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Family Dynamics and Ethics at the End of Life

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Imagine you are a physician, nurse, social worker, or chaplain/pastor who is dealing with the end-of-life care of an elderly, seriously ill 83-year-old man. As you observe the family dynamics that are playing out in the ICU waiting room and even at the patient's bedside, you realize that you need help from someone trained in both family therapy and ethics. To insist that the family is a bit troubled would be a major understatement. In fact, the end-of-life scenario that their loved one is facing has resulted in old wounds resurfacing and long-festering conflicts reemerging.

The family attending to the care of this gentleman consists of his four adult children, some of whom live close and others who live out of state. In addition, the patient has two siblings with whom he is still very close and who are attending to his care. The patient's wife would be, by law, the primary decision-maker while she was living, but she passed away several years ago. In addition to his other medical conditions, he also suffers from dementia, which has rendered

him incompetent to make his own decisions about treatment. The patient does not have an advance directive, nor has he spoken with any family member about what his wishes might be should he no longer be able to make decisions for himself. The family are all Christians, devoted both to their faith and to the welfare of the patient.

The patient suffered complications from recent treatment for pneumonia and is in the ICU. He has serious lung damage but was not considered terminal until, upon further examination, physicians discovered a series of tumors in his lung. His physicians believe that the condition is not curable but treatable, meaning that the cancer can be delayed but not cured. But they are cautious with the family about the likely poor quality of life he will experience due to his age and overall weakened condition. At some point, he would likely require ventilator support to ensure adequate oxygen getting to his lungs. In their view, it would be understandable for the patient to forego aggressive treatments for a regimen of palliative care, leading

eventually to hospice.

As discussions among the family members took place regarding the treatment decisions they had to make, conflicts among them became evident. Some family members insisted that they must do everything to keep their loved one alive since that is consistent with their commitment to the sanctity of life. In addition, they see that any decision to stop, or not start, treatments would constitute them being complicit in killing their loved one. Other family members strongly disagreed, insisting that his quality of life is what counts. One of his siblings even mentioned the possibility of physician-assisted suicide as the most compassionate alternative for him. Once that was mentioned, the discussion became quite heated, and they accused him of wanting to kill their loved one—in effect, he was shouted into silence and out of the room.

In addition, the two adult children who live close to their father attempted to exert their decision-making authority due to their taking care of their dad and shaming their two siblings who live out of state for not caring enough about their dad and his care. This brought up a host of old wounds between

the siblings, including the local sibling's view that their out-of-state siblings had selfishly moved away and prioritized their own lives. They have also accused them of wanting to hasten their father's death so that their inheritance could come to them sooner rather than later. You also discovered that the patient's two siblings believe that they have decisional authority since they have the longest-standing relationships with him and care for him in ways that his adult children do not. They believe that everyone involved in these discussions has ulterior motives that underlie their opinions about what to do. As these discussions go on, they deteriorate further into allegations, guilt, anger, and shaming. They are no closer to consensus about what to do than when they started.

These types of discussions are not uncommon at the end of life. This family needs a theological basis for how they should view the end of life. But their most immediate need is for someone to help them understand the dynamics that have emerged as the discussions became more contentious. This is where knowledge from the field of family therapy as well as Christian ethics can be extremely helpful.

As is often the case at the end of life, ethical decisions are complicated by family patterns of interaction. This family needs help with the ethical dimensions of stopping or continuing treatment, entering hospice/palliative care, and how to view these decisions through the lenses of their Christian faith. But if they do not make progress dealing with the dysfunctional family dynamics, they may not get to a place where they can achieve consensus on the important decisions they need to make for their loved one. This is not to say that physicians, nurses or even social workers need to have the expertise of a family therapist or be a theologian. But a greater understanding of why family members are interacting in destructive ways—along with relevant theological considerations—can help healthcare professionals guide this patient and family toward the decisions that need to be made for the patient's benefit. Ultimately, end-of-life decisions must take into consideration the complexity of what it means to be human by considering one's place in their family, the family dynamics at play, and the family's faith in such an ethical decision-making process. Because practical implications of

our ethical stances are embodied in real-life circumstances and relational contexts, our goal in this essay is to provide a resource for healthcare professionals to better help and support families facing end-of-life decisions. We believe integrating knowledge from the disciplines of family therapy and Christian ethics can significantly expand our understanding of the relational and emotional complexities involved when faced with end-of-life decisions.

