few case studies that show the importance of these issues and offer insight into how to improve physician family communication. I will find these case studies by looking at the case studies available of the AMA *Journal of Ethics* website or in documentaries recommended by Dr. Campbell. The goal of chapter two is to build a research-based rationale behind the practices I will propose to improve the relationship between a patient's family and physician and prevent conflict.

In chapter three, I will present a case study and analyze it using the moral deliberation process. I will also present a set of practices addressing how to best write an advance directive, developed from the research reviewed in chapter two. I will also discuss the difficulties that discourage people from discussing end of life planning and will give some suggestions for both physicians and families on how to start an end of life conversation. I will also present a set of principles that physicians can apply to prevent conflict during surrogate decision making, also developed from the research reviewed in chapter two.

End of life decision making is complex, emotionally charged, and stressful. The ultimate goal is to help the patient die the way that they want to. When the patient is no longer able to communicate that mission remains the same, and it is vital that the patient's family and their physician are able to work together and make the appropriate decision for the patient. Preventing conflict and promoting communication are important to helping all decision makers come to the best decision, and this thesis hopes to help improve that process.

Chapter 2: Literature Review

This chapter will explore current literature regarding end of life decision making and the relationship between physicians and their patient's surrogate decision makers. First it will look at a paper that shows how improved communication can reduce the number of days patients at the end of life spend in the ICU (Lilly et al., pg. 469). Then it will examine research that describes the common conflicts that arise between physicians and patient surrogates, and physician strategies for handling them. Next this chapter will look at research detailing how conflicts can be exacerbated by cultural or religious differences, and some suggestions about how to handle those situations. And finally, it will analyze research about the importance of advance directives, problems with advance directives, an approach to advance directives that looks to limit problems, as well as how to begin conversations about end of life planning. Throughout the chapter there will be case studies to demonstrate the importance of these issues and give examples of how conflicts between physicians and families are resolved.

Communication and the ICU

In the US, 1 in 5 people will die in an ICU, and the vast majority of them will be unable to communicate and will have to rely on surrogate decision makers and physicians to make decisions on their behalf (Hsieh et al., p.294). One of the most challenging decisions physicians and patient surrogates may face is the decision to withdraw supportive technology when it is unlikely to improve the patient's condition. Often this decision is supported by physicians whereas surrogates are less likely to support it (Hsieh et al., pg. 297). Conflict surrounding refusal to stop supportive treatment when there is not reasonable likelihood it will improve patient condition or return function can result in stress and pain for the patient, stress for healthcare workers caring for the patient, and prolonged ICU stays (Lilly et al., pg. 469). A study by Lilly et al., looked at improving communication between physicians, patients, and their surrogates to reduce the length of stays in the ICU, without increasing mortality (p.469). The study compared the length of stay, mortality, and the amount of conflict between families and physicians for patients receiving usual care versus patients receiving a more extensive and proactive method of communication. Their experimental communication method included meeting with the patient’s physician, nurses, family, and the patient if they could participate, within 72 hours of admission to the ICU, subsequent meetings with the family, and weekly case review with the physician, nurses, social workers, and chaplains (Lilly et al., pp.469-470).

In the first meeting the physicians and families were tasked with reviewing the medical condition of the patient, discussing the patient's views on death and intensive medical care, coming up with a care plan, and agreeing on how to determine the success or failure of the care plan. The later meetings with family were held after the plan had either been successful or unsuccessful, and the same procedure was repeated, coming up with a new plan while taking into account the patient’s wishes. The researchers determined the amount of conflict between family and physician by having physicians keep track of every day where there was a disagreement between the physician and the patient's family about what the long-term goal should be; this was then reviewed by a nurse who was not involved in the case. The study found that the median length of ICU stay decreased from 4 days (2-11 days) to 3 days (2-6 days), and mortality rates did not change. They also found that the number of days with family-physician conflict decreased from 65 per 1000 days with usual care to 4 per 1000 days with the intensive communication technique. The study is clear: earlier and more extensive communication between physicians and surrogates decreases length of stay in the ICU and limits disagreements between physicians and surrogates as well as between surrogates themselves (Lilly et al., pp. 469-472).

Sources of Conflict and Resolution Strategies

Key to improving communication between surrogates and physicians is understanding where disagreements arise, what strategies physicians use to dispel them, and which strategies are most effective. A study by Hsieh et al., explored these issues (p.294). Using the dialectical perspective, they analyzed 51 family conferences in which the physician would be broaching the subject of limiting or reducing care for a patient at the end of their life. The dialectical perspective is a way of looking at communication and relationships; it theorizes that every idea has two oppositional forces that are inseparable, called contradictions, and that communication strategies are used to manage these contradictions. While analyzing the family conferences, the study identified five contradictions that arose when limiting life support was discussed; 1) killing vs. allowing to die, 2) death as a benefit to the patient vs. as a burden to the family, 3) honoring patient’s wishes vs. following the family's wishes, 4) contradictory wishes from the patient, and 5) individual decision-maker vs. group decision-making. The killing vs. allowing to die contradiction was brought up in nine conferences and explores the moral dilemma of whether removal of life support is killing the patient or allowing them to die. The study found that only family members ever referred to removal of life support as killing, while all physicians framed it as allowing the patient to die. The second contradiction is a way of looking at the effects of the patient’s death, that, as a benefit to the patient as their suffering would end but also as an emotional burden to the family. This contradiction was discussed in 33 conferences. The most commonly raised contradiction was the third contradiction; honoring the patient’s wishes vs following the family’s wishes. Typically, the family wanted to continue life support while the patient’s previously stated wishes indicated they would not want that. The fourth contradiction was only raised once, a man told his family he wanted life support but told healthcare workers he did not. The final contradiction was about who should be the final decision maker for the patient, a single individual or the family as a whole. Families and physicians alike seemed least comfortable discussing the killing vs. allowing to die contradiction. If it was brought up, it was at the end of the conference and the discussions were brief and highly emotional (Hseih et al., p.294-299).

