



## EDITORIAL COMMENT

**Palliative care in heart failure: An unmet need****Cuidados paliativos em insuficiência cardíaca: uma necessidade**

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In recent years, advances in the treatment of chronic heart failure with reduced ejection fraction have led to significant changes in the prognosis of heart failure patients. Compared to previous decades, we now have a wide range of therapies that improve survival and other important outcomes, such as hospitalizations and quality of life. In addition to pharmacological, non-pharmacological and device therapy, disease management programs have also been shown to be effective for these endpoints.<sup>1</sup> The observed reduction in mortality also leads to more elderly patients living longer with chronic heart failure.

Despite all the advances and regardless of the individual course of each patient, heart failure is, in most cases, a chronic disease with a fluctuating and unpredictable trajectory; it is associated with severe symptom burden and poor quality of life, and progresses inexorably to death. Patients with heart failure usually have high hospital readmission rates due to worsening symptoms secondary to a decrease in cardiac output and/or fluid retention.<sup>2</sup> It is associated with high morbidity and mortality, similar to many types of cancer.

Clinical guidelines and consensus papers<sup>1,3</sup> recommend that communication about the disease's trajectory and anticipatory planning should start when a patient is diag-

nosed with advanced heart failure. They also emphasize that supportive care must be provided concurrently with life-prolonging heart failure therapies. The World Health Organization defines palliative care as care that improves the quality of life of patients and family members facing problems associated with life-threatening illness through prevention and relief of suffering by means of early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.<sup>4</sup>

Although palliative care in heart failure is currently a hotly discussed topic and there appears to be unanimity concerning the need for its application, according to the Heart Failure Association Atlas only 10 out of 42 European countries have designated palliative care units for patients with heart failure.<sup>5</sup> Furthermore, data from the UK indicate that, between 2013 and 2014, only 4% of patients with heart failure were referred to specialist palliative care units.<sup>6</sup> In Portugal, palliative care in heart failure also seems to be difficult to implement. Studies such as those by Cruz et al., published in this issue of the *Journal*,<sup>7</sup> are therefore important, not only to share their center's experience, but also to promote reflection on this issue.

Cruz et al. retrospectively characterized the population with heart failure referred to a palliative care unit and set out to identify those who benefit from early and regular intervention. They data they collected showed that referral occurred mainly (94.4%) during hospitalization, patients were mostly elderly, with multiple comorbidities, and of

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these, a quarter had not previously been hospitalized for heart failure. A very high mortality rate was found in the first month (53.7%), half during the index hospitalization; six months later only 16.7% of the population referred was still alive. No clinical signs predicting mortality within a month of referral were identified. These data show that besides heart failure, the team was dealing with a very frail elderly population with high mortality.

The European Society of Cardiology guidelines for the diagnosis and treatment of acute and chronic heart failure recognize the difficulty in deciding when heart failure patients require specialist palliative or end-of-life care. In clinical practice, similarly to the experience of Cruz et al., heart failure patients are rarely referred for palliative care, and when they are, it is usually very late, at the end of life.<sup>8</sup> There is a wide gap between what is advocated and what happens in reality. Many barriers can be identified on both sides, from healthcare providers and from patients and caregivers. It is extremely important that all participants in the process – patients, caregivers and health care providers – have open communication and that future expectations are discussed. The term ‘palliative care’ has a cultural impact and is charged with negative connotations, often being perceived as synonymous with end-of-life care. Moreover, there is concern that palliative care is designed exclusively for patients dying from cancer and, most importantly, there is a fear that initiating palliative care could mean discontinuation of heart failure treatment. In addition, given the unpredictable trajectory of an individual heart failure patient, health professionals remain uncertain when to involve the palliative care team. Healthcare providers also perceive palliative care in heart failure as being of low priority and many, particularly cardiologists, find it difficult to give up the sophisticated therapeutics that are usually available. Finally, we must be aware that there is a lack of organizational resources and trained staff, which are necessary to ensure the proper function of the palliative care team, referral routes and coordination with the physicians who provide care to heart failure patients.

## Conflicts of interest

The author has no conflicts of interest to declare.

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