A life-threatening illness of an only remaining parent is a major life event for families and can be very stressful, if not a moment of crisis, for all involved. Understanding the factors influencing family dynamics allows the healthcare professional to address conflict proactively rather than being caught off guard and to respond with appropriate support rather than treating conflict as a purely disruptive behavior. While this does not yet solve the ethical dilemma, the reduction in conflict will help the family come to a greater consensus on the decisions ahead. It also honors the humanity of the situation by offering dignity and care to the important relational connections of the patient.

We will first address the family dynamics and conflict by considering family life cycle transitions, family process factors that impact interactions, and destructive entitlement stemming from violations of love and trustworthiness. We will then turn to a theological and biblical framework that can guide ethical decision-making at the end of life.

Families and Transitions

To understand this family, it is helpful to view them first from a developmental frame in order to appreciate family conflict and challenges in light of normal changes, gains, and losses across the lifespan.¹ Family life cycle changes are times of transition requiring new emotional adjustments and changes to the structure and roles of the family system. Some common life cycle transitions can be moving into young adulthood, becoming a couple, having children, launching children, entering midlife, and elderhood. Other examples include life cycle disruptions such as separation, divorce, coping with chronic illness, loss, and death.² Family life transitions, even positive ones, are when stress is at its highest. It requires the family to be more flexible, adaptable, and

take on new demands while maintaining as much continuity and stability as possible. This family has been thrust into the midst of a sudden, unexpected life cycle transition. The adult children are stepping into shifting generational roles, with the need to make decisions and step into greater care of their father. All involved are being faced with the potential and imminent loss of the loved one, requiring coming to terms with this loss and what it will mean to no longer have him in their life. It is not uncommon for families to need extra support through the emotional roller coaster of these transitions, as they are caught between the old way and new way of being.

Ideally, family members turn towards each other during times of crisis and life transitions, but this is not always the case. Furthermore, each family member's own stage of life will influence their capacity to meet transitional moments. For this family, adjustments are required to meet the need for ongoing care and support of the father/brother to attend his doctor appointments, potential treatment, and daily care. While the patient's siblings may have more time to care for their brother, the children also feel a responsibility to care for their father and to be there for him. Despite this desire, complications can arise such as work and their own family responsibilities, which add the stress of juggling all areas of life well. When family members live far away and can't share the load, more responsibility falls on those living locally. This can lead to guilt on one side and resentment on the other.

Each family member may also experience the inevitability of losing their loved one differently. Each family member's ability to adapt to loss can be influenced by prior losses (such as the loss of the mother) and the quality of the relationship with their loved one: the closer the relationship, the greater the emotional loss. However, if the relationship has been conflicted or contentious, guilt and blame can make facing the loss more complicated. The benefit of a developmental framework is that it helps one to appreciate the layered complexity of what the family is facing. Rather than isolated stressors, the family must contend with competing life cycle pressures and the need to reorganize and add roles of responsibility. The emotional work of this transition and the reality of impending loss is often daunting.

By acknowledging and naming these compounding stressors when faced with end-of-life events, healthcare professionals can normalize the enormity of what the family is facing and thereby affirm and acknowledge the level of distress contributing to intense emotions and conflict.