The communication strategies used by the clinicians in the conferences were categorized as either decision centered or information seeking. The decision centered strategies were: arguing against, arguing for, and avoiding. The arguing for and against strategies are straight forward; the physician was either arguing for or against one side of the contradiction. In the avoiding strategy the physician simply avoided discussing the contradiction at all by changing the subject. This strategy did not help to encourage decision making and can prevent or delay it. The information seeking strategies were acknowledging, clarifying, recentering, reaffirming, recalibration, and segmenting. The acknowledging strategy is when the physician clearly acknowledges both sides of the contradiction. Clarifying is when the physician asks questions aimed at learning more about the family’s thoughts on a contradiction; physicians used statements like “‘Tell us…’” in an effort to continue discussion. The recentering strategy was used to help families see the situation from the patient’s point of view, directing them to consider what the patient would say if they could communicate. Reaffirming was a strategy used at the end of conferences to restate the contradiction, reiterate that it would not disappear, and that the family needed to continue to think about it. Recalibrating is when the physician rephrases the contradiction so that the two sides do not seem conflicting. The segmenting strategy is when the physician breaks one decision into smaller decisions and gathers from family how they feel about the smaller decisions. The study found that when families have arrived at a decision, the best communication strategy to prevent conflict is the decision centered approach, to show support for the choice. When the families are still actively struggling with the decision it is best to use information seeking strategies to help the family think through their decision (Hseih et al., p.299-302). By using the most appropriate communication strategies physicians can help families come to a decision about their loved one's end of life care.

However, since the family's decision is not always the one the medical team supports, how physicians navigate these conflicts impacts the family physician relationship. A study by Mehter et al., looked at the approaches ICU physicians apply in conflicts with families about end of life decisions (p.241). The authors asked 18 ICU physicians about how they handle conflicts in semi-structured interviews. The physicians all reported experiencing conflict with patient surrogates, and in all instances the patient surrogate(s) wanted to continue aggressive care while the physicians did not. The study focused on the family meeting, where conflict is most likely to occur, as well as the interactions between family and the physician before and after the meeting. Before the meeting, most physicians reported "sizing up" the family, which included asking nurses about the family and speaking to the family in non-formal settings. This "sizing up" is used to determine the physician's approach in the meeting and to gauge if there will be conflict. If conflict happens during the meeting, the physicians interviewed gave two different approaches to managing it, either acquiesce to the family and do what they want, or attempt to persuade them. Those who acquiesced to families did so citing respecting autonomy as the most important ethical principle. One physician said, "With the right to make decisions comes the right to make what I think are bad decisions, but they are not my decisions to make". Physicians were more likely to acquiesce to the family’s wishes if they felt the family were unlikely to change their mind. The physicians who tried to persuade families said they did so because they felt the families did not understand or accept the gravity of the patient’s condition, and because they felt they needed to advocate for the patient. They also said they were more likely to try to persuade the family if they felt the family was doing a poor job of implementing substituted judgment, or if the patient was suffering significantly (Mehter et al., 2018 p. 242-244).

The study found three methods of persuasion: “pushing hard”, “biding time”, and “changing the conversation”. “Pushing hard” consists of describing the ill effects of aggressive care in detail, or making it seem like the physician’s opinion is what must be done (Mehter et al., p. 244). The “biding time” method of persuasion allows families some time to come to terms with the patient’s prognosis and over the course of multiple family meetings convinces them to ease up on care, similar to the experimental communication method used in the study by Lilly et al., (p.469, Mehter et al., p. 244). “Changing the conversation” is when the physician attempts to persuade the family by highlighting the number of things that have already been done for the patient and the patient's suffering. The more aggressive persuasion tactics were described as potentially counterproductive by the authors as they risk increasing tension and creating distrust. The study found that many of the methods physicians were using were consistent with recommended ways to approach end of life conflicts: allowing the family time to come to terms with the patient’s condition, making recommendations, and taking on some of the decision making burden if the family wants them to. The study concluded that physicians valued family relationships and worked hard to maintain, and if necessary, repair them; at the same time, they often focused on getting the decision that the health care team supported (Mehter et al., p. 244-247). It is unrealistic and unethical to expect physicians to always concede to the family when they make a decision the medical team disagrees with, but any effort to persuade the family should not negatively impact the family-physician relationship.

One of the most difficult conflicts for physicians and families is the killing vs. allowing to die contradiction. It is emotionally charged, controversial, and many people are simply uncomfortable talking about it because cultural norms discourage talking about death. The paper by Hsieh et al., showed that while most physicians see removing a patient from life support as allowing them to die and a compassionate action, while family members may view it as actively killing the patient (p. 297). A case study in AMA *Journal of Ethics* explores this exact situation. A 46 year old mother went into cardiac arrest while at home. She was resuscitated by paramedics but experienced brain damage due to lack of oxygen (Prager, p. 1022). Her 20 year old daughter asked that everything be done for her, and she was admitted to the ICU where she remained for two months. Her brain function did not improve, and her overall condition only worsened. The physicians concluded that further treatment would be futile and were beginning to feel they were violating the do no harm principle by continuing aggressive treatment. However, her daughter refused to consider or discuss end of life care, withdrawing any support, or giving DNR status, saying, "'My mom gave me life, how can I take hers away?'" (Prager, p. 1022).

The commentary for this case argues that continuing life support is not necessarily violating the do no harm principle because there is no proof the mother is in any pain, as she is deeply sedated. Prager also points out that the determination of "futile" only means something in the context of the treatment goal. If the goal is to restore her to her previous mental and physical state, continued treatment is futile, however the daughter's goal seems to be to keep her alive as long as possible (Prager, p. 1022). In this situation, as it is clear that the daughter has made up her mind; the papers from Hsieh et al. and Mehter et al. both suggest that at this point trying to aggressively push the view of the medical team would do nothing but damage their relationship with the daughter (Hsieh et al., p.302, Mehter et al., p.247). It would be more appropriate to adopt the experimental communication technique discussed in the paper by Lilly et al., so the physician and daughter could slowly work towards a goal for her mother's care instead of having it remain up in the air indefinitely (p.469).

