

GPs must play their part in palliative treatment

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Many think mainly on medication and pain relief when life is ebbing away, but spiritual, existential and practical needs are also present. Credit: ThinkStock

Hospitals typically provide excellent end-of-life care for their patients. But when GPs assume responsibility for terminal patients, things don't always go so well.

Perhaps the GP hasn't seen the patient for several years. Moreover, many GPs have very little experience of palliative care.

"In a survey that we've carried out, there are big differences between GPs who follow up and make home visits to terminal [patients](#), and those who neglect this task entirely," says Line Melby at SINTEF. "The majority of those we interviewed say that GPs must be encouraged to take a more active part in palliative care," she says.

Together with her colleagues, Melby has carried out an evaluation of the services offered to persons requiring palliative treatment. The research is being carried out for the Norwegian Directorate of Health. A questionnaire has been sent out to municipal employees, such as managers in community health departments and care homes, municipal physicians and the directors of health trusts. Voluntary organisations and 51 individuals in the municipal and specialist healthcare services have responded to the questionnaire, and data have also been obtained from the Norwegian Patient Registry.

Health service reforms require more resources

"Norwegian health service reforms require that patients shall not occupy hospital beds but be transferred to the care of the municipalities. But, of course, people suffering from a terminal illness can live a long time," says Melby. "For this reason, the municipalities must be well prepared, and many are making good progress. But our research shows that it's difficult to get GPs involved in this work," she says.

Arnfinn Seim is a GP in Rissa, and agrees that GPs should participate in the palliative teams caring for patients, and make home visits when the need arises.

"The health service reforms entail increased workloads, so a consolidation of statutory GP arrangements and more doctors in care homes should be a natural consequence," he says. "With fewer patients on GPs' lists, it will be easier to follow up terminal patients. But

participating actively in palliative care is not just a matter of resources. Doctors must also be challenged to give the issue priority. For example, GPs must be encouraged to get involved by palliative team members in both the specialist and municipal health services," he says.

More than just pain relief

Palliative treatment addresses pain relief and end-of-life care, combined with consideration for the next-of-kin and bereaved. Basic palliation shall be provided at all points where there rests a responsibility for the seriously and terminally ill, including in hospital wards, care homes and within the community care services. Moreover, there currently exist specialised and organised services such as palliative teams or units, out-patient clinics and day centres provided by hospitals.

The first things people think of are end-of-life medication and pain-relief treatments, but spiritual, existential and practical needs are also very relevant. These may include anxieties about anything from family issues, financial matters, awkward conversations and problems related to the Norwegian Labour and Welfare Administration. Many will die, but may nevertheless survive for a long time before they do. Children may be born with disabilities and still live for five or ten years or even longer. This group also needs care.

Many undertreated

The aim of the project for the Norwegian Directorate of Health has been to find out who in Norway has had access to pain relief treatment, and how they experienced the content and quality of the services available.

"Traditionally, it is cancer patients who have had access," says Melby.

"Ninety-five per cent of patients admitted to hospital palliative units are

cancer patients. The prevailing view is that there are other groups that also have needs, and that pain relief services should be provided in many other hospital departments and other institutions. Many seriously ill and terminal patients in the municipalities are suffering from some form of cognitive failure. Patients with chronic heart, lung and kidney diseases, and those with neurological condition, such as ALS, MS and Parkinson's, also deserve mention. Similarly, a large proportion of dementia sufferers is assumed to have pain and could also benefit from pain relief. Studies demonstrate that, in general, the elderly have had relatively poor access to such treatments and are in fact receiving too little [pain relief](#).

Is it best to die at home?

The issue of the benefits of dying at home has been investigated as part of the evaluation. Do [health care professionals](#) believe that this is what patients want? And has Norway facilitated the opportunity for a good death at home?

The public authorities and voluntary organisations frequently make the point that ideally, people should be allowed to die at home. The SINTEF survey revealed that, on the contrary, many thought that the aim of facilitating death at home will place great demands on healthcare professionals, next-of-kin and the municipal healthcare services. One respondent from a palliative care home unit said that he "believed that patients live with the idea of preferring to die at home, but only before they arrive here," referring to the fact that in his experience many people felt insecure at home.

"Very few people in Norway die at home, and we are some way behind other countries such as the Netherlands, where it is common for people to be born and die at home," says Melby. "Norway is more institution-based than other countries, and even the elderly are for the most part in work. Our family and community structures are different. There has

been a lot of discussion on this topic, but in our study the majority of respondents felt that death at home should not be an aim in itself, but that patients should be given the choice," she says.

Municipalities are getting many things right

Prior to the evaluation, the researchers believed that the status of [palliative care](#) services in municipalities and care homes were poor. In fact, however, reports from the survey suggested that quality was considered to be good, although naturally there was some variation between the different municipalities.

"Since the respondents were managers, we might have expected uncritical responses, but we also asked the municipalities' partners as well," says Melby. "For example, on specific issues, hospitals were asked to evaluate municipalities with questions such as: Is there an active palliation initiative in the municipality? Is work being carried out to improve quality? So the overall picture is a positive one. The municipalities are getting many things right, regardless of whether assistance is provided by a palliative team or specialist health services. The Norwegian Cancer Society assigns a "cancer coordinator" in some municipalities, and this person plays a significant supporting role.

Line Melby says that a lot is currently going on in this field. "Firstly, there was the technical report from the Directorate for Health, followed some weeks ago by the publication of the SINTEF evaluation. Now a public administration committee (NOU), chaired by Stein Kaasa, has been convened with the aim of finding out how palliation care should be organised in the future. "It's clear that changes are on the way," says Melby.

Provided by SINTEF

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