

Patient reported outcome measures in hospice, which stories are told?

an analysis of patients who can and cannot self-assess symptoms



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Background

Patient Reported Outcome Measures (PROMs) become increasingly important for hospice care to provide insight into the results and quality of care provided. In daily hospice care patient self-reported symptom intensity scores are used to gain insight into the symptoms and problems patients experience during their illness trajectory. However, not all patients are willing and able to self report.

Aims

The aims of this study are twofold. (1) To gain insight into hospice patients who are willing and able to self-report symptoms, and those who are not. (2) To gain insight into the period self-assessment is feasible, measured from admission and from death backwards.

Methods

A longitudinal, quantitative retrospective cohort study, using prospectively collected data.

Setting and population

All admitted patients to a high care hospice from June 2007 to December 2013 enrolled in this study.

Measurement

The Utrecht Symptom Diary (USD), the Dutch adapted translation of the Edmonton Symptom Assessment System, contains 12 symptoms and a 1-item (un)well-being measure on a 0-10 numerical scale. All USD were prospectively collected during hospice stay and entered in a database (SYMPAL), specifically developed to collect data from palliative care patients in a diversity of palliative care settings.

Outcomes

Demographics: age, age groups: <65, 65-74, 75-84, ≥85, gender, marital status.

Illness characteristics at admission: diagnosis, comorbidity

Phase of palliation: illness, symptom or terminal, Prognosis: <1wk, 1-4wks, 4wks-3month, >3months,

Survival: days from admission-death.

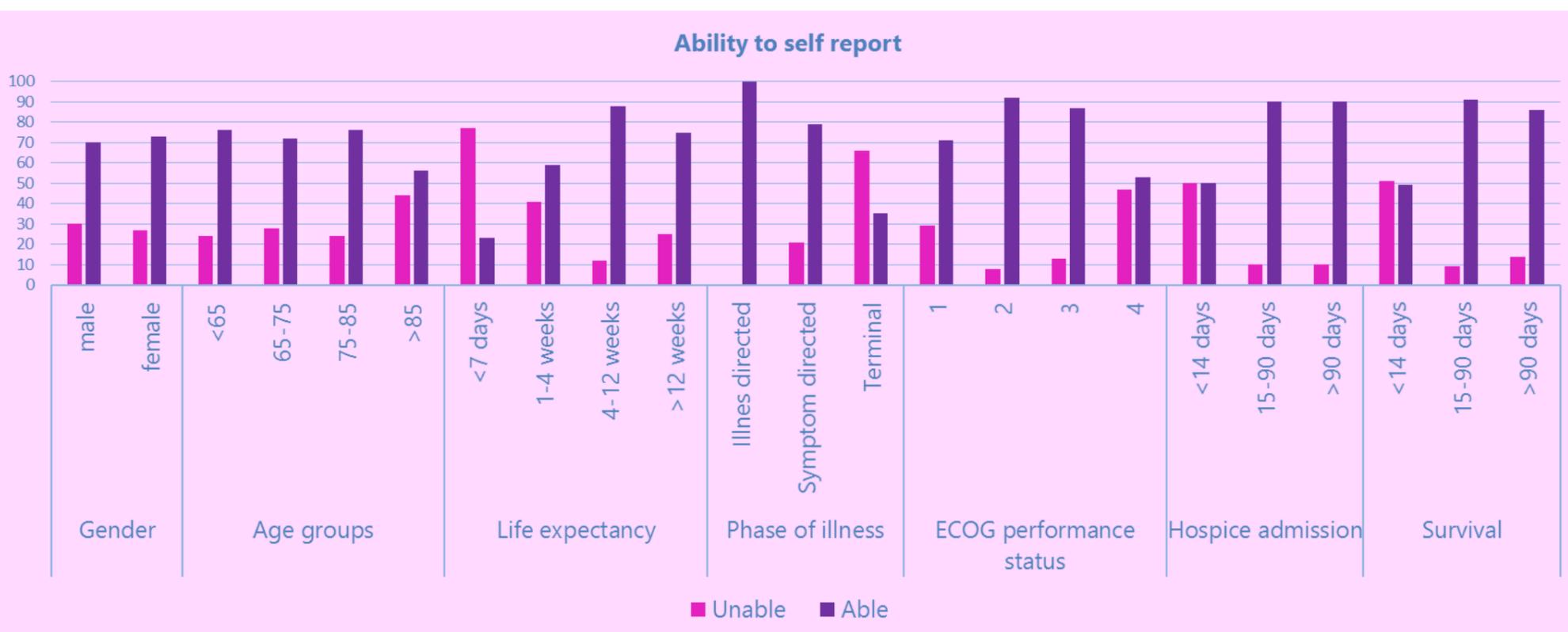
Days from admission-first USD and last USD-death.

Analysis

The outcomes were analyzed using descriptive statistics. Group differences were analyzed using Chi Square for categorical data and independent Students T test or Mann Whitney U test for continuous data.

Results

In total 342 patients, 136 (40%) men, were admitted from June 2007 to December 2013. The median age was 74 (mean: 72,17; 31-100; SD 13,096) In total 246 patients were able and/ or willing to fill in at least one USD during admission.



Within a week after admission 227/246 (92%) patients filled out their first USD. In contrast 117/216 (54.2%) filled out their last USD during the last week of life. The mean period admission-first USD was 2.3 days (0-50; SD 4.497) for last USD-death this was 13.63 days(0-419; SD 33.5).

Conclusion/ Discussion

Patients unable or unwilling to self-report symptom intensity were more likely to be over 85, or had a low ECOG performance status, or a life expectancy less than 7 days, or a survival less than 14 days, or were admitted for less than two weeks. The ability to self-report symptom intensity rapidly declines in the last week of life.

Patient Reported Outcome Measures are feasible in the hospice population. Although, the PROMs story of the very ill and very old need other strategies to be told.