Impact of Cultural and Religious Differences

Surrogate decision making can be further complicated when the patient and their family are an ethnic minority in the hospital where they are receiving treatment (Van Keer et al., p.2). A study in a Belgian hospital looked at conflicts between the healthcare workers and patients' families who were originally from North Africa, Turkey, Central Africa, and Southern Europe, all ethnic minorities in Belgium. The hospital where the study took place is described as "multi-ethnic and urban", though of all the healthcare workers involved in the cases reviewed were part of the majority ethnic group. The study found that conflicts tended to revolve around what families and physicians considered to be "good care". Both families and physicians wanted the patient to receive the best possible care, but healthcare staff were more focused on biomedical care, while the families were focused on the patient's biomedical care, as well as the psychological, social, and religious needs of the patient and other family members. This is likely true whether the family is from the majority or a minority ethnic group, but because of cultural differences in values, religion, communication methods, and behavior conflicts were likely to arise between family and healthcare staff (Van Keer et al., pp.1-10).

The study found that compared to decision making between healthcare workers and families of the same ethnicity, decision making between healthcare workers and families of different ethnicities tends to have more conflicts during all phases of care. The authors suggest that preventing conflict in earlier phases of care will help end of life decision making go more smoothly. The study found that ethno-cultural differences only seemed to cause further conflict in environments where the ICU's policies did not support them. The authors explain that educating healthcare workers on cultural respect and improving their communication skills is not adequate if the ICU policies do not allow for respect of cultural differences. Examples of this are policies that severely restrict who the physician may discuss the patient's care with, visitor limitations, and limits on who may participate in the patient's care. The authors suggest changing ICU policies like these in order to improve communication between healthcare workers and families and reduce the number of conflicts stemming from cultural differences (Van Keer et al., pp.10- 11).

Another factor that can cause conflicts in end of life decision making is religion. Some religions do not see brain death as true death and would like the person to be kept on life support until their breathing stops (Weiner and Sheer, p.996). Other religions insist on continued aggressive care in the hopes of a miracle, or refusal to give up faith, or belief that every moment of life should be preserved, or that suffering is redemptive (Brett and Jersild, p.1645). When a patient and their family practice a religion that has these beliefs it can create many opportunities for conflict with the patient's physician and other healthcare workers. When talking about situations where the family does not consider brain death to be death, not only do many healthcare workers disagree philosophically with this belief, it can be understandably upsetting to have to continue to treat someone who, from their perspective, is a corpse (Weiner and Sheer, p.996). Additionally, there will likely be pressure from hospital administration to remove the patient from life support because hospitals cannot charge insurance with the cost of keeping a brain dead person on life support, and usually pay for it themselves (Weiner and Sheer, p.998).

A case study from AMA *Journal of Ethics* looks at a case where the patient's religion does not acknowledge brain death as death. This particular case focuses on an Orthodox Jewish man who became brain dead following a brain hemorrhage. In Orthodox Judaism, religious law dictates that people are still alive until their breathing stops, so families will usually want to keep brain dead patients on life support even with full knowledge that they will never recover. This case study is accompanied by commentary from two rabbis who recommend that in situations like this the most important things to do are to listen to the families, practice cultural humility, and involve religious leadership. Rabbi Weiner explains that in these cases finding a way to compromise is often best. He points out that while Orthodox Jewish law prohibits withdrawing support; many Orthodox Jewish scholars interpret that withholding support is allowed. This interpretation allows the breathing of brain dead patients to stop by not adding any additional medical support, a method often referred to as "do not escalate" or DNE. Both rabbis stress the importance of communication in these situations; respectful communication between the physician, family and religious leadership are all crucial to prevent conflicts (Weiner and Sheer, p. 996-997).

A different case study from *JAMA Internal Medicine* discusses typically Christian reasons for wanting aggressive medical care continued near the end of life. The article focuses on specifically American Christian religious reasoning and explains that there are four categories of reasoning for insisting on aggressive care near the end of life, 1) hope for a miracle, 2) refusal to give up faith in God, 3) conviction that life needs to be preserved at all costs, and 4) the redemptive value of suffering. The authors explain that religious reasoning like this can often frustrate physicians and other healthcare workers because it is seen as a "trump card" that they cannot argue against and prevents any further discussion. This resentment and frustration can lead to conflict between physicians and families, as many physicians will view continuing treatment on a patient who is near the end of life as over-treatment and violating the do no harm and beneficence ethical principles (Brett and Jersild, pp.1645-1646).

The authors of this article note that physician-family conflicts stemming from religious beliefs are most likely to occur when there is a situation necessitating surrogate decision makers. They explain that this can result in religious-based reasoning made by a surrogate decision maker that is inauthentic and made without respect for the patient's own beliefs. However, the authors say that no matter the situation, communication, compassion, and respect for the family's beliefs are important, as is getting religious leadership involved. They also recommend that the physician familiarize themselves with the patient and family's specific beliefs to better understand their perspective. The authors advise encouraging active discussion and ensuring that families understand the gravity of the patient's diagnosis. They conclude that physicians should not simply give in to the religious reasoning that families give for wanting inappropriate medical treatment, but that they should keep discussion open and work alongside religious leaders to help the patient receive reasonable care (Brett and Jersild, pp.1646-1648).

Decision-Making Standards

The literature reviewed thus far has stressed the importance of communication, and that open communication helps reduce conflicts and makes end of life decision making go more smoothly. However, yet to be discussed is how the surrogate decision making process usually works. An article by Lang and Quill explains how end of life plans are made when the patient cannot communicate and there is not an advance directive (p.719). The article begins by explaining that since advance directives are not common-- only 20% of patients who lose decision making capacity have one-- decision making often falls to the family and physicians.

End of life discussions are incredibly complex and emotional, but it is vital that they happen. The article offers a set of strategies to help conduct these discussions in a way that minimizes tensions and helps to ensure the known preferences of the patient are as closely adhered to as possible.

