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Out-of-hours palliative care by general practitioners

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Summary

Chapter 1. General introduction

Palliative care, although only a small portion of the work of GPs, is considered by them as an important part of their work. Many patients with advanced and progressive illnesses spend most of the final year of their lives at home and medical care for these patients belongs to the domain of the GP. Traditionally, GPs in the Netherlands are family doctors; their care includes the care for the patient and his family and they (or their locums) are used to make house calls 24 hours a day, seven days a week.

The delivery of out-of-hours primary care, however, has changed radically over the past ten years. The use of GP co-operatives in which 40 to 250 GPs take care of populations up to 500.000 inhabitants, is now widespread which has had a negative impact on continuity of patient care. There are GPs who are permanently available for their patients in palliative care, also at night and at weekends, but many GPs leave at least part of this care up to the GP co-operative.

Concerns have been raised regarding the quality of care that complex, time-consuming, patients in palliative care receive during the out-of-hours period.

This thesis aims to contribute to an improvement of out-of-hours palliative care by GPs in the Netherlands by mapping the current quality of this care, highlighting problems in its current provision and making recommendations for improving practice.

Chapter 2. A focus group study on out-of-hours palliative care provided by GP co-operatives.

Our aim was to investigate the experiences of Dutch GPs with regard to the quality of out-of-hours palliative care provided by GP co-operatives and to identify elements of care that might need to be improved.

A main finding was that GPs considered the quality of out-of-hours palliative care in the Netherlands to be meagre. They regarded the services rendered by the GP-co-operatives to be designed more for acute medical problems rather than for palliative care needs. Three major issues influencing the quality of care were identified. The most important problem is the lack of adequate information sent by GPs to the GP co-operative. Secondly, the quality of out-of-hours palliative care is hampered by insufficient anticipatory care during office hours. Thirdly, because no policy on

palliative care has been developed by the GP co-operatives, calls from palliative care patients are not treated with priority and no additional time is available for home visits. Improvements could be made in particular if GPs anticipate problems that could arise after office hours and provide relevant information to the GP co-operatives.

Chapter 3. GPs' views on the transfer of information about terminally ill patients.

This study focused on the views of GPs working in a big city on the transfer of information for terminally ill patients from GP practices to GP co-operatives, and vice versa. It describes a retrospective survey carried out among all GPs in the region of Amsterdam using a web based questionnaire. We wanted to analyse the experiences of GPs with the transfer of information from two perspectives: from their position as a GP caring for their terminally ill patients, and from their perspective as a locum for the GP co-operative.

The majority of the GPs in Amsterdam who responded to our questionnaire reported that they transferred information about most of their terminally ill patients to the GP co-operative. However, in their role as locum, the GPs were not satisfied with the quality of the information that was transferred to the GP co-operative.

Both the GP and the locum agreed about the importance of transferring explicit clinical data. The locums valued the transfer of information about the patients' personal situation more than GPs.

The results suggest a difference in views on information transfer between the GP in his daily practice and the GP as locum in the GP co-operative. GPs apparently do not transfer information as often as they think they do, and the content is not as adequate as they would wish it to be.

Since 70% of all GPs stated that they were available for their terminally ill patients during the out-of-hours periods, this could be a reason for not transferring information.

Chapter 4. The out-of-hours palliative care provided by GP co-operatives and the role of transferred information.

We describe in this chapter the results of a retrospective study of all palliative care phone calls made during a one-year period to the GP co-operative in Amsterdam.

The aim of this study was to investigate the transfer of information about palliative care patients to a GP co-operative and the influence of that information on the care provided by the locums in the co-operative. We carried out an electronic search in the database of the GP co-operative, containing medical data on all calls and also all information transferred by GPs about their patients.

We found that the total number of palliative care phone calls was 0.75 % of all calls to the GP co-operative. Information was transferred by GPs in 25%, and when information was transferred the content consisted mainly of clinical data. Less information was transferred about the patient's wishes and the patient's personal situation.

For patients staying in residential care homes, information transfer took place in only 12%. The majority of all palliative care calls concerned terminally ill patients, and for 29% of these patients information was transferred.

When information was transferred fewer patients were referred to a hospital.

A conclusion is that despite the importance of continuity of care, GPs do not transfer information for the majority of their patients in palliative care.

