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## End-of-life preferences in elderly patients admitted for heart failure

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### Summary

**Background:** Heart failure is increasing in prevalence and incidence, with considerable mortality among the elderly.

**Aim:** To determine preferences concerning cardiopulmonary-resuscitation (CPR) and end-of-life care in elderly patients hospitalized for heart failure.

**Design:** Prospective interview-based survey.

**Methods:** Patients >64 years old admitted for acute heart failure were interviewed to address their preferences regarding end-of-life care and cardiopulmonary resuscitation (CPR) when facing the last stages of their disease.

**Results:** We interviewed 80 patients (mean age 79 years; 58% women). Thirty-two (40%) expressed

a wish not to have CPR. Only two had previously discussed their CPR preferences with their physicians. When recovery from the illness was considered unlikely, 40 (50%) participants preferred to receive treatment at home, 32 (40%) preferred in-hospital management, and 8 (10%) were unsure. Thirty-three patients (41%) expressed a desire for spiritual support, 38 (48%) said not and the remaining 9 (11%) were indifferent.

**Discussion:** Advance planning of end-of-life procedures and doctor–patient communication regarding these items remains poor and must be improved.

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### Introduction

Heart failure is increasing in prevalence and incidence, and causes considerable mortality among old people.<sup>1</sup> Although over the last 50 years survival after the onset of heart failure has been slowly improving,<sup>2</sup> contemporary heart failure management may slow but not stop the progression of the disease. The course of heart failure is difficult to predict;<sup>3</sup> for seriously ill patients with advanced disease, no prognostic criteria have been found to identify which patient will survive in the short- to mid-term.<sup>4</sup> Quality of life for heart failure patients is often poor, and death usually occurs in hospital, even for those receiving community-based long-term care.<sup>5</sup>

Death is fundamental to the nature of human beings; the sort of death that we fear most is dying in pain, unnoticed, and isolated from our loved ones.<sup>6</sup> In order to improve this situation for patients with end-stage heart failure, palliative care approaches have been suggested. However, palliative care for cardiovascular diseases is less widespread than that for cancer, even though survival after a diagnosis of heart failure is worse than that for most common neoplasms.<sup>7</sup> Patients in the final stages of heart failure thus usually continue to receive aggressive medical therapy until the moment of death. Unfortunately, most patients receiving long-term medical care have never been

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engaged by their physicians in discussions about end-of-life topics.<sup>8</sup>

The principle of patient autonomy underpins patients' rights to make decisions regarding their own medical treatment.<sup>9</sup> A better understanding of the factors influencing patients' preferences might help physicians manage end-of-life care of heart failure patients.

We undertook the present study to evaluate preferences concerning cardiopulmonary resuscitation (CPR) procedures, and opinions regarding advance planning for the final stages of the disease among elderly patients discharged after an episode of heart failure exacerbation.

## Methods

Over an eight-month period (January–August 2003), 137 patients >64 years of age were admitted to the Internal Medicine Service of the Hospital Universitari de Bellvitge, a 800-bed teaching hospital, with decompensated heart failure. They were approached by one of the investigators the day before discharge, and asked whether they would like to undergo an interview concerning end-of-life issues related to heart failure. Patients were not considered for inclusion if they suffered from cognitive impairment (4+ errors in the Short Portable Mental Status Questionnaire<sup>10</sup>,  $n=9$ ) or active psychosis or mania ( $n=4$ ), if they were not fluent in Spanish ( $n=3$ ), if the heart failure was unknown to them before the admission ( $n=18$ ) or if they were living in nursing homes ( $n=9$ ). Nine patients refused to participate and five more were excluded because they answered just a few questions. Reasons for refusing to participate or not answering were not asked. In order to minimize potential biases, answers were not obtained through relatives or caregivers. Non-participants age, gender or heart failure-related functional class did not differ significantly from those of participants.

The patients' medical records were reviewed. Collected demographic data included: age, gender, place of residence and marital status. The Charlson score (CS) was used to measure comorbidity.<sup>11</sup> Functional status was assessed by two different professionals using the Barthel Index (BI)<sup>12</sup>, a 0–100 scale that evaluates the level of independence in performing basic activities of daily life. The diagnosis of heart failure was clinical, confirmed on the basis of compatible signs, symptoms and chest-X ray abnormalities on admission. The presumed aetiology and duration of the heart failure was recorded. Finally, pre-admission heart failure-related functional class was measured using the New York

Heart Association (NYHA) four-point scale, ranging from class 1 for asymptomatic patients to class 4 for patients symptomatic at rest or after very small efforts.

