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Anne Fasting

General practitioners’ role in palliative care: map versus terrain

Doctoral thesis

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
Faculty of Medicine and Health Sciences
Department of Public Health and Nursing

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Norsk sammenfatning

I fagfeltet palliasjon er fokuset på lindring og god livskvalitet for pasienter med livstruende sykdom, og deres pårørende. Antallet personer som har behov for palliativ behandling øker med en aldrende befolkning. Helsetjenesten har som mål å gi omsorg og pleie i hjemmet heller enn på sykehus og sykehjem, og pasienter flest ønsker å bli tatt vare på og dø i sitt eget hjem. Likevel dør de fleste på sykehjem eller sykehus. Samhandlingen rundt alvorlig syke og døende pasienter er kompetansekrevende, og krever god kommunikasjon mellom helsepersonellet.

Fastlegen er ansett som en viktig aktør i palliasjon. Nøkkelrollen gjenspeiles i den nasjonale retningslinjen for palliasjon i Norge. Nasjonale retningslinjer for helsetjenesten er viktige verktøy for å omsette oppdatert medisinsk kunnskap til gode og likeverdige helsetjenester for pasientene. Ifølge retningslinjen skal fastlegen i samarbeid med kommunal hjemmesykepleie, inkludert ressurssykepleier (oftest kreftsykepleier), og palliativt team på sykehus ivareta omsorgen for hjemmeboende palliative pasienter. Praksiserfaringer har antydet at det er avstand mellom fastlegens rolle i det virkelige liv, og den rollen fastlegene er tiltenkt med tanke på optimale forløp for hjemmeboende palliative pasienter.

Det overordnede formålet med dette prosjektet var å få innsikt i fastlegenes erfaringer med lindrende arbeid og utvikle ny kunnskap om fastlegenes rolle i palliasjon og barrierer for deres deltakelse. Prosjektet hadde også som mål å undersøke i hvilken grad fastlegene kjente til den nasjonale retningslinjen for palliasjon, og om denne var implementert. Dette betyr at vi sammenlignet retningslinjen som et kart med fastlegenes virkelige terreng.

Vi tilnærmet oss forskningsspørsmålene med to ulike metoder. Den første studien var en spørreskjemaundersøkelse blant fastleger i Møre og Romsdal, for å få oversikt og generell kunnskap om fastlegers erfaring med lindrende behandling. Dette inkluderte deres erfaring med livets siste fase, hjemmedød, og samarbeidet mellom primær- og spesialist-helsetjenesten. Studien undersøkte også i hvilken grad fastlegene kjente til sentrale anbefalinger i retningslinjen. Dette materialet ble beskrevet med deskriptiv statistikk i artikkel I.

Den andre studien baserte seg på fokusgruppeintervjuer med fastleger. Vi gjennomførte fire gruppeintervjuer med til sammen 25 fastleger. Intervjuguiden for denne studien bygget på resultatene fra spørreundersøkelsen og retningslinjen. Vi etterspurte først fastlegenes erfaringer med palliasjon og hva slags rolle de opplevde å ha i dette arbeidet. Deretter utforsket vi fastlegenes erfaringer med, og syn på retningslinjen for palliasjon. Studien tok sikte på å oppnå en dypere innsikt i fastlegenes erfaringer. Vi brukte tolkende fenomenologisk analyse (IPA) i artikkel II, og deretter refleksiv tematisk analyse (rTA) i artikkel III.

I den første studien fant vi at fastlegene hadde få palliative pasienter til enhver tid, og at hjemmedød var sjeldent. Dette gjorde det var vanskelig for fastlegene å opprettholde spesialisert kunnskap og ferdigheter. Arbeidsmetoder anbefalt i retningslinjen var lite brukt, og retningslinjen virket ikke godt implementert blant fastlegene. Mer enn halvparten av legene så seg likevel som sentrale, og kjente seg trygge på å delta i palliasjon. Fastleger med lang reiseavstand til sykehus følte seg tryggere og mer sentrale enn de som jobbet nær et sykehus. De gjorde seg i større grad også tilgjengelig utenfor arbeidstiden (artikkel I).

I fokusgruppene løftet fastlegene frem flere styrker i dette arbeidet. De fremhevet kontinuitet i lege-pasient-forholdet, at de var vant til å koordinere pasientomsorgen og hadde unik kjennskap til pasientene og deres pårørende. Fastlegene mente at deres allmennmedisinske grunnkompetanse ga gode verktøy for å lindre pasientene i mange tilfeller. De var positive til å delta i palliasjon. Likevel inntok de ulike posisjoner når det gjaldt fastlegens rolle; mens noen var svært involvert i dette arbeidet, var andre mindre involvert eller svært sjeldent involvert (artikkel II).

I den videre analysen av intervjuene så vi på hindringer for fastlegenes deltakelse i palliasjon. Mange fastleger mistet kontakten med alvorlig syke pasienter når de var under sykehusbehandling, og da var det en terskel for å komme på banen igjen. Utilstrekkelig informasjon fra sykehuset, kunne gjøre det vanskelig å vite hvordan, og om de i det hele tatt skulle følge opp pasienten. Fastlegene trengte informasjon om pasientens videre fremtidsutsikter. Vi fant at ulike kulturer for samhandling mellom fastlege, kreftsykepleier og det palliative teamet hadde utviklet seg. Noen av fastlegene tenkte at den kommunale kreftsykepleieren skulle samhandle mest med det palliative teamet på sykehuset, og at de selv dermed ikke var involvert i dette arbeidet.

Når det gjaldt innholdet i retningslinjen, mente de fleste fastlegene at den var for omfattende til bruk i allmennpraksis. Kompetansekravene fremstod som urealistiske for en vanlig fastlege, og flere følte at arbeidsmetodene som var anbefalt i retningslinjen ikke passet inn i

allmennpraksis. De mistenkte at allmennleger ikke hadde medvirket i utarbeidelsen av retningslinjen.

Denne avhandlingen tydeliggjør at fastleger med sin allmennmedisinske kompetanse kan tilføre unike kvaliteter til omsorgen for alvorlig syke og døende pasienter, og at deres ferdigheter utfyller andre fagfolk på feltet. Det er nyttig for pasientene at fastlegen deltar i det tverrfaglige arbeidet, da det øker sannsynligheten for å få tilbringe tiden hjemme. Retningslinjens krav til fastlegenes kompetanse fremstår imidlertid som ambisiøse, og rollefordelingen mellom aktørene er uklar. Vi vet i dag for lite om hvilket nivå av spesifikke kunnskaper fastlegene bør ha i dette arbeidet i tillegg til den brede kompetansen de har som allmennleger. Fastlegen er vanligvis portvakt til spesialiserte helsetjenester, og dersom fastlegen forbigås, kan ressursene innen spesialisert palliativ omsorg overbelastes. Avhandlingen problematiserer noen aspekter ved produksjon av retningslinjer. Dette gjelder viktigheten av å vurdere konsekvensene av retningslinjenes krav i alle ledd av helsetjenesten. For allmennleger, som må følge mange retningslinjer, gjelder dette spesielt for den arbeidsmengden som påføres. Å forutse slike konsekvenser krever kunnskap fra praksisfeltet, og i utvalg som skal lage retningslinjer som fastleger forventes å følge bør de være godt representert.

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English summary

Background

In palliative care, the focus is on symptom relief and good quality of life for patients with life-threatening illnesses and their relatives. The proportion of people needing palliative care increases with an ageing population. The Norwegian healthcare service aims to provide care in the home rather than in hospitals and nursing homes, which is consistent with where most patients want to be cared for and die. Yet, most people die in nursing homes or hospitals. Collaboration around seriously ill and dying patients requires professional expertise and good communication between healthcare personnel.

The regular general practitioner (GP) is considered an essential participant in palliative care for home-residing patients. The National Guideline for Palliative Care in Norway underscores the crucial role of the GP. National guidelines for healthcare services are essential tools for translating updated medical knowledge into good-quality and equal health services for patients. Collaboration in palliative care for home-residing patients involves the GP; the municipal nursing service, which includes the oncology nurse (ON); and the hospital-based palliative care team (PCT), representing the secondary care level. To achieve optimal care, the health professionals must cooperate closely. GPs are perceived not to participate in palliative care as intended to ensure optimal trajectories for home-residing palliative patients.

Aims

This project aimed to gain insights into GPs' experiences with palliative care and develop new knowledge about the GPs' role in palliative care and the barriers to their participation. The project also aimed to investigate the extent to which GPs knew of and adhered to the national guideline. This means we compared the guideline as a "map" with the GPs' reality, representing the "terrain".

Materials and methods

We approached the research questions with two different methods. The first study was a questionnaire survey among GPs in Møre og Romsdal, a county in mid-Norway. In this study, we wanted to obtain an overview and general knowledge about GPs' experiences in palliative care. This included their experiences from the final stage of life, home death, and the collaboration between primary and specialist healthcare services. The study also examined the extent to which the GPs were aware of essential guideline recommendations. The results were described using descriptive statistics in Paper I.

The second study was a focus group study. We conducted four group interviews with a total of 25 GPs. We based the interview guide for this study on the survey results from the first study and the guideline. We first asked the GPs about their experiences with palliative care and their perceived role in this work. We then discussed the GPs' experiences with and views on the guideline for palliative care. The study aimed to gain a deeper insight into the GPs' experiences. We used interpretive phenomenological analysis (IPA) in Paper II and reflexive thematic analysis (rTA) in Paper III.

Results

In the first study, we found that GPs had few palliative patients at any given time and that home deaths were rare. This made it challenging to maintain specialised knowledge and skills. The working methods recommended in the guideline were little used, and the guideline did not seem well implemented among the GPs. However, over half of the GPs regarded themselves as central and felt confident about participating in palliative care. GPs who worked at some distance from the hospital felt more secure and central than those who worked close to a hospital and were more available outside working hours (Paper I).

In the focus groups, we uncovered several strengths the GPs perceived themselves to have in palliative care provision. They emphasised continuity in the doctor–patient relationship, that they were used to coordinating patient care, and that they had unique knowledge of the patients and their families. The GPs believed that their competencies as generalists included knowledge that made it possible to alleviate the patients in many cases. They were positive about participating in palliative care. Nevertheless, they took different positions towards the GP's role; while some were very involved in this work, others were less involved or uninvolved (Paper II).

In the further analysis of the interviews, we looked at barriers to the GPs' participation in palliative care and implementation of the guideline. Many GPs lost contact with seriously ill patients when referred to the hospital, creating a threshold for getting back on track. Insufficient information from the hospital could make it difficult to know how and whether they should follow up with the patient. The GPs needed information about the patient's prognosis. We found that different cultures for the collaboration between the GP, ON, and

PCT were established in different places. The GPs in some areas thought that the municipal ON should interact mainly with the palliative care team at the hospital. Consequently, there was no call for the GP to get involved.

When the GPs discussed the guideline content, most felt it was too extensive for general practice. The competence requirements appeared unrealistic to an ordinary GP. Several felt that the working methods recommended in the guidelines did not fit into general practice and suspected that GPs had not participated in its preparation.

Conclusions

This thesis highlights that GPs can add unique qualities to the care of seriously ill and dying patients and that their skills complement those of other professionals in the field. Patients benefit when GPs participate in this interdisciplinary work. However, the guidelines' requirements for the competence of GPs seem ambitious, and the division of labour is unclear. At present, we have insufficient knowledge about which level of competence the GPs need in addition to their broad competence as generalists to improve outcomes for their palliative patients. GPs are usually gatekeepers to specialised health services, and if they are bypassed, resources in specialised palliative care could be overstretched. This thesis also highlights some essential aspects of guideline creation for general practice. The consequences of guideline requirements need to be assessed at all levels of the health service to which it applies. GPs must follow many guidelines; therefore, considering a guideline's impact on GPs' workload is vital. Anticipating such consequences requires knowledge from the field of practice, and GPs should be strongly represented in the committees that draw up guidelines they are required to adhere to.

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Writing a thesis is not possible without the support of many persons. Therefore, this thesis rests on the pillars of people and milieus, each contributing in their special way.

I want to take the opportunity to thank my supervisors. When I first contacted the department with the seedlings of my ideas for this project, my initial main supervisor Irene Hetlevik welcomed me. Calm and structured, she watched me with interest as I plunged into the material, and the project grew into something worth pursuing. Thank you for your patient guidance through the initial stages of this project. As time progressed, Irene retired but continued as co-supervisor, and Bente Prytz Mjølstad took over as the main supervisor. Lively, busy, encouraging and firm. Thank you for your steady guidance through the ups and downs, for your belief in the project and ability to make me focus on the right things at the right time. Without the valuable input from the two of you, this thesis would not have been the same.

To all my colleagues at Allmennmedisinsk forskningsenhet (AFE) (General Practice Research Unit) in Trondheim, thank you for contributing to a milieu that stimulates academic growth. Although my visits to the department were sporadic, I was always welcomed with interest and included.

Another key factor in the process of this thesis was my participation in the National Research School in General Practice, NAFALM. Taking this 2-year course gave me essential tools for the research process and provided a stimulating environment where insights could be gained, and ideas could be discussed.

Special thanks go to Linn Getz for being an illustrious leader figure and academic role model in both these milieus.

Different but equally important environments were my clinical workplaces. In 2004, Kjell Erik Strømskag gave me my first job, at the anaesthesiology department in Molde. He has ever since been an inspirational figure, both professionally and academically. I must also thank all my colleagues at the oncology clinic in Kristiansund. You are the best colleagues, always supportive and cheering for me along the way. Finally, I want to mention the patience of my various leaders over the years, particularly Ragnhild Bjerkås, who has truly grasped the importance of facilitating research and professional creativity in the clinic.

Another setting providing this project with valuable input was the Nordic Specialist Course in Palliative Medicine (NSCPM), where I could present preliminary findings from this study and discuss them with colleagues from Norway and other Nordic countries.

I would also like to thank all the GPs that answered the questionnaire in the first part of this project and those who took the time to participate in the interviews for the second part. The participation of each one of you made this project possible and has provided us with valuable insights into this field. And a special thank you to Marianne Rønneberg for sitting in as an interview observer.

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I am grateful to all my friends and relatives for their understanding and support while I have been writing this thesis.

And to my beloved family, Rune, Kristoffer and Mathias. Thank you so much for your love, support, cheerfulness, encouragement, patience and impatience, enabling us to be an average, everyday, fantastic family throughout this process. I could not have done it without you all.

List of publications

This thesis is based on the following original research papers:

Paper I:

Fasting A, Hetlevik I, Mjølstad BP: "Palliative care in general practice; a questionnaire study on the GPs role and guideline implementation in Norway". *BMC Family Practice* 2021;22(1):64.

Paper II:

Fasting A, Hetlevik I, Mjølstad BP: "Finding their place – general practitioners' experiences with palliative care – a Norwegian qualitative study". *BMC Palliative Care* 2022;21(1):126

Paper III:

Fasting A, Hetlevik I, Mjølstad BP: "Put on the sidelines of palliative care: A qualitative study of important barriers to GPs' participation in palliative care and guideline implementation in Norway". Submitted to *BMC Primary Care June 2023*

List of abbreviations

ACP	Advance Care Plan
AFE	General Practice Research Unit (Allmennmedisinsk forskningsenhet)
AFU	The Norwegian Committee on Research in General Practice (Allmennmedisinsk forskningsutvalg)
AGREE	Appraisal of Guidelines for Research and Evaluation
AMFF	The Norwegian Medical Association's Fund for Research in General Practice (Allmennmedisinsk forskningsfond)
CME	Continuing Medical Education programme
COPD	Chronic Obstructive Pulmonary Disease
CPG	Clinical Practice Guidelines
DSAM	Danish Society of General Practice (Dansk Selskab for Almen Medicin)
ESASr	Edmonton System Assessment System revised
EBM	Evidence-Based Medicine
EAPC	European Association for Palliative Care
EOL	End-of-Life
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
LEON	Lowest Possible Effective Care Level (Laveste effektive omsorgsnivå)
NAFALM	National Research School in General Practice (Nasjonal forskerskole i allmennmedisin)
NFA	Norwegian Society for General Practice (Norsk forening for allmennmedisin)
NSCPM	Nordic Specialist Course in Palliative Medicine
NSD	Norwegian Social Science Data Services (Norsk samfunnsvitenskapelig datatjeneste)
NTNU	Norwegian University of Science and Technology
ON	Oncology Nurse
OOH	Out-of-Hours
PCT	Palliative Care Team
PROM	Patient-reported outcome measure

REK	Regional Committee for Medical and Health Research Ethics Central Norway (Regional komiteer for medisinsk og helsefaglig forskningsetikk Midtnorge)
rTA	Reflexive Thematic Analysis
VAS	Visual Analogue Scale
WHO	World Health Organization
WONCA	World Organization for Family Doctors

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Prologue: The development of this thesis

I guess I always planned to be a GP. At least, when I started studying medicine in 1997, that was my intention. But instead, I ventured into anaesthesiology for three years before, in 2010, deciding, haphazardly, to try out working as a GP, which also included being a nursing home physician. I soon discovered the joys and frustrations of working in primary care. Whereas the independent role and holistic approach of general practice appealed to me, and I thrived in many respects as a GP, some aspects of the job caused concern and frustration.

Having worked in both nursing homes and municipal nursing services as a student of medicine, I found caring for people at end-of-life (EOL) particularly interesting as an anaesthesiologist in the intensive care setting and later as a nursing home physician. As a GP, however, I did not seem to be included in the care loop for the patients at this stage in life. This became very clear to me at one point when a nurse from the local PCT telephoned and asked me to prescribe a specific dose of opioids for one of my patients. I offered to make a house call, but this, I was told, was not at all necessary. The palliative care team was in control and needed me only to make the prescription. In fairness, I was new on the job and did not know the patient, so this could have been in agreement with the patient's preferences. Still, the incident sparked a flame; after all, pain management *is* one of the pillars of anaesthesiology, and from the hospital environment, I had experience in handling syringe drivers, large doses of opioids, pain management with regional techniques and decision-making between life and death in the intensive care setting. However, whereas the anaesthesiologist was the one to call when everything went to pieces in the hospital, I was, as a GP, sidelined when my patients were seriously ill.

A growing uneasiness turned into curiosity about palliative care in the primary care setting, and a wish to explore this further appeared. At this point, in 2012, the guideline for palliative care within the Cancer care action programme had existed since 2007. Yet, I was unaware of the guideline as a GP novice and did not even find it initially when searching for the term "palliasjon" (palliative care) on the internet. Searching for it within the cancer care programme made no sense to me as a GP. However, I found the publication "Standard for palliasjon" (Standard for Palliative Care) from 2004, which still forms the basis of the recommendations for the organisation of palliative care in the guideline. I soon discovered that the suggested role of the GP in this document was very far from my real-life experiences. I also found that GPs were supposed to master a specific skill level that, from my point of view, seemed advanced for a GP. With this vague idea that some things did not add up concerning this guideline, I contacted the General Practice Research Unit at the Norwegian University of Science and Technology (NTNU) in Trondheim to discuss my ideas for a project, which has evolved into this thesis over time.

I think I can speak on behalf of many of my peer researchers when I state that doing research while you are working as a GP can be both challenging and worrisome. After struggling in this landscape for a while, I left general practice and ventured into something new, first as a full-time nursing home physician. Then, an interesting opportunity presented itself in 2015: a part-time position as a physician on the palliative care team at Kristiansund Hospital. And thus, my professional path and this research project have intertwined and evolved over the years. Drawing on this project and my professional experiences in anaesthesiology, general practice, and nursing homes, I have found my place in palliative care.

1. Background

1.1 Overview of this thesis

Due to demographic changes, the number of people who need palliative care is increasing, while there is a shift from providing care in institutions to providing care at home. In research literature and policy in many countries, the GP is regarded as an essential actor in primary palliative care, and this vital role of the GP is reflected in the national guidelines for palliative care in Norway.

This thesis includes three papers focusing on the GP's role in palliative care. Paper I (Study 1) investigated GPs' participation in palliative care and adherence to the national palliative care guideline in a quantitative questionnaire survey. Study 2 was a qualitative focus group study resulting in two papers. Paper II explored the GPs' experiences with palliative care and how they perceived their role in this work. Paper III investigated barriers to GP participation in palliative care and implementation of the guideline.

According to the recommendations for Norwegian theses, references in the background sections should be published before the start of the project (1). As time passed between our two studies, some material published from 2014-2018 influenced the course of the project and study 2, and is included in this section. Furthermore, some recent facts were natural to include in some passages, and links to webpages have been updated. Whereas the 2009 revision was applicable at the time of the first study, no changes in the recommendations considering GPs' role were made in the 2015 version, which was used in the focus group interviews in the second study. Thus, the content we drew on in Study 1 from the previous guideline was not altered, and I will use the version from 2015 as a reference for both studies for simplicity (2).

A further point worth noting is the relative dominance of literature related to cancer care forming the knowledge base in palliative care. Due to this, the background section may seem slanted towards research in palliative cancer care. However, the definition of palliative care is irrespective of diagnosis. As I will clarify in the background section, primary care handles patients with various diagnoses in the palliative phase.

In the rest of this chapter, I will introduce the central concepts for this thesis, such as general practice, palliative care, evidence-based medicine (EBM), clinical practice guidelines, and implementation. Furthermore, I will review the relevant literature on the research topic, i.e., palliative care in general practice.

