Adapting and going the extra mile: A qualitative study of palliative care in rural Northern Norway from the perspective of health care providers

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Abstract

Background

Despite significant developments in palliative care in recent decades, we still find important differences in access to and delivery of care in rural Norway.

Objective

To explore what health care professionals consider necessary to provide equality in care for palliative patients in rural areas.

Methods

A qualitative approach with focus group discussions and individual interviews with 52 health professionals was used, starting with five uniprofessional focus groups of general practitioners and nurses/cancer nurses, followed by five interprofessional groups and six individual interviews. Interview transcripts were analyzed thematically.

Results

We found local variations in organization, competence and access to palliative care, and challenging geographical conditions. It was essential to be proactive, flexible and willing to go the extra mile, but this may conceal the need for a stronger focus on competence and organization of palliative care. Access to written guidelines and practical tools was important, as was forming palliative teams for particular situations.

Conclusions

Palliative care needs strengthening in rural areas, and increased competence for all health care professionals is vital to increase equality in care. Geographical conditions require locally adapted solutions. Access to guidelines and interprofessional collaboration are essential.

Implications for Practice

Rural palliative care needs in Norway are improving, as exemplified by at least 1 cancer nurse assigned to each local authority, and access to guidelines and palliative tools and interprofessional collaboration.

Introduction

Equal access regardless of place of residence is a central value in Norwegian health care, and is also emphasized in the national guidelines for palliative cancer care.^{1, 2} These guidelines offer recommendations for symptom management, organization and competence in palliative care. Despite great improvements in palliative care during the last 15-20 years, a newly published official report on palliative care ² states that there are still geographical differences in access to such care in Norway, and a more systematic approach and stronger collaboration between primary and hospital care are needed.²

High-quality palliative care in rural areas means allowing patients to spend maximum time at home or close to home, and even the possibility to die at home, reducing the need for acute referrals to hospitals.^{3,4} A Norwegian study found that only simple medical interventions were necessary for most emergency admissions to hospitals for patients with advanced cancer.⁴

Expansion in palliative care from primarily cancer and end-of life care to including other diagnoses and early palliative care will increase the number of palliative patients in the community.^{2, 5, 6} However, in small rural communities there are still few palliative patients each year, and keeping palliative competence up to date may be challenging.^{5, 7}

In addition to lack of competence, long distances, less access to specialists and little interdisciplinary teamwork have been shown to be significant obstacles in providing palliative care in rural areas of many countries.^{5, 8, 9} In a study from Greenland, Augustussen et al.¹⁰ found that palliative care still depends on the skills of individual health care professionals (HCPs), and the study underlines the need for careful planning for each patient and strong collaboration between HCPs. To be proactive, flexible and adaptable, and to have team building capacity, were shown to be central elements in providing high-quality care in a study by Collier et al.¹¹

Johansen and Ervik¹² found that teamwork between general practitioners (GPs) and cancer nurses (CNs) worked best when both groups used their complimentary competencies in specific patient situations. We still lack knowledge about the delivery of palliative care in rural areas from the perspective of HCPs,^{2, 13} especially regarding practical challenges, quality of care and organization of care. Pesut et al.¹⁴ argue that urban models of palliative care do not fit well in rural nursing practices. Studies from different rural contexts are therefore required in order to enhance the body of knowledge.¹⁵

Study setting

This study took place in primary care settings in Northern Norway, an area with a population of approximately 500,000 inhabitants, 87 local authorities (LAs), and 11 hospitals of different size and scope. GPs, district nurses (DNs) and CNs play significant roles in providing primary palliative care. ^{1, 16-18} In Northern Norway, CNs are found in 52 of the 87 LAs, and the one-year postgraduate course in cancer care includes theory and practical training in palliative care. About 27 of the LAs have 1-3 beds for palliative care, mostly in nursing homes. ¹⁹ Few GPs and allied HCPs have specialized competence or postgraduate education in palliative care. According to the Norwegian Primary Health Services Act, ²⁰ LAs are responsible for providing necessary health

care services to the local population. However, unlike acute care and rehabilitation, palliative care is not an area subject to legislation.

Aim

This paper is part of a larger study of HCPs' experiences of rural palliative care in Northern Norway. The aim of this paper was to explore what HCPs consider necessary to provide equality in care for palliative patients in rural areas.

