

Quality of life assessment and outcome of palliative care

Campbell FA, Tramer NR, Carroll D, Reynolds DJM, Moore RA, McQuay HJ. BMJ 2001;323:1-6

Prepared by: : Dr Antonio Viganò

Received during: Journal rounds on TPCU on May 17th, 2001

Abstract:

Quality of life (QoL) assessment is crucial for the evaluation of palliative care outcomes. In this paper, our methodological approach was based on the creation of summary measures. Fifty-eight Palliative Care Units (PCUs) in Italy participated in the study. Each PCU randomly selected patients to be 'evaluated' among the consecutively 'registered' patients. At baseline (first visit) and each week the patient was asked to fill in a QoL questionnaire, the Therapy Impact Questionnaire (TIQ). Short-survivors (<7 days) were not included in the QoL study. The random sample of patients (n = 601) was highly representative of the general patient population cared for by the PCUs in Italy. The median survival was 37.9 days. We collected 3546 TIQ, 71.4 % completed by the patients. A Summary Measure Outcome score was calculated for 409 patients (81% of the patients included in the QoL study). The results of this national study showed that cooperative clinical research in palliative care is possible and QoL measures can be used to assess the outcome.

Comments:

Strengths/uniqueeness:

This paper provides some interesting directions for future "epidemiologically" sound research, particularly the use of sampling procedures to obtain a representative sample and keep the workload to a minimum for the health professionals participating in a study. Flow-charts should become a standard for palliative care research. Outcomes were analyzed separately in sub-populations with different median survivals. Finally, reasonable efforts were made to overcome problems related to missing data and proxy versus self-reported data. It was quite interesting to see that the results obtained from proxy plus self-completed QoL assessments were comparable to those obtained using self-completed QoL assessments only. The participation of 58 different centers and the accrual of 505 patients over a period of 6 months are also remarkable.

Weaknesses:

The QoL questionnaire appears somewhat difficult to understand in its scales, sub-scales, summary scales and scores. Particularly, it is unclear how the "intermediate" score differs from the "last" score. There is a sense of overwhelming statistical work.

There is no convincing evidence the TIQ could be used in other countries.

Relevance to Palliative Care:

This study clearly points out that up to 2/3 of terminally ill cancer patients may not be able to complete a self-reported QoL questionnaire. Further studies looking at the feasibility and appropriateness of proxy assessments are needed to better understand the "quantity and quality" of suffering in this patients population.