Family Process of Interactions

Now that we appreciate the emotional and physical demands and adjustments this family faces, we now turn to their process of interaction. Family process refers to the ongoing dynamics, patterns, and communication styles that shape relationships. Family dynamics and ways of relating are heightened during moments of crisis. When crises occur, the added stress leads to an increase in anxiety and reactivity within family systems.³ To understand how a family responds under this kind of stress, it helps to look at Olsen and colleagues' framework, which identifies common dimensions of family interactions: cohesion, flexibility, and communication.⁴ Cohesion is the emotional bonds that family members have towards one another and the balance between separateness and togetherness.⁵ Cohesion exists on a dynamic continuum versus a fixed state and is adjusted depending on family circumstances and developmental level. Several factors impact cohesion, including cultural norms, family relational styles, and the age and developmental stage of those involved. Extreme levels of togetherness (unable to tolerate any differences) and separateness (significantly disengaged systems) tend to be problematic and lead to poor family functioning, while families that find a balance between the two tend to be more functional.

The second dimension, flexibility, refers to the family's ability to adapt interactional style, including family leadership, roles, and relationship rules in the face of life changes and challenging circumstances.⁶ Flexibility is also on a dynamic continuum, shifting over time and life circumstances. Extremely low levels of flexibility (rigidity) and extremely high levels of flexibility (chaos) lead to increased conflict and inability to manage change or crises. Families with more balanced styles can balance change with stability in a more effective way.

The third dimension, communication, functions as a facilitative element within the family system.⁷ Positive communication

skills, such as active listening, empathy, clarity, staying on topic, and respect, are what allows families to shift their levels of cohesion and flexibility to more effectively deal with developmental and situational demands. Negative forms of communication, such as criticism, blame, defensiveness, and withdrawal, impede family functioning. Research has found that families with balanced cohesion and flexibility tend to have good communication skills, whereas families that tend to operate in the extremes have poor communication.⁸

How might we now apply these concepts to the family interactions discussed above, and what might you do in your role as a professional to help? Concerning family cohesion bonds, on the surface it does not seem that these family members are close to one another at all. Yet, they all have gathered together at this crucial moment, even those from out of town. They also have strong opinions on what should be done about their loved one. Although not yet at consensus, the fact that they do have strong opinions and have all shown up underscores the fact that there is a family bond. To be helpful to this family, it would be important to acknowledge the one thing they all have in common, and that is, they really care about their loved one and are concerned for his welfare. Even though they are suggesting different actions, acknowledging the good intentions around their suggestions such as wanting him to live as long as he can, wanting to prevent pain and suffering, or wanting to have integrity with their faith all can be framed as love and care. Acknowledgment of shared goals often takes the heat out of interactions.

Regarding family flexibility, this family is currently struggling to shift roles and make decisions about medical treatment or palliative care. Not having an advance care plan or any prior family discussion about end-of-life decisions contributes to greater family conflict when end-of-life decisions need to be made.⁹ Furthermore, family disagreements over whether to pursue curative treatment versus palliative care are one of the most common reasons for family conflict.¹⁰ Therefore, this family is sitting in a perfect storm of events for conflict to ensue. Furthermore, moments of crisis are when individuals become more rigid in their thinking and heightened emotionally. It can be helpful to empathize with the

family about the enormity of the decision to be made and to help them refocus on what their loved one would want. In fact, if the patient regains consciousness and can articulate his wishes, then encouraging the family to heed his wishes may help them feel more confident and unified in the decision to be made. If this is the case, the physician can intervene and inform them that the law requires them to respect their loved one's wishes. Time will tell whether this family will remain in this activated state or if, given time, the family can rally together for the good of their loved one.

Destructive Entitlement: Violations of Love and Trustworthiness

One final reason for this family's conflict may be preexisting issues between family members that run deep and have a long history. Family theorist Boszormenyi-Nagy conceptualized such conflicts as best understood through a term he coined: *relational ethics*.¹¹ *Relational ethics* is the subjective sense of fairness or moral behavior between family members concerning expressions of love, trustworthiness, and loyalty. In other words, relational ethics refers to the unique way each family interprets or embodies culturally and theological accepted ways and rules about how families should interact. This makes relational ethics particular to each family and an important factor in understanding how patient's families are responding in moments of stress and crisis.

