



Compromised Autonomy

When Families Pressure Patients to Change Their Wishes

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Living with a life-threatening illness is extraordinarily challenging. This challenge intensifies when patients struggle to weigh personal and familial interests when facing difficult medical decisions. When patients are unduly pressured by their families to make medical decisions that are not in line with previously held values, beliefs, or perspectives, autonomy is compromised. A case example, based on a clinical ethics consultation, is used to highlight the complexities of compromised autonomy secondary to family coercion and manipulation at the end of life. Decision making in the context of family involvement and relational autonomy will be explored along with effects of caregiver stressors, patient/family disagreements, and the nuances of substituted judgment. The article closes with a discussion of universal strategies for best working with and advocating for patients who are experiencing compromised autonomy.

KEY WORDS

bioethics, end-of-life, palliative care

Gradually over time and in tandem with the mainstream recognition of modern bioethics, Western health care has shifted away from physicians as medical decision maker. Instead, more emphasis is placed on a patient's right to medical information and the individual's innate decision-making authority. Western health care providers promote autonomous decision making by encouraging patients to make their own decisions about their personal health care. At the same time, family plays a vital role in both caregiving and decision making along the illness continuum. Judicious patients weigh subjective wishes against familial interests before making individual medical decisions.

Individual autonomy is rooted in Western democracy's respect for personal liberty and is a fundamental principle of contemporary bioethics, interwoven with informed consent and shared decision making.¹ Autonomous decision

making occurs in the absence of unsolicited interferences or coercion, including interferences from both caregivers and health care professionals.² Compromised autonomy refers to situations in which persons do not have autonomous decision-making abilities secondary to severe illness, physical decline, cognitive impairment, and/or emotional distress.³

This conceptual article focuses on the form of compromised autonomy that arises when patients with decisional capacity are unduly pressured or coerced by their families into making medical decisions that are not in line with previously held values, beliefs, or perspectives. Family pressure or coercion is defined as occurring when caregivers employ verbal threats, harassment, berating, intimidation, or other manipulative tactics designed to force vulnerable patients to change well-established beliefs or preferences. Patients with a history of power inequities, shifts in familial roles and relationship status, and progressive disease are at higher risk to experience compromised autonomy. The terms family and caregiver are generally understood to be close to and/or "chosen" by the patient.

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CASE REPORT

Mr K was a married, 78-year-old man diagnosed with widely metastatic gastrointestinal cancer. Over the course of 2 years, the cancer progressed despite numerous chemotherapy and radiation treatments. Mr K was admitted to the hospital with acute shortness of breath and was soon placed on an opti-flow machine (high concentrations of oxygen). Upon admission, the gastrointestinal oncology team initiated a goals of care conversation with Mr K and his spouse of 52 years. This discussion explored his noncurative cancer status, limits of curative therapeutic

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treatment options, and Mr K's overall poor prognosis. The team recommended symptom management and transition to hospice care. Mr K was appropriately upset but receptive to this frank discussion regarding his condition. He told the oncology team that although he had always been hopeful, he knew eventually his gastrointestinal cancer would result in his death. Mr K's spouse was not in agreement with this sentiment, she berated him, shouting loudly in rapid-fire succession statements like: "You can't give up. I need you. I can't live without you. Don't you love me? What about the children? They will think you are a weak man if you stop now." After several minutes, Mr K asked the oncology team to leave, abruptly ending the conversation.

The next day, the team met privately with Mr K to further discuss his critical medical condition and limited curative therapeutic treatment options. Discussion explored specific treatment goals, including a "do not attempt resuscitation" (DNAR) order. Mr K confirmed his wish to set limits to his medical care, largely based on his personal definition of quality of life. He identified a close family member's prolonged intubation as "a life not worth living." As per Mr K's wish, a DNAR order was documented.

When Mr K's spouse discovered that he endorsed a DNAR, she was enraged. She was unable to acknowledge her husband's grave medical condition or accept his decision to set limits to his care. Mr K's spouse refused to bear his repeated requests to avoid suffering and would not engage in any discussions about withholding aggressive life-prolonging treatments despite knowing his wishes. Mr K's spouse chastised him until he agreed to rescind his DNAR order. This back and forth went on for several days, resulting in numerous goals of care discussions and a clinical ethics consultation.