The first step the authors recommend physicians take is to determine who has “final say”. In some states, the law defines who should be the final decision maker, in others there is no legal guidance, in which case the most common hierarchy is spouse, adult children, and then parents. However, the authors note that the goal is to try to adhere to the patient's values, and next of kin may not always be the best source for this information. The authors then say physicians should emphasize the difference between substituted judgment and best interest decisions. Substituted judgment is using the patient’s values to make a decision on their behalf, and is the goal. Best interest decisions are made using the family members' own values, and what they believe is in the best interest of the patient (Lang and Quill, pp.719-720).

The next step is to make sure the family understands the patient's condition and prognosis, and physicians should be prepared to offer emotional support during this. The physician can then discuss the range of possible decisions; this will differ from case to case, but it is important the family understands what options there are. The authors then recommend talking with the family to determine the patient’s values regarding quality of life and biomedical interventions, and to build a care plan from this. Lang and Quill suggest offering a range of options for the patient that span from maximal supportive care with the goal of comfortable death to maximal therapeutic care with the goal of maintaining life. It is also important for physicians to be aware of the legality of the procedures and decisions being made, as different states have different requirements for withdrawal of care. The authors then discuss some important aspects of communication; they stress building a rapport with the family, actively responding and listening to emotions, and trying to avoid or dispel feelings of guilt in the family members. It is important that the physician frames decision making in the context of the patient’s values, and to give recommendations accordingly (Lang and Quill pp.720-721). The recommendations of these authors very much follow the standard biomedical ethical decision making process.

Ethical theory is clear about how surrogate decision making ought to go. Currently, most laws, hospital policies, and bioethics textbooks agree that in situations where a surrogate decision maker is necessary, there is a hierarchy of decision making standards that should be followed (Berger et al., p.48). Decisions should be first based on the patient's own wishes, expressed in legally binding documents or otherwise documented in some capacity. If the patient’s express wishes are not known, the decisions should be based on substituted judgment, and if no one is able to provide substituted judgment, then decisions should simply be made in the best interest of the patient. As straightforward and fair as this seems, it is not always what patients, their families, or physicians feel is the correct course. A paper by Berger et al., explains that studies have found that patients, surrogates, and physicians often diverge from the standard decision making hierarchy. This is not that surprising as the standard hierarchy has a few flaws. One of the more glaring issues is that this method of decision making is based on a very western, highly individualistic idea of personal autonomy. In many cultures the line between what the western world defines as the individual and family is blurred; a Pakistani commentator explains that in Pakistani culture, “‘you are your family and your family is you’”. It is difficult for families who hold this value to adhere to the western standard that only the patient's wishes should be considered and attempts to force this can lead to conflicts (Berger et al., pp. 48-50).

Another issue with the standard decision making hierarchy that Berger et al. points out is that it relies very heavily on substituted judgment. Most people do not have advance directives, and so in most cases surrogates are asked to use substituted judgment to make decisions on behalf of the patient. However, Berger et al., explain that often surrogates fail to apply it correctly. They explain that under these highly emotional and stressful circumstances, surrogates often find it very difficult to separate their own needs and values from those of the patient's, leading to decisions that do not always reflect the patient's wishes (Berger et al., p.49).

Advance Directives

Berger et al., also report that studies have shown that many patients do not want their surrogates to strictly adhere to their stated wishes; rather they would prefer they make decisions that consider the patient's current medical situation and take into account the non-medical situations too. This is a problem that comes from both the expectations of the standard decision making hierarchy as well as the way that advance directives are typically written. Berger et al., explain that "Living wills are limited in sensitivity and specificity in that they often fail to capture important preferences of patients, and documented preferences may be inauthentic representations of patients' wishes". Essentially, advance directives can tend to focus too much on which specific medical interventions a patient does or does not want and can obscure the actual values of the patient.

A case study from AMA *Journal of Ethics* exemplifies this issue. The case looks at a 72 year old woman who has mid-stage Alzheimer's and aortic stenosis made worse by congestive heart failure. She is living in an inpatient dementia care facility and requires assistance in all activities of daily living. Her aortic stenosis has progressed to a stage where she needs an aortic valve replacement. She has an advance directive indicating that she would like everything done for her, but the advance directive is 15 years old, written when she was healthy and showed no signs of dementia. The surgery for the valve replacement is invasive and would be stressful for her. Both the physicians and her next of kin are uncomfortable about the prospect of this surgery, as they do not know if she would have requested everything be done had she known this would be the state of her health (Hammes et al., p.348).

This situation illustrates the point of the article by Berger et al.: advance directives and the standard hierarchy of decision making can at times further complicate an already complicated situation. Advance directives often do not take into account future changes in health, and if the patient has not discussed their end of life wishes with their surrogate, then the hierarchy of decision making dictates physicians and family should do what the advance directive says, even if it seems excessive. However, advance directives are still the best way to ensure that the patient's wishes are respected at the end of life, and because of this Berger et al., give some recommendations on things to include in an advance directive. They recommend that people with an advance directive should include to what extent they want their stated wishes to be followed. A statement should be included indicating if the advance directive is a guide, or if the patient wants it followed exactly. The authors also recommend including a clear indication of who the patient wants doing the decision making, a single person or their whole family, and if there is anyone they specifically want excluded from making decisions. They also urge physicians to speak to their patients about including these details in their advance directives. The authors also have recommendations for decision making in the more likely situation that a patient does not have an advance directive. They suggest that everything be done to determine who the patient would have wanted to be included in the decision making, and to determine the patient’s values and medical preferences. They conclude by saying that while individual autonomy is important and deserves respect, current policies need to be reexamined to accommodate families who do not hold to the western view of autonomy, and to allow for the fact that the majority of people will not have an advance directive (Berger et al., pp.49-51).