When family members express love, act fairly, and are loyal towards individual family members and the family as a whole, then a sense of trustworthiness develops within the family. However, when family members experience what they perceive as violations of love and trustworthiness this can lead to *destructive entitlement*.¹² *Destructive entitlement* is when family members act out of a sense of injustice due to these violations and turn to destructive ways of relating that they feel justified in, such as threats, manipulation, blame, and withdrawal.

To complicate this further, because this is a subjective experience, there is potential for family members to perceive fairness differently. For example, one family member's view of compassion and love was seen as possibly assisting his father's passing. This clearly was experienced by other family members as the complete opposite of love

and compassion. It also appears that tension between the family members who moved away versus those who stayed near the father is being seen as a violation of family loyalty. The “out of town” siblings feel it is unfair to have their love or loyalty to the family questioned simply because they moved away. Meanwhile the “in town” siblings may feel they personally sacrificed to remain close to their parents and now unfairly bear the greater burden of caring for their father. This family is clearly showing signs of a lack of trust in one another. It has led to accusations of selfishness, only wanting an inheritance, and distrust of having the father’s best interest in mind.

One sign that violations of love, trustworthiness, and destructive entitlement are at work in a family is the level of intense emotional responses and rigidity. So, what can you as a professional do? Resolution of these issues will take time and is beyond your role at this moment. However, it might be beneficial to provide a referral for family therapy. Nonetheless, there are still things you can do in your capacity. First, seek to listen, understand, and empathize with each of the family members. This can build a sense of trust with you as a professional. This may best be accomplished by talking with some of the family members individually and keeping in mind that each family member has the right to be heard and understood from their perspective. Next would be to refocus the family on their loved one, his needs, and what he would want from them. It can help to share that research shows that family conflict is often hardest on the patient, creating more stress, distress, and feeling unsupported.¹³ As a third party, you can encourage the family that the most loving thing they can do is consider how to work together and share the load as a team to best support and care for their loved one. Certainly, this take on relational ethics does not supersede a more critical perspective or one that is informed by a more dispassionate relational stance. However, when dealing with fractious family dynamics under stress, one must consider how more broad ethical assumptions and prescriptions are animated by other implicit and explicit entrenched family dynamics.

Although medical decisions at the end of life are about the individual patient, families are often highly involved in the decision-making process and are the ones

providing emotional support and help with the physical care of the patient. The psychological dynamics above and the suggested tips hopefully provide a mental framework for understanding what is transpiring when family conflict arises. The goal is to get the family to a place where your expertise can be heard, processed, and taken in by the family to make necessary decisions and changes. For religious families like this one, chaplains and clergy also can provide additional support to the family by addressing the theological and ethical questions that end-of-life decisions evoke. It is these concerns that we turn to next.

Ethical Decisions at the End of Life

Once the family dynamics have been addressed and the family is proceeding in a healthier manner, the family still has some significant ethical decisions to make for this patient. Since this is a believing family, appeal to the Bible carries substantial weight for their decisions. They are at odds with the decision to remove or maintain life-sustaining treatments for their father.

Though one of the family members suggested assisted suicide, it quickly became clear what the majority of the family thought of that option. The fact that someone could bring it up at all suggests that it is legal in their state, which is the case in 11 US states and the District of Columbia, and several countries in Europe. If this conversation were taking place in Canada or Europe, then euthanasia could also be considered. However, regardless of the family’s views on the ethics of assisted suicide, the patient must be able to give consent. Given the patient being incompetent to make medical decisions, this would render the debate about the morality of assisted suicide unnecessary. If the patient was competent to make such a decision, the moral and theological dimensions would then become relevant.

When it comes to the decisions about life-sustaining treatments, those are more complicated, and a family’s lack of consensus about this is not uncommon, both for emotional and moral reasons. What this believing family needs at this point is some theological guidance as well as emotional support for making the necessary decisions when the day comes that the patient loses competence. These important theological aspects may be difficult for the family to

accept, thus making emotional support and empathy important for the family as they wrestle with the implications of the theological framework that the ethicist is giving them. This will likely require listening to the family’s concerns and questions and walking with them through a proper understanding of the sanctity of life and how it applies here. It will also involve consoling a clearly grieving family and helping them accept the eventual loss of their loved one.

