

## Special Article – Family Caregivers

# Frailty: It's Time to Give Family Caregivers a Real Seat at the Table

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## Abstract

The functional impact of lifelong accumulation of health issues (known as frailty), creates several challenges to traditional approaches to care planning and decision-making. In particular, the role of the caregiver (often a family member) in supporting the frail adult's needs is often at odds with how clinicians and teams approach "patient-centered care". As the prevalence of frailty continues to increase, we need to embrace new approaches that widen the circle of care to include the caregiver more prominently in the provision of information and a more nuanced approach to shared decision-making.

**Keywords:** Frailty; Caregiver; Decision-making; Ethics; Dementia; Care planning

## Case Presentation

Florence Green, a 78-year-old widow who lives alone, presents with painless hematuria. Physical exam suggests suboptimal personal hygiene. Investigations show a 6cm abdominal aortic aneurysm; (AAA) and non-muscle invasive, low-grade transitional cell bladder cancer.

According to the standard of care, Mrs. Green consents to and is booked for, elective open repair of her AAA. But, her surgery is twice delayed when Mrs. Green forgets preoperative instructions to fast overnight. The surgeon refers Mrs. Green to a Geriatrician for a cognitive assessment. Mrs. Green refuses this appointment saying, "I manage well. There is nothing wrong with my memory." Her daughter, Karen, is listed as her next of kin, but Mrs. Green prefers that she is not contacted, as "Karen is too busy."

## Mrs. Green's Outcome

The family physician calls Karen to obtain a collateral history. Karen admits to feeling overwhelmed with her mother's care needs and recounts that her mother's memory and thinking has gradually worsened over the past five years. Mrs. Green now requires assistance with all activities outside the home, as well as helps to bathe and dress. She often forgets to eat and has lost weight as a result. Karen is surprised by the scheduled surgery; she was unaware that her mother was scheduled for any intervention and is upset with this proposal.

Karen's history coupled with Mrs. Green's demeanour and physical exam is highly suggestive of dementia. Further comprehensive assessment, including screening for secondary causes of cognitive decline, is negative; the diagnosis is severe stage Alzheimer's disease. This finding is presented to Karen and including the impact this surgery would have on Mrs. Green's quality of life, living circumstances, and future symptom burden. Karen decides to cancel the operation, choosing a wholly symptom-based approach to care for her mother.

## Discussion

Mrs. Green's story highlights the emerging challenges of providing

optimal care to a growing population of older adults with complex health and social issues [1]. Understanding the concept of frailty is central to improving care for this cohort. When the accumulation of health and social deficits (acute or chronic, minor or major) manifest as physical or cognitive problems that impair daily function, we call this "frailty" [2,3]. Frailty is measurable and powerfully associated with adverse health outcomes across a variety of settings and populations [4-8]. The past 30 years of medical advancements have significantly increased the prevalence of frailty. In fact, through excellent management of disease, healthcare propagates frailty by improving survival — which inevitably results in further amassing of health deficits. While the medical community grapples with how to best detect and measure frailty [1], one theme is clear—frailty demands a bold new approach to patient care; one which extends beyond clinical practice and acknowledges that optimal patient care must include family caregivers [9,10].

Mrs. Green's scenario demonstrates that for older adults with frailty, our reliance on the individual's self-report of functional status is problematic. Dementia and other causes of cognitive impairment are prevalent and important drivers of frailty [11,12,13]. However, despite evidence demonstrating that patient self-report for cognitive and functional status [14,15] is unreliable; clinicians in community and acute care routinely fail to assess cognition objectively. This omission is particularly costly when the clinical encounters involve making important medical or surgical decisions.