Method

We used an exploratory and interpretative approach, with focus group discussions (FGDs) and individual interviews to explore HCPs' experiences of providing palliative care. We conducted ten FGDs and six individual interviews with 52 health care professionals (DNs, CNs, GPs and allied health professionals) in 2015-2016 (**Table 1 and 2**). The first five FGDs were held with nurses, and physicians separately in order to let them talk about their experiences without collaborating professions being present, with 3-8 participants in each group. Nurses were recruited by e-mailing participants in a palliative care course and at palliative care network meetings, and the FGDs were conducted in connection with these events. 16 nurses from 14 LAs, The first group of GPs was recruited by e-mail and the interviews were conducted in connection with a meeting for GPs; the second group was recruited by snowballing from the first group and the FGD took place in a local hospital.

To gain deeper insight into everyday interdisciplinary work in the local communities, we purposively selected six rural LAs by their different size, geography and organization. We wanted a broad selection of experiences. We aimed for differences in population size; hence, three LAs had more than 5000 inhabitants, while the other three had a population of 1200- 2500.

We also looked for geographical differences regarding distance to the nearest hospital and travel time within the LAs including dependency on ferries. LAs were also chosen based on our knowledge of how systematically palliative care was developed there and whether the LAs had cancer nurses or not. (**Table 3**)

We asked the local CNs or DNs to find HCPs who usually worked together in palliative care. CNs, DNs, GPs and allied HCPs were eligible to participate. In the first LA, six individual interviews were conducted to gain knowledge of each individual professional's experiences. This was followed by interprofessional FGDs in five LAs with 3-7 participants in each group. In this part of the study, the individual interviews and the FGDs were held on LA premises, in health care centers or in nursing homes. Here we aimed for a discussion among the participants of different professions. ^{21, 22} We used a brief topic guide comprising four main topics, i.e. organization of palliative care, competence, interprofessional work and collaboration between primary and specialized care.

The FGDs lasted around 90 minutes and were moderated by two members of the study team, one of whom is an academic GP and another is a CN by background. Both are experienced in qualitative research and FGDs. A medical student conducted the individual interviews as part of her master's degree, supervised by a study team member. Each individual interview lasted approximately 60 minutes. All interviews were digitally recorded and transcribed verbatim. The participants gave their written consent.

Ethical requirements

The data protection officer (DPO) at the University Hospital of North Norway (UNN) approved the study, No. 0431. Written application to the Regional Medical Research Ethics Committee was not required (DPO at UNN, ref. 2014/5224).

Analysis

Data were analyzed by 2 study team members using a stepwise thematic analysis, including both semantic and latent content. ²³ Initially, all interviews were carefully listened to by both researchers in order to sort out the different voices and become familiar with the data. This process informed us about what was meaningful in the data. We then independently coded the entire transcripts manually by taking notes and marking the text, looking for patterns, incidents, and recurrent topics across the interviews related to the main research question of this paper. Transcripts containing the initial coding were discussed and we started to organize the data. Potential main themes and subthemes were discussed between the researchers in a reiterative process, and the final themes were revised and refined until agreed upon. The text comprising each of the final themes and subthemes was extracted from the transcript and collated. Themes were given names and illustrative quotes were selected to illuminate the content. Trustworthiness was assured by using an audit trail throughout the analysis process; to address credibility we discussed our findings with colleagues with knowledge of palliative care research.

Results

The study comprised 52 HCPs: DNs (15), CNs (15), GPs (17) and allied health care professionals (5) from 25 LAs of different size, geography and organization of care. After the first five FGDs with nurses and GPs separately, some themes recurred regardless of local differences such as: the need to enhance knowledge of palliative care, a strong will to succeed

and find solutions despite often limited resources, and geographical challenges. These themes were repeated, deepened and nuanced in the interviews in the LAs. After analysing all interviews together, we identified four main themes: local variations, local geography, being prepared, and being adaptable and willing to go the extra mile.

Local variations

We found local variations in and between LAs, especially regarding patients' access to HCPs specialized in palliative care, and how systematically palliative care was organized. More than half of the LAs had at least one CN with a formal postgraduate qualification in palliative care. Their strong engagement was essential to maintain the focus on palliative care with often limited health care resources. Many DNs had taken palliative care courses, but only a few GPs. Nurses in particular wished GPs had greater knowledge and showed more interest in palliative care due to their important role in primary care. However, GPs saw their role as generalists and did not plan to specialize in palliative care. Long distances and lack of financial and human resources in LAs were obstacles for DNs to take postgraduate courses, despite being encouraged by their health care leaders. In general, building and maintaining competencies was problematic due to frequent turnover of HCPs.

