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## CLINICAL COMMENTARY

# Advance Care Planning for Chronically Ill Patients in the Primary Care Setting

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An 86-year-old female was admitted to the hospital with increasing dyspnea. She is chronically ill with congestive heart failure, stage 4 chronic kidney disease and chronic anemia. Though physically deconditioned, she lived alone. Her heart failure had worsened over the three years since her initial PCP visit. She presented to the ED and was admitted in atrial fibrillation with rapid ventricular rate. Diagnostic studies included echocardiogram showing worsened aortic insufficiency and cardiac catheterization demonstrating severe pulmonary hypertension. She responded to parenteral diuretics, however her GFR worsened from her baseline of 20 and she developed metabolic acidosis and was started on dialysis, after placement of a tunneled dialysis catheter. Her volume status and acidosis stabilized and she was discharged home with scheduled hemodialysis three times a week.

At her post-discharge follow up visit, she was depressed and shared multiple concerns about hemodialysis. She requires assistance to get to the dialysis sessions and is physically exhausted after each session. She also reports frequent post-dialysis lightheadedness and now has unstable ambulation, even using a walker. She is very unhappy with the three times a week dialysis which consumes too much of her time and asks to reduce dialysis frequency. She tearfully states, if she had known all that was involved with being on hemodialysis, her treatment decision in the hospital may have been different.

Although advance care planning (ACP) had been raised with the patient during several prior outpatient visits, she had not completed an advance directive. In response to prior discussions, she verbalized a fear of death and stated that she wanted to live as long as possible. Although the patient was scheduled for outpatient nephrology consultation, she had not been seen until the hospitalization and had no counseling about ESRD treatments and did not have a good understanding of dialysis. After emergency admission to the hospital, she received aggressive care to stabilize her condition. Although she consented to inpatient dialysis, she did not anticipate need for chronic dialysis until shortly before discharge, and did not have an understanding of what was involved until she started chronic hemodialysis.

Not having completed advance care planning in the ambulatory setting likely hindered decision making for this patient when choices needed to be made in the hospital. The brief Advance Care Planning discussions with the PCP did not delve deeply into the patient's goals and she did not complete the UCLA advance directive, which elicits patients' preferences about varying health states. In retrospect, it would have been preferable to have these discussions with her PCP, who she knew and trusted and who understood her chronic medical problems, functional status and social support. The patient resisted prior discussions and had many medical problems to manage during the ambulatory visits so advance care planning was never the priority. After her emergency admission, she was managed by hospitalists, and her PCP did not learn of the admission until after dialysis had been initiated.

The patient remained on dialysis for about three months. She discussed her concerns with her nephrologist, who reluctantly decreased frequency of dialysis to twice weekly. She was offered palliative care by her PCP, but declined additional consultation. She deteriorated and was readmitted. She accepted palliative care consultation in the hospital and died peacefully shortly after admission.

It is important to consider what discussions could have occurred in the primary care setting that might have improved the patient's outcome and satisfaction with her hospital care and perhaps prevented decisions that were later reversed.

Studies show that advance care plan discussions lead to decreased hospitalizations, reduction of invasive treatments at the end of life, and increased use of hospice and palliative care.[1] The primary care physician plays an instrumental role in elucidating these treatment goals. Primary care practitioners and severely chronically ill patients should ideally discuss advance care planning at outpatient visits prior to hospitalization. These conversations may dive deeply into patient's goals and values and consider what sorts of health states the patient envisions as acceptable. As such, these discussions are different from standard "goals of care" discussions that focus on resuscitation preferences or "code status." They should include topics about specific treatments and the intensity of care. The comprehensive care plan should also take into account the patient's current social situation and whether their goals of care align with their social needs and expectations. An in-depth discussion about the patient's goals and values enables the physician to align a treatment plan with what is most important to the patient.[2] The conversation should begin early in the course of the life-threatening disease.[3] Lastly, it is important that these discussions occur longitudinally and evolve with time.[4]

How does the provider frame the discussion? First it is important for the physician to establish and build a rapport with the patient. A patient-physician discussion can inquire about social activities, values, and what brings meaning to the patient's life. They should explore the patient's current understanding of their disease and prognosis. When discussing the specific topic of long-term care goals, it is helpful to normalize the advance care planning discussion by reassuring the patient that it is an important conversation, regardless of the patient's current disease state or prognosis. Convey to the patient why advance care planning is important in their current state of illness. Lastly, be open to addressing the patient's fears and/or hesitations. Avoid pressuring the patient into having the conversation if it is not the right time. However, do not be reluctant in readdressing advance care planning at future visits. Encourage the patient to involve family members and proxies in the discussion if they desire.[5]

For patients who want less than fully aggressive treatment in their current health state, the Physician Order for Life Sustaining Treatment (POLST) is a valuable tool. POLST is a standardized single-page document that outlines a plan for end of life care. It translates a patient's preferences regarding care at life's end into a doctor's order. Although the POLST form is not legally accepted in all states and requirements vary state to state,[5] the POLST document is a valuable way to communicate and transfer orders for less aggressive treatment.

In the setting of severe, progressive illness with worsening prognosis, a good strategy used in the "goals of care" discussion is the mnemonic, REMAP: **R**eframe, **E**xpect emotion, **M**ap out patient goals, **A**lign with goals, and **P**ropose a plan. In the reframe step, the physician provides a big picture that informs the patient that the status quo treatment is not working. This is followed by actively managing the patient's emotional response (expect emotion). Then, to map the patient's goals, the provider asks open-ended questions designed to help the patient reflect about the values that should guide their future medical care. The clinician then aligns with those values by explicitly reflecting them back to the patient. With the patient's consent, the medical provider uses those principles to propose a medical plan that complements the patient's values. The processes underlying REMAP enable physicians and patients to create patient-centered decisions that foster better end-of-life care.[6]

Pitfalls for the clinician to avoid during "goals of care" conversations include: starting the conversation too late, expecting too much too soon, biasing the discussion, and simultaneously trying to deliver poor prognosis information and always expecting to establish end-of-life care goals.[7]

The process of advance care planning is longitudinal and requires continual conversations focused on treatment plans that are patient-centered. This process is a collaborative effort; the patient-clinician team can achieve the highest standard of patient care and ensure success meeting long-term care goals.

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