

Unequal care for dying patients in Sweden: a comparative registry study of deaths from heart disease and cancer

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Abstract

Background: The Swedish Palliative Registry is a nationwide quality registry aimed at facilitating improvement in end-of-life care. The goal is for the registry to list and report quality indicators related to care during the last week of life in all cases expected death in Sweden.

Aim: To examine the quality of care during the last week of life as reported to the registry for patients with heart disease compared to those with cancer.

Method: A retrospective registry study.

Results: Patients dying of heart disease compared to those dying from cancer had more shortness of breath, fewer drugs prescribed as needed against the usual symptoms and often died alone. Furthermore, they and their close relatives received less information about the imminence of death and bereavement follow-up was less common. The healthcare personnel were less aware of the heart disease patients' symptoms and less often knew about where they wished to die.

Conclusion: Great differences were found in registered end-of-life care suggesting that the care given to patients with heart disease and cancer was unequal even after adjustment for age, sex and setting at the time of death. If our observational findings are confirmed in future studies there is obviously a need for new models for end-of-life management in order to facilitate the provision of equal care to dying patients regardless of diagnosis.

Keywords

Heart disease, cancer, palliative care, quality of care, registry study

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Introduction

Palliative care aims to provide good symptom control, regardless of diagnosis or whether the problem is of a mental, physical, social or existential nature and to offer a support system to help the family to cope during the patients' illness and their own bereavement¹. Comparative studies, using cancer as the reference, showed that patients with heart failure had burden of needs similar to those of cancer patients but did not seem to have equal access to supportive and palliative care^{2,3}. We found no quantitative studies that examine and highlight differences in palliative care received by patients with heart disease and those with cancer.

The Swedish Palliative Registry is a nationwide quality registry aimed at improving end-of-life care. The goal of

the registry is to list and report quality indicators related to care during the last week of life in the case of all expected deaths in Sweden. We investigated whether the quality of care during the last week of life, as reported to the registry for patients with heart disease differed from that of cancer patients.

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Table 1. Demographic data of patients with heart disease and cancer

| Variables | Heart disease <i>n</i> = 5897 | | Cancer <i>n</i> = 25,163 | | OR (95% CI) unadj. | <i>p</i> -val | OR (95% CI) adj. ^c | <i>p</i> -val |
|--|----------------------------------|------|-----------------------------|------|-----------------------|---------------|----------------------------------|---------------|
| Mean age at time of death | 85.4 | | 71.7 | | | .001 | | |
| | <i>n</i> | % | <i>n</i> | % | | | | |
| Sex | | | | | | | | |
| Male | 2610 | 44.3 | 12,606 | 50.1 | | | | |
| Female | 3287 | 55.7 | 12,557 | 49.9 | | .001 | | |
| Settings of death | | | | | | | | |
| Specialised palliative care ^a | 622 | 10.6 | 17,651 | 70 | 19.9 | .001 | 12.1 | .001 |
| Other ^b | 5275 | 89.4 | 7512 | 30 | (18.3–21.8) | | (11.0–13.2) | |

^aAdvanced home care, specialised palliative clinic.

^bHome care, nursing home, hospital.

^cAdjusted for age, sex and setting.

Method

This was a study of the Swedish Palliative Registry with a total number of 31,060 deaths, comprising 5435, 10,747 and 14,878 individuals (17.5, 34.6 and 47.9%,) using data from the year 2006 to 2008. In this study data were based on individual assessments using a questionnaire which covered aspects of care and quality of life during the last week of life. The questionnaire comprises of 27 questions about e.g. information, autonomy, symptom relief, essential drugs administered in the injection route prescribed and whether someone was present in the moment of death. Registrations were made after death of the patient by the responsible nurse and/or physician based on the patient record but also from not documented experience of the care, preferably after a team discussion including experience also from other team members. To be able to register patients, the unit or service has to be enrolled in the Registry, which entails supplying data on the type of unit, statistical information including diagnoses of patients and polices. This information is followed up in an annual questionnaire. Parts of the register is self instructive, other parts may need explanations, included on the register web page or on the online register. The investigation conforms with the principles outlined in the Helsinki Declaration (Br Med J 1964; ii:177), and the study was approved by the Ethics Committee of the Medical Faculty, Umeå University, Umeå, Sweden (reference number Um dnr 08-027 M).