Chapter 2 will present the theoretical perspectives that form a basis for the research. First, I present the theoretical frameworks for the two studies of this thesis concerning how human experiences and thoughts can be investigated from a quantitative, positivist perspective and a qualitative, phenomenological perspective. Furthermore, some concepts and theories surfacing in the discussion of the overall results will be presented. I will examine differences in the philosophical and conceptual perspectives of the two medical disciplines and the concepts of holism, suffering and medical hierarchy.

In Chapter three, I describe the present study. This includes descriptions of the overall aims of the two studies, the study samples and recruitment. The material and analysis will be described for each of the three papers.

Chapter 4 discusses essential aspects of the methods used and the concepts of validity, transparency, and trustworthiness.

In Chapter 5, the results of the three papers are discussed with respect to literature and developments in healthcare. After that, the conclusions are summarised in Chapter 6, and implications and future perspectives are presented in Chapter 7.

1.2 General practice

1.2.1 Definitions and core concepts of general practice

According to the World Organization of Family Doctors (WONCA), "*general practice/family medicine is an academic and scientific discipline, with its own educational content, research, evidence base and clinical activity, and a clinical specialty orientated to primary care*". This definition from 2002 is comprehensive, describing general practice as twelve characteristics of the academic discipline with six corresponding core competencies of the GP, as illustrated in the WONCA tree (Figure 1) (3).

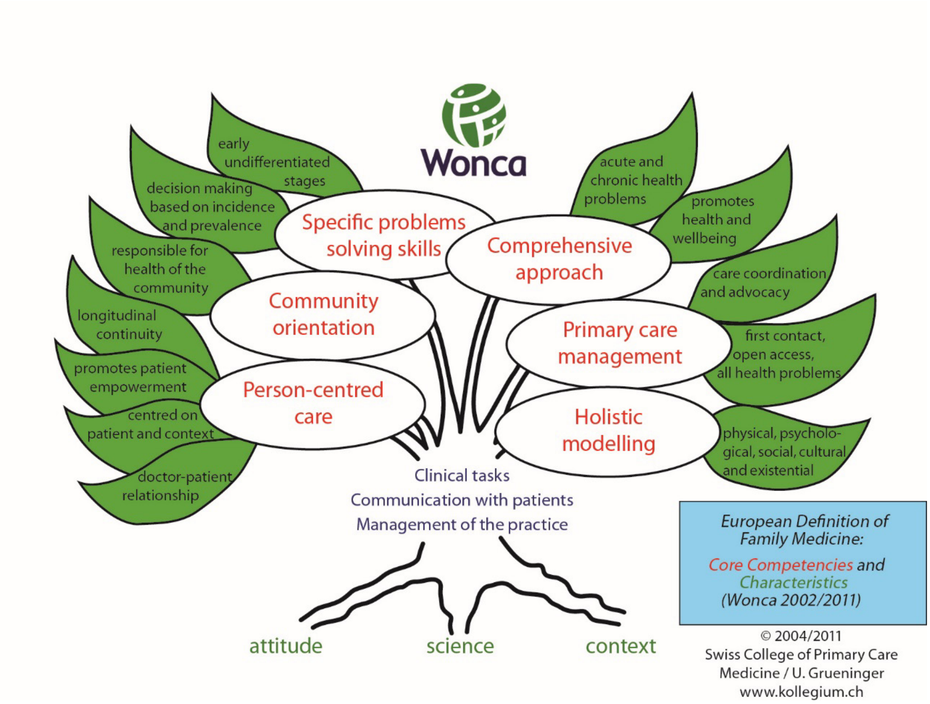

Figure 1. The WONCA Tree. Reproduced with permission © 2004/2011 Swiss College of Primary Care Medicine

The specificity of the GP is that "*the GP is the only clinician who operates in the nine levels of care: prevention, pre-symptomatic detection of disease, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, terminal care and counselling*" (4).

In the Nordic context, statements about the core values of general practice have been expressed through the publication of posters in Norway (Figure 2) and Denmark, each consisting of seven principles for general practice (5, 6). The Norwegian version includes the following principles: 1) Maintain the doctor–patient relationship! 2) Do what is most important! 3) Give the most to those in greatest need! 4) Use words that promote health! 5) Focus on continuing education, research, and professional development! 6) Describe your experiences from practice! 7) Take charge!

Central concepts for this thesis are that the GP should maintain the doctor–patient relationship and focus on the personal meeting and dialogue over time, that the GP is a "witness and companion" for the patient, and that the GP should take charge to ensure good cooperation between the different professionals (7).

SJU TESER
FOR ALLMENNMEDISIN
En oppsummering av NSAMS tenkedugnad 2000- 2001.

Vår samtid anno 2001 preges av økende muligheter for medisinsk behandling, men også av kommersialisering og medikalisering, rettighetstenkning og økt forbrukerbevissthet.

En ny beskrivelse av faget **allmennmedisin** i fastlegeordningen skal

- KLARGJØRE LEGENS ANSVARSOMRÅDER
- FREMME FORSVARLIG BRUK AV MEDISINSK TEKNOLOGI OG MEDIKAMENTER
- GI BASIS FOR INNHOLD I GRUNN-, VIDERE- OG ETTERUTDANNING
- SKAPE REALISTISKE FORVENTNINGER TIL HELSETJENESTEN
- SIKRE FAGLIG IDENTITET OG TRYGGHET FOR LEGEN.

1 HOLD LEGE-PASIENTFORHOLDET I HEVD!

Allmennmedisinens sentrum er lege-pasientforholdet. Det viktigste er det personlige møtet og dialogen med pasienten over tid

2 GJØR DET VIKTIGSTE!

Allmennpraktikerens hovedoppgaver er diagnostikk og behandling. Legen er

- **fortolker av pasientens symptomer og plager**; skiller ut de som har behandlingstrengende sykdom, og forskåner pasientene fra urettmessig å bli behandlet som syke
- **veileder og lærer**; hjelper pasienten til å forstå sin situasjon og hvordan den kan mestres eller lindres
- **vitne og ledsager**; følger pasienten og hans nærmeste gjennom sykdom og lidelse.

3 GI MEST TIL DEM SOM HAR STØRST BEHOV!

Forventningene til allmennmedisinen overstiger både ideelle og praktiske muligheter. Allmennlegen må organisere hverdagen slik at det blir rom for de pasienter som har størst behov for hjelp. Allmennlegen må også ta hensyn til behandlingskostnader; hvis flere behandlingsstrategier er like effektive, skal allmennlegen velge det billigste slik at ressurser som spares kan komme andre til gode.

4 BRUK ORD SOM FREMMER HELSA!

Allmennlegen skal gi pasienten tro på egen mestring av hverdag og helse. Allmennmedisinen skal utvikle et språk som begrenser fokus på risikotilstander og medisinbruk med liten nytteeffekt.

5 SATS PÅ ETTERUTDANNING, FORSKNING OG FAGUTVIKLING!

Fagutøvelsen skal baseres på dokumentert viten, praktiske ferdigheter og erfaringsbasert kunnskap. Faget skal utvikle begreper som knytter sykdom og lidelse til relasjoner og gi en forståelse av hvordan livet setter spor i kroppen. Medisinsk etikk skal beskrive hvordan respekten for menneskets verdighet er en forutsetning for helbredelse.

6 BESKRIV PRAKSISERFARINGENE!

Å forebygge sykdom og uhelse er ofte et spørsmål om å endre samfunnsforhold. Legen skal systematisere og dele sin kunnskap med forvaltning og politikere om sykdoms- og lidelsespanoramaet i sin populasjon.

7 TA LEDELSEN!

Allmennlegen skal ta aktivt ansvar for å sikre god samhandling mellom aktørene i helse- og sosialtjenesten. Allmennlegen skal bidra til at spesialisttjenester prioriteres til dem som har størst behov. I samhandling med andre helsearbeidere må allmennlegen arbeide aktivt for at faglige ressurser utnyttes optimalt. Som leder av legekontoret må legen sørge for at medarbeiderne får utvikle faglig og personlig kompetanse.

NSAM
Norsk selskap for allmennmedisin
The Norwegian College of General Practitioners

Figure 2. Seven principles for general practice (Sju teser for allmennmedisin) from 2001. Reproduced with permission of the Norwegian Association for General Practice (NFA)

1.2.2 The development of general practice and its characteristics

Whereas the roots of general practice can be traced further back, the philosophical and ideological foundation of general practice today largely rests on developments in the 20th century. This section will mention some important milestones in the development of general practice and relate these to the key characteristics and core values on which this thesis builds.

Firstly, the declaration of Alma Ata in 1978 was a strong influence in strengthening the view of primary care as an essential and vital foundation for healthcare worldwide (8). Secondly, the *biopsychosocial model,* launched by Georg Engel the year before, greatly impacted the emerging medical field of general practice. This model of illness recognises that disease at a molecular level does not invariably lead to similar expressions of illness and thus challenges biomedicine's views (9). The model was influential in the development of the *patient-centred* clinical method, which to a large degree is attributed to the ground-breaking works of the English/Canadian physician Ian McWhinney, who is considered one of the founders of modern general practice (10-12). A further development of these concepts is the *person-centred* model, focusing on the patient as a person and an active participant in medical care. Continuity of care, an important characteristic of general practice, facilitates the accumulation of person-related knowledge about patients. This knowledge can provide a basis for better identification of health challenges and needs, providing a basis for offering more tailored treatment and follow-up (13-15). Continuity of care also focuses on the constant development of the doctor–patient relationship (3, 6).

One of the core competencies of general practice, particularly central to this thesis, is *holistic modelling,* which focuses on the physical dimensions of illness and considers each patient's psychological, social, cultural, and existential issues (Figure 1). The general practice approach thus recognises that such contextual factors influence how illness is expressed and rests on Engel's biopsychosocial understanding of illness (10, 11, 16)

In many primary care-based healthcare systems, the GP serves as coordinator of care and gatekeeper to secondary, specialist healthcare and thus has a crucial role in primary care management. Such systems are found in many European countries, Australia, and Canada (17-19). An essential characteristic of general practice is that patients have direct and unqualified access, i.e., open access, to their GPs. Accordingly, the GPs must handle everything from acute to chronic conditions, prevention, diagnosis and active treatment for all kinds of disease trajectories in all age groups, i.e., from birth to death. The threshold for initial contact is low (3). General practice's values and core competencies are adapted to the particular conditions that working in an unselected population provides. In this setting, patients typically present with several health problems simultaneously, early in the disease trajectory, and against a backdrop of low disease prevalence in the population (7, 20). Thus, there is high diagnostic uncertainty, and the diagnostic method is often stepwise and rests on a few simple procedures (7, 21). The GP must therefore have broad competence and be a generalist (22).

In the seminal publication "The Ecology of Medical Care" from 1961, White et al. introduced a model that examined what proportion of the population sought medical care when experiencing illness symptoms and what types of healthcare services they used (23). As services and populations have evolved, this model has been re-examined and further developed. This population-based perspective is valuable for assessing healthcare utilisation and organisation (24, 25). Figure 3 shows a reproduction of the model from 2012, based on the distribution of healthcare service use in Norway (25).

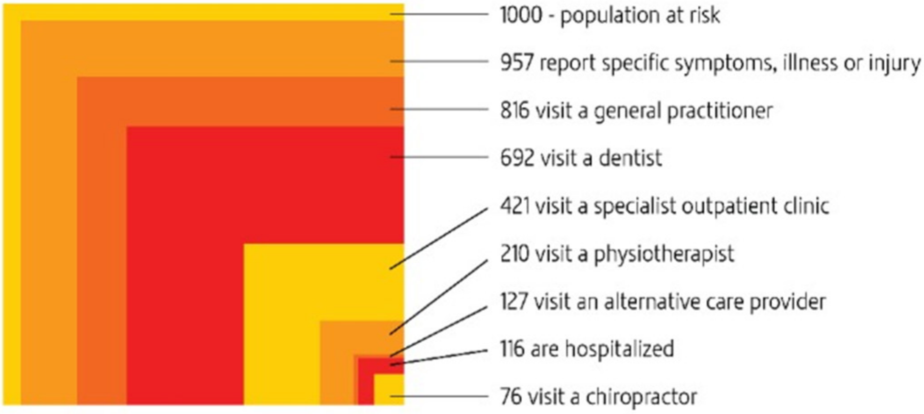

Figure 3. Annual prevalence estimates of self-reported symptoms and illnesses and use of different healthcare services for persons 30 years and over. A.H. Hansen et al., 2012. Reproduced with permission © 2012 SAGE Publications Ltd

A pivotal point to be drawn from this model is that most of the health needs for which people visit their GP are handled by the GP without the involvement of secondary care, as only a small proportion are referred to or hospitalised in secondary care. This means that even small shifts in GPs' referral practices may considerably impact hospital services (23, 25).

1.2.3 General practice and the Norwegian healthcare system

By the mid-19th century, a service of district physicians was established in Norway, and the development and academisation of the profession followed in the wake of advancements in the public healthcare system (26).

Some vital national developments and major international influences on the development of general practice and palliative care in Norway are summarised in Figure 4 to provide a schematic overview of the developments described (with due references) in Sections 1.2.3, 1.3.2 and 1.3.4.

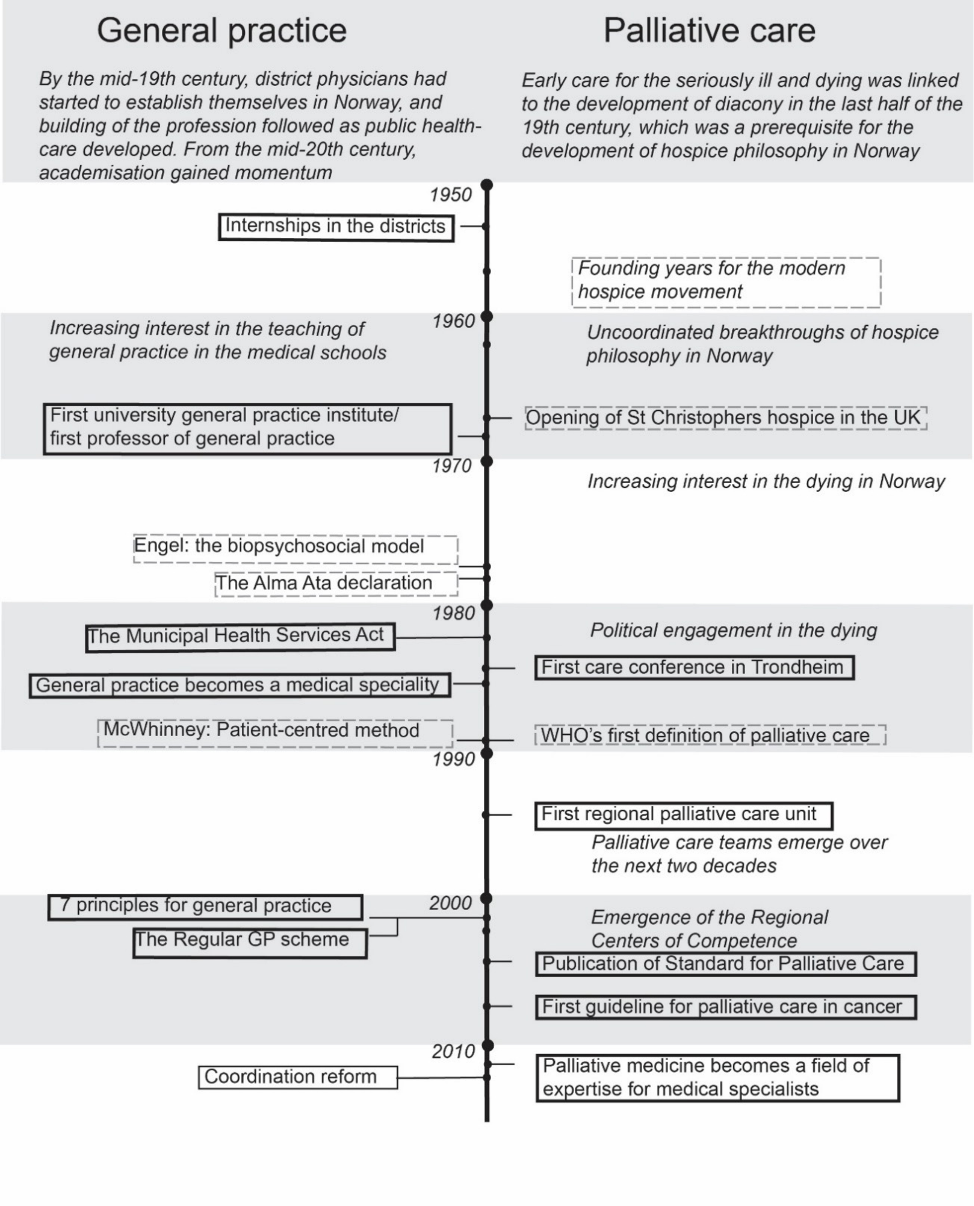

Figure 4. Milestones, and major international influences (dotted boxes), for the academic development of general practice (left side) and palliative care (right side) in Norway

In the early days of the field, general practice and social medicine were not part of the curriculum in Norwegian medical schools. However, as the modern healthcare system developed over the last century, so did the academic grounding of general practice. In 1968, the first Norwegian department of general practice was established, and in the following two decades, an increasing academisation of the field occurred, and it gained ground in the medical curriculum (26). The Municipal Health Services Act of 1982 significantly impacted the development, ensuring all citizens the right to healthcare services (27). In 1985, general practice was recognised as a medical speciality in Norway (28). In the 1990s, general practice was defined as one of three clinical majors in medical schools in Norway, alongside internal medicine and surgery (29).

The speciality of general practice in Norway is achieved through working as a GP alongside a five-year curriculum and tutorial groups. There is also a Continuing Medical Education programme (CME). In 2014, there were approximately 4500 GPs in Norway, and in 2021, there were close to 5000 GPs, of whom 64% were specialists in general practice (30).

In Norway, with a population of about five million, the health-care system is characterised as semi-decentralised (31). The system rests on a set of values common to the Nordic countries, and important features of the Nordic welfare model are universalism and tax financing of essential welfare services (32).

Norwegian GPs work in primary care, which is financed by state funds to the municipalities that provide the services. Most GPs work in group practice and are self-employed, responsible for their facilities and staff. The GPs' payments are a combination of capitation fees, i.e., for each patient on the list, consultation fees from patients and fees for service from state remuneration (31). Most GPs have other municipal tasks, such as being part-time nursing-home physicians and participating in municipal out-of-hour (OOH) services.

Among the various primary care services, we also find home care nursing services and long-term care in sheltered housing and nursing homes. In 2001, a regular GP scheme was implemented in Norway, securing all citizens the right to have a regular GP responsible for the coordination of care (33). Today, 99% of the population is registered with a regular GP (33). Over a year, about 80% of adults will have seen their GP (25). The overall purpose of this reform was to increase the quality of general practice by ensuring every citizen's access to necessary GP services by having a regular GP responsible for coordination and care (33, 34).

Central authorities are responsible for specialised healthcare services at the secondary and higher levels. Ownership is mostly public, and the healthcare system is primarily tax-financed. National health insurance ensures universal access to healthcare, and equity of service provision is a crucial principle. Furthermore, there is a focus on providing integrated healthcare to all citizens instead of special care arrangements for groups of patients with special needs. The latter were abandoned over the last few decades in favour of home-based services and sheltered housing integrated into the municipalities (35).

The regular GPs have a central coordinator role and receive all the discharge and outpatient after-visit summaries from the hospital specialists. They also cooperate closely with the municipal home care nurses. As mentioned earlier, a central premise in Norway, as in many other countries, is that primary care is the first point of contact with healthcare. Access to secondary care requires a referral from a GP, who thus functions as a gatekeeper to secondary care (31). The most common referral and discharge routines in the collaboration between physicians and nurses in the Norwegian healthcare system described here are summarised in Figure 5 to illustrate the most common pattern or flow of communication in Norwegian healthcare.

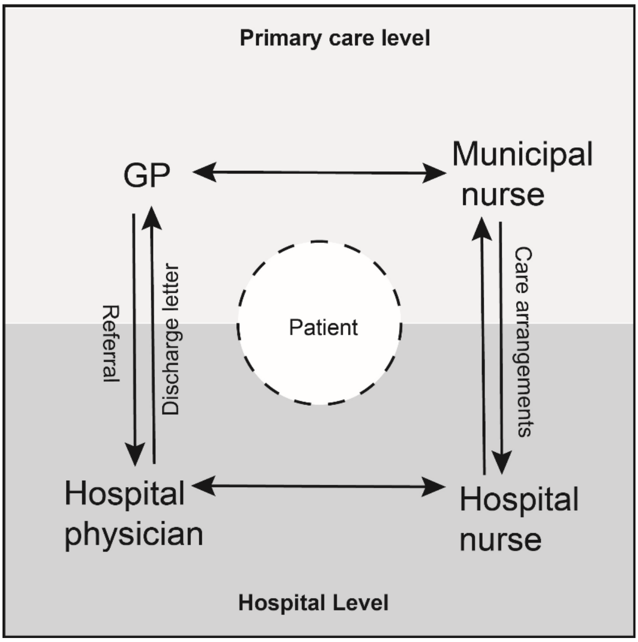

Figure 5. An illustration of the most common discharge and referral routines between nurses and physicians in primary and secondary care

Exceptions to this model include direct admission to the hospital in emergency medical situations. Direct admissions are more common in urban areas (36). Furthermore, specialised hospital nurses sometimes conduct independent consultations with patients in the outpatient setting, thus generating after-visit summaries they send to GPs. Although municipal nurses may receive summaries directly from hospital physicians, a key point worth noting is that there is usually little direct interaction between hospital physicians and municipal nurses.