When the presence of dementia is missed, the clinician cannot support their patient's right to self-determination. Practitioners are in danger of committing serious ethical and legal breaches by failing to obtain truly informed consent when a patient at risk for frailty is not examined to ensure capacity to consent [13,17]. Clinicians could be cued to involve family members or caregivers in the frail older adult's clinical decision-making process by recognizing the presence of cognitive decline and appreciating the well-established association between dementia (and even Mild Cognitive Impairment; (MCI)) [12, 18-20] with impaired medical decision-making capacity. The substitute decision-maker (SDM) has a duty to make decisions on

behalf of the patient based on their understanding of how the patient would want to be treated [14,21]. However, frailty involves dynamic degrees of dependency; as such, it is not always the case that decisions need to be fully “substituted”. Rather — if we take seriously the right of frail older adults to informed choice — a deliberate and systematic approach for implementing *assisted* or *supported* decision-making may be more appropriate [22,23]. This type of framework would apply to all frail older adults, regardless of cognitive status, who may have a diminished ability to fully engage in the informed-choice process given a high volume of complex information [22]. Caregiver(s), patients and health care providers [24] become a decisional unit, bound together both in the decision-making process and in dealing with the outcomes — whether good or bad — of whatever decisions are made as a result.

The caregiver account provides particularly valuable insight into the patient’s degree of frailty, the trajectory of health, the tenuousness and sustainability of the patient’s living circumstances, as well as the caregiver’s ultimate suitability as an SDM. The early involvement of caregivers in assisted or supported decision-making also has implications for advance care planning; (ACP), where patients often create directives and appoint an SDM without involving those who will ultimately participate in decision-making or its outcomes. A common example of this phenomenon is an advance directive that states: “I wish to avoid long term care,” without regard for the practicalities for caregivers in delivering upon this wish. Advance care planning has been lauded as the antidote to pain and suffering at the end of life [25], but current ACP programs fail to acknowledge the complexity of outcomes in frailty — particularly where the same outcome may mean benefit or suffering depending on whether the referent is the patient or the caregiver.

A range of obstacles inhibit the meaningful integration of frailty and informed decision-making. Many therapies that have become the standard of care (based on demonstrated effectiveness) for fit or less frail adults, can actually be harmful to the overall health and quality of life of those who are frail [26]. Standards of practice, like the AAA surgery offered to Mrs. Green, normalize aggressive and life-advancing treatment options without sufficient research or evidence of proportionate benefits [27]. The decision of whether to pursue surgery needs to consider competing risks and the impact of surgical outcomes and sequelae on both patients and their family caregivers. Importantly, if the treatment of one health issue according to the established standard of care is successful and improves survival, it may ultimately extend life through more severe stages of another health issue, which in Mrs. Green’s case would undoubtedly mean further progression of her dementia.

Our current system champions concepts of “patient-centered care” and “autonomy” to uphold the practice of allowing patients and care providers to make decisions as though in a vacuum. Many practitioners would argue that based on Mrs. Green’s directive, and as a measure of protecting her autonomy, it would be inappropriate to contact her daughter without consent. While there may be reason to be concerned about the impact of conflict and secondary gain on SDMs and family caregivers, it is equally concerning that the clinical team accepted Mrs. Green’s authorization for the procedure as valid consent when she clearly would not have met the test for capacity.

Our approach must reflect the fact that most SDMs and caregivers, by their very willingness to take on these roles, are well-intentioned.

By the same token, SDMs and caregivers (much like Mrs. Green’s daughter, Karen), are often directly impacted by the decisions that are made. As such, it is important to acknowledge that family members and/or SDMs can perceive the role of decision-maker as burdensome [28]. Caregivers often report guilt and stress when asked to make decisions and indicate a preference for information and guidance from clinicians to reduce said feelings [29]. Such guidance may be particularly important in circumstances where there is high emotionality or signs of maladaptive coping on the part of the decision-maker and family [30,31]. In these scenarios, clinician guidance and navigation for decision-making can help to unburden family members while supporting the patient’s autonomy.

Based on this case scenario and discussion, we conclude:

1. Identification of frailty should be integrated into routine, standard care in environments in which older adults are required to make complex or interventional medical/surgical decisions;
2. When an older adult is frail, the standard of care should include family caregiver input on health and function;
3. Identification of dementia and frailty will impact decision-making due to competing risks for mortality and the increased vulnerability to poor outcomes that is associated with frailty.
4. Decision-making in frailty needs to be appropriately guided by health professionals which would require the involvement of a substitute decision-maker (SDM) [12,16].

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