Data analysis

Descriptive statistics, with means and standard deviation (SD) values for continuous variables and percentages for categories, were compiled for baseline characteristics. Differences in mean values between groups were analyzed using Student's two-tailed *t*-test for normally distributed data. For variables that were not normally distributed the

non-parametric Mann–Whitney *U* test was used. Differences in proportions were tested using the Chi-square test. Logistic regression analyses were used to calculate odds ratios (ORs) and 95% confidence intervals (CIs) in univariate and multivariate models. Adjustment was made in the multi-variable analysis for age, sex and type of unit/setting at death. All analysis was performed using Statistical Package for the Social Sciences (SPSS) version 11.5.1 (Chicago, IL, USA). A *p*-value of <0.05 was considered statistically significant.

Results

Patients dying from heart disease were older and more often female and died much more frequently in settings other than specialised palliative care, compared to patients dying from cancer (Table 1).

Death was significantly ($p < 0.001$) more often expected among patients with cancer (97%) than among heart disease patients (80%) (Table 2).

When comparing symptoms that were not fully relieved between the groups, patients with heart disease more often ($p < 0.001$) had dyspnoea but cancer patients had significantly more unrelieved symptoms of nausea, anxiety and pain. It was significantly ($p < 0.001$) more often unknown whether patients with heart disease had unrelieved symptoms (9.2%) compared to cancer patients (3.9%). The question about whether a visual analogue scale (VAS) or numerical rating scale (NRS) was used to assess pain intensity during the last week of life was only answered by 10.4% of the cancer patients and 3.7% of the heart disease patients. However, the missing value for this item was high. About one third of the patients in each group did not have any distressing symptoms. The risk of having or developing decubitus was significantly ($p = 0.009$) higher for cancer patients than for patients with heart disease (Table 3).

Table 2. Death expected

| Variables | Heart disease <i>n</i> = 5897 | | Cancer <i>n</i> = 25,163 | | OR (95% CI) unadj. | <i>p</i> -val | OR (95% CI) adj. ^a | <i>p</i> -val |
|--|----------------------------------|------|-----------------------------|------|-----------------------|---------------|----------------------------------|---------------|
| | <i>n</i> | % | <i>n</i> | % | | | | |
| Death | | | | | | | | |
| Expected | 4728 | 80.2 | 24,297 | 96.6 | 0.17 | .000 | 0.87 | .000 |
| Unexpected | 910 | 15.4 | 636 | 2.0 | (0.12–0.15) | | (0.89–0.88) | |
| Unknown | 259 | 4.4 | 230 | 0.9 | | | | |
| Did place of death conform with the latest wish of the patient? | | | | | | | | |
| Yes | 1891 | 32.1 | 14,829 | 58.9 | 1.1 | .260 | 0.77 | .006 |
| No | 212 | 3.6 | 1524 | 6.1 | (0.9–1.3) | | (0.64–0.93) | |
| Known | 2103 | 35.7 | 16,353 | 65.0 | 3.3 | .001 | 1.2 | .000 |
| Unknown | 3753 | 63.6 | 8750 | 34.8 | (3.1–3.5) | | (1.6–1.81) | |
| Missing | 41 | 0.7 | 60 | 0.2 | | | | |

^aAdjusted for age, sex and setting.

The probability of having the necessary drugs by the injection route prescribed differed between the groups. For patients with cancer the odds ratio of having drugs prescribed was 3.4 for pain relief, 2.4 for nausea 1.9 for anxiety and 1.5 for death rattles compared to patients with heart disease (all significant, $p = .000$), (Table 3). The probability of consulting specialists concerning unrelieved symptoms was significantly ($p = 005$) higher for cancer patients than for heart disease patients (Table 3).

There were great differences between the two groups regarding communication of the information that the patient was dying, both to patients and their close relatives. The probability of having an informative talk with patients about their imminent death was significantly ($p = .000$) higher for cancer patients than for patients with heart disease. Close relatives of cancer patients ($p = .000$) received informative talks about the patient was dying more often. A higher proportion of patients with heart disease (20%) than patients with cancer (12%, $p = .000$) were alone at the moment of death. Bereavement follow-up was more common if the patient died of cancer. However, information about this issue was registered as unknown to a greater extent among close relatives of patients with heart disease (20.5%) compared to those of patients with cancer (8.3%, $p < 0.001$) (Table 4).

