

Title: Yet a search for a way to have better referrals to specialist palliative care.

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Background: In DK as in most countries palliative care needs are met at two levels; basic palliative care is delivered by the primary and secondary healthcare services, and specialist palliative care (SPC) is provided by palliative care teams and units in cooperation with community caregivers and others. As resources for specialist palliative care are limited, a good allocation is essential. Physician referral is mandatory and should contain the information needed for safe evaluation of complex needs and to establish the correct level of care. Unfortunately, adequate information is seldom delivered. Stories are told; a) in pursue of demands to referrals, improvements have only lasted for a short period of time; b) pursuing is in expense of patients enduring suffering while battling; c) it may not be trustable to have non-palliative care healthcare workers to evaluate specialist palliative care needs. A more positive and comprehensive approach is to assume that referring physicians know the needs, but fail to pass them over.

Study object: To investigate if the referring physicians are aware of the palliative care needs of the patients whom they refer to specialist palliative care.

Method: A short, simple to answer, questionnaire was constructed and sent to referring physicians immediately after a date was set for the first appointment by the palliative care team. In the questionnaire, palliative care needs were condensed into 10 topics.

Answers were compared to the evaluation done by the palliative care team for the same topics.

Questionnaires were distributed through the electronic questionnaire program SurveyXact. A corresponding questionnaire was collected by hand after the first visit by the SPC team.

Results: 36 questionnaires were distributed to referring physicians. Immediate response rate was 50%, 58% after reminders. Responding physicians were 11 oncologists, 6 other hospital physicians and 4 primary healthcare physicians. One patient died before visit by the team, thus 20 sets of data were compared. For each data set the comparison of the 10 topics showed equally assessed topics in range 0-9, mean 6.2 and median 7. For each of the topics, the equal assessments ranged from 4 of 18 sets to 17 of 20 sets. Adjusted to 20 sets, equal assessment was mean 12.6 and median 13. In 8 topics the answer "I don't know" was optional. Range for that answer was 0-10 (total 20), mean 3.5. Overall, 17% of 160 questions were answered "I don't know". Regarding the team evaluation as the correct assessment, 25% of answers to 133 questions (total minus "I don't know") were wrong. The need for specialist care was overestimated in 30% and underestimated in 70% of wrong assessments. Two topics referred to assessment of symptoms; topic pain and topic physical symptoms of any kind beside pain. Within these two topics, 27% of answers were wrong; need for specialist care overestimated in 45% and underestimated in 55%. Overall in 20 referrals, needs for specialist care was overestimated in 8 and underestimated in 16. In 36% of the asked assessments the referring physician made either an incorrect assessment or did not know to assess the topic.

Conclusion: In this study a questionnaire condensing specialist palliative care needs into 10 topics was distributed to referring physicians and compared to assessments for the same topics by the specialist palliative care team. Overall result point to 5 topics for which knowledge needs to be shared or enhanced in the effort to ensure specialist palliative care for those in need of it.