



Invited Commentary | Cardiology

# Improving Primary and Specialist Palliative Care in Cardiovascular Disease

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Palliative care (PC) focuses on improving quality of life for people with severe illness of any age. Palliative care can be provided by a multidisciplinary team of PC specialists or by other health care professionals as primary or basic PC. Palliative care can be provided concurrent with life-prolonging or curative care as needed from time of diagnosis. In contrast, hospice (as defined in the United States) is a form of PC focused on providing comfort to people with an estimated prognosis of 6 months or less. Two 2017 systematic reviews<sup>1,2</sup> present early evidence of the benefit of PC in cardiovascular disease (CVD), particularly for patients with heart failure.

Warraich et al<sup>3</sup> conducted a retrospective study using a PC registry to understand changes in characteristics and trends among 1801 patients with CVD referred to PC specialists during a 3-year period, from 2015 through 2017. The main question was whether patients with CVD were seen earlier in the disease trajectory over time, measured using the palliative performance score, a health care professional-rated measure of functional status. Warraich et al<sup>3</sup> found that 28.9% of patients (521 of 1801) had low palliative performance scores, consistent with being bedbound and requiring total care. This percentage did not change through time. Patients reported moderate to severe symptoms, including poor well-being, tiredness, anorexia, dyspnea, and pain. The study identified some changes from 2015 to 2017, including a reduced proportion of black patients (11.9% in 2015 vs 6.3% in 2017), an increased proportion of coronary artery disease and valvular heart disease diagnoses (25.6% in 2015 vs 30.1% in 2017), and a reduced proportion of referrals from cardiologists (16.5% in 2015 vs 10.5% in 2017). This study offers insights on the emerging role of PC specialists in CVD.

The characterization of functional status using the palliative performance score in such a large, multicenter population is unique, to my knowledge. Warraich et al<sup>3</sup> concluded that the data do not support that PC consultation is occurring earlier over time but rather that referrals are made late in the illness trajectory. While this may be accurate based on functional status, functional status is only 1 marker of illness trajectory. Other markers to consider include those validated in prognostic models, time since diagnosis, time to death (in a retrospective study), and patient-reported health status. An important challenge in using functional status to understand the CVD illness trajectory is the rapid improvements in function many patients report soon after hospitalization.<sup>4</sup> Other issues to consider regarding the lack of change in functional status are the relatively short study time (3 consecutive years) and the study sites (a single site contributed more than one-third of the patients).

Despite the evidence for PC in CVD (particularly heart failure), and even though CVD is the number 1 cause of death in the United States, the use of specialist PC and hospice remain low. Compared with other health care professionals, Warraich et al<sup>3</sup> found that cardiologists made few of the referrals to PC (12.4% of total referrals), and the proportion decreased through time. While the changes in this and other referral patterns (and, perhaps, patient characteristics) could be explained in part by the rapidly increasing registry membership during the study, the low proportion of referrals is concerning. A 2011 editorial<sup>5</sup> discussed barriers to PC referral by cardiologists and solutions have been offered. When will we see a multisite study demonstrating interventions that lead to success in improving referrals?

Ultimately, PC referrals are just one way to improve outcomes important to patients with serious or advanced CVD and their caregivers. There are many studies describing important outcomes, including physical symptoms, anxiety and depression, adjustment to illness (eg, physical

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limitations, loss of job, changes in role), planning for the future, and navigating situations when curative or restorative care is unlikely to benefit or achieve patient and family hopes or goals. Specialist, multidisciplinary (eg, nurse, social worker, chaplain) PC teams are ideally positioned to address many of these outcomes. However, many PC teams are not fully multidisciplinary, only exist in inpatient settings or cancer centers, or aren't available at all in certain settings.

There are other challenges to improving outcomes important to patients and caregivers. These outcomes can vary during the illness course. For example, adjustment to illness and quality of life are not necessarily associated with prognosis. In addition, many outcomes of interest to patients and informal caregivers are not included in the clinical or administrative data that are routinely collected. These outcomes must be identified by asking patients and caregivers. Outcomes of importance to patients and caregivers should ideally be integrated into the electronic health record so that they can be measured and tracked. The PC registry that served as the basis of the study by Warraich et al<sup>3</sup> is an example of such integration.

There are not enough PC specialists to see all the patients with serious CVD who may benefit from PC, so it is critical to develop capacity and competency in primary (ie, basic) PC and refer appropriate patients to specialist PC teams. A 2018 randomized clinical trial<sup>6</sup> examined a team-based, collaborative care approach to improve quality-of-life outcomes for patients with serious heart failure, and some patient-reported outcomes improved. Other approaches, such as the use of technology and peer support, have potential to enable patients and informal caregivers to benefit without relying on busy, complicated health systems.

What aspects of primary PC are addressed by cardiology, primary care, and mental health, and how can this be improved? Roles, capacities, and competencies vary depending on the health system, clinicians, and resources available. Primary PC requires collaboration among different health care professionals (eg, cardiologists, PC specialists, primary care specialists, mental health specialists, physicians, nurses, social workers, chaplains). A 2017 review<sup>7</sup> proposed key primary and specialist roles in PC for patients with heart failure. Leveraging the skills of affiliate health care professionals (eg, nurses, social workers, chaplains)<sup>5</sup> and engaging patients and caregivers using technology are approaches to improve primary PC in CVD.

We should be encouraged that practitioners, professional societies, health care systems, and research funding agencies are starting to recognize the importance of PC for patients with serious CVD. Future work should focus on fostering capacity and competency among cardiologists and other health care practitioners to provide early, primary PC and to appropriately refer patients to PC specialists.

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#### ARTICLE INFORMATION

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