For those that do have the chance to write an advance directive or make end of life care plan, coming up with the advance directive usually falls to the patient themselves. However, a paper by Sudore and Fried argues for involving surrogate decision makers and the physician in the advance planning process. While in theory advance directives help surrogates better understand the wishes of the patient, Sudore and Fried explain that advance directives have not been shown to improve the quality of care patients receive, or to help surrogates better understand the patients’ preferences. Sudore and Fried argue that the idea of planning specific care in advance is flawed because the patient's condition could change in numerous unforeseen ways, and it is impossible to prepare for every situation. They also explain that broad statements can be too general, and unhelpful in helping surrogates to make the more specific decisions. Sudore and Fried suggest that instead of completing an advance directive that is highly specific or too broad patients should instead focus advance care planning on preparing surrogates and physicians for in the moment decision making. The authors say that this process should include the patient, their surrogates, and their physician and that they should all work together to 1) choose a decision maker, 2) clarify and articulate patients' values overtime, 3) and establish leeway in surrogate decision making. They conclude by saying that advance care planning should try to prepare physicians and surrogates to work together and encourage communication between the patient and surrogate(s) about the patient’s wishes (Sudore and Fried pp.256-259). As discussed in the previously reviewed articles, one of the best ways to limit or prevent conflicts is to increase communication and discussion; beginning discussions early would help with this (Lilly et al., pg. 469).

One of the biggest challenges preparing for the end of life is starting a conversation about it. A paper by Larson and Tobin describes the many barriers to such discussions between patients and families, for health care professionals, and from the medical system. A few barriers that can prevent patients and families talking about end of life planning include, patients feeling like they should hide their pain and fears about the end of life or feeling embarrassed about having to talk about it. Family members may not want to talk about it for similar reasons or may further complicate matters by refusing to accept the patient’s prognosis or end of life wishes. There are also significant cultural taboos on discussing death, dying, and the hard choices that it brings. Physicians and other healthcare professionals can struggle to bring up end of life planning as well. There are many reasons physicians may be reluctant to start such a conversation: fear of delivering bad news, naivete about advance directives, lack of training on how to do it, seeing death as the enemy, anticipation of disagreement, or simply feeling threatened by these conversations. Larson and Tobin point out that many physicians have received no training on how to start a conversation on end of life planning, so when they are faced with a situation where they ought to, they may shy away from it. Another barrier is that the medical system as a whole does not promote end of life discussions. Patients often have multiple physicians, making it difficult to know who is responsible for having the discussion. In addition, physicians don’t usually have a lot of time for these discussions, physicians are very rarely compensated for end of life planning, and people often do not have a long term physician they know well. But the discussions still need to happen. Larson and Tobin review ways to enhance these discussions from the side of the physician and healthcare system. They recommend improving physicians' interpersonal communication skills, moving to a patient centered care model, focusing on quality of life, and enabling physicians to begin these discussions earlier (Larson and Tobin pp.1573-1576).

Summary

This chapter looked at an assortment of research articles and papers that discuss decision making and the relationship between physicians and patient’s families. The literature examined the importance of communication, sources of conflict and resolution strategies, how cultural and religious differences can change conflicts, how decisions are typically made, and advance directives. The overarching theme throughout the papers was the importance of communication, whether that was increasing the amount of communication or its quality, communication is key. The next chapter will use the information discussed in these papers to review a case study, and to develop a set of practices to improve advance directive writing, and to prevent conflict between physicians and patient’s families.

Chapter 3: Case Study Discussion and Practices

This chapter will use the literature explored in chapter two to determine practices that help to minimize conflicts between families and physicians during the decision making process. It will look at a case study from the Frontline documentary “Facing Death” and use it as an example of how these practices can prevent conflict. This chapter will then address how advance directives can ease the decision making process, and the practices that can make them work effectively. Then it will discuss the ways literature recommends starting a conversation about end of life planning, both for physicians and for patients and their families. This chapter will then discuss the recommendations from the literature for preventing conflict when an advance directive is not available. Finally, it will use an ethical deliberation process to work through the decision making made in the case study from “Facing Death” and discuss literature recommendations for what to do if conflict does arise.

Facing Death: A Family Conflict

Before looking at the practices to limit conflicts, we will review the case study from “Facing Death”. In this case an 86 year old woman, Marthe, with late stage Alzheimer’s has been on a ventilator for two weeks after she aspirated on her own saliva. Her physician explains to her family that she needs to be either given a surgical tracheotomy or she needs to be taken off the ventilator and made comfortable; she cannot remain on the tube ventilator any longer as there is a risk of infection. Her daughters, a nurse and a physician, have to decide what to do. Her granddaughter is also acts as a surrogate for Marthe, but she does not share her opinions about Marthe’s care with the documentary. Doing the tracheotomy would commit her to living the remainder of her days in the hospital attached to a ventilator, but not doing it means Marthe will likely die in the coming days. Marthe does not have an advance directive and she has not clearly discussed her wishes for a situation like this with her daughters (Navasky and O'Connor).

Marthe's daughter Nadege, who is a nurse, says her mother, "[L]oves life, she is one that always says, 'I [would] call 911, right away'". In spite of this, Nadege is against the tracheotomy as she feels it would be more compassionate to let Marthe go. Marthe's other daughter Sherley, a physician, does not agree; she feels that it would be cruel to deny her mom treatment and says, "I don't want to be the one to say 'DNR', or to be responsible for her death before her time". Marthe's physician, Dr. Mann, says in an interview that she believes the most humane thing to do would be to take out the tube and see if Marthe can breathe, and if not to make her comfortable. She went on to say that that opinion was her own personal bias and that she tried not to impose it on the family. In the family meeting Sherley expressed a belief that Marthe would have wanted everything done for her, and seemed more concerned with extending her mother's life than her quality of life saying, "The quality of life, the arguments will be the same, … we don't know if she will be better tomorrow, or if she's not improving, but, you know, we don't know exactly how long she is going to survive". The arguments being that they should do the tracheotomy because that is what Sherley believes Marthe would have wanted (Navasky and O'Connor).