FAMILY INVOLVEMENT IN DECISION MAKING, A RELATIONAL AUTONOMIST VIEW

The level of family involvement in medical decision making is largely based on long-standing family dynamics and the scale of decisions being considered.⁴ Most families have a history of collaborating around critical personal and family decisions long before entering a medical setting. These intimate relationships shape the family's core values and beliefs and inform decision making. Family involvement in decision making is well documented in certain ethnic groups, including Asians and Hispanics, and is considered the norm for countless non-Western families living in North America and abroad.⁵⁻⁷

Given the importance of family, is there such a thing as autonomous decision making? Relational autonomists argue that families are uniquely positioned to both advocate for and assist patients with decision making.⁸ Relational autonomy theory further emphasizes that all

decisions are influenced by historical, cultural, social, class, race, gender, and familial contexts.⁹ Patients in close-knit families do not always see themselves as independent decision makers, largely relying on the collective family unit for guidance. Relational autonomists suggest that intimate relationships lend themselves to better understanding of a person's goals and expectations. Family solidarity during stressful times provides support for the patient and preserves dignity in a way the health care team is unable to by remaining focused on the patient's personal identity and selfhood.¹⁰ Family involvement can lessen the objectifying, isolating, symptom-focused landscape of the modern health care delivery system.

Many patients and families take into account both personal and familial interests when making decisions, medical and otherwise. Family dynamics dictate who and how decisions are made. Shared patient/family decision making is perfectly acceptable, as long as collaboration is desired. There is concern, however, when families' overinvolvement muddles the decision-making process, resulting in unnecessary conflict or patient exploitation.¹¹ Although relational autonomy in decision making has emerged as a culturally acceptable, Western medical law and bioethics have yet to conceptualize a framework to accommodate individual autonomy in the context of family dominant decision making.¹² When family involvement is unsolicited by the patient and decisions are pressured and not consistent with well-established wishes, autonomy is compromised.

CAREGIVER STRESSORS

Without doubt, caregiver stressors impact decision making and can cause patient/family disagreements. Patients rely on caregivers for assistance managing complex medical care, navigating health care systems, and communicating with the health care team.¹³ Although some consider cancer a personal experience, undeniably, it impacts the entire family, profoundly affecting family dynamics, relationships, adaptability, and resiliency. Caregiving for seriously ill patients results in a myriad of psychosocial stressors (emotional, psychological, socioeconomic, occupational, legal, and environmental) that affect coping mechanisms, social functioning, mood, vulnerability, and decision making abilities.^{14,15} Health care professionals should be aware of and sensitive to family members who are experiencing increased stressors. Faced with the prospect of losing a loved one, caregivers can cling to patients in late-stage illness. When crisis hits, these caregivers may desperately demand that all measures be taken to prolong life.

PATIENT/FAMILY DISAGREEMENT

As cancer advances and treatment efficacy is less certain, patients and families may come to terms with overall



prognosis at different speeds. This phenomenon frequently results in patient-family disagreements about the course of treatment regimens and medical decision making. Discordance is a common occurrence among cancer patients and their families. In a large US comprehensive cancer hospital study analyzing decision making in lung cancer patients and caregivers, Zhang et al¹⁶ reported that 65% of caregivers experienced treatment disagreements. The same study revealed that families and caregivers were less likely to agree with patient choices regarding decisions to discontinue therapeutic treatments or DNAR status. As cancer progresses, escalating conflict has a significant impact on patient depression and stress levels.¹⁷ Such disagreements also increase family stress and have a negative impact on long-term family adjustment.¹⁸

During periods of physical and cognitive decline, families are more active in decision making.⁴ Although patients may benefit from decision-making assistance, increased family pressure during uncertain times is problematic for patients who are less able to articulate and defend well-established beliefs and values.

SUBSTITUTED JUDGMENT AND FAMILY CENTERED DECISION MAKING

Family members are influenced by both multigenerational struggles and illness-specific experiences. It is difficult for caregivers to ignore personal interests when helping to make treatment decisions because family is intimately involved in patient's care and has an emotional stake in the outcome.¹⁹ Although the case example presented in this article discusses a patient with decisional capacity, the patient-spouse conflict regarding treatment decisions mirrors patient/surrogate discrepancies described in the substituted judgment literature.^{20,21} These conflicting perspectives inform the discussion on compromised autonomy in the setting of family pressure and are worth exploring in more detail.

When patients lack capacity and do not have advanced directives, health care professionals seek a substituted judgment, asking surrogate decision makers what the patient would have wanted if he/she could communicate. Generally speaking, surrogate decision makers are close to the patient (typically a family member or friend) and positioned to best understand how the patient would want to proceed medically. Surrogates who are emotionally involved are more likely to show empathy toward patients, respecting their previously stated wishes.^{22,23} Substituted judgment supports patient autonomy by seeking to make decisions based on a patient's previous medical decisions, values, and stated preferences. If no information about the patient's previous wishes are available, then surrogates and health care professionals rely on the best-interest standard.