RNIT6: "... after some time you get to be more of an expert both in the hospital and in patients' homes. With home care nurses, there's always a lot of turnover. Lots of them leave, and new ones start, and so on. So to keep things going here... That's a real challenge."

Designated palliative beds in nursing homes are found in 28 of the 87 LAs. These nursing homes were often resource bases for the HCPs in the community, providing practical help with e.g. SC syringes and discussions of specific patient-related problems.

None of the participating LAs had palliative teams with regular meetings and there were few palliative plans. At least one CN or DN from each LA participated in a regional network for cancer and palliative care nurses. The regional advisory unit for palliative care organizes the network, which holds two meetings a year with instruction sessions and discussions.

Some participants described the provision of palliative care as "random" in their community, where quality of care was dependent upon the expertise of the HCPs present in the individual situation. They raised the question of whether patients and their relatives actually had access to palliative care services when needed. In some places, palliative care was described as an area of low priority from local politicians and/or health care leaders, and thus often lost out in competition with other important local health care issues.

CN2T5: "What I've seen at the nursing home is how differently patients are treated depending on who's on duty, which nurses and doctors have seen them and ... as for palliative care, some had morphine prescribed and were well cared for, while others got next to nothing."

Local geography

Local geography with dispersed settlements, long distances and islands caused problems with round-the-clock service, especially during weekends and holidays. Ferries often operated only during daytime, leaving some communities without access to nurses at night. Living far from the community center often meant fewer home visits than for patients living closer to local centers. Care provision was therefore sometimes described as unfair. Long travelling distances were time-consuming and strained nursing resources, especially if the patient needed frequent visits or the end-of-life process was prolonged.

CNT2: "It's a bit about logistics... The ferries stop running and ... well, yes. And of course, trying to run a... patients lying there and dying for a month... one thing's the money, but another thing is actually the people. You don't just need some hands, you need some heads too, so there's some expertise there."

Limits to postal deliveries caused practical problems, e.g. medication for subcutaneous administration from the retail pharmacy had to be ordered in advance and adjusted to postal delivery times.

CNT1: "... Fridays are not a good day for dispatching medications, then it will just lie there in the post delivery system (during weekends)."

Sometimes patients or relatives took over medicine administration due to geographical conditions. In these situations, nurses worried about patient safety, and felt that a huge burden was being placed on the relatives' shoulders, practically and emotionally. During wintertime, which is half of the year, strong winds or heavy snow could close roads. Then the only solution was often to refer patients to nursing homes nearer the community centers.

Being prepared

Being prepared and proactive was the optimal scenario when receiving new patients from the hospital, or providing care for patients already known in the community. Despite most discharges from hospitals being well prepared, patients sometimes arrived at short notice, leaving limited time for practical preparations and for ensuring human resources with the necessary skills. In these situations, nurses in particular had to rush here and there and do their best.

CNT1: "But then I said, look, I've just got to have that mattress. And it's got to come now. Well OK, but they arranged it. They said we'll help you, we'll send it by courier. So I picked it up at a crossroads at a petrol station and got the mattress in place."

Providing care for palliative patients at home meant always being prepared for changes in their situation. However, there were no individual plans for patients, despite these being described as essential in preventing consultations with unfamiliar doctors at the local emergency unit or referrals to hospital. Video consultations (VCs) between HCPs in the local communities and HCPs at the University Hospital were an option, and in some situations, consultations with the palliative team in the hospital or admission to hospital were necessary.

Easy access to practical written guidelines was an important factor. The "Handbook of Palliative Care" ²⁴ published by the regional advisory unit for palliative care at the University Hospital was well known and perceived as particularly useful for managing the most common physical symptoms. Most participants had heard of a medication kit containing the four most common medicines in palliative care during end of life, with instructions for use. However, GPs' and nurses' skill and confidence in managing the medicines determined their use, as many expressed worries about how to administer them.

CNT4: "... stuff like Dormicum and then I sort of think, well, what... I mean, we sort of haven't seen the reactions and know exactly what... We haven't got any experience of that. No, it's not something we know how to do, and then it can be a bit kind of... you know."

Adaptable and willing to go the extra mile

Available human health care resources in the local community were used in a flexible way. Patients receiving home care sometimes spent days at the local nursing home, or nurses from nursing homes provided care in the patients' home. When necessary for medication administration, nurses sometimes continually followed each other on 12-hour shifts in communities with few nurses, or without nurses at night. We also heard stories of GPs visiting patients on their way home from work if the patients lived far from the GP's surgery.