This case illustrates the importance of having an advance directive, or at least a conversation between family members about the end of life. This decision would have been made much easier for the daughters and the physicians had Marthe made an end of life plan or talked about her wishes more in depth with her daughters. Expressing a wish that 911 be called in the case of an emergency is not the same as asking to extend life under any circumstance. Though Sherley seems convinced that her mother would have wanted everything done it is difficult to take this at face value, as the article by Berger et al., explains that when making decisions based on substituted judgment, surrogates tend to overtreat relative to the patient's preferences. Unfortunately, there is no way to know what Marthe would have wanted, as there is no advance directive and there is no consensus between the daughters. As shown in the paper by Lilly et al., communication helps to limit conflicts between family members as well as between family and physicians (p. 469). It is hard to know how often the physicians and family have met to discuss Marthe's condition, but it would have been best had they started holding meetings as soon as Marthe was intubated the first time. However beneficial more meetings would have been, it would have been far preferable had Marthe, her family, and her physicians worked out an end of life care plan prior to her reaching this condition. Having an advance directive, or at least a clear understanding of Marthe's preferences, would have helped to prevent the conflict between the daughters, and the unseen disagreement from Marthe's physicians.

The Role of Advance Directives

An advance directive can be the best way for a patient to ensure that their end of life care is in accordance with their wishes and values. An article from the Mayo Clinic explains that each state will have their own set of forms that needs to be filled out to complete an advance directive, but that most include papers that give power of attorney or health care proxy status to a surrogate(s) of the patient's choice, as well as papers that opt the patient in or out of certain end of life procedures like mechanical ventilation, tube feeding, dialysis etc. These papers will likely need to be witnessed and notarized (p.1-3). The advance directive forms provided by the Oregon Health Authority has space to list three surrogates, a section with prewritten statements about end of life care that the patient can choose from, and a few sections that can be filled out that state the patient's values (p.2-11). While it does give the patient some control over their end of life planning, limiting specificity about their wishes for care to prewritten statements means that the Oregon Advance Directive Form is both too specific and not specific enough.

Berger et al. points out the problems this can cause, advance directives can unintentionally complicate decision making if they are too specific or too broad, and often they do not clearly represent the patient's actual wishes. But an advance directive is better than nothing. Berger et al., explain that in the absence of an advance directive patient surrogates are asked to apply substituted judgment, a process which can be stressful for the surrogate and executed poorly, so for someone who cares deeply about their end of life care, an advance directive is the best option (p.49). Not only does an advance directive help those who care deeply about their end of life care, filling one out helps to start conversations between the patient and their surrogates about their end of life wishes. The Oregon Advance Directive Form requires signatures from the patient’s prospective surrogates, so filling one out forces the patient to have a conversation with their surrogates about their end of life wishes (p.11). That is where the true value of advance directives lies, it starts the conversation.

There are ways to improve advance directives so that they are helpful to patients, surrogates, and physicians. From the literature review, three practices have emerged as important in writing an advance directive; 1) begin planning earlier rather than later, 2) include surrogate(s), physicians, and anyone else who will be participating in decision making in the end of life planning process, 3) advance directives should include how strictly the surrogate(s) are to follow them (Sudore and Fried p.257; Lilly et al., 469). Sudore and Fried explain a method of end of life care planning that includes the patient, surrogate(s), and physicians, with the goal being to enable physicians and surrogates to confidently make decisions for the patient in the moment. This method of end of life planning is set up to be better at ensuring that the surrogate(s) and physicians more accurately understand what the patient wants, hopefully eliminating any confusion that a too broad or too specific advance directive would create. Sudore and Fried's advance directive development method would both help solidify the patient's end of life preferences and begin communication between the physicians and surrogates much earlier than is typical. And finally, the paper by Sudore and Fried as well as by Berger et al., discuss the importance of telling the surrogates how strictly the patient wants the advance directive to be followed. Burger et al., explains that studies have shown that often patients do not want surrogates to follow their advance directive exactly, instead wanting them to respond dynamically to the changing conditions.

Having Conversations

Writing the advance directive might be the easy part. Much more difficult for patients, physicians, and surrogates is knowing how to bring up the discussion. Talking about the end of life is understandably extremely emotionally charged for all involved, and many people would rather avoid the conversation. As discussed in the paper by Larson and Tobin, there are many barriers to initiating a discussion about end of life planning: embarrassment and fear on the part of the patient, surrogates who refuse to accept the patient's prognosis, and physicians who are uncomfortable for reasons ranging from a lack of training to guilt about "letting death win" (p. 1575). To add to it all the medical system is not set up to foster these discussions, patients don't usually have a single physician, and physicians have little time to have them (Larson and Tobin p. 1575). But to avoid conflict, and ensure the patient receives the end of life care they want, these conversations are unavoidable.

From the literature explored in chapter two and an article from the American Medical Association, there are a few practices that have been recommended to help physicians initiate an end of life discussion. Sudore and Fried recommend beginning by assessing a patient’s readiness to start end of life preparation by asking the question, “‘If you were to get very sick, is there anyone you trust to make medical decisions for you and have you talked to this person about what is important to you?’” (p. 259). They explain that if the patient’s response indicates they are not yet prepared for this discussion to explain why it is important: it reduces surrogate burden, gives the patient peace of mind, and helps them keep control of their healthcare even when they can no longer communicate (Sudore and Fried p.259). The article from the American Medical Association gives another approach to initiating the conversation; they recommend normalizing the conversation, beginning it with saying, “‘I ask this of all of my patients’”, so patients do not feel singled out (p.2). They also suggest using a template the patient can fill out on their own that asks the patient to identify what matters most to them, important future milestones, how their family likes to deal with bad news, how medical decisions are made in their family, and other questions about their end of life wishes. While a template like this is not legally binding, it will give the physician some information on the patient's end of life goals and is a good gateway to more concrete and legal planning (*Advance directives…*, p.2).

While the physician may be responsible for beginning an end of life conversation with the patient, the responsibility of beginning the conversation with the patient’s family falls to the patient. Initiating these kinds of conversations among family members is difficult. The Conversation Project, a public engagement project from the Institute of Healthcare Improvement, is dedicated to helping people start end of life conversations and has a guide to starting the conversation with family members. In their guide they recommend that patients first think about what matters to them, and ask patients to answer the questions, “What does a good day look like for you?”, “Who or what supports you during difficult times?”, and “What matters to me through the end of my life is…”. They next recommend that patients plan out their talk, filling out another set of questions asking about their healthcare preferences. Then they give various phrases to use to actually approach people with the conversation, and a list of things to include in the conversation, and they finish by encouraging patients to continue the conversation as their health changes (The Conversation Project 2021 p.3-9). This method of beginning the conversation is practical, makes the process straightforward, and would be something that a physician could easily recommend to any patient struggling to have an end of life conversation with their family.