Best-interest standard is a decision-making practice whereby medical decisions for an incapacitated person are made in terms of what a "reasonable person" would decide in a similar situation. Treatment options are generally weighed in the context of burdens and benefits.

Unfortunately, a number of studies on substituted judgment have indicated that surrogate decisions are based on false assumptions of patient's values and treatment wishes.^{24,25} Generally speaking, surrogates have difficulty separating their own beliefs and values from those of the patient. Surrogates subsequently have a tendency to misjudge the extent to which their personal views are shared by others. Additional research shows that the surrogate's personal preference broadly influences decision making for others.

Fritch et al²⁶ differentiated between surrogate-centered factors and patient-centered factors when considering decision making. Surrogate-centered decisions are based on surrogate wishes, religious beliefs, interests, and family consensus. Surrogate-centered decision making takes into account personal needs, emotions, values, beliefs and past experiences of the caregiver versus patient-centered decisions based on previous knowledge of patient's wishes and sovereign decision making. Some caregivers note that their main focus is to keep the patient alive, and that regardless of severe treatment side effects, any treatment is better than none at all. In addition, families often feel that pursuing treatment options "buys" their loved one more time for future therapeutic opportunities. This sentiment is highlighted in the case example provided.

Although Mr K and his spouse verbalized an understanding of the severity of his illness, their beliefs regarding treatment in the setting of his noncurative cancer differed. Mr K acknowledged that his cancer was terminal and indicated that he was working to emotionally prepare for his death. Mr K's spouse vehemently opposed her husband's position, citing her need for him to continue "fighting" the cancer. She repeatedly requested that "subhuman treatment" (experimental therapy) be used as a means to preserve Mr K's life for as long as possible.

DISCUSSION

Research on caregiver stressors and substituted judgment illustrates that patient/family discord regarding treatment decisions and goals of care exists. It is this very same discord that plays out in a more profound way when patients with decisional capacity experience compromised autonomy as a result of family coercion. It is troublesome when families pressure patients to make decisions based on individual or familial needs instead of the patient's personal interests and previously stated wishes.

Early identification of complicated family dynamics and relationships, family conflict, and unhealthy decision-making



patterns may help thwart family pressure. Sometimes, simply identifying differing opinions in real time allows patients and families to engage in thoughtful conversations about their distinct approaches to medical treatment. Whenever possible, the goal should be to resolve patient-family conflict. Taking time to validate both the patient's and family's views helps alleviate distress. Effective communication about discordance may naturally lead to an acceptable agreement, compromise, or resolution among the parties. At the very least, patients and families may agree to disagree. Respect and honor the patient's strongly held values and beliefs.

When Patients Cannot/Will Not Share Wishes With Caregivers

If a patient is unable to acknowledge and communicate differing medical views and treatment goals in the presence of family, the health care team should make all efforts to speak privately with the patient, creating a safe environment to voice medical wishes and any concerns about possible family coercion. The health care team should attempt to empower the patient to speak directly with his/her family. If this is not possible, the team can offer to address concerns with the family on the patient's behalf, preferably in the patient's presence. When taking on this task, the health care team ought to spend time listening to, normalizing, and validating family concerns. Effectively exploring differing views on therapeutic and end-of-life treatment can clarify misconceptions and provide much needed support.

When Caregivers Do Not Accept Patient's Differing Wishes

When family is unable to acknowledge differing views and/or uses repeated attempts to override the patient's treatment decisions, extra precautions should be taken to protect the patient's autonomous decision making. It is important to note that although the focus remains on patient autonomy, all efforts should be made to avoid unnecessary family conflict. Disagreements do not automatically mean patients and families care less for each other. In addition, not all family members and caregivers will agree. Sometimes, opinions, values, and preferences differ within the family constellation. These factions have the potential to negatively affect long-term family coping and resiliency and should be addressed. Preserving family relationships is an important objective. The health care team can help facilitate patient/family communication surrounding patient wishes, thereby avoiding shock and surprise if treatments and medical care are not executed in the manner in which the family prefers.

Although the health care team's allegiance is to the patient, measures should be taken to support family through the difficult and uncertain situation. Allowing family to discuss their apprehensions regarding treatment options, prognosis, and end-of-life concerns may help alleviate feelings of alienation while still supporting the patient's wishes.