The probability of knowing when patients lost their ability to exercise self-determination was higher among patients with cancer ($p = .000$), (Table 3). Furthermore, knowledge about the patient's last expressed wish about the place of death was higher for cancer patients than for patients with heart disease (Table 2). Healthcare personnel estimated the degree of satisfaction with care provided significantly ($p = 000$) higher for patients with cancer than for patients with heart disease.

Discussion

Our main finding revealed great differences in end-of-life care suggesting that patients with heart disease and those with cancer received unequal care. Patients dying of heart disease, compared with patients who died from cancer, more often had shortness of breath, were prescribed fewer drugs on demand against the usual symptoms and more often died alone. Furthermore both they and their close relatives seemed to receive less information about the imminence of death and bereavement follow-up was less common. The healthcare personnel were less aware of symptoms and less frequently knew where patients with heart disease wished to die. In summary, our results suggest that patients with heart disease received less adequate care during the last days of life compared to patients with cancer, based on the registered indicators of quality. This result is in line with the overall estimation of satisfaction with the care delivered as reported by healthcare personnel. Murray et al.⁴ also showed that patients with heart failure received less information about their condition and prognosis and were less involved in decision making than lung cancer patients. A few had developed a long term relationship with a key professional; a consultant, general practitioner or specialist cardiac nurse.

A systematic review of symptom prevalence in advanced cancer, AIDS, end-stage heart failure, chronic obstructive pulmonary disease and chronic renal failure found a great heterogeneity in prevalence of symptoms and a high rate of prevalence for almost all symptoms. Pain, breathlessness and fatigue were the most common reported symptoms among the patients⁵. Our results showed that parenteral drugs for pain, secretions or death rattles, nausea and anxiety were reported to be more seldom prescribed for the

Table 3. Symptoms

| Variables | Heart disease <i>n</i> = 5897 | | Cancer <i>n</i> = 25,163 | | OR (95% CI) unadj. | <i>p</i> -val | OR (95% CI) adj. ^a | <i>p</i> -val | |
|--|----------------------------------|------|-----------------------------|--------|-----------------------|---------------------|----------------------------------|------------------|------|
| | <i>n</i> | % | <i>n</i> | % | | | | | |
| Has NRS scale (0–10) been used for assessment of pain during the last week of life | | | | | | | | | |
| Yes | 219 | 3.7 | 2613 | 10.4 | 3.49 (3.0–4.0) | .000 | 1.3 (1.1–1.6) | .003 | |
| No | 3171 | 53.8 | 10,867 | 43.2 | | | | | |
| Missing | 2507 | 42.5 | 11,683 | 46.4 | | | | | |
| Symptom not fully relieved during the last week of life | | | | | | | | | |
| Dyspnea | 619 | 10.5 | 1724 | 6.9 | 0.62 (0.57–0.69) | .000 | 0.48 (0.43–0.57) | .000 | |
| Confusion | 232 | 3.9 | 1095 | 4.4 | 1.11 (0.96–1.28) | 0.154 | 0.93 (0.76–1.12) | .934 | |
| Nausea | 161 | 2.7 | 1028 | 4.1 | 1.51 (1.28–1.80) | .000 | 1.46 (1.60–2.39) | .000 | |
| Death rattles | 758 | 12.9 | 3098 | 12.3 | 0.95 (0.87–1.04) | 0.256 | 0.92 (0.86–1.00) | .043 | |
| Pain | 580 | 9.8 | 3751 | 14.9 | 1.60 (1.46–1.76) | .000 | 1.59 (1.42–1.78) | .000 | |
| Anxiety | 745 | 12.6 | 3814 | 15.2 | 1.24 (1.14–1.34) | .000 | 1.11 (1.00–1.23) | 0.06 | |
| Others | 129 | 2.2 | 841 | 3.3 | 1.5 (1.28–1.87) | .000 | 1.08 (0.86–1.36) | 0.516 | |
| No distressing symptoms | 2089 | 35.4 | 8778 | 34.9 | 0.89 (0.92–1.04) | 0.43 | 1.11 (1.03–1.20) | 0.009 | |
| Unknown ^a | 543 | 9.2 | 974 | 3.9 | 0.38 (0.36–0.44) | .000 | 0.65 (0.57–0.74) | .000 | |
| Prescribed drug injection on demand the last day of life | | | | | | | | | |
| Pain | Yes | 4528 | 76.7 | 24,051 | 95.6 | 6.7 (6.2–7.3) | .001 | 3.4 (3.1–3.8) | .000 |
| | No | 1328 | 22.5 | 1052 | 4.2 | | | | .000 |
| Missing | | 41 | 0.7 | 60 | 0.2 | | | | |
| Death rattles | Yes | 4139 | 70.2 | 21,340 | 84.8 | 2.4 (2.2–2.5) | .001 | 1.5 (1.4–1.7) | .000 |
| | No | 1717 | 29.1 | 3763 | 15.0 | | | | |
| Missing | | 41 | 0.7 | 60 | 0.2 | | | | |
| Nausea | Yes | 1721 | 29.2 | 17,982 | 71.5 | 6.1 (5.7–6.5) | .001 | 2.4 (3.0–2.5) | .000 |
| | No | 4135 | 70.1 | 7121 | 28.3 | | | | |
| Missing | | 41 | 0.7 | 60 | 0.2 | | | | |
| Anxiety | Yes | 3642 | 61.8 | 21,988 | 87.4 | 0.79 (0.72–0.86) | .000 | 1.9 (1.7–2.1) | .000 |
| | No | 2214 | 37.5 | 3115 | 12.4 | | | | |
| Missing | | 41 | 0.7 | 60 | 0.2 | | | | |
| Consultant involved concerning not relieved symptom | | | | | | | | | |
| Yes | 804 | 13.6 | 2530 | 10.1 | 0.79 (0.72–0.86) | .001 | 1.16 (1.1–1.3) | .005 | |
| No | 2530 | 42.9 | 15,482 | 61.5 | | | | | |
| Missing | 2563 | 43.5 | 7151 | 28.4 | | | | | |
| Decubitus the last week of life | | | | | | | | | |
| Yes | 136 | 2.3 | 1044 | 4.1 | 1.1 (1.0–1.2) | .000 | 1.2 (1.0–1.23) | .009 | |
| No | 4719 | 80 | 19,375 | 77.0 | | | | | |
| Missing | 1042 | 17.7 | 4744 | 18.9 | | | | | |