The theological aspect of death and dying begins with the sanctity of life. This is fundamentally grounded in the notion of human beings made in the image of God. It is important to recognize that the image of God is a status bestowed on human beings that gives them their intrinsic dignity, regardless of their ability to perform the functions often deemed necessary for full human personhood. For if both the image of God and human personhood are dependent on those functions (such as self-awareness, consciousness, capability for relationships, etc.), then both become degraded properties, which in Scripture they are most certainly not. The intrinsic dignity conferred by the image of God is the reason why taking innocent human life is prohibited in the Bible. In addition, Ecclesiastes 3:1–2 indicates that there is a time “to be born and a time to die,” suggesting that it is God who appoints those times. Hebrews 9:27 echoes this when it says that “it is appointed for man to die once, and then comes judgment” (ESV)—again, appointed by God himself. That is, God is the One who determines the timing of our deaths.

However, the theological account does not end there. To go deeper involves how the Bible views death and the dying process itself. As a result of the general entrance of sin, death and the dying process entered the world, making it an enemy of the good that God had created and not a part of God’s original design. Though it is true that death and dying are a normal and natural part of everyone’s life, that does not make it morally neutral, as the broader culture often assumes. Theologically, the reason that these things constitute a natural and normal part of life is due to the pervasiveness and universality of sin (Rom 5:12). But the good news theologically is that death, although an enemy, is a *conquered enemy* by virtue of the death and resurrection of Jesus (1 Cor

15:50–57). What follows from this for the end of life is the critical point for this family—that is, if death has been conquered, not only does it not have to be feared, but *it also need not always be resisted* by medical means. That is, under the right conditions, it is morally and theologically acceptable to say “enough” to medicine and allow disease to take its natural course. The decision to say “stop” to medicine can actually be seen as the family entrusting the patient back to God and accepting from his hand the patient’s remaining days before his home-going.

The conditions under which decisions to stop life-prolonging treatments are morally and theologically consistent are critical for the family to understand. First, under the law, if the patient himself, while competent, indicates a desire, either in writing or orally, to stop treatments, the physician and the family must accept the patient’s wish and stop aggressive treatments, transitioning the patient to a regimen of palliative care. If the patient has a valid advance directive, the family and physicians are obligated to follow it, even if they disagree with what it indicates. If a family member has been designated as the surrogate decision-maker, in the event the patient loses the ability to speak for himself or herself, their role is to enforce the terms of the advance directive, not override them.

In most cases, the patient or family will make such a request when one or more of the remaining conditions are met. A second condition is that continuing such treatments would be futile. Though there is a long discussion of what constitutes medical futility, the consensus that has emerged is that a futile treatment is one that will not reverse an imminent downward spiral toward death for the patient. A third condition is the most common one—a treatment is more burdensome than beneficial for the patient. Families are sometimes not aware of the physical and emotional burden of life-sustaining treatments for their loved ones, and sometimes patients are not well informed about the burdens of continuing treatments that may have a serious adverse effect on their ongoing quality of life. No one is obligated to increase the net level of suffering for loved ones, and no patient is obligated to endure a degree of suffering that is disproportionate to the potential benefit of a treatment.

We would suggest that it is almost always immoral to subject a loved one to treatments that increase their net level of pain and suffering. One reason this sometimes happens is that families are unwilling to let go of their loved ones for the variety of reasons we discussed above. Although their loved one will be in a better place once they have died and are no longer suffering, that is not true of the family and other close friends, who will have to deal with the pain of the loss of a person dear to them. It also may be that the family has not been prepared for the decisions they will have to face, leading them in some cases, to “dig in their heels,” resisting making the decision to stop treatments and transition to palliative care.