Chapter 5. Systematic review on barriers and facilitators for GP-patient communication in palliative care.

The objective of this review was to identify barriers and facilitators for GP-patient communication in palliative care. Computerized searches to find empirical studies yielded 990 articles from seven databases. Finally twenty-two articles were included in our study, fifteen with a qualitative design and seven with a quantitative design. The main perceived barriers in communication were GPs' lack of availability, and patients' and GPs' ambivalence to discuss a 'bad prognosis'. The main perceived facilitators were GPs being available, initiating discussion about several end-of-life issues and anticipating various scenarios. The results of our review suggest that, to be effective communicators in the palliative care setting, GPs should be available for their patients, they should have an open approach and full commitment, and they should be more forthcoming to initiate honest discussions about the many relevant end-of-life issues. Empirical studies are needed to investigate the effects of these perceived barriers and facilitators on the outcomes of palliative care.

Chapter 6. A controlled trial to assess the effectiveness of introducing a handover form on palliative care.

In this chapter we describe a controlled trial among GPs. Its objective was to evaluate the effects of the introduction of an information handover form on the presence and the quality of information transferred in contacts with the GP co-operative for patients in palliative care. Two groups of GPs were formed, the experimental group received a structured handover form and an invitation for a training, the control group did not receive a handover form or training.

The main finding from this controlled trial is that the introduction of an information handover form combined with the training of GPs in transferring information on their patients in palliative care to the out-of-hours GP co-operative had a positive, statistically significant, influence on the number of contacts in which information on the palliative patient was available in the co-operative. However, despite the absolute increase of 9%, the percentage of contacts in which information was available remained low (30%) in the experimental group. The majority of GPs in the experimental group did not attend the training and received only the introduction letter and the handover form. There is no proof that the one-hour training session contributes to the effect.

Our intervention did an appeal on GPs to overcome the barriers in writing information transfers by convincing GPs of the importance of good anticipatory care and by giving them a standardised handover form. A factor that might have contributed to our positive result may be that the intervention was based on our prior needs assessment by means of focus group discussions.

The effect of the intervention, however, remained moderate. Our intervention focused mainly on the improvement of knowledge and skills. This is perhaps not enough to bring about a change in behaviour of the GPs.

Chapter 7. The evaluation of the introduction of an information handover form on patient outcomes in palliative care.

This study is the second part of the controlled trial, described above. We measured aspects of quality of care by telephone interviews with the involved patients in palliative care or with their family carers after their first contact with the GP co-operative of Amsterdam. We held 324 telephone interviews (42% of all first palliative

care contacts), from which 10% with patients, 60% with family and 30% with home care professionals.

No significant difference was found between the experimental and the control group when asked if locums were adequately informed about the patient's situation. Nevertheless, in a subgroup analysis according to family of patients, locums were significantly better informed after the intervention. There were also no significant differences between the experimental and the control group of GPs on other aspects of quality of care.

In both experimental and control group of GPs the patients and their carers are positive about the aspects of quality of care examined.

The reason that we found few differences on patient outcomes is related to the fact that there was only a small increase in information transfers in the experimental group compared to the control group.

Chapter 8. Information transfers for out-of-hours palliative care and effects on quality of care.

This study builds further on the evidence found in the trial. We compared contacts in which information transfer from the GP to the GP co-operative took place or not.

We analyzed 324 telephonic interviews, for 63 patients in palliative care the patient information was transferred, for 261 patients no information was transferred.

When information was transferred the patients or their carers find the locum more often well informed. They also state more often that there was improvement regarding the problem they called for. It is possible that a locum with information on the patients' situation is more able to handle a difficult situation properly. No difference was found when asked if the locum addressed the reason for encounter and in their trust regarding out-of-hours primary care.

These outcomes underline the importance of information transfer regarding patients with palliative care from GP to out-of-hours service providers.

Chapter 9. General discussion.

In this chapter the results of our research are linked together and discussed from different perspectives, taking the viewpoint of the GP, the patient and the GP co-

operative. Our results have implications for the improvement of practice and for the policy of GP co-operatives. A key finding is that the quality of out-of-hours palliative care benefits from information transfer. This needs to be encouraged, and the introduction of a handover form is useful but not enough. GPs should take an anticipatory approach to the provision of (out-of-hours) palliative care, which includes the transfer of information.