^aAdjusted for age, sex and setting.

patients with heart disease than for those with cancer during the last days of life. As a consequence, it is possible that dyspnoea and death rattles were not fully relieved the last week in life for the latter group. The odds of pain-relieving drugs being prescribed were as much as 6.7 times greater for patients with cancer compared to heart disease patients. Even though patients with cancer more often had unrelieved pain, our result showed that about one in ten patients with heart disease also had unrelieved pain. Other studies have shown that patients with heart disease at the end of life suffered from pain even to an even greater extent^{6,7}. The National Palliative Registry also showed that healthcare

personnel significantly more often reported unrelieved symptoms among heart disease patients as unknown.

The traditional view of palliative care, based on palliative assessments which are founded on the care of people with cancer, is that curative treatment is terminated when palliative care takes over, close to the patient's death cf.⁸. This view is in line with recently published results concerning physicians⁹ and nurses¹⁰ attitudes and experiences of palliative care for patients with heart failure. Studies have shown that identifying dying is more difficult in patients with heart failure, because of the unpredictable course of the illness, than in patients with cancer^{9–11}. The transition,

Table 4. Information and communication

| Variables | Heart disease <i>n</i> = 5897 | | Cancer <i>n</i> = 25163 | | OR (95% CI) unadj. | <i>p</i> -val | OR (95% CI) adj. ¹ | <i>p</i> -val |
|---|----------------------------------|------|----------------------------|------|-----------------------|---------------|----------------------------------|---------------|
| | <i>n</i> | % | <i>n</i> | % | | | | |
| Informative dialogue with the patient conveying that he/she was dying. | | | | | | | | |
| Yes | 1578 | 27 | 18,482 | 73 | 9.2 | .001 | 6.0 | .000 |
| No | 3035 | 51.5 | 2590 | 10.3 | (8.7–9.9) | | (5.7–6.5) | |
| Missing | 1243 | 21.1 | 4028 | 16.0 | | | | |
| Informative dialogue with relatives conveying that the patient was dying. | | | | | | | | |
| Yes | 4558 | 78 | 23,543 | 94 | 8.58 | .000 | 7.2 | .000 |
| No | 934 | 15.8 | 559 | 2.2 | (7.7–9.6) | | (6.2–8.4) | |
| Missing | 405 | 6.9 | 1061 | 4.2 | | | | |
| Time-point for loss of patient's ability to self determinate | | | | | | | | |
| Knew all time-points | 5001 | 85 | 24,176 | 96 | 3.82 | .000 | 1.98 | .000 |
| Unknown | 896 | 15.2 | 987 | 3.9 | (3.5–4.2) | | (1.8–2.2) | |
| Anyone present at the time of death? | | | | | | | | |
| Yes | 4682 | 79.3 | 22,220 | 88.3 | 1.78 | .000 | 1.47 | .000 |
| No | 1174 | 19.9 | 2883 | 11.5 | (1.6–1.9) | | (1.5–1.6) | |
| Missing | 41 | 0.7 | 60 | 0.2 | | | | |
| Bereavement follow-up with relative? | | | | | | | | |
| Yes | 2928 | 49.7 | 1939 | 7.7 | 5.9 | .000 | 1.6 | .000 |
| No | 1720 | 29.2 | 21,076 | 83.8 | (5.5–6.4) | | (1.5–1.8) | |
| Missing | 1249 | 21.1 | 1148 | 4.6 | | | | |
| Known | 4648 | 78.8 | 23,161 | 92 | 3.1 | .000 | 1.2 | .000 |
| Unknown | 1208 | 20.5 | 2002 | 8.3 | (2.9–3.4) | | (1.1–1.4) | |
| Missing | 41 | 0.7 | 0 | 0 | | | | |

¹Adjusted for age, sex and setting.