As Norway is a large and relatively sparsely populated country, geographic equity of health services is also a matter of particular concern (31). An essential administrative principle in the Norwegian healthcare system is that services should be provided at the lowest possible effective care level, i.e., in primary care (Norwegian acronym: LEON) (37). Primary care provision and gatekeeping are associated with reduced healthcare inequalities (38).

One of the main challenges for healthcare in many countries today is the increasing workload in general practice and all parts of the service. In 2010 the proportion of elderly over the age of 80 in Europe was about 5%, whereas this is expected to increase to 11% by 2050. The ratio of older people in the population is thus expected to grow at the same time as birth rates decline (39, 40). This development implies that the proportion of healthy working-age adults will decrease (41). These changes in the population will not only lead to an increase in public healthcare expenditure and challenge economic sustainability but also put pressure on the human resources of the workforce.

In January 2012, the Coordination reform (NO: Samhandlingsreformen) was introduced to improve coordination and cooperation in Norwegian healthcare. The reform focused on reorganising the division of labour between primary and secondary care. This reform aimed to increase the proportion of patient care carried out at home to relieve the hospitals from the increasing pressure and improve service efficiency (42).

The health authorities recognised a need for more GPs in the municipalities when tasks were to be transferred from the hospitals to primary care. However, such an increase in the total number of GPs did not follow. Therefore, the introduction of the Coordination reform is regarded as an important reason for the increasing workload of GPs. One strategy to reduce the workload has been to reduce the length of the GPs’ patient list, but the mean length has so far only been moderately reduced, from 1200 patients per GP in 2001 to just short of 1100 in

2020 (30, 43). Many now believe that general practice in Norway is on the verge of crisis, with too few GPs handling too many tasks (44).

1.3 Palliative care and palliative medicine

1.3.1. Definitions

In this thesis, the definition of *palliative care* in the Norwegian Directorate of Health's action programme for palliative care from 2015 is used:

> *"The active treatment and care for patients with incurable disease and short life expectancy. Relief of the patient's physical pain and other symptoms is central, along with measures aimed at mental, social, and spiritual/existential problems. The goal of all treatment and care is the best quality of life for the patient and the relatives. Palliative treatment and care neither hastens death nor prolongs the dying process, but regards death as part of life"* (2).

This definition is in accordance with the definitions from both the European Association for Palliative Care (EAPC) and the World Health Organization (WHO) (45, 46). The principles apply to all patients with life-threatening illnesses and may also be relevant early in the disease trajectory (2).

Palliative medicine is a term used for the medical field connected to palliative care in European countries today but does not have an internationally agreed definition. The terms *palliative medicine* and *palliative care* are often used synonymously (47).

Primary palliative care is palliative care provided by clinicians with no palliative care specialisation. These can be clinicians in primary care or in hospital. Primary palliative care focuses on basic palliative needs (48). It involves basic management of pain and other symptoms and providing psychosocial support to the patient and their family. In the Norwegian guideline for palliative care, a specific level of competence (Level B) is defined for each of the different healthcare personnel who provide primary palliative care (2).

Speciality or specialised palliative care is provided by clinicians working within the speciality of palliative care, e.g., in specialised palliative care facilities and managing complex palliative care issues (48). According to the Norwegian guideline, this level of care handles patients with complex needs that cannot be handled in primary palliative care, and the healthcare personnel at this level should master specialised skills (Level C) (2).

1.3.2 The emergence of palliative care as a medical field

The approach of palliative care is rooted in *hospice philosophy*. The English nurse and physician Cicely Saunders founded this care philosophy in the 1950s. At that point, Western medicine was changing, with an increasing focus on curing severe diseases, and advancing new medical specialities. There was an increase in patients dying in hospitals rather than at home, and death was, in many ways, regarded as a failure of medicine (49).

Saunders worked as a nurse and social worker early in her career. Through her work, she acknowledged that patients with serious illnesses had complex needs towards EOL. The patients not only needed medical attention and nursing care but also attention to their social needs and the psychological, spiritual and existential suffering experienced when facing life-threatening illnesses. Saunders characterised this as “total pain”. The label “holistic” is frequently used about this approach, underscoring its comprehensiveness (50).

The emergent hospice philosophy was strongly linked to a Christian view of life, but the contemporary palliative care forms also draw on humanitarian values (50).

Saunders created a care philosophy and established an academic grounding of palliative care as an emerging medical field. Research and teaching were considered important activities at St Christopher’s Hospice, which is regarded as the first modern hospice and opened in London in 1967. Thus, the focus in EOL care shifted from charity, Christian mercy, and voluntary work towards professionalisation and involvement of health professionals. Thus, palliative care was established within the professional healthcare setting (50). This development must also be seen in the context of the general growing interest in research in healthcare development in this period (49).

As an academic field, modern palliative care has also evolved as hospital specialists’ attention was directed towards cancer-related suffering. Pain management is one of the pillars of anaesthesiology, and the principles of pain management designed to help the postoperative patient could be transferred to treat cancer pain (50, 51). Several early founders of palliative medicine had a background in anaesthesiology, and the oncological societies also have solid ownership of this medical discipline (50).

1.3.3 Characteristics of palliative care

Today, palliative care is recognised worldwide as an interdisciplinary approach where several professions collaborate closely to improve the quality of life for patients and relatives.

Cancer patients comprise the largest group receiving care in specialised palliative care facilities (2). Cancer incidence in Norway has doubled during the last 50 years, and the burden of cancer is increasing in Europe and worldwide (52-55). This is related to the demographic changes described in Section 1.2.3.

In Norway, cancer is a leading cause of death, constituting about 25% of all deaths (53). Nevertheless, this means that most people die from other causes than cancer. In primary care, death from organ failure and frailty or on a backdrop of multimorbidity is more commonly encountered than death from cancer (56). The scope of palliative care is evolving to include patient groups with other incurable and life-limiting conditions who could benefit from the approach, including the paediatric population (2, 57). This thesis, however, focuses on palliative care as it is organised for the adult population.

The course of a disease may vary between individuals, but some recognisable trajectories of dying have been identified and are illustrated in Figure 6 (58). Cancer deaths typically follow the "terminal illness" trajectory, with rapid functional decline towards the end. Patients dying from diseases like COPD and heart failure typically follow a path of "organ failure" with multiple exacerbations. Finally, the "frailty"-curve is characterised by persistently reduced function and gradual decline (58). The pivotal point is that these latter trajectories are less predictable, with a more gradual loss of function, and these patients may thus need a different model of care than cancer patients (56). Furthermore, recent evidence suggests that the trajectories of disability may be far more heterogenous (59).

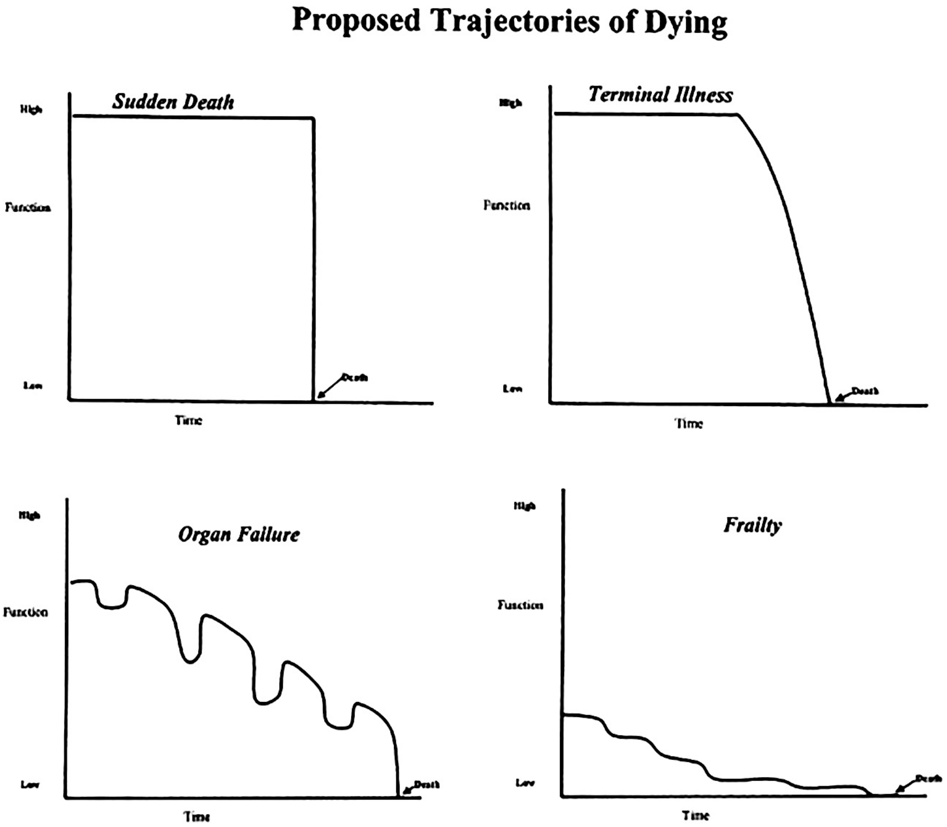

Figure 6. Profiles of Older Medicare Decedents. J.R. Lunney et al., 2002. Reproduced with permission © John Wiley and Sons

Another central issue in palliative care is an emphasis on the active user involvement of the patient and their family in care decisions, including a focus on allowing patients to spend time and, if possible, die in their preferred place of care. Several studies have documented that most people would prefer to die in their own homes, given that they can receive adequate medical support (60-62). Thus, a key goal in palliative care is that patients should be allowed to stay in their own homes as long as possible. If possible, they should also be allowed to die at home, and the proportion of home deaths is an important quality indicator in palliative care (57, 61, 63-66).

A feature of palliative care that has changed significantly over the last decade is the timing of palliative care efforts in the disease trajectories. Introducing palliative care early in disease trajectories has been shown to improve quality of life, increase longevity and reduce hospitalisation (67, 68). Similarly, early discussions with patients about their wishes towards EOL have been shown to reduce "aggressive" medical care near death (69).

Palliative care involves early identification and comprehensive, impeccable assessment of symptoms, function and needs and includes psychosocial care for the whole family (47, 50, 70). Therefore, patient-reported outcome measures (PROMs) and systematic assessment tools are strongly advocated in this field (2, 71).

Finally, as symptoms and health conditions can change rapidly towards the EOL, palliative patients are likely to move between the organisational levels of healthcare frequently. Therefore, interdisciplinary collaboration and cooperation between the different organisational levels, i.e., *shared care,* are vital (72-74). Shared care typically involves the joint efforts of physicians or teams from primary care and hospital specialities and communication exceeding the regular discharge and referral routines (75, 76).

1.3.4 Palliative care in Norway and the National Guideline for Palliative Care

The first breakthroughs of the modern hospice philosophy in Norway can be traced to the 1960s and 1970s. Thereafter, the development took the form of a growing social movement advocating better care for the seriously ill and dying. A surge of academic activities followed, leading to the opening of the first hospital department for palliative care (Seksjon for lindrende behandling) at the Cancer Department at the Regional Hospital (currently St Olav's Hospital) in Trondheim in 1994 (50). The first guideline for palliative care was issued in 2007 (2, 77). Since 2011, palliative medicine has been a field of expertise (NO: kompetanseområde) for physicians, with a two-year build-on to a pre-existing relevant clinical speciality (78). Some selected milestones in this development are summarised in Figure 4.

The organisation of palliative care in Norway corresponds closely to the National Guideline for Palliative Care in Cancer Care (Nasjonalt handlingsprogram med retningslinjer for palliasjon i kreftomsorgen), which in the following will be referred to as "the guideline". It was revised three times before the 2015 edition, which forms the basis for this thesis (2). The guideline was published in a paper version of 188 pages and an online version. The guideline's target groups are all health personnel handling palliative patients and even patients and relatives. The guideline's scope is mainly oncological patients, but it states that the general chapters are relevant for palliative patients regardless of diagnosis (2).

The first part of the guideline describes the discipline of palliative care and serves as "guidance" to recognise the characteristics and challenges of the field. The next part is described as "clinical practice guidelines" (CPGs) for treating symptoms and conditions. Finally, the third part represents a departure from the usual structure of national guidelines. It is described as "recommendations" for the organisation of the service and competence requirements for the various professions involved, which is particularly interesting for this thesis. The guideline contains no specification of how the nuances between "guidance", "clinical guideline", and "recommendations" are to be understood (2). However, the publication had status as one of the National Clinical Guidelines (Nasjonale faglige retningslinjer). Practices deviating from National Clinical Guidelines should be documented and justified (79). Furthermore, GPs are specifically obligated to follow national guidelines according to the regular GP regulations (33). Thus, the entire publication must be regarded as normative, with judicial implications for the clinicians involved.

In Norway, palliative care should be provided at all levels of healthcare. In the primary care setting, palliative care is provided at home, in nursing homes or specialised palliative care units in nursing homes. Most hospitals have palliative centres with PCTs providing inpatient and ambulatory/outreach services locally and regionally, i.e., at the secondary and tertiary levels. There are few hospices in Norway, as palliative units are primarily incorporated in the existing nursing home facilities (2). As mentioned, and in line with the international ideals of palliative care, patients should be allowed to spend as much time as possible in their preferred place of care, which is often the home (2). Yet, only about 15% of all deaths in Norway occur in the home, and most die in nursing homes or hospitals (53)**.**

According to the guideline, PCTs are mandatory in the palliative centres of hospitals. The teams must include a physician who works mainly with palliative medicine and a nurse experienced in palliative care with relevant special education. Furthermore, the teams are required to contain additional professionals who are necessary to work inter-professionally. These can include physio- and occupational therapists, nutritionists, chaplains, psychologists and more. The PCTs are supposed to function as a bridge between primary care and hospital services for palliative patients.

The PCT physician has an advisory role towards the treating physicians in primary care and hospitals. This role includes transferring necessary information to primary care and addressing the division of responsibilities upon patient discharge from the hospital. In addition, the PCTs can, according to the guideline, for shorter durations and “by agreement”, take over care and treatment for patients with complex conditions (2).

The guideline underlines that the regular GP should be the treating physician and coordinator of medical care when the patient resides at home. The GP is expected to provide necessary home visits to patients, work actively towards involving other professionals and ensure continuity in case of a planned absence. Furthermore, there should be a clear routine for accessing medical assistance outside the GP’s regular working hours. The GP is in charge as long as the patient stays at home unless otherwise agreed (2).

Regarding competence, beyond primary education, there is no compulsory education in palliative care to practise as a GP in Norway or as part of general practice specialist training (80). The guideline, however, recommends that GPs should manage palliative care at a specified level, “B”, which applies to *all* physicians who handle cancer patients (Figure 7) (2):

Competence Level B
All physicians who treat cancer patients should
• Know different types of pain and the effect of different relief methods • Be able to carry out examination, mapping and diagnostics of pain and other symptoms • Know and be able to use common tools for symptom registration (Edmonton Symptom Assessment System (Revised) [ESAS-r] and other mapping tools) • Know the importance of adequate diagnostics to clarify the cause of pain and other symptoms and be able to refer to diagnostics • Be able to prevent and treat pain, nausea, constipation and other ailments from cancer • Have insight into emergency conditions in cancer patients, especially a threatening cross-sectional lesion, superior vena cava syndrome and hypercalcaemia, and know how these are treated • Ensure that the patient is adequately assessed in relation to tumour-directed treatment and have referral routines for this treatment • Know the World Health Organization pain scale • Be able to start treatment using a subcutaneous syringe pump for the delivery of analgesics and possibly other drugs, for example, for nausea • Know the complications and side effects of treatments and be able to treat them • Have referral routines for relevant palliative treatment for patients with incurable cancer • Maintain interdisciplinary collaboration with other specialists and professions and be able to create a treatment plan that considers physical, psychological, social and spiritual/existential aspects • Be able to make relevant ethical assessments in collaboration with the patient, the patient’s family and other healthcare personnel

Figure 7. Translation of Competence Level B from the Norwegian guideline for palliative care.

The municipal home-based nursing service must ensure round-the-clock access, and there should be a designated “resource network nurse”, preferably an oncology nurse (ON) serving as an advisor on palliative care and having a coordinator role for cancer patients (2).

In 1982, a programme for the formal education of ONs in Norway was started. These nurses have specialised competencies and skills in caring for cancer patients (81). Although they initially mainly worked in oncology departments in hospitals, the municipalities eventually also started to employ ONs.

ONs have vital functions in primary palliative care in many Norwegian municipalities. In 2011, about one in three municipalities had a dedicated ON (82). Since 2012, the Norwegian

Cancer Society has partially financed the employment of nurse coordinators for cancer patients (NO: Kreftkoordinator), which has led to an increase in municipal ONs (83). In 2019, 70% of the population had access to an ON (84). However, some municipalities have not implemented ON coordinators, as they do not wish to create such special arrangements for selected patient groups and rely on nurse generalists (85).

According to the guideline, municipal resource network nurses are the primary contact point for the PCTs. As there seems to be a significant overlap between the functions mentioned here, I will in the following use the abbreviation "ON" also for the resource network nurses in general and the nurse coordinators in this thesis, as they are most commonly ONs. The resource networks aim to increase palliative care competence in the municipalities. Continuing education of the networks is driven by the four regional palliative centres in collaboration with the local PCTs (2).

The guideline thus describes a more complex collaboration between primary and secondary care than the usual routines illustrated in Figure 5. A point worth noting is that the ON is supposed to be the primary point of contact for the PCTs, which opens for direct interaction between the PCTs and the municipal nursing services. The guideline also recommends several measures to ensure good interaction and comprehensive care, such as keeping updated patient records in the home to make them available OOH, joint meetings and addressing the division of tasks before hospital discharge. Thus, the collaboration model aligns with the concept of shared care, with procedures exceeding normal discharge and referral routines (2, 73). Figure 8 represents a simplified illustration of the features of the collaboration between nurses and physicians at the primary and secondary care level for home-residing palliative patients:

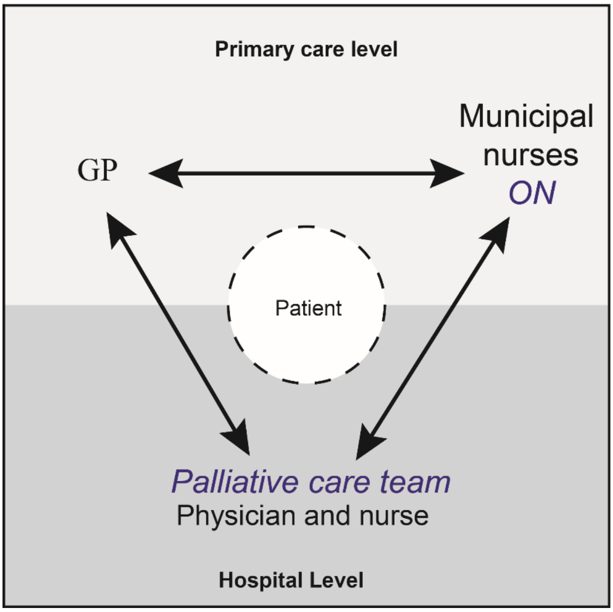

Figure 8. Illustration of shared care between PCT, municipal nurses and GPs, based on the guideline description of responsibilities (see also Figure 5).

1.4 Palliative care in general practice

This thesis focuses on palliative care in general practice. In this section, I will review the literature on different aspects of the GP's role in palliative care based on published literature, research, and public policy papers.

In the 1950s, there was a discussion about managing "hopeless" medical cases where cure and recovery were impossible (86). Dr Ronald Gibson was an experienced GP and an important contributor to the medical society in Britain in his day (87). In an interesting discussion paper from 1958, he broke down the definition of "hopeless" patients into two groups: those whose life expectancy was reduced by the disease and those who would not recover but whose life expectancy was not reduced. He presented his elaborate, practical approach to all such patients and their families. The over-arching idea was maintaining hope and daily activities while striving for symptom control, applying a "total care" concept: "*I am acknowledging that chronic illness has a social as well as a biological character*". Thus, Gibson's approach started with practically adjusting the home environment and preparing and enabling the relatives. The patient should be encouraged and supported to embrace life and establish a routine of daily existence, including work, hobbies, and entertainment. Medical treatment of symptoms like pain, nausea, skin conditions, and constipation, as well as dietary interventions, physiotherapy, social and vocational therapy, spiritual and psychotherapy, were all essential to this approach. Gibson's description leaves an impression of him as an instigator and coordinator of the various professional efforts involved (86). Gibson's account of the GP's responsibilities towards seriously ill patients resembles the central values of the hospice philosophy founded in the same time period (see Section 1.3.2) (50). Historically speaking, neither the palliative patient nor the core values of what is currently the field of palliative medicine were strangers to the GP.

Yet, from more contemporary literature, it seems like an estrangement has occurred, distancing the GP from the realms of palliative care. Some 20 years on, the earlier mentioned founding father of family medicine, Ian McWhinney published a paper on the "Family Physician's Role in Cancer Care". The authors pointed to an apparent diminishing role of the GP in cancer care, pointing to a loss of contact between cancer patients and their family physicians. This development could have adverse effects, especially concerning continuity at EOL (88). In a subsequent paper in 1994, McWhinney pointed to how the palliative care movement had developed into two different models of home support for dying patients: one where the multidisciplinary PCT provided all care (a total care model) and one where the PCT had an advisory and supportive role towards the patient's GP and regular home care nurses (89). Other authors have also described the tension between GPs and specialists who took over care, leading to a conflict of interest between the GP and the specialist, and pointed out that such practices will end with deskilling of GPs and primary care nurses (90).

