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## Quality of life and palliative care needs of elderly patients with advanced heart failure

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### Abstract

**Objective** To examine the quality of life and palliative care needs of elderly patients with advanced heart failure (HF). **Methods** This was a correlation descriptive study conducted at a 650-bed sub-acute hospital. Patients who were aged 65 or over, diagnosed with HF of New York Heart Association Class III or IV symptoms, and mentally sound were eligible to the study. The Edmonton Symptom Assessment Scale, the overall quality of life single item scale, and the McQuill Quality of Life Questionnaire (MQoL), were used for measurement. Multiple regression analysis was performed to determine factors for predicting quality of life. **Results** A convenience sample of 112 patients was recruited. Their age was  $81.5 \pm 8.5$  years. The three most distressing symptoms reported by the patients were tiredness ( $5.96 \pm 2.78$ ), drowsiness ( $5.47 \pm 2.93$ ), and shortness of breath ( $5.34 \pm 2.96$ ). Their mean overall quality of life single item scale score was  $4.72 \pm 2.06$  out of 10. The mean MQoL physical subscale score was the lowest ( $4.20 \pm 1.767$ ), whereas their mean psychological subscale was the highest ( $7.14 \pm 2.39$ ). However, in a multivariate analysis model, quality of life was significantly associated with existential wellbeing, physical wellbeing, psychological wellbeing and educational level. **Conclusions** The findings highlight that spiritual concerns are significant palliative care needs among elderly patients with advanced HF, in addition to symptom management. This is in line with the argument that palliative care that places great emphasis on holistic care should be integrated to the care of this group of patients.

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## 1 Introduction

Heart failure (HF) is a broad clinical syndrome resulting from cardiac disorders that impair the myocardial function.<sup>[1,2]</sup> Since the cardiac function is compromised, patients usually experience a number of coexisting symptoms, including dyspnea, fatigue, xerosis and edema.<sup>[1-4]</sup> The severity of these symptoms increased as the condition progresses to advanced stage, with a 5-year mortality rate of approximately 50% following diagnosis.<sup>[3]</sup>

In recent years, palliative care has been advocated to be integrated into the care for patients with advanced HF.<sup>[5-7]</sup> It is considered as an appropriate care approach for this group of patients not only because HF is a life-limiting disease that is unresponsive to curative treatment, more importantly, studies

found that the symptom burden between patients with advanced HF and patients with terminal cancer were comparable.<sup>[8-10]</sup> Evidence consistently suggest that many patients with advanced HF suffered from severe pain, psychological distress and poor quality of life.<sup>[11-13]</sup> Therefore, palliative care which aims at improving the quality of life of patients with advanced progressive illness would be beneficial to patients with advanced HF.<sup>[14]</sup>

Despite such awareness, previous studies only focused on the prevalence and severity of pain and other symptoms and how these affect patients' physical, psychological and social functioning, or quality of life in general.<sup>[9-13]</sup> While the findings of these studies could reveal the need of improving symptom control for patients with advanced HF, they provide limited information about their unique palliative care needs. Palliative care highlights the importance of holistic care to prevent and relief suffering brought by pain as well as other physical, psychosocial and spiritual problems,<sup>[14]</sup> and thus its scope is more than good symptom management.

Moreover, the existing palliative care for cancer patients may not directly relevant to patients with advanced HF giv-

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given that these two groups of patients are heterogeneous.<sup>[5]</sup> The illness trajectory of HF is relatively longer than cancer and so patients usually have to live with the illness for years filled with repeated episodes of exacerbations and remission.<sup>[7–10,15]</sup> Furthermore, the average age of patients with advanced HF is higher than those with cancer, the impacts of illness may be further complicated by age-related physiological changes, co-morbidities and drug-drug interactions.<sup>[16–18]</sup> Little research has been conducted on examining the unique palliative care needs of elderly patients with advanced HF.

To fill this gap, we conducted a cross-sectional correlational descriptive study. The purpose of this study was to identify the significant factors in the aspects of physical, psychological, social and spiritual contributing to quality of life of patients with advanced HF. Ethical approval for the study was obtained from the New Territories East Cluster Clinical Research Ethics Committee of the Hospital Authority. Findings of this study will offer valuable insights into strategies for improving the quality of life of this group of patients.