Patients should be assured that their treatment decisions are supported and will be honored regardless of family views. When situations like this arise, the health care team should encourage patients to complete advanced directives

TABLE Compromised Autonomy: Communication Strategies

Situation	Sample Conversation Starters
When conflict is identified Encourage patient/family communication Name the conflict Normalize and validate differing views Identify commonalities Engage the family Actively listen, normalize, and validate concerns Clarify misconceptions Build alliance Seek resolution or acceptance of conflicting views	"We can't begin to imagine what you are thinking and feeling. How has your outlook changed? Can you try to help us understand?" "Can you tell us your understanding of xx's condition?" "Knowing xx the way you do, are you surprised by his/her sentiments?" "Now that you have a better understanding of how xx is feeling, is it possible to support his/her decision?"
When patients cannot/will not share wishes with caregivers Speak privately with patient; solicit values, perspectives, wishes Offer assistance facilitating communication	"I understand that it can seem overwhelming, but the health care team can help you speak with your family." "This is an opportunity to share your personal experiences and views with your family. Together, we can try to help them understand what you are going through."
When caregivers do not accept patient's differing wishes Take precautions to protect the patient's autonomous decision making Support patient and family	"The health care team is obligated to honor xx's wishes regarding his/her medical care." "I can see that your family cares about you very much. This is their way of trying to support and advocate for you." "This is common situation. Just because you do not agree does not mean you care less for each other."



directing their care and appointing a health care proxy who can best represent their personal beliefs and values. In addition, the team should clearly document patient's wishes in the medical record. Advanced directives and documentation detailing expressed medical wishes are important tools to ensure that patient wishes are honored when he/she is no longer capacitated.²⁷ Ethics committees and clinical ethics consultation services are useful tools to help navigate these complicated circumstances.

A clinical ethics consultation was requested when Mr K's respiratory status began to deteriorate because the team was concerned that his true end-of-life wishes were not being honored by his spouse. The team relayed that Mr K repeatedly stated that he did not want to be intubated. Yet, when his spouse was present, she would express her opposition to his request and he would recant his DNAR order. The ethics consultant met extensively with Mr K, at which point he clearly stated that he was ready to die and that he did not want a "breathing tube." A DNAR was formalized and further discussion with Mr K focused on his comfort and palliation.

The ethics consultant then met with Mr K's spouse and extended family to explain that in accordance with Mr K's stated wishes, a DNAR order had been placed. The family was distressed and adamant that Mr K did not know what he was agreeing to. Mr K's spouse abruptly left the meeting and went to his bedside to plead with him to change his decision. After much discussion and considerable pressure from his spouse, Mr K redacted his earlier endorsement of DNAR and palliation, indicating that he would "do whatever is easiest for my wife." The ethics consultant discussed this change in preference with Mr K and determined that Mr K was capacitated and understood the ramifications of his decision. Mr K told the ethics consultant that he was willing to modify his wishes to accommodate his family's emotional needs.

Mr K was intubated and transferred to the intensive care unit (ICU). He died of multiorgan failure 2 weeks later. The ethics consultant remained involved for the duration of Mr K's ICU admission, providing much needed staff support. The ICU staff spoke openly about their distress and reluctance to provide aggressive care to Mr K because they felt it was both futile and not a representation of his "true wishes." The ethics consultant, in collaboration with the ICU social worker, met regularly with the staff, both normalizing the staff's reactions and sharing with them the complicated family dynamics that informed Mr K's decision.

When Patients Concede to Caregiver Pressures

As is illustrated in Mr K's case, sometimes, patients concede to family pressures to avoid conflict or as a means to protect broad family interests. These cases are most troubling to staff and often lead to moral distress. Moral distress is a painful

feeling or psychological vulnerability that occurs when the ethically right course of action is known but cannot be carried out. Moral distress is commonplace in critical care settings where staff is asked to provide aggressive life-prolonging medical care in a manner contrary to their personal beliefs and professional values.²⁸ In the case example, the ICU team felt strongly that they were not only providing aggressive, nonbeneficial care, but doing so against Mr K's wishes.

It is important to note that many patients reconsider previously held values, wishes, and preferences in the setting of broader effects on family. In this situation, support should be provided to the health care team to help facilitate staff understanding of patient's choice to align with family. Patients may decide to set aside personal wishes for the good of the family or as a means to maintain peace and harmony with loved ones. Given the interconnectedness present in many families, it is reasonable for patients to altruistically consider others when making serious medical decisions, even decisions in conflict with strongly held beliefs. Offering a window into the intricate family dynamics affecting patient decision making can be a consolation to staff (Table).

CONCLUSION

An essential feature of autonomy is a person's ability to make independent decisions. True autonomous medical decision making should be free of coercion. Patient/family discord regarding treatment decisions and goals of care often exists. It is this very same discord that plays out in a profound way when patients with decisional capacity experience compromised autonomy secondary to family pressure. When a patient has compromised autonomy, all measures should be taken to protect the patient's interests while acknowledging that, at times, family emotional needs will influence and overshadow patient's personal wishes. As relational theory exemplifies, it is not unreasonable for patients to make complex medical decisions with their family's well being at the forefront.

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