Thus, as the concept of palliative care developed, attention turned to its integration into primary care.

1.4.1 The GP's role in palliative care

By the start of the 1980s, studies showing GPs' shortcomings in the follow-up of cancer patients had emerged, and a debate arose as to whether this was due to the GPs' ignorance or connected to the structure they worked in (91). In a British study from 1986, Still and Todd argued that variation in GPs' attitudes towards treating the terminally ill could be due to role ambiguities and conflict with the ideal of a "curing role" of the physician, which must give way for a "caring role" to complement the "dying role" of the patient (91, 92).

Although GPs find it demanding, studies from different countries have repeatedly confirmed that they value participation in palliative care and are devoted to their cancer patients (90, 93, 94). Although there is debate, several authors have advocated for the GP's central, crucial role in primary palliative care (63, 64, 95-97). Research on patients and relatives from Denmark in 2011 suggests that the GP could be the ideal key worker and coordinator in palliative care (98). The GP's central role in primary palliative care is widely recognised worldwide (2, 99, 100). As described above, the Norwegian guideline for palliative care also acknowledges the central role of the GP in palliative care.

However, in 2017, a Norwegian public report on palliative care services was published, evaluating service content, quality, and availability. Already in the introduction, GPs were characterised as "*on the sidelines*" (NO*: spilt av banen*) and called to become more active participants in palliative care (57). The evidence thus suggests that it can be challenging to integrate Norwegian GPs into palliative care (101).

1.4.2 Barriers to GP involvement in palliative care

Several studies from different countries have investigated and identified barriers to GP participation in palliative care. Groot et al. explored the barriers GPs encountered when providing palliative care. At the personal level, lack of necessary competence was a significant barrier, but also the emotional burden and time constraints (102). Furthermore, barriers can arise from poor communication and collaboration between the multiple professionals involved and at the organisational level, where compartmentalisation and bureaucracy can cause delays and unnecessary transfer to the hospital (73, 102, 103). Whereas evidence thus suggests that barriers at the organisational level are prevalent, there seems also to be a persistent emphasis on individual-level barriers such as lack of knowledge or interest in palliative care (104-106).

1.4.3 The GP's competence and educational needs

In primary palliative care, simple medicine regimens with easy medication administration, such as patches, mixtures, and suppositories, may provide satisfactory symptomatic relief for many patients with advanced disease (63). This does not necessarily require specialist skills. Therefore, a central issue addressed in many studies is the GPs' competence and educational needs in palliative care.

According to a paper by Barclay et al., in 2002, GPs were well equipped to handle common symptoms like pain but were less aware of how to treat less common symptoms. GPs were, however, in need of support from specialists “readily available” to give advice, as a GP cannot be expected to “read the small print” of every speciality (107). These authors thus suggested that the GP is central but must rely on support from specialists. This “GP with a supportive team” approach is supported by other authors (89, 108, 109).

Several studies have aimed at identifying GPs’ shortcomings in providing palliative care, and numerous different educational measures to improve GPs’ knowledge and performance in various domains of palliative care have been studied. For example, improving GPs’ identification of palliative patients, general knowledge, prescription habits, or communication skills in dealing with patients and relatives may improve practice in those domains (105, 106, 110-116).

A different view was presented in the US national consensus conference report from 1999. The group pointed to the deficiencies in the general education of physicians and suggested that EOL care should be better integrated into basic education (117).

Studies have also explored how GPs can best learn palliative care. A systematic review in 2002 found that GP interaction and cooperation with PCTs could enhance the GP’s competence and improve outcomes (93). More recent findings support that GPs experience lifelong learning in the workplace through collaboration with ONs and PCTs (116, 118).

1.4.4 Associations between the GP’s participation in palliative care and home death

As mentioned, the proportion of patients who die at home under adequate care is an important quality indicator in palliative care. Several studies have examined the correlation between the desired and actual place of death and which factors contribute to achieving the preferred place of death. Although many factors have been shown to influence the possibility of dying at home, there is a link to the quality of care provided by the GP (90, 119, 120). Furthermore, the continuity of care provided by the GP, and the GP’s willingness to make house calls may increase the likelihood of home death (119, 121-125).

1.5 Evidence-based medicine and clinical practice guidelines

1.5.1 Definitions

The term “evidence-based medicine” (EBM) was introduced as an approach to teaching and practising medicine at McMaster University in Canada in the 1990s. The over-arching idea of the concept is that evidence from clinical research should form the basis for clinical decision-making (126). In 1996, Sackett et al. defined evidence-based medicine as "*the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research"* (127).

A well-recognised strategy to facilitate evidence-based clinical practice is developing CPGs. A definition used by both the Guidelines International Network and the United States' Institute of Medicine is the following: *"Statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options"* (128).

1.5.2 Clinical practice guidelines and implementation

EBM has been subject to controversies, and many have argued that it represents a restricted approach to scientific knowledge. However, EBM is currently the accepted dogma and represents the gold standard for clinical decisions in medicine (129).

Clinical practice guidelines are generally developed to ensure good quality of care and avoid disparities in service (unwanted variation) by translating the best evidence into applicable advice that can be disseminated among practitioners (79).

The health services' ability to use research depends on the knowledge being implemented in clinical practice (130). Clinical guidelines can be regarded as a map meant to be applied to the terrain of the clinic to create the best possible health in the population. However, the mere dissemination of guidelines among the practitioners seems insufficient, and a substantial research-practice gap is recognised in several disciplines (131, 132).

Knowledge of implementation precedes the development of EBM and CPGs. One influential sociological theory was the diffusion of innovations theory launched by Rogers in 1962 (as cited in Nutley and Davis) (133). In 1973, Pressman and Wildavsky (as cited in Graham) turned their attention towards policy implementation, showing the potential for implementation failure (134). The research-practice gap in healthcare has led to a surge in the development of methods, strategies, and frameworks to promote the uptake of findings and the study of facilitators and interventions to overcome barriers (135, 136).

In the early days of EBM, a linear relationship between innovations and individual clinicians' behaviour was assumed (137). In other words, a guideline's success depended on the physician's adherence. Thus, classical, individual-level theories of behavioural change from psychology, e.g., the theory of reasoned action or self-efficacy, could apply, focusing on the relationship between the individual's attitudes, beliefs, and behaviour (138, 139). Accordingly, intervention studies aiming to improve the implementation of CPGs would often focus on dissemination, reminders, audit and feedback, or educational outreach, typically producing moderate effects (136).

Multiple barriers to guideline implementation at the individual level have been identified. The clinician may be unaware of the guideline or unfamiliar with its content, i.e., lack of knowledge. Health professionals' attitudes can also constitute a barrier through, for instance, lack of agreement with the guidelines, lack of outcome expectancy, lack of self-efficacy, and practice inertia. Thus, knowledge and attitudes are important determinants of guideline adherence (140).

However, implementation was soon acknowledged as a more complex activity, warranting change at the organisational level (136, 137). External barriers beyond the clinician's control, such as patient, guideline, and environmental/organisational factors, must also be acknowledged (140). As the quality of CPGs influences adherence, the Appraisal of Guidelines for Research and Evaluation (AGREE) has developed tools to appraise the quality of CPGs (141). According to the governing body for Norwegian CPGs, this framework is also recommended for use in evaluating existing guidelines and creating new ones (79). Although individual-level theories still prevail, there is an increasing interest in organisational-level theories to understand the implementation process, shifting the focus from self-efficacy towards organisational culture and context (139, 142).

1.5.3 Implementation of CPGs in general practice

Whereas GPs generally assess them as both necessary and useful, CPGs are known to be particularly difficult to implement in general practice. Studies on implementation problems in general practice have yielded valuable knowledge in recent years. The General Practice Research Unit at NTNU in Trondheim, the research group I have worked with, has contributed essential findings concerning the appropriateness and sustainability of CPGs in general practice over the last two decades. This thesis originates from within this scientific environment (143-148).

The individual-level barriers to guideline implementation listed in the section above apply to most clinicians on some level. It has been debated whether poor adherence may be due to GPs' attitudes and willingness to change or if it has more to do with the content of the guidelines or external factors (144, 145, 149, 150). However, a growing body of evidence suggests that the context of general practice represents a challenge that should be acknowledged to a larger degree when guidelines are developed.

The GP encounters various diseases in general practice, meaning they must deal with multiple guidelines in their daily clinical work. According to Austad et al., GPs found it difficult to adhere to guidelines due to guideline overload concerning the total number of guidelines, their comprehensiveness and accessibility. The study also demonstrated how multiple guidelines could apply to a patient simultaneously, which was challenging (151). Furthermore, according to a systematic analysis from 2011, guidelines for single diagnoses do not address how to handle comorbid conditions in individual patients, which challenges their applicability in general practice (152).

Evaluating the potential consequences of implementing a guideline in clinical practice is recognised as necessary in guideline development today (79, 141). However, recent evidence suggests that the assessment of consequences must go beyond the computation of immediate costs to healthcare. For example, too extensive guideline recommendations for risk prevention could lead to population medicalisation and threaten healthcare system sustainability (153). Furthermore, sustainability can be challenged if the workload in general practice imposed by the guideline procedures is not considered (146). Guidelines will likely promote more aggressive recommendations if they are not created according to the quality criteria or when made by speciality societies (154). Methodological rigour in guideline creation is, therefore, vital (141).

According to the AGREE II framework, groups developing guidelines should include representatives from relevant professional disciplines (141). The involvement of GPs as stakeholders has been suggested to be particularly important in developing guidelines involving primary care. At the same time, GPs are not likely to get significantly involved in developing guidelines they have not initiated or do not feel ownership of (155).

2. Theoretical perspectives

In medicine, we draw on knowledge from both natural and human sciences to understand the complexity of the human body and human being. The natural sciences study the physical world. The practice of medicine strongly relies on knowledge acquired through the scientific method, which focuses on establishing objective facts through testing, experimentation, and control of variables to confirm or reject hypotheses (156). In bio-medicine, knowledge generated through randomised controlled trials has the highest status in clinical research (157). However, this modality of knowledge acquisition is insufficient to serve the needs of the discipline of general practice; relying heavily on the doctor–patient relationship and generalist knowledge, the GP needs a knowledge base that integrates multiple ways of knowing (158, 159).

Firstly, this project combines quantitative and qualitative methods, and an account of how scientific theories provide an epistemological foundation for the different methods applied should therefore be included. This section will provide an overview of the central theories and the epistemological position underpinning this thesis' methodological choices. I will shortly describe how the quantitative study finds support within a positivist view of research in the social world. I will also account for how phenomenology provides a foundation for the qualitative approach. Furthermore, I will briefly describe other theoretical underpinnings for my qualitative analysis methods: hermeneutics and idiography.

Secondly, this thesis is based on three different analyses corresponding to the three papers. The guideline for palliative care was used as a map, i.e., a conceptual model of desired practice, and the project sought to explore the terrain, i.e., the GPs' experiences with palliative care. The approach was inspired by phenomenological thinking in that we intended to study a phenomenon as experienced from GPs' point of view. As work on the papers progressed, theoretical and conceptual perspectives worked their way into consciousness and aided the discussion in the thesis. I will draw attention to some similarities and differences between general practice and palliative care, touching on the concepts of suffering and holism. Finally, the concepts of power and hierarchy in medicine were helpful when reviewing the overall results.

2.1 Theoretical framework for the studies

2.1.1 Knowledge acquisition in general practice

As mentioned in the introduction to this chapter, the natural sciences have a strong standing in medical research. However, the knowledge base in general practice rests on integrating various kinds of knowledge. The discipline must combine the subjective, experiential knowledge of the practitioner and the community and objective knowledge about the healthcare system and diseases. Thus, knowledge gathered by subjective, participatory research and objective methods complements each other to form an extended knowledge base adapted to the particular context of general practice (158).

Both studies in this project aim to examine people's thoughts, opinions, and behaviour in the real world. Thus, we need a framework for acquiring knowledge in such a setting. We need to answer how the social world can be investigated quantitatively and qualitatively, particularly how the latter can rely on first-person accounts as a valid source of knowledge.

In a positivist view of research in the social world, we can test theories or hypotheses through objective and rigorous observation similar to the methods frequently applied in the natural sciences (160). The researcher should strive for objectivity. This was the epistemological framework for the quantitative study in this thesis, where we performed a cross-sectional survey, collecting data to analyse statistically.

The assumption that the social reality investigated was an external, objective reality with a stable, objective ontology could be challenged by a more constructivist view of the social phenomena as in a state of constant revision (160).

In the research strategy of Study 2, the emphasis shifted towards how individuals interpret their world, seeing the social reality as constantly shifting and evolving (160). We wanted to capture and understand the participants' perspectives of reality, thus recognising subjectivity as a valid source of knowledge (161). Thus, the qualitative study rests on a different epistemological stance.

2.1.2 Phenomenology

As already mentioned, this entire project was inspired by phenomenological thinking in the sense that we wanted to study the role of GPs in palliative care based on their perceptions. Phenomenology was also the overall framework underpinning Study 2 – and for the analysis in Paper II.

The emergence of phenomenology in the first part of the 20th century was, in many ways, a reaction to the positivist notions of research in the social world (160). First conceptualised by Edmund Husserl, phenomenology in this context provides the philosophical basis to approach and study individuals' subjective conscious experiences (162).

In Husserl's view, subjective consciousness was a prerequisite even for perceiving objective matters. This means that consciousness is always directed towards the world and that there is a correlation between the experience and the object being experienced (163). A key point for this thesis is that lifeworld experiences can be accessed through first-person accounts, opening them for systematic exploration into the essence of lived experiences to fully understand the world and the human beings in it. The ideas of Husserl were subsequently developed by philosophers acknowledging the person as positioned or embedded in a physical, social, and cultural world (162).

For qualitative researchers, phenomenological philosophy has provided an epistemological framework for how and under what conditions human experiences can count as valid knowledge (161, 163). Underpinned by this elaborate philosophy, different methods for studying phenomena in their natural context have evolved (163). The common principle is that reality is represented by what the informants perceive it to be (161-163). Such methods are suitable for providing knowledge about subjective experiences, perceptions, thoughts, expectations, motives, and attitudes, relying on descriptions and interpretations. The researcher often has the role of both observer and participant in dialogue with informants. This requires researchers to make their point of view explicit and be conscious of their preconceptions (161, 163). Reflexivity throughout the research process is therefore of vital importance, and this is further described in Section 4.1.2.

2.1.3 Hermeneutics and idiography

Hermeneutics concerns the activity of interpretation and was initially developed in the context of the interpretation of biblical texts. One of the influential philosophers in this respect was Martin Heidegger, one of Husserl's students. Heidegger saw phenomenology as seeking after meaning, which in turn was linked to the activity of interpretation (162, 163).

In hermeneutics, interpretation is seen as a circular process, with a dynamic relationship between the individual parts and the whole of a text or other human expression. Thus, the whole must be envisioned in terms of the parts, whereas the parts must be seen in the context of the whole (162). In other words, the meaning of a sentence depends on the meaning of the individual words, which in turn can only become apparent if seen in the context of the whole sentence, which again must be considered within the section of text in which it occurs, and so on. Thus, interpretation involves repeated, i.e., iterative processes, moving back and forth between the multiple levels of units of the whole text to understand it completely (162).

Idiography concerns describing individual cases, and the focus is thus on the particular (162). In the context of this research, every single case should be examined thoroughly before arriving at general statements. It is thus the opposite position of establishing general laws at the group level (164).

2.2 Analytical perspectives to guide further discussion

2.2.1 Aspects of human pain and suffering

Pain and human suffering are medical concerns and central concepts in palliative care and general practice. Thus, exploring how they are understood in the medical literature is relevant.

According to the biomedical model, the human body is best understood when investigated in terms of the more basic, simple units in isolation, e.g., the molecules or organs of a human being (165, 166). Central to this notion, termed *reductionism*, is the dualistic stance, i.e., that the mind and the body are separate entities, which originated with René Descartes in the 17th century (167). Consequently, pain is often understood as a neurologic phenomenon of the body, corresponding to “measurable damage”. This perspective has provided a framework for pain research and significant advances in pain treatment (168).

However, pain is modulated by psychological, spiritual, and existential mechanisms. Such processes cannot be measured objectively, and criticism against the biomedical model emerged from the beginning of the 1960s from different medical milieus. Thus, the emerging hospice movement, described in Section 1.3.2, was part of this reaction, introducing “care” as a central goal in medicine and the concept of “total pain”, which was later also termed “total suffering” to distinguish it from physical pain (50, 168, 169). The biopsychosocial model launched by Engel in 1977 (see Section 1.2.2) also fits into this context.

In 1982, physician and philosopher Eric Cassell published “The Nature of Suffering and the Goals of Medicine” (as cited in Duffee et al.). Cassell distinguished between pain and suffering, basing his definition on what a person is: a thinking, feeling human being with a past, in multiple relationships with others. This work has been influential, conceptualising suffering as *“a person’s severe distress at a threat to their personal integrity”* (170). According to Cassell (as cited in Bueno-Gómez), pain and suffering have not only a physical or nociceptive quality but also psychological dimensions which can have meaning and cannot be abstracted from the mind of the sufferer. Furthermore, physicians could develop methods to use the subjective experience of pain to provide “holistic” treatments (168).

As phenomenology is a central theoretical concept in this thesis, it is worth mentioning that this comprehensive philosophy can also be helpful in conceptualising pain and suffering. From a phenomenological stance, the person is situated and the mind “embodied”, meaning we experience the world through our bodies. From this perspective, the person is a psychophysical whole, with no mind–body dichotomy. Suffering is the lived experience of the person who suffers and can be understood and shared from the first-person perspective (168).

2.2.2 Conceptual similarities and differences in general practice and palliative care

A term mentioned in the previous section was *holistic* treatments, which Cassel saw as a goal for medicine (168).

Holism is the theory concerning the relationship between the parts and the whole in different systems. In his work *Metaphysics*, Aristotle (as cited in Stempsey) discussed how the whole was something greater, or something else, than the sum of its parts. As a current academic term, holism essentially means that the elements, through their inner relations, constitute a whole that is somehow *more* than the parts (171).

Holism in medicine has emerged as a reaction to biomedical reductionism (see Section 2.2.1) and is thus also connected to the dualistic debate and the problem of suffering. However, holism is used in many ways in healthcare and is sometimes associated with alternative or complementary medicine (172, 173). Thus, the concept of holism in one medical discipline may not be directly transferable to another medical field.

The background section describes general practice and palliative care as holistic medical approaches (see Sections 1.2 and 1.3). Both fields are thus different from the organ-specific specialities, which can be perceived as more reductionist in nature and often focus their diagnostic efforts on single-organ diseases (50, 172, 174).

According to WONCA Europe, *holistic modelling* in general practice means having the ability to use a biopsychosocial model, with attention to the physical, psychological, social, cultural, and existential dimensions of health problems (see Section 1.2) (3, 7, 10, 16). This wording is almost identical to the domains of “total pain” in hospice philosophy, which, however, also include the spiritual dimension (see Section 1.3) (50). Furthermore, both approaches use similar vocabularies, such as person-centredness, family perspective, continuity of care, and comprehensiveness.

However, even if these concepts are expressed with the same vocabulary, they are not identical in content. Whereas the holistic approach of the GP concerns health problems in general, palliative care focuses specifically on suffering towards EOL. It is also worth noticing that continuity of care in general practice means over time and from a life-span perspective. In contrast, the disease trajectory delimits continuity in palliative care in time and space.

These differences are reflected in the clinical approaches of the two disciplines. As described in Section 1.2.1, the GP’s method relies heavily on the development of the doctor–patient relationship over time and a stepwise diagnostic approach comprising little technology. The approach is adapted to the population characteristics in general practice (see Section 1.2.2). In many instances, the GP may be the only healthcare professional a patient has been seeing for several years. Thus, the GP uses accumulated knowledge about the patient in the diagnostic process. The GP follows the patient over time, often knowing the patient as a person (15). According to McWhinney, this will enable experienced GPs to develop an “organismic mindset”, which involves multi-level non-linear thinking and recognition of the complex nature of human beings (10).

On the other hand, palliative care professionals see the patient over a much shorter period, delimited by a disease trajectory. In palliative care, the focus is on the interdisciplinary approach, combining the team efforts of multiple professionals. The “impeccable assessment”, with systematic mapping of every aspect of the patient’s challenges by detailed assessment tools, such as the ESAS-r, which can appear almost reductionist, is advocated in this discipline.

As already touched upon, palliative care is an integral part of general practice. At the same time, it is an area of medical expertise connected to extensive training. Studies have shown that the prestige of medical specialities and even diseases is informally ordered hierarchically in the medical community (175, 176). Specialised medical fields, especially those relying on sophisticated technology, are typically rated higher than generalist medicine (177). Working on the three papers revealed tension between the customs of the GPs and the field of specialised palliative care in our material. Thus, the hierarchy of medical specialities became an additional analytic perspective for this thesis.

3. The present study

3.1 Aims

The point of departure for this project was an assumption that the guideline for palliative care was not well implemented among GPs. More specifically, these concerns centred around whether GPs performed their role in palliative care in line with what the guideline specified and whether they possessed the specific skills required by the guideline.