Senior physicians who had no previous relationship with the patients and were not involved in their hospital care performed the interviews, which lasted 20–25 min. During the interview the patients were asked, in an open question, whether they were aware of the predictable course of heart failure—answering 'a chronic and progressive disease' was considered to be proof of awareness. Patients were asked to rate their quality of life ('How would you rate the overall quality of your life at present?') on a five-point scale ('excellent', 'very good', 'good', 'fair' or 'poor').<sup>13</sup> Patients were also asked about their relationship with their general practitioners or cardiologists on the same five-point scale, and whether they had discussed their resuscitation preferences with them. They were also questioned about who should undertake CPR decisions: patients, doctors, family or all together.

The question about resuscitation preferences was as follows: 'As you probably know, there are a number of things that doctors can do try to revive someone whose heart has stopped beating, which usually includes a machine to help breathing. Thinking of your current condition, what would you want your doctors to do if your heart ever stops beating? Would you want your doctors to try to revive you, or would you want your doctors not to try to revive you?'. Only patients who explicitly and unequivocally answered negatively were classified as refusing resuscitation.<sup>13</sup>

Another question was whether they would prefer, as the disease progressed to an end-stage state, a course of treatment focused on extending life, even if that meant more pain and discomfort, or instead would prefer care focused on comfort and palliation.<sup>14</sup> To explore their willingness to maintain consciousness even in the very final stages of the disease, patients were also asked 'Thinking of the time from your last hospitalization to death, would you prefer to remain alert until the end or not?'.<sup>14</sup>

Patients were also asked about which of the following aspects were of most concern to them in an end-stage case: (i) control of pain, shortness of breath and other disease symptoms; (ii) inappropriate prolongation of their life; (iii) to maintain self control; (iv) to decrease the load on the caregiver; or (v) to optimize the relationship with their loved ones. Patients were free to choose one or more options.

The preferences for site and characteristics of care at the end of the disease were assessed with the following questions 'If recovery from your illness

was unlikely, what site of death would you prefer: home or hospital?'. 'When thinking ahead to your own dying, would you prefer to have your family and friends present?' and also 'Would you like to receive religious support?'.

No patients expressed distress derived from answering the questions. The institutional Ethics Committee of the hospital approved the study and all patients gave written informed consent before enrolment.

## Statistical analysis

Normally distributed continuous variables are reported as mean, standard deviation (SD) and 95%CI. Categorical variables are reported as proportions. The following variables were examined in a univariate analysis: age, gender, marital status, months elapsed since the diagnosis of heart failure, aetiology of heart failure, NYHA status and previous HF-related episodes of CPR or need for mechanical ventilation. For bivariate analyses, Student's test was used to compare continuous normally distributed variables, and nonparametric tests were used to compare variables not normally distributed.  $\chi^2$  or simple logistic regression analyses evaluated the categorical and continuous variables respectively, of the patients' answers to questions. All statistical tests were two-sided, with  $p=0.05$  indicating statistical significance.

## Results

Overall, 80 patients were finally included; 58% were women. Their mean age was  $79\pm 8.7$  years (range 65–92; 95%CI 77.1–80.9). Some 49% were widowed, 45% were married, and 6% were single or divorced. Before admission, their mean Barthel Index was  $88\pm 8$  (range 75–100; 95%CI 80–96); 25 patients (31%) remained fully independent in performing basic activities of daily life. Their mean Charlson score value was  $1.7\pm 0.5$  (range 0–6; 95%CI 1.2–2.2).

The aetiology of heart failure was: hypertensive 41%, ischaemic 36%, valve disease 9%, other 9% and undetermined 5%. The mean duration of the disease before the present admission was  $28.1\pm 23.2$  months (range 1–160; 95%CI 4.9–51.3). Pre-admission NYHA was class 2 for 8 patients (10%), class 3 for 59 patients (74%), and class 4 for 13 patients (16%). Only seven patients (9%) patients had previously received mechanical ventilation for complications of their cardiac disease, and none had previously had an automated cardioverter defibrillator implanted.