In general, CNs had a more flexible work schedule than DNs and GPs, and therefore often represented continuity for patients, relatives and other HCPs. Nurses found themselves going the extra mile to try to meet the needs of patients and relatives. They described a moral obligation to stand by the patients "all the way" for those wanting to die at home. Others described palliative care as being close to their heart and felt proud of and committed to their work.

CN3S1 "But there's a kind of eagerness from the leaders and from us who work there that once they've agreed (to dying at home), then we try to fulfil the patient's wishes, then we're very eager to put in some extra effort for a few days, maybe a week, to make it possible, because it's like the patient's last wish. And then when maybe it's a neighbour or a colleague, it's very close and then, well, you do it, don't you?"

Being flexible had its drawbacks, especially for CNs who were often involved in most palliative patients in the local community. Despite close collaboration with colleagues, CNs often took greater responsibility for patients' needs and problems than their position required, which for some led to a feeling of loneliness in their work. On the other hand, leaning too hard on CNs

made the service vulnerable, and DNs encouraged CNs to include them and allied HCPs more systematically.

CNIT6"... I was the one who had that role and... coordinated everything, you know, when the others left, I had an overview of everything. In that respect, I've started to step back a bit now, like I've come to realize more and more that my role's changed because of the increase, we're getting more expertise in the different places. So (thinking) ... others take over."

Most HCPs preferred local palliative care teams put together for individual patient situations. Especially in smaller LAs, the doctors and nurses involved often knew the patient well, and such impromptu teams were found to be more practical, more flexible and less bureaucratic than permanent palliative care teams.

Discussion

Our exploration of HCPs' experiences of day-to day palliative care in rural North Norway showed a mixed picture, and we identified four main themes of importance in providing equality in care for palliative patients in rural area; local variations, local geography, being prepared, and being adaptable and willing to go the extra mile.

We found local variations between and within LAs, especially regarding competence and organization of care. CNs played a significant role in the coordination of care and in enhancing the focus on the need for palliative competence for all HCPs. Geographical conditions caused practical problems with delivery of care. Questions were raised regarding the feasibility of equal access to palliative care in rural areas, and whether too heavy a burden was placed on the shoulders of patients' relatives. In order to provide care and strengthen equality in care, it was

essential to be proactive, flexible and willing to go the extra mile, and to have access to practical tools and guidelines.

The local variations found in this study underscore the need to enhance palliative care in rural primary care settings. However, equality in care does not necessarily mean care organized and provided in the same way, as LAs differ considerably in geographical size, population, culture and access to HCPs. According to Robinson et al., these local differences often require "tailored approaches to palliative care ... in order to optimize care". Delivery of care needs adjustment to local resources. However, it is important that local variations do not legitimize differences that may be reduced or removed by better organization. HCPs need basic competence in palliative care, and Robinson et al. 15 found that the higher the level of palliative care education HCPs had, the more they saw the need for enhanced competence. Our study reflects this finding with the CNs' significant role in maintaining and enhancing competence. Additionally, GPs' palliative care skills need strengthening as part of their generalist portfolio, thus avoiding dependency on individual GPs' personal interest alone.

CNs' comprehensive local knowledge enabled them to be proactive and highly mobile to find flexible solutions in each individual patient situation. This may be understood as an important skill and crucial for patients to stay at home as long as possible or die at home. However, nurses expressed a moral duty to meet the needs and wishes of patients and their relatives, and personal relationships in small communities may place a strong obligation on individual HCPs in this respect. Being too flexible and willing to go the extra mile may therefore be a weakness in a long-term perspective, and may conceal the need for more staff or resources or even lead to exhaustion in nurses.

In an Australian study, Brury and Inma²⁵ found that patients had a better experience and more streamlined care in communities with CN coordinators. In Norway, LAs that have CNs often have only one, and leaning too heavily on that person may imply that palliative care will be unavailable when the CN is off duty.⁷ Thus, focusing on a robust organization seems important and nursing homes with designated beds may be an important contribution.