The overall aim of this thesis was to develop new knowledge about the GP's role in palliative care and barriers to GPs' participation in palliative care, including barriers to the implementation of the guideline in general practice.

We conducted two studies to meet these aims, approaching the research questions quantitatively and qualitatively. Both studies explored to what degree GPs were familiar with the guideline for palliative care and adhered to it. As the guideline described the GP's responsibilities and the division of labour in palliative care, it could serve as a gold standard, i.e., a map, for comparison to what the GPs reported their reality to be, i.e., the terrain.

In the first study, we aimed to investigate a larger group of GPs to provide an overview and gain knowledge about their experiences with palliative care. The aim of Study 1 was:

1. To investigate GPs' adherence to the guideline, their experience with palliative care, and whether they reported having a central role in palliative care (Paper I).

In the second study, we qualitatively explored in greater depth GPs' real-life experiences with palliative care provision, how they defined their role in palliative care, and barriers to their involvement in this work. We also explored how these experiences compared to the guideline requirements for GPs. The more detailed aims of the two papers from this study were:

2. To explore GPs' experiences in palliative care regarding their involvement, the definition of their role, and their possible contribution to this work (Paper II).
3. To explore GPs' experiences in palliative care to gain insight into barriers to their involvement in palliative care and implementation of the guideline for palliative care in general practice (Paper III).

3.2 Methods and materials

Since this project aimed to gain both an overview and more profound knowledge of palliative care in general practice, combining quantitative and qualitative methods seemed appropriate.

A common way of combining quantitative and qualitative methods is first to explore the topic qualitatively to generate theories that can subsequently be tested quantitatively (160). As mentioned, this project, however, departed from assumptions based on experiences from practice. Therefore, it appeared most appropriate to test these assumptions quantitatively in the first study to see if they were more general and not just anecdotal. The emerging phenomena from the first study could then be explored qualitatively in the second study to gain further insights.

The two studies are presented separately below.

3.2.1 Study 1: The questionnaire study

Design

The first study aimed to provide an overview and achieve knowledge about a larger group of GPs' experiences in the field of palliative care, and a cross-sectional questionnaire survey was chosen. No pre-existing, appropriate, or validated questionnaire was available to suit the purpose of our study. Therefore, the questions in the questionnaire were created based on content from the guideline relevant to general practice, practical knowledge from the field, and previous research findings. Peer GPs and a specialist in palliative care were consulted during this process.

The questionnaire contained 17 topics. Most of the questions were related to the organisation of palliative care services, specific competence requirements for GPs, and the recommended collaboration procedures in palliative care. In addition, the survey sought information about the GPs' experience with palliative care and whether they agreed with the GP role outlined in the guideline. The topics were divided into six themes: background/demographic information, symptom assessment, symptom treatment, the GP's role, collaboration, and terminal care. Four questions had room for written comments in addition to checking boxes. The responses were either categorical, numerical or Likert-type items, i.e., on a three- or five-point scale ranging from "fully agree" to "strongly disagree".

The questionnaire contained Likert-type scales, i.e., combinations of several related questions (Likert-type items), for the following themes: the GPs' use of guideline-recommended procedures (as a proxy for adherence to the guideline), the regular GP's role in palliative care (how central they reported themselves to be in this work), and the GPs' confidence in the provision of palliative care.

A combination of Likert-type questions and categorical data explored the GPs' amount of experience in palliative and terminal care.

The questionnaire is supplied in Appendix 9.2.

Study sample

We wanted to survey a sample of GPs likely to be representative of Norwegian GPs in general. The GPs in the county of Møre og Romsdal were assessed as reasonably representative of a typical Norwegian county overall.

In 2014, the county had about 250 000 inhabitants and four hospitals. It consisted of both rural and urban areas. There were 248 GPs, 101 females (41%) and 147 males (59%). For the GPs up to 54 years, gender distribution was fairly even, but in the group of GPs 55 years or older, there were only 16 females (20%) and 62 males (80%). At the time, the age and gender of the GPs in the sample were similar to the distribution among GPs nationally. The total number of GPs in Norway was about 4500 at the time of this study, with 53% males and 47% females in the group up to 54 years, but 74% males in the age group over 55 years (178).

The names of all regular GPs in the county and their clinics' addresses were accessed through a national registry for GPs, which is freely accessible to all citizens (179). All except two GPs in the county were eligible for inclusion in the study. The two excluded GPs currently or recently worked part-time as palliative care physicians in hospitals and thus were not likely to be representative of GPs in general.

The sample size was determined from a published table and should ideally be about 150 participants (60% response rate) for a population of about 250 GPs to reach a 5% error precision level (180).

Data collection

The questionnaire was sent by post to 246 GPs in the county of Møre og Romsdal in 2014, addressed to each GP in person, and containing a pre-paid return envelope. No economic or other incentives to participate were given. An introductory letter explaining the research aims was enclosed (Appendix 9.1). The answers were anonymous. After one reminder, there were 142 respondents, i.e., a 57.7% response rate.

Analysis and interpretation

The PhD candidate transferred the questionnaire answers to IBM SPSS Statistics for Windows (Version 25.0. Armonk, NY: IBM Corp.). Analysis was descriptive, investigating quantitative distributions of frequencies, and bivariate correlations, also reported as frequencies. Considerations regarding inferential statistics on this material are discussed in Section 4.1.1.

Differences in answers between GPs were analysed considering the following participant characteristics: the size of the patient lists, travel time to the hospital (<30 min, 30-60 min, >1 hour), which of the four hospitals they were affiliated with, and whether the GP was also working as a nursing home physician. Nine respondents answered the questionnaire as a group. They had summed up the frequencies of their answers in a single questionnaire form, presumably as part of a CME or tutorial group session. This questionnaire form was excluded from the analysis of subgroup differences.

For the written comments in the questionnaire, a content analysis was performed. The written statements were used to support the interpretation of the quantitative findings, and direct quotes translated from Norwegian to English were included in the results section of Paper I.

3.2.2 Study 2: The qualitative focus group study

Design

In Study 2, we performed focus group interviews with GPs. A semi-structured interview guide was created based on findings from Study 1 and contents of the guideline for palliative care that were relevant to GPs.

The interview guide had two distinct parts. The first part of the interviews focused on the GPs' experiences with palliative care and how they defined their role in this work. In the second part of the interviews, the participants were presented with a paper copy of the guideline. Sections from the guideline that concerned the GP's role and competence requirements were read aloud by the interviewer and discussed in the groups. The interview guide is supplied in Appendix 9.4 of this thesis.

Study sample, setting, and data collection

We identified pre-established CME and tutorial groups with regular GPs of variable gender and age in Mid-Norway. Furthermore, we sought out groups from various areas affiliated with different hospitals, including the regional university hospital (St Olavs Hospital). We ensured that GPs from rural and urban environments were included. Sampling was thus both purposive and convenient, and the participants were likely to have varying opinions and diverse perspectives on the study subject.

The administrators of the groups were contacted personally by the PhD candidate by telephone or email and accepted on behalf of the groups. In this process, only one group declined to participate as they did not have the time.

Four groups were interviewed, with a total of 25 participants, 10 females and 15 males. Ages ranged from 29 to 67 years, with a median of 42 years. Most worked in GP clinics with other GPs, and two were solo practitioners. List sizes ranged from 540 to 1450, with a median of 1020 inhabitants per GP. Experience in general practice varied from 1 to 39 years, with a mean of 10.5 years. Eleven participants had their medical practice in an urban area, and the rest practised in a rural environment. Nine of the GPs also worked as municipal nursing home physicians, and twelve had other functions besides being GPs. The fourth group was a tutorial group under specialisation as GPs, with only the tutor being a specialist GP. In this group, the median age was 32, excluding the tutor. A summary of the demographic and professional data is given in Table 1.

Group/ setting	Gender	Age range/ mean	Mean list length	Specialist GPs	Experience as GPs range/ mean	Other previous or current occupational experience in the group
G1 URBAN	3 M 1 F	41-48/ 44 years	1300	4	9-15/ 12 years	Nursing home physician, academic/PhD, and school physician
G2 URBAN	3 M 2 F	45-67/ 53 years	850	3	7 – 39/ 20 years	School physician, nursing home physician, seafarers' doctor
G3 RURAL	4 M 3 F	33-61/ 44 years	1000	5	6-30/ 11 years	Children's health care physician, nursing home physician, local medical officer, supervisor of intern doctors
G4 RURAL AND URBAN	5 M 4 F	29-48/ 34 years	1000	1	1-15/ 4 years	Children's health care physician, nursing home physician, officer of public health and communicable diseases, seafarers' doctor

Table 1. Summary of focus groups' (G1-4) demographic and professional details. M= male, F = female

The first interview took place in February, and the last in June 2018. The groups themselves chose where they wanted to be interviewed. All participants gave informed, written consent before the interviews. There were no economic or other incentives for participation.

The PhD candidate moderated all the interviews, which were audio-recorded. In addition, an experienced qualitative researcher was present to support the moderator and observe and note non-verbal cues and other significant information during the interviews.

After the fourth interview, the total material was assessed as varied and well-suited for the study's aims, and data collection was terminated. Information power was considered sufficient to illuminate our research questions (181).

Analysis

The PhD candidate transcribed all the interviews verbatim. The recordings were uploaded into the NVivo software (QSR International, Melbourne, Australia), which was used for manual transcription and initial data handling.

In a focus group interview, the researcher interacts with the participants, and thus influencing the material is unavoidable. Due to this, the researcher's preconceptions need to be made explicit and continuously reflected upon during the whole course of the research process, including the analysis (161). Such reflections were made explicit through extensive field notes before, during, and after the interviews and by noting down insights from the point of the transcription process and throughout the analysis. Furthermore, discussions within the research group and with peers at venues where the research was presented were also written down. Reflexivity in the research process is described below (see 4.1.2).

Data analysis of Paper II: The method of analysis for the second paper was an approach inspired by IPA. As we, based on the quantitative study, expected variability considering the GPs' involvement in palliative care, we believed that the idiographic commitments of IPA suited our purposes. Smith et al. described this analysis method, which was initially intended for individual interviews (182). As we applied the method to focus groups, we followed the seven steps described by Smith. We added some adaptations in line with suggestions from other authors who have successfully analysed focus groups with an IPA approach (183, 184). The theoretical underpinnings of this method are phenomenology, hermeneutics and idiography, described in Chapter 2. The analysis proceeded according to the following steps (182):

1) Reading and re-reading the first interview

At this stage, we immersed ourselves in an active engagement with the data and gained an overview of the overall structure of the data.

2) Initial exploratory noting

This step consisted of comprehensive commenting and exploration of the semantic content, reflections on the language and attention to emotions displayed. The notes were descriptive but could also be interpretations, as this was a hermeneutic and reflective process. The PhD candidate used the NVIVO software in this process.

3) Development of emergent themes or “experiential statements”

At this stage, the transcript with the notes from Step 2 was further analysed, looking for the essential features of the initial notes. At this point, the emergent themes were directly related to the participants’ experiences and thus lay close to the transcript itself. The material was transferred to a Word document during this process.

4) Searching for connections across emergent themes

The emergent themes from Step 3 were now organised according to how they seemed to fit together and no longer in order of appearance. Next, we arranged the themes in a table, exploring connections and similarities. Finally, the themes were organised and integrated into a pattern that made sense.

5) Developing over-arching themes, the “experiential themes”

We now worked with the emergent themes and organised them into more abstracted, over-arching themes.

6) Analysing the other interviews

We analysed each interview in the same way as described in Steps 1-5

After completing Step 6 for all the interviews, we reviewed each participant’s contributions through the transcripts. We analysed them separately for Steps 1-6, treating them as individual cases within the material and allowing isolated voices to come through in the results. The idiographic framework for IPA support this. Not all participants contributed to the extent that allowed their accounts to be thus analysed.

7) Development of over-arching themes for the whole dataset

At this stage, the over-arching themes from all the interviews were compared, looking for similarities and differences and developing higher-order over-arching themes for the interviews taken together, deepening the interpretation.

Finally, the results were written as a narrative illustrated by direct quotes from the interviews translated from Norwegian to English.

Data analysis of Paper III: To analyse Paper III, we used reflexive thematic analysis, using the seven steps described by Braun and Clarke (185). Unlike IPA, this analysis method is not committed to a specific theoretical orientation. Instead, it provides guidelines for analysis that can be used within different ontological and epistemological orientations (185). Our orientation towards the data was inductive, i.e., deriving meanings from the data. We looked for semantic and latent content in the interviews (185).

The analysis consisted of the following steps (185):

1) Familiarising

This stage was very similar to Step 1 in the IPA method. Familiarisation started with the verbatim transcription of the interviews, and the transcripts were read several times. Ideas and interesting observations about the material were noted down in this early phase.

2) Coding

At this stage, codes were generated from the material. Codes consisted of interesting semantic or latent content that seemed significant. The generated codes were basic units of meaning close to the raw data of the transcripts. Each code received equal attention in this process to guard against anecdotal generation of themes. The initial coding was done in the NVIVO software.

3) Generating initial themes

The codes from Step 2 were now organised into potential themes. This was done by developing a table in a Word document, where codes were organised under preliminary themes and subthemes. It was a slow and gradual process, exploring several ways to organise codes.

4) Developing and reviewing themes

Step 4 involved revising the resultant themes generated in Step 3. Firstly, the themes were revised considering thematic overlap. Secondly, the entire interviews were re-read to examine whether the data supported the themes. Furthermore, re-reading the text with the generated themes in mind led to new insights about the data and the identification of additional codes. The table was now a thematic map for the analysis.

5) Defining and naming the themes

The specifics of the themes in the thematic maps were now refined, and the themes were thus more clearly defined and named.

6) Writing it up

When the themes were sufficiently processed, the analysis was completed through the final stage: writing the resulting report, supported by direct quotes from the interviews, translated into English.

3.2.3 Ethics

Approvals

Both studies were submitted to the Regional Committee for Medical and Health Research Ethics Central Norway (Regional komiteer for medisinsk og helsefaglig forskningsetikk Midtnorge). Study 1 did not require formal approval (2013/1732/REK midt). Study 2 was approved by the committee (2017/903/REK midt).

The project was registered with the Norwegian Social Science Data Services (Norsk samfunnsvitenskapelig datatjeneste), which had no further interests in this project (NSD 55031/3/AGL/LR).

Ethical considerations

Both studies were performed in agreement with the declaration of Helsinki.

Study 1: The questionnaire was anonymous and distributed with an introductory letter containing thorough information about the purpose of the study. By returning the questionnaire, the participants consented.

Study 2: All participants in the focus groups were personally informed about the study at the start of the interviews and were given a written invitation letter. They all gave written consent before the interviews, and data were anonymised while transcribing the interviews. In addition, all participants were informed of their right to withdraw from the study at any point.

We restricted the focus group study to Mid-Norway and recruited groups from two counties. Due to this, the age of participants was given as intervals, and list lengths were rounded in the results sections so as not to expose individual GPs.

3.3 Summary of Results

3.3.1 Synopsis of Papers I – III

Paper I

Palliative care in general practice; a questionnaire study on the GPs role and guideline implementation in Norway

Fasting A, Hetlevik I, Mjølstad BP: *BMC Family Practice* 2021;22(1):64.

The first paper investigated GPs' adherence to the guideline for palliative care, their experience in this field, and how they saw their role in palliative care. This part of the project was a cross-sectional questionnaire study focusing on the key concepts, recommendations, and requirements for GPs found in the guideline. The number of palliative patients each GP had, the frequency of participation in home death, and whether they saw themselves as central actors in this work were essential questions. We also investigated the GPs' use and knowledge of the recommended working methods and specific skills they were expected to have. Answers were analysed descriptively.

Results

We distributed the questionnaire to 246 GPs. One hundred forty-two responded, achieving a 57.7% response rate. Although more than half of the GPs reported feeling secure when providing palliative care and perceived themselves as central in this work, each GP had few patients needing palliative care at any given time, and participation in terminal care was infrequent. Therefore, it was difficult to maintain specific skills and knowledge requirements as specified in the guideline. GPs from urban environments felt central to a lesser degree than their rural colleagues. We also found that the GPs did not use the working methods and assessment tools recommended in the guideline. Few GPs had participated in joint meetings across care levels.

Conclusion

Our findings indicate that the GPs did not adhere to the Norwegian guideline for palliative care. Over time, the limited number of palliative patients each GP saw challenged the sustainability of learning and maintaining complex skills and knowledge. The working methods advocated in the guideline may not match those of the GPs.

Paper II

Finding their place – general practitioners' experiences with palliative care – a Norwegian qualitative study

Fasting A, Hetlevik I, Mjølstad BP: *BMC Palliative Care* 2022;21(1):126

Study 2 was a focus group study intended to elaborate on the findings from the questionnaire study. Paper II investigated GPs' role in palliative care. The interview guide had two parts, and the data for this paper were drawn from the first part. The focus of this paper was the GPs' involvement, how they defined their role, and what they thought they realistically could contribute to palliative care. The focus was eliciting accounts of the GPs' real-life experiences working with palliative patients and descriptions of how they engaged in this work. Analysis of the four focus group interviews with GPs was inspired by IPA.

Results

We found that the GPs highlighted several general practice characteristics that could enable them to provide proper care for palliative patients, such as general medical knowledge, being the coordinator of care, and the family perspective of general practice. The GPs underscored how their personal and longitudinal knowledge of the patient and family was essential in this work. Despite having general positive attitudes towards palliative care, the GP participants in our study did not have a common understanding of their role in palliative care. Based on the GPs' accounts of their experiences, three different positions could be defined, as the GPs tended to be either highly involved, weakly involved, or uninvolved in palliative care. Rural GPs appeared to be more actively involved in palliative care than urban GPs.

Conclusion

Our findings indicate that GPs have strengths to contribute to palliative care. However, they need to rely on their general medical knowledge and thus need the support of specialists whose skills complement those of the GPs. Multiple factors interact in complex ways to determine how GPs see their role and how involved they are. GPs may lose their skills in palliative care if they are not included in this work.

Paper III

Put on the sidelines of palliative care: A qualitative study of important barriers to GPs' participation in palliative care and guideline implementation in Norway

Fasting A, Hetlevik I, Mjølstad BP: Submitted to: *BMC Primary Care*, June 2023

In Paper III, we investigated barriers to GPs' participation in palliative care and to the implementation of the guideline for palliative care in general practice. The paper was based on data from Study 2, namely the focus group interviews, and this time we analysed the data focusing on both the GPs' real-life experiences within palliative care and their experience with and views of the guideline. We performed reflexive thematic analysis.

Results

There seemed to be different local cultures of collaboration between primary care and specialised palliative care. Some GPs who perceived themselves as uninvolved in palliative care thought they were not expected to be involved. The PCTs and ONs sometimes handled the patients without involving the GP. Referral to the hospital often led to discontinuity of the GP-patient relationship creating a threshold for the GP to get involved. Some GPs reconnected or maintained the GP-patient relationship, by being proactive. Unclear clinical handover and missing prognostic information from the hospital were barriers. The GPs lacked knowledge about the guideline, and those who perceived themselves as not having a role in palliative care did not see it as applicable in their daily practice. We found a mismatch between the guideline and everyday general practice. The GPs called for the involvement of representatives of their discipline when guidelines involving GPs are developed.

Conclusion

We found structural barriers to guideline implementation that need consideration when guidelines involving GPs are made. Specialised nursing roles in primary care need to be managed and integrated into the existing healthcare structure. The guideline suggests measures for enhanced collaboration which fit well with general practice. Furthermore, sustaining the GP-patient relationship throughout serious illness could lead to increased involvement of GPs in palliative care.

3.3.2 Key findings

The GPs’ contribution to providing palliative care rests on the medical knowledge of their speciality. General practice offers continuity of care. GPs have generalist knowledge in many fields, are skilled at care coordination and possess unique knowledge about patients and their families, all of which may contribute to the care of their palliative patients.

However, due to having few palliative patients at any one time, the GPs cannot maintain skills and knowledge that are too specialised. Thus, we have shown a mismatch between the Norwegian guideline for palliative care and the reality of general practice; the guideline requirements were too advanced for GPs, and the working methods and tools recommended in the guideline did not fit the GPs’ preferred clinical approach.

Furthermore, we found that the extent to which GPs were involved in palliative care varied, which in turn was mirrored in descriptions of different cultures for how the palliative service was organised. Thus, the GPs’ understanding of their role in palliative care was influenced by a complex interaction between individual barriers to participation and structural obstacles connected to the collaboration between the GP, ON and PCT.

An overall finding was that the guideline for palliative care was not well implemented among GPs. Individual and structural factors hampered implementation. Most significantly, the guideline did not seem to fulfil the GPs’ needs for easily accessible advice, and the requirements did not fit with practice.

4. Discussion of design, methods, and ethics

4.1 Discussion of methods

This thesis comprises three papers based on one quantitative and one qualitative study. By mixing methods, we got information about a larger sample of GPs in the first study, whereas we could explore the phenomena more deeply in the second study. In qualitative research, methodological triangulation is a recommended strategy for validation (156, 161). The mixed method design is an overall strength of this project, as we could use different sources to investigate different aspects of the same phenomena. Furthermore, the interpretation was enriched by using various analytic tools and perspectives. Additional triangulation could have been obtained by exploring, for instance, the views of ONs, PCT professionals, or even patients.

The following will reflect on the methodological choices and discuss the strengths and weaknesses of the two studies separately.