## Knowledge about the predictable course of heart failure

Fifty-one patients (64%) reported they were aware about the chronic and progressive course of the disease. Patients who were not aware asked for advice regarding this subject.

## Self-reported quality of life

The answers were: 'excellent' 0%, 'very good' 3%, 'good' 33%, 'fair' 42%, 'poor' 22%.

## Relationship and physician discussion about advanced planning and life-sustaining care

The answer about the relationship with their own doctors were 'excellent' 4%, 'very good' 6%, 'good' 60%, 'fair' 24% and 'poor' 6%. Only two patients acknowledged having discussed their wishes about life-sustaining interventions with them.

## Who should decide questions of resuscitation?

The answers regarding this question were: patient 39%, doctor 17%, family 2%, all together 42%.

## Patients' preferences about resuscitation

Thirty-two patients (40%) did not wish to be resuscitated in case of cardiac arrest. There was a significant relationship between acceptance of CPR and a better self-reported quality of life ( $p<0.004$ ), but no relationship with any of the following: baseline NYHA functional class ( $p=0.06$ ), age ( $p=0.4$ ), gender ( $p=0.7$ ), marital status ( $p=0.3$ ), heart failure duration ( $p=0.5$ ), aetiology of heart failure ( $p=0.6$ ) or previous episodes of mechanical ventilation ( $p=0.9$ ).

## Patients preferences about palliative care in terminal state

Some 66% of the patients advocated for palliative care, as opposed to a more invasive disease management (34%). Preferences for comfort care were also correlated with a poor self-reported quality of life ( $p<0.0005$ ).

## Preferences in the last hospitalization prior to death

Twenty-nine patients (36%) preferred to remain alert until the end, 47 patients (59%) did not, and four (5%) patients did not answer this question.

When patients were also asked about possible concerns in the end-stage of their disease, they responded: (i) control of pain, shortness of breath and others disease symptoms, 70 (87%); (ii) inappropriate prolongation of life, 38 (47%); (iii) maintenance of self control, 20 (25%); (iv) decreasing the caregiver workload, 26 (32%); and (v) optimizing their relationships with their loved ones, 20 (25%).

### Patient preferences regarding the circumstances of death

When recovery from the illness was unlikely, 40 (50%) participants preferred to continue treatment at home, 32 (40%) preferred in-hospital treatment (among them 53% of the patients who had reported worries about the load on the caregiver) and 8 (10%) were unsure. Some 61 (76%) wanted to be accompanied by family or friends, and 24% preferred to remain alone. Thirty (41%) expressed a desire for religious support, 38 (48%) said not, and nine (11%) were indifferent. Age, gender or NYHA class did not influence the choices regarding these three questions.

### Discussion

Caregivers and healthcare providers may often offer useful information about patients' experiences at the end of their lives,<sup>6</sup> but may not accurately interpret the dying experiences of others,<sup>15,16</sup> so knowing the patient's opinion is of fundamental importance. We only evaluated information obtained from heart failure patients and, in order to obtain a homogeneous sample, institutionalized patients (who in our country often show very advanced degrees of disability and cognitive impairment) were excluded.

Patients with heart failure have less information about the course of their disease and poorer understanding of their condition and prognosis, and are less involved in decision-making procedures, than are patients with cancer.<sup>17</sup> For instance, patients often attribute the symptoms of heart failure to advancing age, and believe that nothing can be done about them.<sup>18</sup> Surprisingly, most of our patients (64%) knew about the course and prognosis of their disease, which probably relates to more widespread information concerning the characteristics of heart failure, provided more extensively to the public recently by general practitioners and health centres.

Most patients said they enjoyed either good (33%) or fair (42%) quality of life. Another study performed with heart failure patients using a more sophisticated

tool (the SF-36 test) to address that issue showed that quality of life decreased as NYHA functional class worsened.<sup>19</sup> The discrepancy might be related to the simple, 5-point scale used in our study—however, as previously reported,<sup>13</sup> patient's self-assessment of their quality of life with a single item has been found to correlate with resuscitation preferences.