## 2 Methods

### 2.1 Setting and subjects

The study was conducted in a 650-bed sub-acute hospital in Hong Kong. Patients were eligible to the study if they were aged 65 years or over, diagnosed with heart failure of New York Heart Association (NYHA) heart failure functional classification III or IV and cognitively sound by the Abbreviated Mental Test (AMT). They were excluded if they could not communicate due to language or physical problem, were clinically unstable or receiving specialist palliative care. A trained research nurse screened the medical records of all patients staying in the ten medical wards and then approached and explained the study purpose and nature to patients who meet the inclusion criteria. Written consent was then obtained from those who were interested in the study. The research nurse assisted them to complete a questionnaire. All participation was on voluntary basis and the patients can refuse answering any questions or withdraw from the study without reprisal.

### 2.2 Instruments

The questionnaire comprises four parts: demographic and clinical background, physical functioning, symptom and quality of life. The first section collected demographic data including age, gender, educational level and living status, and clinical data including comorbidities and number of readmission in the past 12 months. The second section

about physical functioning included the Staircase Activities of Daily Living (ADL) and the Palliative Performance Scale (PPS). The former was used to assess the level of strain experienced by the respondents in performing personal and instrument ADL on a 1–3 rating scale, with a higher score means a higher level of strain,<sup>[18]</sup> and the latter was used to measure the overall functional status.<sup>[19]</sup> In the third section, the Edmonton Symptom Assessment Scale (ESAS) was used to measure the severity of nine symptoms using a 0–10 numeric scale, with a higher score denotes a higher degree of severity.<sup>[20]</sup> The last section on quality of life included the McGill Quality of Life Questionnaire (MQoL) and a 11-point single item scale (SIS) for the overall quality of life. The MQoL was a specific tool for assessing quality of life in four aspects: physical, psychological, social and existential among patients nearing the end of life.<sup>[21]</sup> The scores for negatively framed items were reversed in the analysis so that a higher score denotes a higher level of satisfaction with the item or aspect. The Chinese version was validated among cancer patients, with three items about eating, sex and face being added.<sup>[22]</sup> In addition, respondents were asked to rated their overall quality of life using a 0–10 numeric SIS. It is proved in an earlier study that the overall quality of life SIS was significantly strongly associated with quality of life instrument among frail older adults.<sup>[23]</sup>

### 2.3 Statistical analysis

All statistical analyses were carried out by using the SPSS version 22.0. Descriptive statistics were used to summarize the participants' demographic and clinical characteristics, symptom severity and quality of life. Pearson's correlation tests were performed to examine the association between quality of life and all items in the ESAS and MQoL. Multiple regression analysis (forward) was performed with all variables that are significantly correlated with the SIS score to determine factors for predicting quality of life. The criteria of probability-of-F-to-enter and probability-of-F-to-remove were  $> 0.05$  and  $< 0.10$  respectively. A  $P$  value  $< 0.05$  was considered as statistically significant.<sup>[24]</sup>

## 3 Results

### 3.1 Respondents' characteristics

A convenience sample of 112 patients completed the questionnaire, with a response rate of 89.5%. Their demographic and clinical characteristics were shown in Table 1. Their mean age was  $82.9 \pm 6.5$  years, ranging from 65–95 years. More than half of them were male. The majority of them received primary education or below and were living

**Table 1. Respondents' characteristics (n = 112).**

|  |                            |
|--|----------------------------|
| Mean age, yrs                                  | 82.9 ± 6.5<br>Range: 65–95 |
| Male   | 65 (58.0%)                 |
| Marital status                                 |                            |
| Married  | 59 (52.7%)                 |
| Widowed  | 46 (41.1%)                 |
| Divorced/separated                             | 2 (1.8%)                   |
| Single   | 5 (4.5%)                   |
| Education level                                |                            |
| Lower than primary education                   | 42 (37.5%)                 |
| Primary education                              | 54 (48.2%)                 |
| Secondary education                            | 13 (11.6%)                 |
| Tertiary education                             | 3 (2.7%)                   |
| Living arrangement                             |                            |
| Living alone                                   | 10 (8.9%)                  |
| Living with family/friend                      | 86 (76.8%)                 |
| Living in residential care home                | 16 (14.3%)                 |
| Clinical characteristics                       |                            |
| CCI  | 3.89 ± 2.87                |
| PPS  | 55.80 ± 12.71              |
| Staircase Personal ADL score                   | 0.78 ± 0.64                |
| Staircase instrumental ADL score               | 1.47 ± 0.63                |
| No. of hospitalization over the past 12 months | 2.58 ± 1.21                |

Data are presented as mean ± SD or n (%). ADL: activities of daily living; CCI: Charlson comorbidity index; PPS: palliative performance scale.

with family or friends. Nearly all of the participants have three or more co-morbidities. The mean Charlson Comorbidity Index (CCI) was 3.89 ± 2.87 and the mean PPS score was 55.80 ± 12.71. Their mean personal and instrument ADL scores were 0.78 ± 0.64 and 1.47 ± 0.63, respectively. They had been hospitalized for 2.58 ± 1.21 times over the past 12 months.