4.1.1 Discussion of Study 1: The questionnaire study

Reflections on design, study sample and data collection

To investigate the aim of Study 1, we chose a cross-sectional study conducted as a questionnaire survey. The strength of this type of study is that it is a method recognised as effective in reaching out to a larger sample (186). Low response rates are a common challenge with surveys, and GPs are known for having low participation rates in such studies (187). Against that backdrop, our response rate was acceptable for making the needed inferences, which is a strength of this study.

As previously mentioned, the research group created the questionnaire, as no validated questionnaire was suitable for our purpose (see Section 3.2.1). There were few studies to lean on to assess the internal validity of our questionnaire (156). To increase our confidence that the questionnaire addressed our research questions, we consulted both peer GPs and a specialist in palliative care. Based on this, we have reason to think that the questionnaire was suitable for the study, which addresses the issue of internal validity (156, 186).

A strength of the study is that the survey was distributed to all eligible GPs (N = 246) in a geographical area comparable to other parts of Norway, which we thought would increase external validity (156). The sample size was determined from a published table and should ideally be just short of 150 GPs to arrive at a 5% precision level (180). Our result of 142 was close to this target. For the total population of Norwegian GPs, which at the time was 4500, the sample was large enough to reach a precision level between 7-10%. As the county did not include a larger city with a university hospital, we do not know how including GPs from such a setting would have influenced our results. Thus, generalisations must be made with caution. However, we believe that it was safe to assume that our findings were sufficiently valid and transferable in the context of Norwegian general practice, and that we could proceed with the data to Study 2.

A self-completed questionnaire survey opens opportunities for biases, and the participants may have exaggerated answers they believed were socially desirable (138). The participating GPs could have customised their responses according to what they thought to be the expected professional standard. However, the survey captured a variety of answers from different participants, indicating honesty and increasing the results' validity.

The GPs' experiences were likely influenced by how the PCT team at their local hospital collaborated with primary care. Therefore, getting participants affiliated with four different PCTs strengthens the validity of the results, as the customs of one single PCT team were not likely to dominate and bias the overall results.

When we created the survey in 2013, we were worried that some participants would refrain from participating due to fear of being identified due to the many participant characteristics we planned to gather. This was a particular concern regarding the oldest and youngest GPs in the region due to small numbers (see Section 3.2.1). As gender and age did not seem relevant to our research questions, we omitted these characteristics from the survey. In retrospect, we see that specification of age and gender distribution in the sample could ease the assessment of the representativity of the sample. On the other hand, it may have contributed to the high response rate, representing an essential strength of the study.

We believed that assurances of preserved anonymity in answering the questionnaire were essential to allow the GPs to express themselves freely, which we regard as a strength of this design. The reminder resulted in an additional 32 forms returned. As we did not know who had answered, there was a risk of GPs answering the survey two times. It could have been wise to distribute this questionnaire differently. However, the reminder was sent shortly after the first invitation, and it is unlikely that many GPs took the time to complete the form more than once.

We did not, however, distribute a second or third reminder, which is recommended and could have increased response rates and reduced non-responder bias (186). Non-responder follow-up was not performed and could have supplied valuable information and increased external validity (156).

The questionnaire was distributed in a paper form addressed personally to each GP in the county. In this way, we could reach all the GPs with our invitation and avoid concerns of self-selection to a more generally distributed survey, and this is a strength speaking to the validity and transferability of the results.

Reflections on analysis of Paper I

The frequencies of answers and tendencies within the material were analysed in this study. In addition, we also reported the frequencies of differences between subgroups.

Even statistical interpretation must consider the kind of phenomena being explored. We were investigating GPs' participation in palliative care to increase the understanding of this aspect of the discipline in the immediate and foreseeable future. The assumption that the social reality investigated was an external, objective reality could be challenged (160). Due to the purpose of the study and the nature of the material collected, inferential statistical tests had restricted value, and we found it more transparent to report the results as frequencies.

Some inferential statistical procedures were performed but not reported in the results section of Paper I. A Cronbach's analysis indicated adequate inter-item reliability for the combined Likert-type items. Significance levels were explored with the chi-square statistic and the Mann-Whitney U-test, both showing similar significance levels. Surveys of this kind are straightforward to analyse statistically, but this involves transforming qualitative statements into numeric variables, which is not unproblematic (188, 189). However, associations that did not meet a high confidence level ($p<0.05$) were not included in the results section of Paper I, strengthening the validity of the findings.

Only a few of the GPs took the opportunity to write comments. Although this could introduce a bias, we included some examples of translated quotes in Paper I to illustrate the variety of expressed opinions and to substantiate the findings. The written comments were also inspirational when we made the interview guide for the second study.

4.1.2 Discussion of Study 2: The focus group study

Reflections on design and study sample and data collection

A qualitative method was appropriate for Study 2 (Papers II and III). Whereas individual interviews were considered and could have been a suitable design option, focus group interviews are considered a fast and convenient method to gain access to several participants simultaneously. Group interaction is also shown to stimulate good discussions and may thus enrich the perspectives captured in the interviews (161, 190).

We recruited a sample of GPs of different ages, genders, experiences, and distances to hospitals. The groups were within the usual size of focus groups (5-8) (190). We chose to use pre-existing groups where the participants already knew each other, contributing to a safe discussion climate in the groups where conflicts of opinion also occurred (190). The semi-structured interview guide worked well and provided the flexibility to explore such issues and alter the order of topics during the interviews, allowing for more in-depth knowledge to be obtained, which was a strength of this design. Furthermore, topics we had not considered could surface in this setting, thus adding broader perspectives to the discussions.

Recruiting existing groups had other clear benefits. Recruiting GPs in research is acknowledged to be difficult, and GPs who are interested in the topic are more likely to participate (103, 191). Including pre-existing groups probably reduced the probability of self-selection of GPs with a particular interest in the subject. Furthermore, we saved time since we did not spend it establishing a group culture, and shyness did not appear to be a problem, both of which can be issues in focus groups with unacquainted participants (192).

However, focus group interviews also have some limitations. During such interviews, participants disclose information about themselves and their thoughts and can be apprehensive of being evaluated and susceptible to normative influences. Participants may answer in ways they believe are expected from them or exaggerate attitudes they think are socially desirable (138, 192). As these were pre-existing groups, concerns about how the participants wanted to be seen by their colleagues could arise. There may also have been pre-existing social ties in the groups that we were unaware of, which could influence who took part in the dialogue and how. These issues were of particular concern in the fourth interview, as the group tutor participated in the focus group. However, we took steps in all the interviews to encourage all the participants to express themselves, and our impression was that all the participants felt free to speak.

The role of the moderator was another concern, as I could be considered both a peer GP and a hospital “specialist” of palliative care. The latter could elicit feelings of inferiority (175, 193). This could favour the expression of answers “pleasing the expert”, and to mitigate this, we used the questionnaire findings consciously to normalise and encourage different perspectives to surface.

Bringing an experienced qualitative researcher to the interviews was of great value in the data collection process, providing helpful input during and after the interviews. Furthermore, they provided extensive notes that helped with transcription.

Reflections on analysis of Paper II

The method of analysis used for Paper II was inspired by IPA, a methodology closely connected to its philosophical and theoretical commitments and compatible with the study design and aims. The method is well recognised and described, adding to the transparency and transferability of results, which we believe is a strength. However, this method is most often used to analyse small samples of individual interviews of relatively homogeneous participants to deeply explore the phenomena of interest. When used in focus groups, restricting the number of participants is recommended (162). As these were pre-existing groups, we included all members, which may have limited the depth of the analysis. However, the sample size was small, and the groups’ participants were reasonably homogeneous, consisting of physicians all working as GPs. We considered the material as suited for this method of analysis.

The focus group interview is a context where the researcher and participants interact, and multiple possible influences come into play, as previously described. Furthermore, the idiographic commitments of the IPA method are challenged in this setting (162, 183, 184). However, other researchers have successfully applied this method to focus groups, and we followed some key suggestions for adaptation (183).

Furthermore, honouring the idiographic perspective, we could pursue the individual voices within the interviews, which broadened and strengthened the findings (183). In my view, going back and forth between the group and the personal level in this way added to the depth of the analysis. My overall impression is that our IPA approach was well suited to analyse this material.

Reflections on analysis of Paper III

To analyse Paper III, we used reflexive thematic analysis as described by Braun and Clarke (185). As I have accounted for in Section 2.1.2, phenomenology provided the over-arching epistemological framework for exploring subjective experiences in the search for knowledge, underpinning the qualitative part of the project (161).

However, according to Braun and Clarke, the researcher has many options for approaching the analysis methodologically. Firstly, we assumed an *inductive* orientation to the data – we wanted to start with the GPs' experiential accounts to acquire new knowledge. Secondly, we needed to explore the discussions at the semantic level, i.e., the words that were actually said, and look at the *latent* content, i.e., the factors the participants took for granted and did not specifically address (194).

Applying two different qualitative analysis methods to the same material was a strength in Study 2, as there was a significant difference in the structure of the materials for Papers II and III:

Paper II was based on the first part of the focus group interviews, centred around the GPs' experiences and role when working with palliative care, collectively and individually.

In Paper III, we analysed the entire data material from the focus groups. We saw no need to examine the individual accounts to the same degree as in Paper II, as we were after more general experiences that could constitute barriers. A method consisting of more straightforward steps seemed more appropriate for this analysis, and we chose to use the method described by Braun and Clarke (185).

In retrospect, approaching the material a second time with a new analysis method and different aims was beneficial. The second analysis provided new insights into broader perspectives that could have been lost if we had derived the two papers from one initial analysis.

Reflexivity in the research process and the researcher's role

In qualitative research, reflexivity is an activity that should permeate the research process from beginning to end (161). It involves a consciousness of the researcher's thoughts, assumptions, and values, reflection on the methodological choices and the context within which the research is conducted (194). Active reflection aids the researcher in addressing not *whether*, but *how* these factors have influenced the research.

Firstly, we need to address the context of the research group. All three were physicians with experience as GPs. The two supervisors were experienced researchers, and one had extensively researched guideline implementation problems in general practice. Furthermore, the main supervisor had broad experience with qualitative methods. When we started Study 2, I had worked as a palliative care physician in the hospital for two years. Thus, the accumulated knowledge of the research group facilitated the study's design and conduction.

At the same time, this meant that some unspoken perspectives, which the researchers took for granted, could seep into the research and colour our interpretations (194).

In focus group interviews, the researchers engage actively in the process, thus influencing the material and "co-creating" the participants' meaning-making (184). The researcher is in danger of favouring findings that agree with expectations and preconceptions (156). Furthermore, in researching colleagues, we acknowledged the threat of losing academic distance (195). Therefore, these situated perspectives needed to be made explicit and reflected upon.

The interview guide was created with careful attention to the structure of the text to avoid wording that could lead the participants towards particular answers. Thus, it was semi-structured with open-ended questions, and the question order was flexible. In my view, the findings from the quantitative study added a broader perspective and helped balance the content of the interview guide.

The preconceptions inevitably influence how the researcher makes sense of the participants' experiences. Thus, we needed to question our understanding of the participants' accounts while interviewing, during transcription, and throughout the analysis. This meant constantly asking ourselves whether alternative interpretations could fit equally or better.

In the interview setting, the participants were asked questions to confirm or correct my interpretation of what they said when needed. The extensive field notes provided helpful information about non-verbal cues in the transcription process. I also kept a trail of extensive reflexive notes throughout the study, making thoughts explicit and available to be revisited and adjusted as the work progressed. Although it was initially an unfamiliar practice for me as a novice qualitative researcher, I believe that systematic reflection through extensive notes was a strength in this study. This process provided depth to the analyses.

Validity, trustworthiness, transparency, and transferability

In quantitative research, quality is assessed in terms of validity; internal validity concerns whether the data support the conclusions, and external validity concerns whether the results are generalisable beyond the project's specific context (156, 186). In qualitative research, these questions are more about assessing what the study can be "true" about and in which conditions the findings can apply (161).

An important issue in qualitative studies is how to assess the quality of the research (161, 196). Different frameworks, such as the checklist developed by Tong et al., have been developed (197). Qualitative approaches are, however, many and varied, and establishing standard quality criteria is complicated (198). We found the concept of trustworthiness to be helpful guidance and took steps accordingly to ensure quality in this study (196):

The *credibility* of the results concerns whether the researcher presents the participants' contributions in a way that fits with what they said. The audience for the research must be able to trust the interpreted data. Author IH read and did the initial analysis of the interviews independently of the other two authors and could check whether our analyses corroborated with her general impression of the material. In addition, we discussed the preliminary results in different forums of peers, which added to the credibility of our results. As previously mentioned, IPA rests on a firm theoretical framework. Furthermore, both IPA and rTA are well-recognised methods with clearly described steps, which enables the reader to understand how we arrived at our results. The audit trail and extensive reflexive activity throughout the research process added to the *dependability* and *confirmability* of findings (182). We also accounted in detail for the research setting and context and provided the reader with direct, translated quotes, aiming for high *transparency* of the results. This, together with the extensive and transparent reflexive activity, increased the *transferability* of the results (196).

According to Braun and Clarke, another helpful framework we used throughout the analysis of Paper III was the ten common problems in TA research (198).

4.2 Discussion of ethics

Study 1, the questionnaire study, was rated by the regional committee for medical and health research ethics central Norway (REK) not to be mandatory for presentation (2013/1732 / REK). Study 2 was approved by REK Central Norway (2017/903 / REK Midt Norge). The project was reported to the Norwegian social science data service (Norsk samfunnsvitenskapelig datatjeneste) (NSD 55031/3/AGL/LR). They had no conditions, as it was an anonymous survey.

Consent

The GPs participated freely, and all focus group participants gave written consent and were informed of their right to withdraw their consent. Written information about the purpose of the studies was provided in both studies.

Confidentiality and anonymity

The questionnaire study was anonymous, and no information gathered could identify individual participants directly or indirectly. Data on demographics and professional variables were collected in the focus group interviews. A coded list coupled these variables to the individual GPs, who were anonymised in the transcripts, and this list and the transcripts were kept at different locations to ensure that third parties could not identify participants. We deleted the audio files after transcription. We retained the transcripts on a safe server only accessible to the research group. In the results sections of Papers II and III, we did our best not to include data that would identify individual participants. In retrospect, we could have been more restrictive with these details in Paper II. The data will be kept on the safe server for some time after the publication of the last paper and subsequently deleted.

Risk of harm

Although social pressures could come into play in the focus groups, especially as these were pre-formed groups, this research involved little risk for the individual participants. The participants were informed of the possibility of withdrawing from the study.

Whereas participation had a low risk of being harmful to the participants, this kind of research needs to be proportional to the time expenditure, and the participants must expect that the information is used according to the described purpose and that their views are somehow represented in the findings.

The participating GPs did not benefit from the research directly. However, GPs, in general, could benefit from the acquired knowledge resulting from the research.

5. Discussion of results

The starting point for this project was to explore the GP's role in palliative care in light of the guideline for palliative care. Our findings demonstrated a guideline–practice gap. The guideline was poorly implemented, and its competence requirements seemed unfit for general practice. The GPs had no common understanding of their role in palliative care, and involvement was variable, reflected in different cultures of service organisations. However, the GPs had evident strengths that could contribute to palliative care.

In the following chapter, I will discuss the key findings of this project and consider updated literature and developments.

Firstly, I will discuss further the mismatch between general practice and guideline recommendations. This will include a discussion about the GPs' generalist competence considering the specific demands of the guideline.

Secondly, the mismatch between the map and terrain we have demonstrated also concerns the GPs' variable involvement in palliative care and the different established cultures for organising the service. The discussion below will explore the GPs' involvement and competencies, i.e., their strengths, considering the concept of shared care and the division of tasks in palliative care.

Thirdly, the findings will be put in relation to recent developments in palliative care in Norway and the global primary care crisis. This prepares the ground for a discussion of palliative care service provision considering the core principles and future challenges of the Norwegian healthcare service.

To conclude the discussion, I will revisit the issue of guideline implementation, considering our overall results.

5.1 The GP's generalist approach to palliative care

General practice is a medical speciality resting on a set of characteristics and core competencies of a generalist nature (Figure 1) (3). In the following, I will further discuss some guideline items that did not seem to agree with the clinical reality as perceived by the GPs. More specifically, I will discuss the appropriateness of the specified competence level B, considering the generalist competencies of the GP and the clinical approach in general practice.

5.1.1 The generalist competence versus the specialised requirements

About half of the GPs in the questionnaire study agreed that they felt secure in providing palliative care. This contrasts with several studies documenting that GPs lack confidence in some of the skills believed to be necessary for their palliative care provision, such as medical treatment towards EOL and administering subcutaneous medication (199-202). A Danish study revealed that most GPs were somewhat confident about being responsible for palliative care provision. However, they were confident in providing aspects such as psychosocial care (200). This essential component of palliative care provision was also one of the strengths of the GPs we found in the second study. Thus, in line with our findings, GPs are probably most confident in tasks for which they can lean on their everyday skills as generalists.

On the other hand, we found that specific skills were challenging to maintain, which also aligns with other studies (203). Furthermore, confidence, skills, and knowledge in providing palliative care increase with the increasing age and experience of the GP (200-202, 204). As accounted for in the background section, lifelong learning in the workplace through interaction with other professionals is vital to increase GPs' competence in palliative care (see Section 1.4.3).

However, it is reasonable to assume that some skills and knowledge may be essential and should constitute a minimum level of knowledge all GPs must master, irrespective of experience. According to the guideline and the latest official Norwegian report on palliative care, educational interventions are recommended to ensure sufficient competence among professionals (2, 205). Competence level B, defined in the guideline to apply to all physicians who treat cancer patients, could provide the necessary learning objectives for GPs (see Figure 7) (2). Thus, considering our findings, discussing the appropriateness of this competence level is relevant.

As the GPs had few palliative patients, they rarely encountered complex procedures connected to palliative care. Although we have no information about the frequency of syringe driver use among home-residing palliative patients, this is likely to be even less frequent for GPs to handle than home death, which was rare (Paper I). Most such treatment is likely initiated in nursing homes or hospitals or ambulatory by PCTs. Although some experienced GPs in our material could master it, our findings suggest that this guideline requirement is difficult for the average GP to acquire and maintain.

Thus, educational measures may need to be mandatory for GPs to ensure equity of service provision. However, if all of Norway's approximately 5000 GPs were to take even a one-day course at a set interval to sustain their skills required in this single guideline, this would equal a considerable expenditure of clinician time. It will impact workforce capacity and healthcare economy. These effects are accentuated by the GPs having many guidelines to follow. Furthermore, many stakeholders want to educate GPs in different specialised medical fields or direct their attention towards specific patient groups (151, 206-208).

As highlighted in Paper III, the GPs found the competence requirements that applied to them unrealistic and inappropriate for general practice. This aligns with views also presented in background Section 1.4.3, that the GP should handle the more common problems in palliative care while relying on specialist support for the more complex aspects of care, which also finds support in more recent publications (107, 202, 209). In a study from 2019, GPs connected best practices towards EOL to experience and communication skills rather than specialised medical knowledge (209). Considering our results, it is reasonable to question whether competence level B (Figure 7) is appropriate as a minimum requirement for GPs.

5.1.2 Similar values but different clinical approaches

The working methods of the GP are adapted to the special condition of working with an unselected patient population, handling most of the population's healthcare contacts (see Section 1.2.2). I will discuss a key finding in this project worth acknowledging: the apparent conflict between the clinical approach in general practice and specific methods the GPs must use according to the guideline. This topic was central in Papers I and III.

According to the guideline, GPs should "know and be able to use" symptom assessment tools in palliative care. The ESAS-r is explicitly mentioned and described as a "common" tool for symptom assessment (see Figure 7) (2). This PROM is also included in most Norwegian hospitals' referral criteria for specialised palliative care (2). PROMs for systematic assessment of the relatives' needs are also strongly advocated in palliative care (205).

However, we found that using the ESAS-r was *uncommon* in general practice in both studies (Papers I and III). Furthermore, the GPs were reluctant to use this tool. It is thus reasonable to discuss the use of PROMs specific to palliative care in general practice.

Firstly, although the ESAS-r is easy to use, misinterpretation of its items occurs. Thus, using this tool may require knowledge and training of health personnel (210-212). This must be seen in relation to the relatively few palliative patients GPs have, as pointed out in Paper I. Secondly, most seriously ill patients in primary care do not have cancer, but die from other causes (see Section 1.3.3). There are few validation studies of the ESAS-r for non-cancer populations (213). While working on this thesis, I have not found other studies exploring the use of the ESAS-r among GPs. According to McWhinney, transferring a technique from a specific clinical context to the context of general practice may not be straightforward (214). Thus, it is worth questioning whether GPs may have good reasons not to adhere to recommendations to use the ESAS-r.

Our findings align with concerns detected in research on PROMs in general practice (215-219). According to a recent survey, 186 different PROMs were in use in UK general practice, most of which were related to common health complaints in general practice. Identifying and selecting appropriate PROMs were challenging (216). However, some PROMs, e.g., the Montgomery-Aasberg depression rating scale, are widely used in general practice. However, from the patient's perspective, although the tool helps increase understanding of the condition, what is most important is still that the GP listens and understands (220).