In a previous study, almost all (>95%) of the heart failure patients manifested interest in discussing advanced care planning with their physicians but, in spite of that, only 15% did so.<sup>20</sup> Carers of people who have died from heart disease have reported that, although many patients believed that they were actually dying, few reported having discussed that with their doctors.<sup>21</sup> In our study, 70% of patients described their relationship with their general practitioners or cardiologists as 'good' or better, but only two patients had discussed end-of-life issues with their doctors. In an interesting study involving general practitioners and consultants in cardiology, geriatrics and palliative care, the doctors supported the development of palliative care for patients with end-stage heart failure, with a central role for the general practitioner.<sup>22</sup> Recently it has been reported that in a significant number of cases, general practitioners appear to be aware of the need for a palliative care approach aimed at patients in the final stages of heart failure.<sup>23</sup>

Some studies have indicated that between 73% and 90% of elderly out-patients would prefer CPR.<sup>24,25</sup> Nevertheless, that rate drops to 43–88% when only hospitalized patients are considered,<sup>26,27</sup> and further to 20–45% when patients are suffering from serious, disabling diseases.<sup>24–26,28</sup> Recently, Krumholz *et al.*<sup>13</sup> reported that physicians did not correctly perceive CPR preferences of 24% of hospitalized patients with severe heart failure—almost a quarter of patients expressed their preference not to undergo CPR, but a substantial proportion (40%) of them changed their minds within just 2 months following hospital discharge. Nevertheless, as death approaches, during the last 6 months of life in heart failure, patient preferences against resuscitation become more common.<sup>14</sup> We found that, at the time of hospital discharge after a successful treatment for an exacerbation of heart failure, 60% of our patients would choose to undergo CPR if needed. Most patients think that this decision must be their own (39%), or shared with both doctors and family (42%).

Choices between palliation of symptoms and prolongation of life should be discussed.<sup>29</sup> Levenson *et al.*<sup>14</sup> found a trend toward increasing preferences of comfort care as death approaches. In our study, 66% of patients opted for comfort care in the final stages of their disease, when it is refractory to usual

therapy. In Levenson's study, as many as 63% of patients experienced severe dyspnoea in the last three days before death.<sup>14</sup> Probably because they have experienced such symptom at the time of admission or in previous exacerbations, most of our patients expressed concern about controlling dyspnoea and other symptoms when nothing else can be done to sustain life.

Adequate community medical, nursing and social support should also be available, so that patients nearing death can be offered the option of a supported death at home.<sup>9</sup> Fried *et al.*<sup>30</sup> reported that 43% of older persons preferred to receive terminal care at home. Similarly, half of our patients wished to die at home. Of note, a significant percentage of our patients who expressed their wish to die in the hospital seemed to be trying to reduce the load on their caregiver by doing so.

The majority of patients evaluated preferred to have family or friends with them when nearing the end of life. Family involvement before death may reduce the use of technology and increase the use of comfort care at patient's death.<sup>31</sup> In addition, almost half the patients wished to be provided with religious support. Being sensible to patient's religious preferences is very important—spiritual well being has been found to offer some protection against end-of-life despair among cancer patients for whom death is imminent.<sup>32</sup>

A major limitation of this study is that all our patients were approached after experiencing a successfully treated, hospital-managed acute exacerbation of heart failure; CPR and other end-of-life care preferences may be different when patients are approached upon admission, before therapy has proved to be successful. In our case, both the investigators and the Ethics Committee of our Hospital preferred to avoid questioning acutely ill elderly patients about death. Such patients are often unable to answer or provide consent, and trying to do so provokes considerable distress among the relatives of such patients in Spain. Another potential bias is that only individuals willing to discuss issues concerning death agreed to participate.

In conclusion, this study sheds some light on preferences concerning resuscitation and care at the end-of-life among a subset of elderly patients admitted because of acute heart failure—those surviving the episode. As mentioned above, communication with heart failure patients is often inadequate. Planning health services, educating practitioners, framing problems, and assessing proposed reforms to better assist patients with advanced heart failure are all essential.<sup>5</sup> Good communication requires the ability both to listen and to impart relevant information; disease-specific barriers

to effective communication, such as short-term memory loss, confusion, and fatigue should always be addressed.<sup>18</sup> It is also necessary to forge a better agreement between patient and caregiver about the outcomes of treatment.<sup>33</sup> In the future, planning for care of patients in the final stages of heart failure should include end-of-life policies to improve comfort and well-being<sup>34</sup> and enhanced communication channels between all the health professionals<sup>35</sup> involved in the care of patients with this progressive, fatal disease.

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