

## **'Good' palliative primary care according to advanced cancer patients and their relatives: An interview study on needs**

**Authors:** G.A. (Gé) Donker MD PhD<sup>1</sup>, P.M. (Mieke) Rijken PhD<sup>1</sup>, J.C. (Joke) Korevaar PhD<sup>1</sup>, B. (Bianca) Custers<sup>1</sup>, J.(Jolien) Hofstede<sup>1</sup>, A.L. (Anneke) Francke PhD<sup>1,2,3</sup>

Affiliations:

1 Netherlands Institute for Health Services Research (NIVEL), Utrecht, The Netherlands

2 Expertise Center Palliative Care VUmc, Amsterdam

3. EMGO+ Institute, VU University medical center Amsterdam

**Background:** Cancer causes approximately one third of all deaths in industrialized countries. Hence advanced cancer patients and their relatives are a main target group of palliative care.

**Methods:** In qualitative interviews with 13 Dutch patients and 14 relatives confronted with advanced cancer perspectives, experiences and needs regarding palliative care from GPs and home care nurses were explored. Interview data were analyzed qualitatively, by using principles of thematic analysis.

**Results:** Patients as well as relatives find it important that their GP and home care staff provide medically proficient care, that they are available, personally involved, and pro-active. Pro-activity means for example that the GP takes the initiative to discuss with the patient and close relatives what their care needs and preferences are. Additionally, adequate information transfer and continuous care are considered essential for good palliative care. However, patients and relatives also emphasize that their own alertness is vital for receiving the care one needs. Participants worry about other people who might not be alert enough.

**Conclusions:** Patients with advanced cancer and their relatives require GPs and home care nursing staff to be medically proficient, available, personally involved and taking care of good information transfer and continuity of care. Moreover, pro-activity of GPs and home care nurses is considered essential, particularly in people who are not alert regarding their own care needs and how these have to be met.