GPs may also experience PROMs as intrusions into the consultation, foreign elements that hamper dialogue and have little clinical value for the GP (215, 217). In contrast, relying on the patient-centred method of general practice, GPs may depend on more nonlinear approaches (see Section 2.2.2. and Paper I). For instance, it has been shown that GPs' "gut feeling" is a common reason for referral to secondary investigation and has predictive diagnostic value. Such judgements are typically based on verbal and non-verbal cues and contextual knowledge (221, 222). GPs may suspect cancer diagnosis by combining intuitive, tacit knowledge and clinical suspicion (223). Likewise, GPs work intuitively with the existential dimensions of serious illness (224).

On the other hand, GPs frequently miss significant symptoms in palliative patients, and the use of structured assessment of the needs of cancer patients improves patient care in general practice (93, 225). When asked open-ended questions, patients do not always volunteer all relevant information about symptoms (226). Furthermore, cultural barriers may prevent GPs from addressing their patients' existential and spiritual needs (224). Thus, evidence suggests that the GPs must somehow be prompted to systematically investigate a more comprehensive array of symptoms than they do today.

A final point is that evidence suggests that PROMs in general practice need integration with the clinical systems and that implementation should proceed bottom-up in accordance with the GPs' perceived needs (216).

5.2 Shared care – a teamwork perspective on the GP's contribution to palliative care

The shared care model for palliative care in Norway was described in the background sections and illustrated in Figure 8. In this Section, I will discuss the importance of acknowledging the strengths of each profession in the interprofessional teamwork approach in palliative care. From this perspective, I will further explore the central findings of GPs' variable involvement in palliative care and the different cultures of the service organisation. In Paper III, we related this to ambiguities in the guideline. I will demonstrate how the distinction between primary and specialised palliative care largely depends on the clinicians' evaluations of task complexity (see Section 1.3.1). Thus, the findings will finally be discussed in the context of this subjective nature of task division in palliative care.

5.2.1 Teamwork and the GP's unique contribution to palliative care

This thesis has demonstrated a tension between GPs' generalist perspectives on palliative care provision and the specialised demands in the guideline for palliative care. Furthermore, some differences in philosophy and terminology between these two medical fields were highlighted previously. Such conceptual differences between professions will likely challenge interprofessional collaboration and shared care (227).

As discussed in Paper II, the GPs possess special competencies that could enable them to provide palliative care to many patients. As previously accounted for, GP participation in palliative care may improve patient outcomes, including increasing the possibility of home death. In Paper II, we discussed the uniqueness of the GPs' contribution and how more recent literature supported that GP continuity of care was essential in the OOH emergency setting to avoid unnecessary hospital admissions (see Paper II for this discussion).

Whereas palliative care physicians can be expected to have much more extensive and specialised knowledge in palliative care, our findings, however, indicate that the GP provides unique qualities to the care of their palliative patients. Accumulated knowledge supports this view (98, 228, 229). GPs' capabilities complement those of the other professionals working with palliative care (230).

A prerequisite for interdisciplinary collaboration in palliative care is that the different clinicians are aware of the potential contributions of the other professionals, i.e., that they have a clear view of their role in relation to the expertise of their professional partners (73, 227).

Figure 9 is a model conceptualising the complementary competencies of the GP, ON, and PCT based on the findings of this thesis and the guideline.

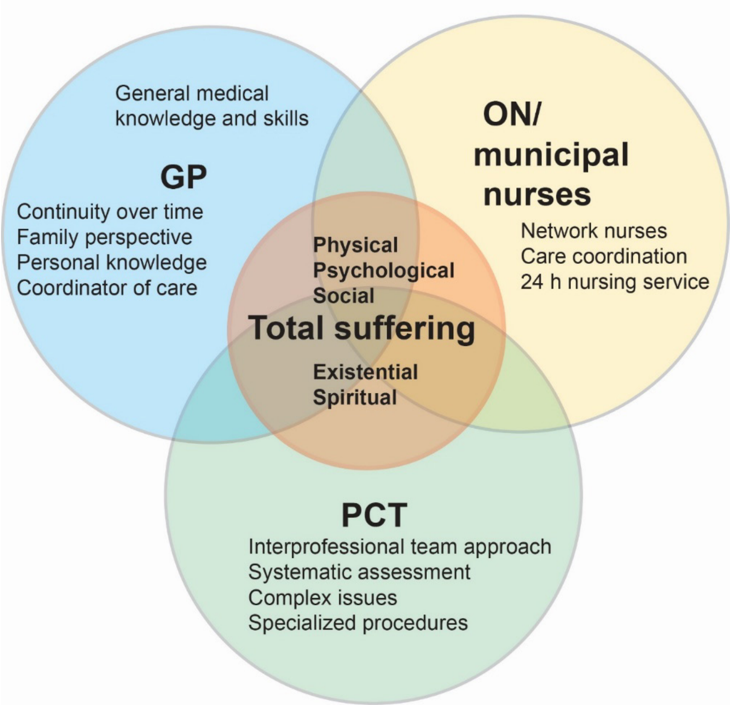

Figure 9. A model for the unique and overlapping competencies of the GP, ON, and PCT in the care of home-residing palliative patients.

5.2.2 The subjective nature of task division in palliative care

A clear division of tasks is also essential for optimal shared care (73). A central finding in this project was that the division of the tasks and professional roles in palliative care was unclear, associated with uncertainties and variable practices (Papers II and III). This aligns with the findings of Wyatt et al., who concluded that roles needed clarifying in palliative care (202).

Primary and specialised palliative care definitions sometimes refer to whether or not specialists in palliative care provide the service (see Section 1.3.1). Quill et al. described primary palliative care as "basic" care of symptoms and assessment of needs. In contrast, specialised palliative care should manage refractory symptoms and management of "more complex" problems (48).

Thus, defining whether a patient needs primary or specialised palliative care has a subjective nature. This is reflected in the guideline for palliative care. For instance, being responsible for treatment with subcutaneous administration of medicines by way of a syringe driver is listed as a basic level B skill but also as an advanced procedure available at palliative centres (2). This illustrates how the GP and PCT physician may have some overlap in knowledge and abilities.

As previously mentioned, lifelong learning through experience is how GPs primarily expand on their knowledge in palliative care. Thus, more experienced GPs' capabilities may overlap with the PCT physicians to a larger extent than their less experienced colleagues (see also Figure 9). Although the GP and the PCT physician each bring distinctive qualities to the patient's care, they could work interchangeably within the overlapping competencies. This aligns with the unclear role of general practice at EOL (202). Consequently, only the individual GP can know exactly which specific clinical problems exceed their capabilities.

Thus, without a clear-cut boundary between primary and specialised palliative care tasks, the division of labour seems to be left at the healthcare workers' discretion, as discussed in Paper III. Usually, it should be the GPs' call to refer patients to secondary care due to their gatekeeping role (see Figure 5).

One central finding was that the ONs and PCTs in some places seemed to be handling palliative patients in primary care without the involvement of the GPs. This model for service delivery is illustrated in Figure 10, a modified version of Figure 8.

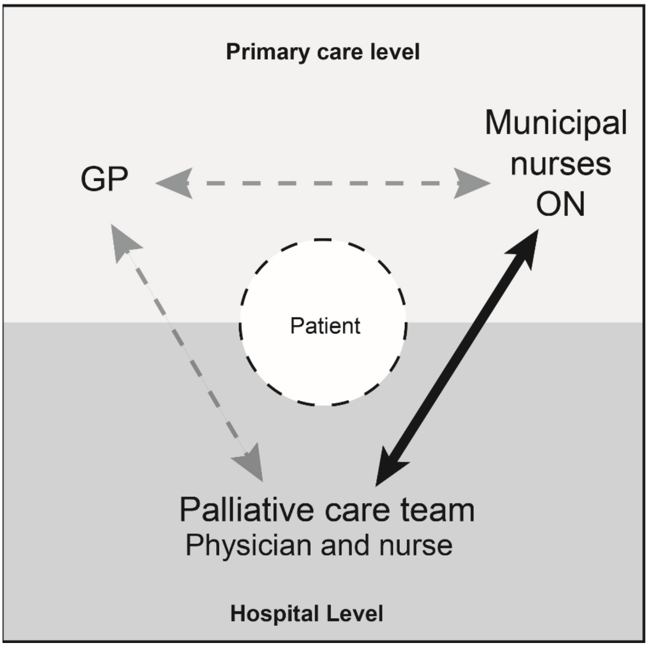

Figure 10. Collaboration in palliative care:
The GP is on the sidelines.

The issues above could indicate that some GPs are unaware of their role in palliative care, i.e., there are individual barriers to their participation. In contrast, it could also mean that the GPs' strengths in palliative care provision and their gatekeeper function are either not recognised or ignored by the other partners in the collaboration. The latter is supported by previous research demonstrating a lack of awareness of working culture and mutual respect between professional partners in palliative care teamwork (73, 227). A third interpretation, discussed in Papers I and II, is that there could be variations in specialist service provision, supported by our findings of differences between rural and urban areas. As pointed out, this challenges the equity principle, as specialist palliative services are a restricted resource that may be underused in rural areas (see Paper II).

5.3 Providing palliative care in a healthcare system under pressure

Our findings indicate that many GPs cannot fulfil the requirements and that the palliative care service delivery model may not be consistent with the guideline everywhere. Thus, the map did not fit the terrain. Consequently, either adjusting the guideline or increasing efforts to fulfil the guideline's intentions could be warranted. In the following, I will discuss the sustainability of palliative care provision considering our findings and the main principles of the Norwegian Healthcare system.

Furthermore, since this project started in 2014, the terrain has changed significantly, and the findings thus need to be discussed considering recent developments in healthcare services.

5.3.1 Integration of palliative care in the existing healthcare system

As mentioned, the suggested model for service organisation in the guideline for palliative care places the GP in a central position as care coordinator. Although the shared care model (Figure 8) comprises more extensive communication between health personnel than usual, the overall intention of the guideline seems to be to integrate the shared care model into the existing healthcare structure (2). This complies with central principles in the Norwegian healthcare system, namely integrated rather than special care arrangements and the LEON principle. Furthermore, the GP is the gatekeeper to secondary care, and even small shifts in the GPs' referral rates could significantly impact workload and expenditure at the hospital level (see Figure 3). The vital importance of the GPs' gatekeeping to avoid unnecessary use of secondary care has recently been demonstrated (231).

Against this backdrop, a model for service provision that does not include the GP in the palliative care trajectories (see Figure 10) could potentially increase healthcare costs. As mentioned above, the need for specialised palliative care services in Norway exceeds the available resources (57). Considering this, bypassing the GPs could be particularly detrimental, as it could lead to unnecessary depletion of the resources at the specialist level.

The shared care model encourages extended communication, thus allowing direct contact between the PCTs and municipal ONs, who are also assigned a coordinator role (Figure 7) (2). This places the ONs at a pivot point between a GP and a PCT physician with few objective criteria concerning whether to contact the GP or the PCT on specific issues.

However, gatekeeping is a clinical skill connected to GPs' characteristics and experience (232). Thus, GPs are trained to refer patients to secondary care when tasks exceed their abilities. Our findings indicate that the GP's gatekeeper function is not automatically preserved in the shared care model. If gatekeeping is left to the ONs, it could be unclear to them which physician tasks the GPs could handle, and which ones need the attention of the PCT physician. This could lead to the inappropriate use of hospital specialists, conflicting with the LEON principle and the goals of the coordination reform.

5.3.2 Expanding palliative care in a healthcare system under pressure

The tension between the evolving palliative care services and the traditional responsibilities and roles of GPs arose early in the development of the field. Paper II discussed how expanding palliative care services could diminish GPs' possibilities to participate and maintain their knowledge in palliative care.

Figure 4 summarises some essential developments in palliative care up until the start of this project. Since 2014, there has been an increasing focus on palliative care in Norway; it seems to be a medical field in expansion. In 2017, an official Norwegian report, *On Life and Death* (NO: På liv og død), was released, leading to a white paper in 2020, processed in the parliament the same year (205, 233). The parliament decided to establish palliative medicine as a new medical speciality in Norway, a significant milestone in the academisation of this medical field.

The official report recognised the importance of integrating the services into the existing system. However, the ambition for future palliative care services comprised *"adjustments and changes based on the current structure in healthcare"*. Establishing municipal palliative care units with ambulatory teams resembling hospital-based PCTs was recommended. Ideally, such teams should be led by a specialist in palliative medicine overseeing palliative care in nursing homes. For home-residing patients, the municipal palliative care specialist should be available to support or even replace the GP (2, 205).

This development offers new interpretations of our findings, which could mean that the needs of palliative patients are too complex or too extensive to be handled efficiently within the existing structures. A sign of this could be the different cultures of service provision we found. It could mean that the models for service delivery deviating from what is intended are steps in a necessary development towards better patient care.

According to the economic evaluation, the suggested service restructuring would require redistribution of the current resources and "some" increased funding. However, a concurrent development in Norwegian healthcare is the crisis in the regular GP scheme. The municipalities are struggling to recruit and keep GPs. A similar phenomenon is seen in countries like the UK (234). Evidence suggests that the increasing workload on primary care physicians is causing a global crisis in primary care (235). Many believe the Norwegian regular GP scheme has been underfunded over time, and capacity is now reduced (236). Thus, the ambitions of relocating funds within primary care to employ medical specialists from a different field would conflict with the interests and goals of future general practice.

In 2023, an official report on sustainability in Norwegian healthcare was released (237). According to the report, the LEON principle and building services from the bottom up focusing on broad, generalist competencies will be the key to sustainable healthcare services in future. Thus, the sustainability of introducing new specialists in primary care can be debated. Furthermore, the previously mentioned official report on palliative care was unclear on the evidence or experiences the suggested changes are based on and points to a lack of knowledge about the current quality of palliative care provision in nursing homes (205). Thus, there may be insufficient evidence concerning the need for specialists in palliative medicine to oversee nursing home palliative care.

In comparison, there was a discussion about employing geriatricians to oversee care in municipal nursing homes in 2009. However, it soon became apparent that recruitment to the field needed to focus on covering the needs of secondary care in the foreseeable future (238). The latter conclusion is worth noting, as relatively few physicians are qualified in palliative medicine as a field of expertise (239). These are needed to supervise physicians in training for the new speciality, which is the responsibility of the Hospital Trusts.

However, 14 years on, many geriatricians work in municipal nursing homes in Norway (personal communication with The Geriatrics Association). This suggests that municipalities see the need for increased competence in the care of their ageing population. However, sustainability of primary care service development rests on bottom-up approaches based on local demands (237).

5.4 Guidelines in general practice

A starting point for the research forming this thesis was the assumption of implementation problems concerning the guideline for palliative care in Norway (2). As is evident from the background section, several issues in guideline implementation in general practice have been identified previously.

Our findings indicated weak implementation of the guideline for palliative care (Papers I and III). Although individual factors contributed, the structural barriers seemed significant; having few palliative patients in the first place, loss of contact, unclear communication, and a service organisation that did not correspond to the guideline recommendations increased the threshold for GP involvement in palliative care. Consequently, the guideline was rarely used and unknown to most GPs. Furthermore, another important point is the sustainability of the guideline requirements, as discussed earlier.

In this final Section of the thesis, I will discuss the findings considering current knowledge on guideline creation and sustainability of guidelines in general practice.

5.4.1 Evaluating the consequences of guidelines in general practice

The Norwegian guideline for palliative care was created according to high standards of process and methods (2, 79). However, as pointed out in Paper III, the level of evidence in palliative care is generally low. Concerning the competence levels and organisation of the service, consensus rather than evidence formed the basis of recommendations (2). Guideline creators are generally recommended to evaluate the consequences of implementing the resulting recommendations (79).

In the guideline for palliative care, it was stated that the costs at the hospital level would not increase due to its implementation. In contrast, no statements were made about the consequences for the primary care level (2). Previously, several researchers have demonstrated how the contents of guidelines can impact the workforce resources of general practice, especially for recommended procedures that apply to a considerable proportion of the population. Furthermore, GPs' workload increases if multiple guidelines are to be followed for individual patients (146, 148, 240, 241).

Recently, Johansson et al. launched the concept of "time needed to treat". These authors advocate that the clinician time needed to improve the outcome for one patient should be considered when guidelines are made. The concept can be helpful in screening and preventive settings where large parts of the population are eligible for the procedures (242). However, our findings indicate that acquiring and sustaining complex skills and knowledge that apply to only a few of the GP's patients will also have a relatively high clinician time cost per treated patient, which should be considered when creating such requirements.

Another consequence of this guideline follows from the detailed description of how the palliative care service should be organised. This is probably done because collaboration in palliative care depends on a model for shared care, which differs from ordinary care (Figures 5 and 8). As discussed in Paper III, the guideline appoints both the GP and the municipal ON to a coordinator role. However, this could potentially allow GPs to withdraw themselves or actively put them on the sidelines of palliative care (Figure 10). This weakening of the GP's gatekeeper function seems to be a consequence the guideline creators did not anticipate when appointing the municipal ONs to this role.

5.4.2 Creating CPGs for general practice

The competence requirements in palliative care emerged in 2004 and have been part of the Norwegian guideline for palliative care since 2007 (2). These requirements are not reflected in the learning objectives of the speciality of general practice (2, 77, 80). This fits well with our findings that the guideline requirements did not match the competencies the GPs believed they had. The Norwegian Directorate of Health is responsible for national CPGs and specialist education. The observed discrepancy could indicate poor coordination between the departments governing guidelines and education and that the guideline requirements should be incorporated into the learning objectives for general practice or even into primary medical education.

On the other hand, the discrepancies could also be interpreted as a sign that the realities of general practice were not sufficiently considered when creating the guideline. Our findings and a growing body of research indicate that guidelines from different specialities seem to be made without evaluating how they may impact the GP's way of working. For instance, very little evidence exists about the consequence of displacing GPs' patient-centred approach and organismic mindset in favour of PROMs and assessment forms (222, 243, 244). If the methods suggested in a guideline have not been studied in the general practice setting, it is uncertain whether they will improve overall care by GPs.

In Papers I and III, we discussed the need for GP representation when creating guidelines applying to general practice, which is in accordance with the recommendations (79). The guideline for palliative care is interdisciplinary; thus, stakeholders of several professions participated in the creation process (2). In such an assembly, the ideology of general practice may be suppressed, as the GPs are outnumbered, and their professional values are outweighed by the asymmetry between GPs and hospital specialists (see Section 2.2.2) (154, 245, 246).

5.4.3 Towards sustainable use of guidelines in general practice

In the age of CPGs, many resources are spent developing guidelines for different patient groups. As we have seen in this thesis, implementing the various guidelines in general practice is now a well-recognised challenge. In a recent systematic review, thirty different strategies for implementing guidelines were evaluated, typically showing only moderate effects (247). In the context of general practice, the GP must navigate between a variety of different guidelines. Thus, every guideline cannot be implemented by employing time-consuming efforts such as educational meetings, web-based learning programmes, audits and feedback, or mandatory CME courses for GPs.

As tools for achieving best practices, CPGs appear inadequate for GPs. There seems to be a "missing link" between multiple guidelines emerging from different specialities and the needs of the GP as a generalist. GPs need tools to navigate between a wide array of guidelines to get practice-oriented decision support. Denmark is an example of how to resolve this issue, as they have a publicly funded electronic knowledge portal (248). Furthermore, the Danish Society for General Practice has been setting the tone for developing general practice as a medical field. Accordingly, a practical guide to palliative care with an associated electronic application for GPs has been created in Denmark (249). All authors of the practical guide were GPs or specialists in general practice. Considering the overall findings of this thesis, a similar, bottom-up approach to strengthening the GP's role in palliative care may prove beneficial.

6. Conclusion

This thesis has highlighted that the GP's perspective can add unique qualities to the care of palliative patients. The other professionals in the service must acknowledge GPs' strengths to achieve optimal collaboration. The GP's skills complement other professionals in the field, and GP participation in palliative care improves patient outcomes. Therefore, the GP should naturally participate in interprofessional collaboration in palliative care.

The guideline has not succeeded in creating a sustainable minimum level of competence for GPs. The current requirement is too ambitious and is unsustainable in general practice.

GPs must rely on their generalist competencies as specialists in their field, which is sufficient to master many tasks in primary palliative care. There is probably a minimum level of specific skills and knowledge that GPs should master to ensure good-quality care and equity of palliative care service provision. Specialist guidance for tasks that exceed GPs' individual abilities is vital. However, there is little evidence concerning which skills and knowledge are essential for GPs and will improve patient outcomes.

The demarcation between primary and specialised palliative care is poorly defined. Bypassing the GP's gatekeeper function may exhaust the restricted resources of specialist palliative care.

There is a conflict of interest regarding the specific guideline demands for GPs, which are demonstrably unsustainable in general practice. This thesis has highlighted the importance of evaluating the consequences of a guideline at all service levels in which it is intended to be implemented. General practice is a particular context requiring special attention to the workforce demands resulting from a guideline. This guideline intervenes deeply into the structure of primary care, which may warrant more robust stakeholder participation in guideline creation. Anticipating the impact on primary care requires contextual knowledge.

This thesis has demonstrated the tension between an expanding medical field recommending that their speciality moves into the realms of the generalists in primary care. The ambition to establish specialists in palliative medicine in primary care may also challenge the core principles of the Norwegian healthcare service.

7. Implications and future perspectives

Healthcare services are facing challenges of demographic changes, altered disease panoramas, and increasing transfer of care to municipalities. Consequently, more people will need to be cared for at home in the future. Thus, the number of patients the GP must take responsibility for in the palliative stage will increase. Gatekeeping is vital for the future to limit costs in a healthcare service under pressure. This calls for a robust and reliable healthcare service. To achieve this, the cooperation between health professionals and healthcare levels must follow predictable patterns.