Our findings reflect results from the study by Goodridge et al.⁸ regarding variation in patients' access to satisfactory relief of pain and other physical symptoms. National guidelines are often wide-ranging and practical guidelines like the "Handbook of Palliative Care" (ref) seem more suitable in day-to-day care. The medication kit known as the "Comfort Care Kit" or "Hospice Emergency Kit²⁰ was used in many places. Our study supports the findings by Chellappan et al.,²⁷ showing that remoteness in itself is not a barrier to using advanced medication kits, as long as GPs and nurses have the required competencies²⁶. However, there are limitations to what can be achieved in rural localities, and it is important to take seriously nurses' worries about patient safety when long distances mean fewer home visits and relatives administering medication.²⁷ Multi-professional palliative teams have been suggested as one way of organizing palliative care in LAs.² We found that rather than permanent palliative teams, close collaboration between GPs and CNs or DNs in individual situation may be a better way of organizing palliative care in small rural communities. In this case, the HCPs are already familiar with the patient's situation, and GPs' and CNs' complimentary competencies could be utilized and further developed. 11, 12 Locally adjusted palliative teams in areas without specialized HCPs have also been suggested by Robinson et al.⁷

While larger palliative units or hospices are found in many urban areas, designated beds or small palliative units in nursing homes seems to be an appropriate way of organizing inpatient care in

sparsely populated areas. In a study by Trosten,²⁸ designated palliative beds were found to enhance quality of care in nursing homes; however, limited access to doctors with palliative care skills was challenging.

As there are few HCPs specialized in palliative care, participation in networks such as the regional networks for nurses in cancer and palliative care is important for obtaining updated information and knowledge. Further, taking part in VC with HCPs at the University Hospital allows for discussions of specific challenges and reduces the distance between rural primary care and the University Hospital. ^{10, 13, 29}

Limitations

This study comprises 52 HCPs and 25 LAs of different size, geography and organization. The study was conducted in a North Norwegian context; however, in our opinion, the results have transfer value to countries with corresponding populations and geography. BEs position and knowledge of the region as head of the Regional Advisory Unit for Palliative Care and MLJs position as an academic GP influenced the study design and may be seen as both a constraint and a strength. Our professional backgrounds provided credibility and access to HCPs working in palliative care.

Conclusions

Competence is a key issue in enabling equality in access to care, and it seems necessary for health care leaders to focus more strongly on palliative care to prevent excessive reliance on

Palliative care needs strengthening in rural areas to reduce the variation we see today.

enthusiastic individuals. CNs play an essential role for patients, relatives and other HCPs in day-

to-day care and coordination of care. Thus, financial incentives for the postgraduate education of

nurses and other HCPs should be formalized and strengthened. Courses for doctors need to be adjusted to geographical challenges, and online courses may be a suitable solution. HCPs' flexibility and extra efforts may compensate for limitations in human resources and organization, and locally adjusted approaches are necessary and useful in rural areas. However, many LAs need better organization of palliative care. As there may be few palliative patients each year, access to written guidelines and practical tools is vital. In addition, focusing on interprofessional collaboration and participating in professional networks may prevent the feeling of being alone with a huge responsibility, especially for CNs. VCs between HCPs in primary care and in hospitals may be used in a more systematic way for training and discussing specific patient situations.

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Tables

Table 1: Participants								
Profession	N	Age Group	Gender					
Cancer nurses	15	35-60	All women					
District Nurses	15	26-61	All women					
General practitioners	17	27-68	6 men, 11 women					
Allied HCPs	5	27-55	1 man, 4 women					
Total	52							

Table 2 Experience as HCPs							
Profession	N	Experience (total) (y)	•	Place of work			
			Cancer nurses (y)				
Cancer nurses	15	14 (9-37) median	5 (1-17) median	- · · · · · · · · · · · · · · · · · · ·	13		
				Nursing home	1		
				Community care			
				and nursing home	1		
District nurses	15	11 (2-35) median		Community care	8		
				Nursing home	6		
				Community care			
				and nursing home	1		
General							
practitioners	17	11 (0-34) median					
Allied HCPs	5	12 (1-26) median					
Total	52						

Abbreviations: HCP, health care professional.

Table 3 Professions and Local authorities areas represented							
	N	N of Professio	ns	N of areas	Population size of areas		
Nurse FGDs	16	Cancer nurses District nurses		14	1200-9600		
GP FGDs	8	GPs	8	5	1200-50000		
Team FGDs + interviews	28	Cancer nurses District nurses GPs Allied HCPs	_	6	2000-8000		
Total	5	2		25			

Abbreviations: FGD, focus group discussion; GP, General practitioner, LAs Local authorities