

Considering Informal Caregivers' Needs in Palliative Home Care

Evidence from Patient Documentation in German Services

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Background

Evidently, informal carers (ICs) play a vital role in the provision of palliative home care. Moreover, they form a group with own needs and rights as defined by the palliative care approach. A lack of systematic assessment of their needs in service delivery led to the development of the Carer Support Needs Assessment Tool (CSNAT) which has proven to be effective [1-3].

In a first step of a research project to implement the CSNAT to hospice and palliative home care services in Germany, we focused on describing the status quo by approaching the issue through analysis of patients' records and discussing the results with the palliative home care teams.

Aim & Research Question

Which role do ICs play in the daily practice of hospice and palliative home care services and how is the "work" with ICs in palliative home care reflected in the documentation?



Results

All services used different electronic or paper-based record systems and they all provided different options to integrate informal carers' issues. However, ICs' needs and/or specific support for ICs were **rather marginal in patients' records**. This is illustrated by a researcher's note from the screening process (see # 1).

Entries regarding ICs were **strongly related to patient's needs or caring activities**. Little attention was paid to family carers themselves. Entries #2 and #3 are quite typical for this kind of documented interventions, and staff members confirmed this in the focus groups.

We found a **strong tendency to write "about" ICs** and their problems and no evidence for any systematic assessment of carers' needs.

If conversations with family carers were noted, it **remained open, what was spoken about** and whether further steps were agreed on. As illustrated by entry #4, it remained unclear with whom exactly they had the conversation. Was it the patient or the informal carer? At least, this issue is clear in entry #5. However, information is still rather poor in contrast to #6.

In the focus groups, the teams were convinced that they did a lot more than was written down and that there was a huge **gap between "what is done" and "what is written down"**. One explanation for this can be found in quote #7. However, the lack of systematic assessment of ICs' needs was broadly confirmed.

Conclusion

Analysis of records was useful to raise awareness for the need of approaching ICs as a group with own needs more systematically. Especially since there seems to be a gap between what is done and what is documented by staff members. This might be due to funding guidelines, where ICs needs or interventions focused specifically on ICs are not considered. In this regard, palliative care professionals are providing extra work when they listen to ICs and support them. If this extra work does not even appear in the records, the chance of getting funding for this will be even smaller. The results will serve as a basis for evaluating the implementation of the assessment tool and a wider introduction of KOMMA, which is the German translation of the CSNAT, in the services.

Method & Procedure

An exploratory methodological approach was chosen to analyze patients' records of the four hospice and palliative care services which participated in the study to implement the German CSNAT. The design consisted of the following two steps which were applied subsequently in each service:

(1) Analysis of case notes of four hospice and palliative care services After screening a representative sample of records (n=200) from a defined period of all four services, a detailed qualitative analysis was performed for a subsample of cases (n=50). To ensure sufficient information in the data for qualitative analysis, a "recognizable substantial involvement" of informal carers in the records was the major selection criterion for the subsample (see Table 1). Content analysis was conducted with the aim to map various themes which emerged in the data.

Table 1: Sample characteristics

Service	A	B	C	D	Total
Area covered by service (inhabitants)	260 000	60 000	260 000	450 000	--
Number of patients in 2015	50	40	194	400	--
Representative subsample (screening)	50	40	54	56	200
Sample included in detailed qualitative analysis (substantial involvement of ICs)	18	10	11	11	50
Participants focus group	6	8	7	4	25

(2) Subsequent focus groups with hospice and palliative care professionals in each service (n=4, total of 25 persons). In a first step, results of the record analysis of the particular service were presented. The following discussion focused on the question in how far the results represented their work with informal carers. Statements informed the interpretation of the record analysis' results.

Record Entries and Quotations

#1 "In the first assessment, even a genogram was made, showing that the patient is married and has four adult children. In the further course, these relatives were not mentioned any more. Nobody seemed to have asked for them or tried to involve them." (Researcher's note)

#2 "Interventions: Guidance about mouth care with family carer." (record entry)

#3 "Mr. F's daughter told me that her father was agitated at night, he had removed his bandage. She asked whether she should give him some pills; had a conversation with her that she should wait and observe him another night and give me feedback tomorrow." (record entry)

#4 "Scaly skin – Conversation and pain and symptom control done." (record entry)

#5 "Conversation with the family. Wife and daughter in law were calm and satisfied afterwards." (record entry)

#6 "Had a long talk with the daughter in law about the trajectory and our support; gave advice to relieve the wife." (record entry)

#7 "The records are guided by the necessity to proof for funding, but supporting informal carers or listening to them will not be funded directly so why shall we put too much fuzz on this in the records?" (Staff member in focus group 4)

References:

- [1] Grande, G. E. et al. (2015). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ supportive & palliative care*.
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