or turning point, defined as entering the dying phase, was shown in medical and nursing records to be late, with a documented median time of within the five last days of life¹². A frequency of 70% was found for recorded turning point in the care providers' documentation¹³. The turning point was also shown to be significantly associated with the patients' deteriorating condition. The lowest estimated probability for a documented turning point (27%) was obtained among individuals with cardiovascular diseases who were not sporadically confined to bed and did not have a deteriorating condition¹². A study has shown that documented procedures following the turning point were that patient-centred efforts were described minimally compared to the family-centred efforts made. Thus, the use of a turning point as a proper time to start palliative care did not seem to be appropriate since it usually occurred too late as the patients were then too close to death to be actively involved in the care and the families begin to act as proxies¹³. The unpredictable process of heart failure makes it difficult to have informative talks about the imminence of death and there is a great risk that these patients and their close relatives will not have information about the prognosis and access to palliative care [cf. 8].

Our results indicate that the course of illness for patients with cancer represent a 'model of dying' for health care

providers and that there is a need to move away from the idea of identifying a specific turning point at which to switch to palliative care to the idea of starting palliative care earlier in the illness. This is in line with the World Health Organization's¹ recommendation that palliative care should begin early in the course of illness. Furthermore, it is in line with a model discussed in connection with the goals for care of patients with heart failure cf.^{14–16}, and those with cancer¹⁷, including both palliative care and active treatment of heart failure or cancer to varying degrees, beginning at the time of initial diagnosis through the whole process of the illness into death. Support for those close to the patient before and after the patient's death is included in the model. Thus, palliative care should not only be offered to patients who are expected to die within days or weeks. This model could be a way of further improving and including palliative care regardless of diagnosis or whether the problem is of a mental, physical, social or existential nature.

Strengths and limitations

The large number of registered patients is strength of this study making possible appropriate adjustments in the multivariate analysis. But the obvious limitations are that these

patients were selected, and the study was retrospective and observational in design, meaning that our results can only be regarded as hypothesis generating. Another limitation is that the person who reported the answers to the Registry may have had only a brief contact with the patient, or was not involved in the care, which means that the answers might not always be accurate and could include a recall bias. It could be argued that such a recall bias should be equally distributed between heart disease patients and those with cancer but a deeper knowledge of one type of disease may affect the answers. Some questions had a high number of 'unknown' answers or missing data, substantially hampering drawing of conclusions regarding some answers. It is also probable that there is a selection bias, i.e. units that registered were particularly interested in palliative care so the answers may not be representative of more generalized units caring for dying patients. Some of the parameters in the register have a high degree of validity, such as drug prescription, whereas other questions such as existence of respiratory tract secretions (death rattles), the content of an informative dialogue or loss of self-determination is still not well defined. Further, to be able to achieve a close to 100% registration rate there is a balance between clinical assessment and scientific accuracy. There is an ongoing work to investigate and improve validity of the questionnaire¹⁸.