The Absence of Directives

The vast majority of people who can no longer make their own medical decisions do not have advance directives. They may have discussed it in depth, but without an advance directive or other legal documentation, the surrogate(s) will have to rely on substituted judgment to make their decisions. As discussed previously in this chapter, substituted judgment is not always in accordance with the patient’s wishes, but it is not always possible to prepare an advance directive. In cases where the use of substituted judgment is necessary, Lang and Quill provide a set of recommendations for how physicians should guide decision making on the basis of substituted judgment. They recommend to first make sure the family understands substituted judgment and confirm that they agree to make the decision that the patient would have wanted. They suggest listening to what the family says the patient’s values are, and to make note of the family members' phrasing and behavior because that may reveal more about the patient’s values. Lang and Quill also recommend that the physician give their own recommendations and frame the value of survival and a comfortable death as equal. They point out that it is important to acknowledge the family’s feelings too and recommend that physicians offer emotional support and ask them about how they are feeling (Lang and Quill, p.722). The paper by Hsieh et al., also has recommendations for helping families make decisions based on substituted judgment: they advise encouraging communication and discussion and using information seeking strategies when families have not yet come to a decision (p. 302). These practices are designed to help the physician keep the substituted judgment decision making as close to what the patient would have wanted as possible. However, there are cases, like Marthe's, where even managing that is difficult.

One way to approach decision making when using substituted judgment is difficult, or there is an ethical conflict, is to use a decision making strategy called the moral deliberation process. The moral deliberation process is a set of six steps that help walk people through decision making when the most ethical choice is not obvious and is similar to the decision making process set forward by Lang and Quill (pp. 719-721). The steps are 1) ethical framing, 2) fact-finding, 3) ethics jam, 4) ethics crossroads, 5) the ethical verdict, and 6) moral compass tests. In the first step, ethical framing, the primary ethical question, decision makers, and stakeholders are all determined. The second step, fact-finding, looks at what information is currently available, the reliability of that information, and what other information is needed to make a decision. The third step, ethics jam, tries to identify what ethical values are creating the conflict. In the context of a biomedical ethical dilemma, the ethical principles are: 1) respect of patient autonomy, 2) beneficence, 3) do no harm, and 4) social and professional justice. The fourth step, ethics crossroads, is where all the options are explored, and it is determined if there are any "win-win" options or creative solutions to solve the ethics jam. The fifth step, ethics verdict, is where the most ethical decision is decided on. And in the sixth step, the moral compass tests, the chosen verdict is tested: is it practical? Reversible? Could it be publicized? Do colleagues agree with the choice? Will it theoretically work? And does it feel right? If the decision passes these tests, then it can be applied with the knowledge that it is the most ethical decision.

The moral deliberation process could be applied to any decision making situation, but it can be especially helpful when other decision making methods have failed, as in Marthe’s case. Beginning with ethical framing, the primary ethical question is when Marthe is taken off the ventilator, should she be given a surgical tracheotomy or made as comfortable as possible and allowed to die? The surrogate decision makers are her daughters and granddaughter, and the stakeholders are Marthe, her family, and the healthcare workers taking care of her. The next step is fact finding; determining the information the decision-makers are missing, which is Marthe's medical preferences. However, she has no advance directive, she cannot currently communicate, and her daughters cannot agree on what she would have wanted (Navasky and O’Connor). Both daughters are in agreement that Martha loves life, but one interprets that as all life and the other only life she can consciously experience. Beyond Marthe’s medical preferences, the decision-makers need clear medical information about the benefits and risks of the options presented by the physician. The physician indicates that continuing ventilator support will create an infection risk, but it is unclear what the risk is, and how severe it will be. In addition, it is unknown if she will be able to breathe on her own when the ventilator is removed, but if she cannot breathe without it, she will need to have a surgical tracheostomy placed or she will die.

The next step in the moral deliberation process is to evaluate what is creating the ethics jam. In this situation the ethics jam is a result of conflicts between the principles of patient autonomy, patient welfare, and refraining from harm. For patient autonomy it is an issue of a lack of knowledge about what the patient would want. For patient welfare and refrain from harm, the jam is caused by the questions, “is the tracheotomy in the best interest of the patient?” and, “is not doing the tracheotomy doing harm?” A physician working on Marthe’s case, Dr. Mann, believes that not performing the tracheotomy would be the humane thing to do, while Marthe’s daughter Sherley has concerns about “being responsible for her death before her time” if they do not do the tracheotomy. The next step the next step in the deliberation process is the ethics crossroads, which considers the array of available options open to the decision-makers. In this case, the physician puts forward a strong alternative: removing the ventilator tube, if Marthe is able to breathe on her own, allow her to do so until she passes naturally, if not place a tracheotomy. It is a solution that takes the choice out of the daughter's hands. However, the daughters are in favor of a vote to decide if the tracheotomy will be done, it is unclear if the granddaughter agrees with this choice or was allowed to give input on it.

The next step is to decide on the decision, the ethics verdict. In this case the daughters decide to take a vote. This could be a fair decision as there is no way to know what Marthe would have wanted and because they disagree, however in this case it ends up putting all the decision making pressure on the granddaughter because her vote will be the tie breaker. And finally, the moral compass tests, this choice easily passes the practicality and theoretical tests. It is hard to say that it passes the reversibility test, because this is a decision that could end in Marthe’s death. As this is a decision made by the family it doesn’t need to pass the collegiality test, though Marthe’s physicians seem in favor of not doing the tracheotomy. It passes the publicity test, however, in my opinion it does not pass the moral gut check. The only people eligible to vote are the two daughters and one granddaughter, which puts the granddaughter in a terrible position of having to choose the side of her mother or her aunt and puts her as essentially deciding her grandmother’s fate. The glimpses of the granddaughter that the documentary gives shows a fairly young woman who is clearly upset, it seems incredibly cruel to force her to be the deciding voice.

