Capsule Commentary on Jones et al., the Future as a Series of Transitions: Qualitative Study of Heart Failure Patients and their Informal Caregivers

Ariel R. Green, MD, MPH

Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine, Baltimore, MD, USA.

J Gen Intern Med 30(2):238
DOI: 10.1007/s11606-014-3134-0
© Society of General Internal Medicine 2014

Jones et al.¹ performed a qualitative study to determine how patients with heart failure and their caregivers perceive the future. This knowledge could enhance advance care planning for a disease with a prolonged and variable clinical course. Clinicians in outpatient cardiology and geriatric clinics at a single medical center recruited potential subjects with NYHA class II–IV heart failure. In total, 33 patients and 20 of their informal caregivers participated in one-on-one interviews. The major finding was that patients and caregivers experienced four transitions in grappling with heart failure: shock after diagnosis, adjustment to life with the disease, taking control, and accepting mortality.

Patients with advanced heart failure must make decisions about therapies that can extend life but carry potential trade-offs. Clinicians need guidance on fostering high-quality, shared decision-making.² Attention to the transitions experienced by patients with heart failure may inform such discussions.

The findings have some limitations. Patients were recruited from one medical center. Longstanding relationships with their clinicians may have biased their perceptions. The patients had been living with heart failure for a median of 5 years (range: > 1 to 27 years), yet the study is cross-sectional. The median survival of patients with systolic heart failure is approximately 3–5 years. Patients who are doing poorly may never achieve a sense of control or acceptance.

Two findings warrant particular note: One, many patients expressed frustration that clinicians failed to address uncertainty. This is consistent with recent reports suggesting that

patient–physician communication surrounding implantable cardioverter-defibrillators (ICDs), a complex therapy for advanced heart failure, is characterized by “omission of information” and “lack of attention to psychological and long-term risks.”³ Two, patients who felt more in control “set limits” regarding therapy. In a recent study, 70 % of ICD patients said they would deactivate their ICD in hypothetical scenarios such as severe cognitive impairment.⁴ Fear of death, and medicine’s difficulty with anticipating the future, may underlie society’s drive to do everything possible to extend life, even at the expense of its quality.⁵ To enable patients to make decisions that reflect their values, we must help them move from bewilderment to control.

Conflict of Interest: The author has no conflicts of interest with the material in this article.

Corresponding Author: Ariel R. Green, MD, MPH; Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine, Baltimore, MD 21224, USA (e-mail: ariel@jhmi.edu).

REFERENCES

1. Jones J, Nowels CT, Sudore R, Ahluwalia S, Bekelman DB. The future as a series of transitions: Qualitative study of heart failure patients and their informal caregivers. *J Gen Intern Med*. 2014. doi:10.1007/s11606-014-3085-5.
2. Allen LA, Stevenson LW, Grady KL, et al. Decision making in advanced heart failure: A scientific statement from the American Heart Association. *Circulation*. 2012;125(15):1928–52.
3. Hauptman PJ, Chibnall JT, Guild C, Armbrrecht ES. Patient perceptions, physician communication, and the implantable cardioverter-defibrillator. *JAMA Intern Med*. 2013;173(7):571–7.
4. Dodson JA, Fried TR, Van Ness PH, Goldstein NE, Lampert R. Patient preferences for deactivation of implantable cardioverter-defibrillators. *JAMA Intern Med*. 2013;1–3.
5. Finucane TE. How gravely ill becomes dying: A key to end-of-life care. *JAMA*. 1999;282(17):1670–2.