Conclusion

Our main finding revealed great differences in quality of end-of-life care between patients with heart disease and cancer as measured by the Swedish Palliative Care Registry. In order to facilitate equal care for dying patients regardless of diagnosis this study highlights the necessity of reflecting on and changing the view of palliative care in everyday healthcare practices, to include both palliative care and active treatment in varying degrees, beginning at the time of the initial diagnosis and continuing throughout the process of the illness into death. Otherwise, there could be a risk that patients with heart disease because of the more unpredictable process of their dying, might be treated sub optimally. If our observational findings are confirmed in future studies there is a serious need for new models of end-of-life management in order to facilitate equal care for dying patients regardless of diagnosis.

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Conflict of interest

None declared.

References

1. World Health Organization. National cancer control programs: policies and managerial guidelines 2nd: 2002. Geneva.
2. O'Leary, N, Murphy, FN, O'Loughlin, Tiernan, E & McDonald, K. A comparative study of the palliative care needs of heart failure and cancer patients. *Eur J Heart Fail* 2009; 11: 406–12.
3. O'Leary, N. The comparative palliative care needs of those with heart failure and cancer patients. *Curr Opin Support Palliat Care* 2009; 3(4): 241–6.
4. Murray, SA, Boyd, K, Kendall, M, Worth, A, Benton, TF & Clausen, H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *Br Med J* 2002; 325: 929–32.
5. Solano, JP, Gomes, B & Higginson, IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage* 2006; 31: 58–69.
6. Evangelista, LS, Sackett, E & Dracup, K. Pain and heart failure: unrecognized and untreated. *Eur J Cardiovasc Nurs* 2009;8(3): 169–73.
7. Goebel, JR, Doering, LV, Shugarman, LR, Asch, SM, Sherbourne, CD & Lanto, AB et al. Heart failure: the hidden problems of pain. *J Pain Symptom Manage* 2009;38(5): 698–707.
8. Gibbs, J, McCoy, A, Gibbs, L, Rogers, A & Addington-Hall, J. Living with and dying from heart failure: the role of palliative care. *Heart* 2002;88(Suppl. II) 36–9.
9. Brännström, M, Forssell, A & Pettersson, B. Physicians' experiences of palliative care for heart failure patients. *Eur J Cardiovasc Nurs* 14 may 2010; 10.1016/j.ejcnurse.2010.04.00510.1016/j.ejcnurse.2010.04.005 Available online.
10. Brännström, M, Brulin, C, Norberg, A, Boman, K & Strandberg, G. Being a palliative nurse for persons with severe congestive heart failure in advanced home care. *Eur J Cardiovasc Nurs* 2005; 4(4): 314–23.
11. Hanratty, B, Hibbert, D, Mair, F, May, C, Ward, C & Capewell, S et al. Doctors' perceptions of palliative care for heart failure: focus group study. *Br Med J* 2002; 325(7364): 581–5.
12. Jakobsson, E, Bergh, I, Gaston-Johansson, F, Stolt, CM & öhlén, J. The turning point: clinical identification of dying and reorientation of care. *J Palliat Med* 2006; 9(6): 1348–58.
13. Jakobsson, E, Bergh, I & öhlén, J. The turning point: identifying end-of-life care in everyday health care practice. *Contemp Nurse* 2007; 27(1): 107–18.
14. Jaarsma, T & Leventhal, M. Special paper. End-of-life issues in cardiac patients and their families. *Eur J Cardiovasc Nurs* 2002; 1(4): 223–5.
15. Murray, SA, Kendall, M, Boyd, K & Sheikh, A. Illness trajectories and palliative care. *BMJ* 2005;330:1007–11.
16. Hupcey, JE, Penrod, J & Fenstermacher, K. Review article: a model of palliative care for heart failure. *Am J Hosp Palliat Care* 2009;26(5): 399–403.
17. Higginson, IJ & Costantini, M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008; 44: 1414–24.
18. Martinsson, L, Heedman, PA, Lundström, S, Fransson, G & Axelsson, B. Validation study of an end-of-life questionnaire from the Swedish Register of Palliative Care. *Acta Oncol* 2011; 50(5): 642–7.