For these reasons, the family is likely to have some difficulty with the idea that one can say “stop” to medicine for the patient. They may think that terminating treatment will cause the death of their loved one—that is, they have killed their father. It is not hard to understand why they might feel this way. They could easily envision a scenario in which they request ventilator support to be removed and within a relatively short time following that removal the patient will likely die. It may be hard to escape the notion that their decision and subsequent removal were the actual cause of death, when in reality it is the underlying disease progression that has been allowed to take its natural course. The emotional toll this might take should not be underestimated and may involve pastoral care or even therapy to help them process what they have decided and deal with the grief of their loss. They may even have the sense that they are “playing God” with their father’s life, and if they were actually causing his death, that might be true. But the term “playing God” refers to human beings usurping a prerogative that belongs to God alone, including the taking of innocent life, which would be the case if assisted suicide was a consideration. At a minimum, they should be encouraged to see their decision as entrusting their father back to God to live out his days as from the hand of God but without burdensome medical interventions.

They may also wrestle with the thought that their decision to remove treatments violates the biblical notion of the sanctity of life. They may be approaching this with a view of the sacredness of human life that mandates keeping their loved one alive at

all costs, no matter what. But that is a misreading of the sanctity of earthly human life. For if it is true that they are obligated always to keep the patient alive, then they are making a theological statement that I do not think they actually believe—that earthly life is the highest good for human beings. Theologically, that is simply not true. Our highest good is our eternal fellowship with God, which renders earthly life a *penultimate* good, not the ultimate good. A family’s desire to keep their loved one alive indefinitely often reflects a view of earthly life that is not theologically consistent with the Bible. In my role as a hospital ethics consultant, I have often been tempted to ask believing families (but more often than not refrained), “Do you really believe what you say you believe about resurrection and eternal life?” It’s very important for families in these situations to realize that the sanctity of life does not obligate them to continuing aggressive treatments indefinitely, and to realize that their decision to “keep going” may only be delaying an inevitable and imminent home-coming for the patient.

The family’s desire to “keep going” may also be expressing hope for a miracle, and such a hope may be a statement of their faith in a miracle-working God. Though it is true that medical miracles do occasionally occur, the family should be encouraged to view this through the framework of resurrection and eternity as opposed to a miracle on this side of eternity. The much greater miracle will be accomplished when their father meets the Lord in heaven, when this disease and all others will be healed and, in addition, his character will be like Christ’s. In some cases, this hope for a miracle is masking an understandable reluctance to let go of their loved one. It would be tempting to say to the family, “If we’re hoping for a miracle, then let’s really go for it, and remove everything, because God doesn’t need medicine to work miracles.” Perhaps if you know the family quite well, this might be appropriate, but perhaps not if you don’t have that kind of relationship with them.

Conclusion

Many end-of-life scenarios present these kinds of complex family dynamics for which most people in healthcare teams are not trained, save for some chaplains and social workers skilled in family interactions. In fact, it seems that a good deal of

family dysfunction that is not normally evident comes out in these stressful life cycle moments. This is the case even without the ethical issues that come to the fore when decisions about treatments and even about assisted suicide are on the table for discussion. The ethical part further complicates the decisions that have to be made and can exacerbate existing family tensions. It is not enough to deal with the family dynamics or the ethical issues alone, as they are often intertwined. As a result, the expertise of

both the ethicist and family therapist can help families come to these decisions and do so peacefully, without leaving family wreckage in its wake. It is common for healthcare personnel to enlist the services of the hospital's ethics committee, and social workers and chaplains are sometimes capable of helping families sort through their issues. But we are suggesting that the resources of people trained in both family dynamics and ethics are crucial contributors to effective decision-making at the end of life. Since we

are whole persons who are integral parts of families and who care deeply about our loved ones, end-of-life care and decision-making should not be reduced to treatments and technologies. Rather, appreciating the complexity of who we are as human beings and the families that we are a part of should take into account a person's place in the family and the family dynamics involved in end-of-life decisions.

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