### 3.2 Symptom distress and quality of life

Table 2 shows the mean scores of ESAS items and the correlation coefficients of each item with the SIS score. The most distressing symptoms reported by the respondents by means of ESAS were tiredness, drowsiness and shortness of breath. Six symptoms, including depressed, anxiety, poor appetite, short of breath, pain and reduced wellbeing were significantly correlated with the SIS score. Concerning quality of life, their mean SIS score of quality of life was 4.72 ± 2.06 out of 10. When comparing the mean MQoL subscale scores, their mean physical subscale score was the lowest whereas their mean psychological subscale was the highest. Table 3 shows the mean scores of all MQoL items and the correlation coefficients of each item with the SIS

score. All the correlation coefficients in this matrix were lower than 0.58 that preclude the condition of multi-collinearity.<sup>[24]</sup> Apart from the three items on fear of future, face and sex, all items in the MQoL were significantly correlated with the SIS score. No association was

**Table 2. Mean scores of ESAS and correlation with the overall quality of life SIS.**

| Symptoms            | Mean ± SD   | r       |
|---------------------|-------------|---------|
| Tiredness           | 5.96 ± 2.78 | 1.00    |
| Drowsiness          | 5.47 ± 2.93 | -0.16   |
| Shortness of breath | 5.34 ± 2.96 | -0.18   |
| Reduced wellbeing   | 5.28 ± 2.06 | -0.28** |
| Pain                | 4.26 ± 3.01 | -0.85** |
| Poor appetite       | 3.71 ± 3.12 | -0.19*  |
| Depressed           | 3.38 ± 3.24 | -0.19*  |
| Anxiety             | 3.12 ± 3.06 | -0.33** |
| Nauseated           | 1.04 ± 2.39 | -0.32** |

\*P ≤ 0.05, \*\*P ≤ 0.01; n = 112. ESAS: Edmonton symptom assessment scale; SIS: single item scale.

**Table 3. Mean scores of MQoL questionnaire and correlation with the overall quality of life single item scale SIS (n = 112).**

| Subscales/Items             | Mean ± SD   | r      |
|-----------------------------|-------------|--------|
| Overall quality of life SIS | 4.72 ± 2.06 | --     |
| MQoL                        | 5.81 ± 1.45 | 0.66** |
| Physical                    | 4.20 ± 1.67 | 0.44** |
| Physical symptom 1          | 2.83 ± 1.82 | --     |
| Physical symptom 2          | 3.81 ± 2.19 | --     |
| Physical symptom 3          | 4.15 ± 2.38 | --     |
| Physical well-being         | 4.87 ± 2.06 | 0.48** |
| Eating                      | 4.77 ± 3.60 | 0.20*  |
| Psychological               | 7.14 ± 2.39 | 0.36** |
| Depressed                   | 7.48 ± 3.20 | 0.28** |
| Anxious                     | 6.43 ± 3.24 | 0.29** |
| Sad                         | 7.01 ± 3.26 | 0.35** |
| Fear of future              | 7.70 ± 2.64 | 0.08   |
| Every day 'seems a gift'    | 6.36 ± 2.85 | 0.51** |
| Face                        | 8.16 ± 3.01 | 0.14   |
| Existential                 | 6.07 ± 1.79 | 0.57** |
| Personal existence          | 5.23 ± 2.44 | 0.38** |
| Achieving life goals        | 6.23 ± 2.45 | 0.47** |
| Life is worthwhile          | 6.24 ± 2.26 | 0.54** |
| Feel good about myself      | 6.74 ± 2.28 | 0.31** |
| Support                     | 6.58 ± 2.11 | 0.31** |
| Closeness to people         | 7.40 ± 2.32 | 0.32** |
| World is caring             | 5.79 ± 2.87 | 0.22*  |
| Sex                         | 6.13 ± 3.91 | 0.56   |

\*P ≤ 0.05; \*\*P ≤ 0.01. MQoL: McQuill Quality of Life; SIS: single item scale.

noted between the demographic or clinical characteristics and the SIS score, except educational level.

