



***Yet a search for a way to
have better referrals to
specialist palliative care***

*Course Project for
Nordic Specialist Course
in Palliative Medicine*

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Background:

In Denmark, as in most countries, palliative care needs are met in two levels of the healthcare service.

- Basic palliative care is delivered by the primary healthcare service and secondary healthcare services.
- Specialist palliative care (SPC) is provided by palliative care teams and units in cooperation with community caregivers and others.

As resources for SPC are limited, it is of great importance to insure access for the patients in need of it.



Background:

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 healthcare workers to evaluate specialist palliative care needs.

A more positive and comprehensive approach is to assume, that referring physicians are aware of the needs, but fail to pass them over.

Study object:

To investigate if the referring physician are aware of the palliative care needs of the patients, who are referred to specialist care.



Method:

An electronic questionnaire was send to the referring physician immediately after a date was set for the first appointment by the palliative care team.

The questionnaire was constructed to be short and simple to answer. For that purpose, palliative care needs were condensed into 10 topics, and options for answers were like “Yes”, “No” or *“I don’t know”*.

A corresponding questionnaire to the SPC team was collected by hand after the first visit.

The answers of the two sets of questionnaires were compared.



Condense of palliative care needs into 10 topics:

The take off was the perspective of methodology and content into which the palliative care team approaches a new patient.

At first visits, one of the main tasks is to make an overview over the situation, and to qualify the extend of immediate involvement by other interdisciplinary team members. In practice we use an interview board to assure us to review a list of topics.

Other tasks are also imminent, data collection to the national palliation registry and to the ongoing national work for development of quality standards for palliative efforts.



10 topics for palliative care needs:

1. Does the patient have a close relationship to children or young adults up to age 25?
2. Beside the patient, are other persons in the household burdened with disease?
3. Until now, is home care or primary care nurse connected to the home?
4. Knowledge about financial support. Do you know if
 - a) patient maintenance is safe (sickness benefits or retirements),
 - b) release of sums for critical illness has been taken care of,
 - c) opportunities for supporting the relatives has been thought of?
5. Knowledge about the psychology/mental state of the patient. In your opinion, is the reaction and behaviour different/worrisome/stronger than your experience would recognise as to be expected?



6. Knowledge about the psychology/mental state of the relatives. In your opinion, is the reaction and behaviour different/worrisome/stronger than your experience would recognise as to be expected?
7. If the patient experiences pain. In your opinion or experience, is the pain within that category, that proper relief is not only a question of titration of usual analgetics?
8. If the patient experiences physical symptoms beside pain. In your opinion or experience, are the symptoms within that category, that proper relief is not supposed by ordinary targeted symptom treatment alone?
9. In your opinion, does the state of illness imply a risk for a sudden situation of emergency? (ex. exsanguination, suffocation, bowel obstruction, not warned seizure or similar)
10. In your opinion, beside the referral to the palliative care team, might this patient have other possibilities for having a supported and relieved further course?



Results:

- Data was collected from 16. January to 4. April 2019.
- 36 questionnaires were distributed to referring physicians.
- Immediate respond 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.
- 197 data pairs compared (3 pairs missed; 2 for topic 4 and 1 for topic 6)



Data set number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Total (197)	Range (0-10)	Mean
Equal assess	8	6	4	8	9	6	7	9	7	4	5	5	7	7	9	7	9	3	5	0	125	0-9	6.2
Team assess higher	2	2	2	1	0	2	2	0	2	3	2	2	1	1	1	0	0	5	2	1	31	0-5	1.5
Physician assess higher	0	0	1	0	0	1	1	0	1	0	0	2	1	1	0	2	0	1	0	4	15	0-4	0.7

RESULTS FOR DATASET ASSESSMENTS



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Topic number	Equal assessments/no. pairs	Answer "I don't know"	Team assess higher	Physician assess higher
1	12/20	5	3	0
2	13/20	5	1	1
3	17/20	1	2	0
4	4/18	9	4	1
5	16/20	0	2	2
6	10/19	3 (1 no team assess)	6	1
7	15/20	not optional	3	2
8	13/20	not optional	4	3
9	13/20	2	2	3
10	12/20	2	4	2
Total	125/197	27	31	15
Range	4/18 -17/20	0-9	1-6	0-3
Mean	12.6 (adjusted to 20 sets)	3.4	3.1	1.5

RESULTS FOR TOPIC PAIR ASSESSMENTS



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Results:

- In 63% of comparisons assessments were found to be equal.
- In 17% of 159 questions (*160 minus 1 missed answer*) the physician answered “*I don’t know*”.
- Assuming the team evaluations are the correct assessments, the total amount of wrong answers was 23% (*46 of 197*). The palliative care needs were overestimated in 33% and underestimated in 67% of wrong answers.

Added up, in 36% the referring physician was not aware of the palliative care needs of the patient (72 of 197).

- Overall, overestimation of needs were seen in 8 of these 20 referrals, and underestimation was seen in 16. None were equally assessed. None were assessed without any “high- level- need” for palliative care.



Results:

- The topic with the best equal assessment was concerning established care in the home.
- Second best topic was concerning assessment of the mental state of the patient.
- The topic with the poorest equal assessment was about handling of financial support.
- The second poorest topic was concerning assessment of the mental state of the relatives. In perspective of needs referred to the entire family, referring physicians did not show to focus on close relatives of young age or relatives also burdened with disease.
- Asked to assess pain and any other physical symptoms beside pain, 27% of answers were wrong compared to evaluations by the SPC team.



Conclusion:

This small study intended to “*search for a way to have better referrals to specialist palliative care*”.

The study approach was, in a topic manner, to ask simple “*Yes/No/I don’t know*” answers for the palliative care needs of a patient, just referred to specialist palliative care (SPC).

The study results confirm the general impression, still a need to enhance and share knowledge regarding how to assess the level for palliative care.

Results suggests 5 areas for which sharing of knowledge probably would help the referring physicians to assess the palliative needs more distinctly, thus contribute to establish level for delivery of palliative care.



5 areas for teaching/share of knowledge:

1. Look for need of financial support
2. Look for need of support to relatives concerning psychological/mental distress
3. Have a look for extra supportive needs in families with close relatives also burdened with disease or young of age
4. How to assess when palliation of physical symptoms (pain or otherwise) can be met by ordinary treatment options or when a specialist/multidisciplinary approach is necessary
5. To consider supportive needs if existence of risk for a sudden situation of emergency



Thank you for
your attention !
Please ask..