In the end Marthe's family voted, and it was decided that if Marthe began to struggle to breathe again after the ventilator tube was removed, they would do the surgical tracheotomy. When the tube was removed Marthe was able to breathe on her own for a day, but a tracheotomy was done as soon as she began to struggle to breathe. At the end of the documentary, they noted that a year later she was still living with the tracheotomy. A doctor interviewed in the documentary described cases like hers as "survivors of intensive care" (Navasky and O'Connor).

It is difficult to say if the "right" decision was made, but no matter the actual decision made the physicians did a good job helping the family to make a decision and avoiding conflict with them. During the meeting with the family, before they decide to take a vote, they encouraged conversation using information seeking strategies (Navasky and O'Connor). As recommended by Hsieh et al., they did not try to argue for or against a choice when the family was still deciding (p.302). They used the acknowledging strategy, acknowledging both of the sisters' arguments, and they used the clarifying strategy, asking both of the sisters their thoughts and feelings on both of the choices (Hseih et al., p.299). The physicians also offered their recommendations but did not "push hard" or try to convince the family to make a choice one way or the other, which was suggested by Mehter et al., as beneficial to the family physician relationship (p.247). One of the most important aspects of conflict prevention that the documentary did not show was how often the physicians met with Marthe's family.

Despite the complexities of family decision-making when their loved one is not capable of articulating their wishes, a simple set of practices physicians can use to prevent conflict in situations where there is no advance directive has emerged, 1) be respectful of the family and their choices, 2) communication with the family should begin early and happen often, and 3) ensure communication strategies are appropriate for the situation. The articles discussing conflicts due to cultural differences and religious beliefs show that respect for the family's beliefs is important. From the literature review it is clear that one of the best ways to prevent conflict is through communication. There are two aspects of communication that are important, the quantity and the quality. Lilly et al., demonstrate the importance of quantity of communication with the family in their study that shows when communication begins early and happens regularly, ICU stays are shortened and the incidence of disagreement between the family and the physician decreases (p. 469). The paper by Hsieh et al., explains why using the correct communication method is important: using the information seeking method when the family has decided makes it seem as though the physician does not trust their decision, while using the decision centered method when they have not made a decision can seem paternalistic (p.302).

As discussed in the paper by Larson and Tobin, many physicians do not feel equipped to have conversations about the end of life, so it would be unlikely they would know how to navigate conflict at the end of life (p.1575). Not every physician will need to know how to navigate end of life conflict, but it would be beneficial to everyone if all physicians at least knew the basics. Practices like the one presented in this thesis should be taught to medical students so that they have some idea of what to do if conflict happens. Physicians who choose specialties where they will often have to help patients through end of life care should spend time in their residency learning more about how to prevent end of life conflicts. Expecting physicians to be perfect communicators or to always know what to do is unreasonable; they need to be taught how to best handle end of life conflict.

Chapter 4: Conclusion

The goal of this thesis was to determine the reasons for conflict between physicians and patient's family in situations where surrogate decision making is necessary, and to come up with a set of practices to prevent conflicts from occurring. This was accomplished by analyzing available research on surrogate decision making and end of life conflicts, as well as reviewing case studies from the AMA *Journal of Ethics* and documentaries. It was found that conflicts are most likely to stem from decisions regarding reduction of care for the patient, in situations where the patient's family does not want to remove or limit care while the physician does (Hsieh et al., p. 294). The research also determined that one of the best ways to reduce conflict and shorten ICU stays is to increase communication between the family and physicians (Lilly et al., p. 469). It also found that while advance directives are not always perfect, they are better than nothing, and can be significantly improved by using a set of practices when writing them (Sudore and Fried, p. 257). Those practices include 1) beginning end of life planning early, 2) including surrogate(s), physicians, and anyone else who will be participating in decision making in the planning process, and 3) including how strictly the surrogate(s) should follow the advance directive (Sudore and Fried p.257, Lilly et al., p.469). The review of the available research also found a number of methods that both physicians and families can employ to begin the end of life planning process. As well as a set of practices for end of life planning, through analysis of the research a set of practices to prevent conflict were also developed; 1) be respectful of the family and their choices, 2) communication with the family should begin early and happen often, and 3) ensure communication strategies are appropriate for the situation.

However extensive the research, it solely focused on already available studies and cases. While the breadth of the research reviewed was extensive, it would have been preferable to have been able to interview families and physicians about their experiences with end of life conflict specifically. It would have been particularly beneficial to ask physicians their opinion on the sets of practices that were developed. As it stands, it is unclear how practical applying the developed practices would be. In the future, further studies need to determine the practicality of applying practices similar to the ones developed in this thesis. If they are deemed impractical, it would also be wise to determine why they are impractical and what should be done to solve that.

Additionally, the available research tended to focus on the perspective of the physician, leaving a gap in information about the experiences of families and other healthcare professionals. It would have been interesting to look at more research pertaining specifically to how nurses play into these situations. While nurses are generally not included in the physician-family conferences to discuss the patient's prognosis and health care goals, they do typically spend more time with the family than the physician does. The reason the majority of the research reviewed did not include nurses, and none of it focused specifically on nurses likely has to do with the method with which articles were sourced.

Another limit of this thesis came from the way in which the research was found. As explained in chapter one, I found most of my research articles by a simple search on Google Scholar. However, the phrases that I was using to locate articles generally contained the word "conflict" and "physician" in them, which may have limited the research papers I saw to choose from and could have affected some of the conclusions drawn in this thesis.

While this thesis has been unable to contribute any new data to the discussion, it has served to collect the available information about surrogate decision making and the family-physician relationship and show what is already known. It looks at the research that has been done and tries to find the best ways to apply it. The practices that I have developed are not perfect, but they are a start. There is no way to prevent any conflict from ever happening. There will always be situations where the family’s choice is not what the physician supports. But there are ways to minimize the chances of this happening, and they should be used.

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