### 3.3 Multivariate regression analysis

For the regression analysis, 18 variables (including 12 items in the MQoL, five items in the ESAS and educational level) which were significantly related to the SIS score were entered into the model in a stepwise fashion. The item of reduced wellbeing in the ESAS was not included in the model because its correlation coefficient with the SIS score was high indicating high covariability.<sup>[24]</sup> The results were shown in Table 4. In the model, five items, including life is worthwhile, physical wellbeing, every day 'seems a gift', feel good about myself and educational level, showed significant association with the SIS score, accounting for 52.0% of the total variance. Among these variables, the item on life is worthwhile demonstrated the strongest explanatory power ( $R^2 = 28.0\%$ ,  $P < 0.001$ ,  $\beta = 0.49$ ), followed by the item on physical wellbeing which accounted for an additional 15% of variance ( $\beta = 0.31$ ,  $P < 0.001$ ).

## 4 Discussion

This study aimed to understand the unique palliative care needs of elderly patients with advanced HF by identifying the significant factors influencing their quality of life. The findings of this study are consistent with previous studies that patients with advanced HF experience multiple severe symptoms,<sup>[11-13]</sup> but the findings further revealed that these physical symptoms are not the only factors influencing their quality of life. Although all variables that demonstrated significant correlation with the SIS item were entered into regression analysis, four out of five factors being identified in the model were MQoL items. The item on physical wellbeing seems to summarize the overall impacts of illness and symptoms on the physical health as perceived by the respondents. The other three MQoL items were all from the subscale of Existential and Psychological wellbeing. It appears that existential wellbeing is overarching in the quality of life of patients with advanced HF. Hence, symptom management may be considered as fundamental care to promote

patient comfort, but in addition to symptom control, spiritual and psychological care is equally important in palliative care for patients with advanced HF.<sup>[10]</sup> Previous qualitative studies noted that the existential distress or spiritual concerns among patients with advanced HF arisen from the loss of meaning and purpose in life and sense of depersonalization.<sup>[10,25]</sup> Built on these understanding, further studies are needed to develop strategies for promoting their existential wellbeing.

On the other hand, one variable, every day 'seems a gift', in the psychological domain was identified in the model. This is in contrast to other studies noting that psychological distress is one of the significant factors predicting quality of life among patients with advanced HF. Literature generally noted that emotional disturbances and sense of uncertainty are prominent among patients with advanced illness.<sup>[16,25,26]</sup> In the present study, although the item on fear of future was not significantly correlated with the SIS score, its correlation with other items in the psychological wellbeing subscale, such as depressed, worry, and sad, should not be overlooked. This result is congruent with a narrative review of qualitative studies that patients with chronic HF are living in fear.<sup>[15]</sup> Hence, the linkage between fear about future and negative emotions noted in the present study warrants attention as this may be a common experience among patients with advanced illness when coming to term with the impending loss and death.

Lastly, the findings showed that items on face and sex, demographic and clinical characteristics of the patients, except educational level, generally were not significantly associated with their quality of life. One earlier local study also noted that educational level is a factor influencing quality of life of patients with HF,<sup>[16]</sup> but this observation was not noted in other studies. A possible explanation is that most of the Chinese older adults had not received education due to historical events and so educational level plays an important role in their culture on how they interpret their life quality.

This study has added to our knowledge the importance of existential wellbeing contributing to quality of life among Chinese elderly patients with advanced HF. Yet, we have to acknowledge a study limitation that the findings were drawn from a convenience sample through a cross-sectional study at a single centre.

In conclusion, in this study, five factors in the aspects of existential wellbeing, physical wellbeing, psychological wellbeing and educational level, were identified as significantly associated with quality of life of elderly patients with advanced HF. The findings underscore the importance of holistic care in addressing the different palliative care needs of patients with advanced HF.

**Table 4. Stepwise regression of the correlates of quality of life.**

| Variables                | B     | SE(B) | $\beta$ | t     | R <sup>2</sup> | P      |
|--------------------------|-------|-------|---------|-------|----------------|--------|
| Life is worthwhile       | 0.43  | 0.07  | 0.49    | 6.00  | 0.28           | <0.001 |
| Physical wellbeing       | 0.32  | 0.08  | 0.31    | 3.88  | 0.43           | <0.001 |
| Every day 'seems a gift' | 0.17  | 0.06  | 0.24    | 2.99  | 0.46           | 0.003  |
| Educational level        | 0.51  | 0.19  | 0.19    | 2.70  | 0.49           | 0.008  |
| Feel good about myself   | -0.26 | 0.08  | -0.29   | -3.01 | 0.52           | 0.003  |

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