Implications for service organisation

The future organisation of palliative care provision is an issue of concern. Based on the findings in this thesis, it is reasonable to question whether palliative care services should be integrated into the existing structure or changed as suggested, i.e., by establishing palliative care specialists in primary care. The evidence considering patient outcomes and economic impact is weak. It is a dramatic change, apt to deplete the hospitals of palliative care specialists in the foreseeable future, and conflicting with the municipalities' needs to strengthen the regular GP scheme.

Furthermore, to ensure equity of services, the future model should not weaken specialist support to small and rural municipalities that may not have the resources to employ a palliative care specialist. However, municipalities must also be allowed to adjust and find solutions tailored to their local needs. Thus, geriatrics and palliative medicine specialists may supplement the generalists in palliative care in the future, either as municipally employed or through extended ambulatory specialist services.

The GP's normal function as gatekeeper and care coordinator represents a simple and predictable way of healthcare collaboration. New service delivery models must be introduced with attention to how they fit into the existing structure, and the division of labour should be specifically addressed.

Implications for guideline creation

This thesis shows that GPs need to be strongly involved as a discipline in creating guidelines for general practice. Guideline requirements for GPs must correspond to their generalist skills and the working conditions in general practice.

General practice represents a particular challenge for guideline implementation. Future efforts should focus on generating manageable systems for accessing the best evidence to support clinical decisions in general practice.

Implications for research and teaching

Determining which skills, knowledge, and working methods the GP must master to perform adequately in palliative care may need to be explored from a bottom-up approach, focusing on GPs' perceived needs and patient outcomes rather than consensus among professionals external to the context of general practice. Such an exploration could potentially draw a more apparent distinction between the tasks of the GP and the PCT physician. Furthermore, it could raise the GPs' awareness of their responsibilities towards their palliative patients. Palliative care must be built into general practice on the GP's terms.

More research is needed considering introducing and integrating non-generalist specialities in primary care.

As a governing body for the National CPGs and specialist education, the Norwegian Directorate of Health should ensure that health personnel's guideline requirements agree with the learning objectives of their specialities.

8. Source of data

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9. Appendix

9.1 Invitation to participate in questionnaire study

NTNU
Det medisinske fakultet
Institutt for samfunnsmedisin

Vår dato	Vår referanse
08.01.2014	
Deres dato	Deres referanse

Fastleger i Møre og Romsdal

Invitasjon til deltagelse i forskningsprosjekt

Prosjektet som er beskrevet på baksiden og som handler om at du blir bedt om å svare anonymt på et spørreskjema, utføres av Anne Fasting med midler fra Allmennmedisinsk forskningsutvalg (AFU) (‘Allmennpraktikerstipend’).

Undertegnede er veileder for Anne Fasting og arbeidet er i regi av Allmennmedisinsk forskningsenhet (AFE) ved Institutt for samfunnsmedisin (ISM), NTNU.

Data som samles inn vil bli publisert som en vitenskapelig artikkel.

Takk for at du deltar og bidrar til kunnskap på dette viktige området

Med hilsen

Irene Hetlevik

Irene Hetlevik
Prof.dr.med, spesialist i allmennmedisin
Leder AFE Trondheim

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Kristiansund 08.01.2014

Kjære kollega

Jeg vil be deg om å svare på et spørreskjema som omhandler kunnskap om og erfaring med palliativ behandling i primærhelsetjenesten. Jeg håper at du vil bruke de ca. 10 minuttene som behøves.

Bakgrunn:
Samhandlingsreformen stiller fastleger overfor nye krav og utfordringer. Det er et mål at tilstander skal behandles på laveste effektive omsorgsnivå og nye oppgaver delegeres derfor til førstelinjen. Fastlegerollens økende kompleksitet følges av en forventning om kompetanseheving på flere områder, inkludert palliativ behandling. Det er liten kunnskap om hvordan dette best kan gjøres. Jeg håper derfor at DU vil bidra til økt kunnskap på feltet.

Pasienter i palliativ fase av sykdommer som kreft, KOLS, hjertesykdom m.m. møter helsevesenet på flere nivåer. Spesialister på sykehusene, spesialiserte palliative team og palliative enheter på sykehjem skal sammen med fastlegen legge løpet for den palliative behandlingen. Også hjemmebaserte tjenester er involverte. Grunnleggende palliasjon skal utføres på alle kliniske sykehusavdelinger og i primærhelsetjenesten og det legges vekt på en sammenhengende behandlingskjede. Fastlegens forventes å ha en sentral rolle i dette arbeidet.

Formålet med undersøkelsen er å kartlegge aspekter ved dette fra fastlegenes ståsted, med fokus på mestringsfølelse, praksis og erfaringer fra palliative forløp samt erfaringer rundt det tverrfaglige samarbeidet om pasienter med behov for palliativ behandling.

Jeg vil be om svar innen 07.02.2014
Vedlagt frankert konvolutt

Vennlig hilsen

Anne Fasting
Fastlege

Definisjon: palliasjon er aktiv behandling, pleie og omsorg for pasienter med inkurabel sykdom og kort forventet levetid. Lindring av pasientens fysiske smerter og andre plagsomme symptomer står sentralt, sammen med tiltak rettet mot psykiske, sosiale og åndelige/eksistensielle problemer. Målet med all behandling, pleie og omsorg er best mulig livskvalitet for pasienter og de pårørende. Palliativ behandling, pleie og omsorg hverken fremskynder døden eller forlenger selve dødsprosessen, men ser på døden som en del av livet.
- European Association for Palliative Care (EAPC)/ Verdens helseorganisasjon (WHO) (1)

Kristiansund 14.03.1014

Kjære kollega

Du har tidligere mottatt denne spørreundersøkelsen. I og med at den besvares anonymt er det nødvendig å purre samtlige inviterte, og dersom du tidligere har svart ber jeg om at du ser bort fra denne henvendelsen.

Dersom du ikke har hatt tid til å svare på undersøkelsen tidligere, oppfordrer jeg deg til å svare nå, og helst innen 11.04.2014

På forhånd takk!

Vennlig hilsen

Anne Fasting

Fastlege

9.2 Questionnaire

Fastleger og fastlegevikarer bes besvare skjemaet. Fastleger ansatt ved palliative team skal ikke svare. Turnusleger skal ikke svare.

Generell informasjon

1a: Er du fastlege

JA ☐ ----> spm 2

NEI ☐ -------> **1b: Er du fastlegevikar?**

NEI ☐ Du skal ikke besvare undersøkelsen

JA ☐ ---->

1c: Hvor lenge har du vært vikar i *denne* praksisen?

0-6 måneder ☐

> 6 måneder - 1 år ☐

> 1 år ☐

2: Hvilket sykehus/sjukehus er *primært* ditt *lokale* sykehus/sjukehus? Ett kryss.

Kristiansund Sykehus ☐

Molde Sjukehus ☐

Ålesund Sjukehus ☐

Volda Sjukehus ☐

Ingen av nevnte ☐

Kommentar:____

3: Hva er størrelsen på fastlegelisten du betjener?

Opp til 600 pasienter ☐

600 - 1000 pasienter ☐

>1000-1500 pasienter ☐

> 1500 pasienter ☐

4a: Arbeider du også som sykehjemslege?

NEI ☐ -----> gå til spørsmål 5

JA ☐ -----> **4b: hvor mange timer i uken?**

1-4t/uke ☐

5-7,5t/uke ☐

> 7,5t/uke ☐

5: Hvor mange pasienter med behov for palliativ behandling vil du *anslå* at det er i din pasientpopulasjon *nå.*

Jeg mener at jeg har ☐ pasienter med behov for palliativ behandling nå

6: Hvor mange av disse pasientene har regelmessig konsultasjon eller sykebesøk?

Jeg har ☐ pasienter med behov for palliativ behandling som konsulterer/får hjemmebesøk regelmessig

7: Hvilket av sykehusene forholder du deg *hovedsakelig* til når det gjelder behandling av pasienter med behov for palliativ behandling? Ett kryss

Kristiansund Sykehus ☐

Molde Sjukehus ☐

Ålesund Sjukehus ☐

Volda Sjukehus ☐

Ingen av nevnte ☐

Kommentar:____

8: Hvor lang reisetid er det til dette sykehuset fra din kommune?

< 30 min ☐

30 min -1 time ☐

>1 time ☐

9: Finnes det kreftsykepleier i din kommune?

JA ☐

NEI ☐

Vet ikke ☐

10: Kjenner du til «standard for palliasjon» av 2004?

Ja, jeg har inngående kjennskap til innholdet ☐

Ja, i hovedtrekk ☐

Ja, jeg vet at den finnes ☐

Nei ☐

11: Har du deltatt på kurs i palliativ medisin siste 5 år?

JA ☐

NEI ☐

12:Planlegger du å delta på kurs i palliativ medisin innenfor det neste året

JA ☐

NEI ☐

Kommentar:____

I denne delen av undersøkelse ber vi deg angi i hvor stor grad enkelte utsagn stemmer for deg. Ett kryss for hver linje.

13: Kartlegging av symptomer og plager

Hvordan kartlegges symptomer og plager hos pasienter med behov for palliasjon i din praksis? Det finnes standardiserte skjema for symptomregistrering som brukes på sykehus og i palliative team og som fanger opp flere dimensjoner enn den enklere Visuell Analog Skala (VAS-skalaen). Eksempler på dette er Edmonton Symptom Assessment System (ESAS)- og Forløpsskjema. Lite er kjent om bruken av slike skjema i primærhelsetjenesten.

	Enig	Litt enig	Både og	Litt uenig	Uenig
Jeg bruker skjema for symptomregistrering (unntatt VAS) systematisk og regelmessig	☐	☐	☐	☐	☐
Jeg er ikke kjent med bruken av denne typen skjema	☐	☐	☐	☐	☐
Hjemmesykepleien bruker slike skjema og rapporterer resultatet til meg	☐	☐	☐	☐	☐
Slike skjema gjør det lettere å gi god symptomlindring	☐	☐	☐	☐	☐
Slike skjemaer har liten nytteverdi for meg som fastlege	☐	☐	☐	☐	☐
Jeg bruker skjemaene så sjelden eller har så få kliniske tilfeller at nytteverdien er lav	☐	☐	☐	☐	☐
Jeg baserer i stor grad behandlingen på slike skjema	☐	☐	☐	☐	☐
Den palliative behandlingen styrer jeg ut fra mitt kjennskap til pasienten og sam- -taler på kontoret eller ved sykebesøk	☐	☐	☐	☐	☐
Personlig kjennskap og eventuelt VAS er tilstrekkelig for kartlegging av symptomer og plager til mitt bruk	☐	☐	☐	☐	☐

Kommentarer____

____

____

____

14: Symptomlindring

Symptomlindring i den palliative fasen er svært viktig. Dette gjelder i det daglige, hvor smerter, gastrointestinale problemer, tung pust, etc. kan være et problem, samt i ø-hjelpssituasjoner ved akutte komplikasjoner.

	Enig	Litt enig	Både og	Litt uenig	Uenig
Jeg opplever at pasienter med behov for palliasjon stort sett har god symptomlindring	☐	☐	☐	☐	☐
Ivaretakelse av ø-hjelpssituasjoner fungerer godt i forhold til palliasjon i min kommune	☐	☐	☐	☐	☐
Jeg opplever at det er vanskelig å gi god palliasjonsbehandling i allmennpraksis	☐	☐	☐	☐	☐
Jeg opplever at mine pasienter ofte ikke får god nok palliasjon i situasjoner som oppstår utenom min arbeidstid	☐	☐	☐	☐	☐
Hjemmesykepleien følger godt opp mine pasienter med behov for palliasjon	☐	☐	☐	☐	☐

15: Fastlegens rolle

	Enig	Litt enig	Både og	Litt uenig	Uenig
Jeg har tilstrekkelig kunnskap om palliativ behandling	☐	☐	☐	☐	☐
Jeg har stort nok antall palliative pasienter til å opprettholde min kompetanse i palliasjon	☐	☐	☐	☐	☐
Jeg har behov for å bedre mine kunnskaper om palliasjon	☐	☐	☐	☐	☐
Mine pasienter i palliativ fase konsulterer meg ofte når det gjelder smerte og symptomlindring	☐	☐	☐	☐	☐

Palliasjon håndteres i stor grad av spesialisthelsetjenesten, og jeg er ofte ikke involvert	☐	☐	☐	☐	☐
Jeg opplever ofte at spesialisthelsetjenesten styrer behandlingen mens jeg kun skriver resepter etter deres ordinasjoner	☐	☐	☐	☐	☐
Jeg har nok tid i min arbeidshverdag til å dra på hjemmebesøk til pasienter med behov for palliasjon	☐	☐	☐	☐	☐
Jeg tror pasienter med behov for palliasjon ofte har nok med de legene de møter spesialisthelsetjenesten og ikke føler behov for fastlegen	☐	☐	☐	☐	☐
Jeg er en sentral aktør i den palliative behandlingen av mine pasienter	☐	☐	☐	☐	☐
Jeg føler meg trygg i behandlingen av pasienter med behov for palliasjon	☐	☐	☐	☐	☐
Jeg føler meg usikker når det gjelder palliativ behandling	☐	☐	☐	☐	☐
Mine pasienter i palliativ fase ønsker at jeg skal være tilgjengelig utenom arbeidstiden	☐	☐	☐	☐	☐
Hjemmesykepleien forventer at jeg er tilgjengelig utenfor arbeidstiden	☐	☐	☐	☐	☐
Når pasienter har behov for palliasjon er jeg tilgjengelig for pasient og pårørende også etter kontortid	☐	☐	☐	☐	☐
Jeg ønsker en mer sentral rolle i forhold til mine pasienter med behov for palliasjon	☐	☐	☐	☐	☐

16: Dokumentasjon og kommunikasjon mellom aktørene

16a: I hvor stor grad passer utsagnene for deg? Ett kryss for hvert spørsmål

	Enig	Litt enig	Både og	Litt uenig	Uenig
Aktuelle pasienter har alltid en palliativ plan som er tilgjengelig for alle	☐	☐	☐	☐	☐

nivåer i behandlingskjeden					
Mine pasienter har alltid en hjemmejournal/felles journalnotater når de har behov for palliasjon	☐	☐	☐	☐	☐
Jeg har ingen erfaring med hjemmejournal/ felles journalnotater	☐	☐	☐	☐	☐
Hjemmejournal er et viktig verktøy for at legevakt kan få godt nok beslutningsgrunnlag i akutte situasjoner	☐	☐	☐	☐	☐
Hjemmejournal brukes i liten grad hos mine pasienter	☐	☐	☐	☐	☐
Hjemmejournal/felles journalnotater bør brukes oftere	☐	☐	☐	☐	☐
Kommunikasjonen mellom behandlingsnivåene fungerer godt.	☐	☐	☐	☐	☐
Epikriser og annen kommunikasjon fra sykehus og palliative team kommer ofte sent	☐	☐	☐	☐	☐
Det er lett å få tak i spesialist eller palliativt team for rådgivning slik at problemer kan løses uten innleggelse	☐	☐	☐	☐	☐
Jeg benytter meg ofte av konferering med spesialist eller palliativt team	☐	☐	☐	☐	☐
Rådføring med spesialister og palliativt team hindrer unødige innleggelser.	☐	☐	☐	☐	☐
Spesialister og palliativt team har god forståelse for arbeidsformen og tilgjengelige ressurser i primærhelsetjenesten	☐	☐	☐	☐	☐
Sykehuset og/eller palliativt team har urealistiske forventninger til fastlegens og hjemmesykepleiens ressurser	☐	☐	☐	☐	☐

16b: Har du deltatt i fellesmøter med sykehus før utskrivelse av pasienter med behov for palliativ behandling i hjemmet?

Aldri ☐

Sjelden ☐

Av og til ☐

Regelmessig ☐

17: Terminal pleie

Flere studier viser at mange døende ønsker å få dø i sitt hjem. Likevel er det et stort antall pasienter som dør i institusjon (sykehus, sykehjem, hospice). Det er av interesse hva fastleger opplever som hemmende og fremmende i forhold til hjemmedød.

17a: Hvor ofte har du vært behandler ved planlagt hjemmedødsfall i din pasientpopulasjon siste 3 år?

Aldri ☐

1-3 tilfeller ☐

>3-5 tilfeller ☐

>5 tilfeller ☐

17b: Har du siste 3 år opplevd at hjemmedød ikke har latt seg gjennomføre selv om pasienten har ønsket det?

NEI ☐

JA ☐

Dersom ja, i hvor stor grad mener du følgende faktorer bidro til at hjemmedød ikke lot seg gjennomføre?

	I høy grad	Bidro noe	I liten grad
Pasienten ombestemte seg	☐	☐	☐
Hensyn til de pårørende	☐	☐	☐
Enslig pasient/ingen pårørende i hjemmet	☐	☐	☐
For dårlig symptomlindring i hjemmet	☐	☐	☐
Akutte komplikasjoner som ikke kunne håndteres	☐	☐	☐
Pasientens komorbiditet	☐	☐	☐
Manglende ressurser i hjemmesykepleien	☐	☐	☐

Manglende kompetanse i hjemmesykepleien	☐	☐	☐
Innleggelse utenom fastlegens kontortid	☐	☐	☐
Legevaktslege hadde ikke nødvendig innsikt i situasjonen	☐	☐	☐
Legevaktslegen manglet erfaring med palliativ behandling	☐	☐	☐
Kommunikasjonssvikt mellom behandlingsnivåer	☐	☐	☐
Manglende hjelp/rådgivning til fastlege/hjemmesykepleie	☐	☐	☐
Palliativ plan mangelfull eller ikke tilgjengelig	☐	☐	☐
Ingen hjemmejournal med oppdaterte opplysninger	☐	☐	☐
Jeg manglet kapasietet til å følge opp behandlingen	☐	☐	☐

9.3 Information about participants in focus grups

Informasjon om deltakerne i fokusgruppeintervjuer

Kjønn:

Alder:

Studiested:

Uteksaminert:

Jobber ved et legekontor på landet/ i en by:

Solopraksis/flerlegepraksis:

Antall listepasienter (ca):

Antall år som fastlege:

Spesialist/ikke spesialist i allmennmedisin:

Annen relevant (side)utdanning/ yrkeserfaring:

Annen spesialitet eller kompetanseområde:

Sykehjemslege:

Annen bistilling:

9.4 Interview guide

Intervjuguide fokusgruppeintervjuer; Palliasjon i primærhelsetjenesten

Målsetning for fokusgruppestudien: Utforske hvordan fastleger definerer-, og tenker om-, sin rolle og utfordringer i arbeid med «palliative pasienter» i primærhelsetjenesten (PHT). Deres forhold til retningslinjen på området er av interesse. Studien tar sikte på å utdype noen aspekter/ resultater fra tidligere spørreskjemaundersøkelse, samt å få ny kunnskap fra 1.personperspektivet.

Fastlegers generell erfaring med palliasjon

Starte med å oppmuntre/ stimulere legene til å komme med pasienthistorier fra egen praksis. Deltagerne instrueres i å anonymisere pasient/ situasjon under intervjuet.
Kan dere komme på / fortelle om pasienter der dere som fastlege har vært involvert i et palliasjonsforløp? Evt oppfølgingsspørsmål; *Etterspørre spesifikt pasienthistorier der pasienten døde hjemme. (knytte opp mot spørreundersøkelsen hvor dette var sjeldent)*

Fastlegens rolle i palliativt arbeid

Hvordan definerer og tenker dere om fastlegens rolle i palliativt arbeid i PHT?
Evt oppfølgingsspørsmål: *Er fastlege en sentral eller perifer aktør?* (med henvisning til spørreundersøkelse der 50% av fastlegene sier de er en sentral aktør)
Hvilke utfordringer har dere møtt i dette arbeidet (evt kan se for deg dersom ikke erfaring med palliativ pas)? (stikkord: kompetanse/tid/tilgjengelighet..)
Evt oppfølgingsspørsmål: *Hva er realistisk at fastlegen bidrar med i dagens helsetjeneste? Hva hadde vært ideell rolle/ bidrag fra fastlegen – dersom man kunne legge til rette for dette?*
Hva er det viktigste fastlegen kan bidra med for disse pasienten?
(stikkord/ tema som kan etterspørres hvis ikke kommer opp av seg selv i diskusjonen; tilgjengelighet, medikamentell palliasjon, koordinerende rolle, kontinuitet, kjenner pasienten/ familien fra før, støtte pårørende, vitne/ ledsager)
Kan dere referer til noen vesentlige innsikter – eller læringssituasjoner i arbeid med palliative pasienter som faktisk var nyttig?
Evt oppfølgingsspørsmål; *Hva trengte du faktisk hjelp til – og hvor fikk du den hjelpen? Hva lærte du som faktisk var nyttig?*

Fastlegenes erfaringer med - og synspunkter på retningslinjen for palliasjon

Utforske legenes kjennskap til – og tanker rundt - en omfattende retningslinje. Retningslinjen vises frem i en papirkopi – referer kort omfang/antall sider (190) og tittel.
Hvor mange av dere har hørt om denne /kjenner til denne?
Hva tenker dere om omfanget av denne retningslinjen (gitt at det er relativt liten pasientgruppe men samtidig et kompleks fagområde)?

Kan vi kikke litt sammen på hovedinnholdet og diskutere det sammen?
(Leser opp innholdsfortegnelse – evt referer kort hovedpunkter i retningslinjen)
Hva tenker dere om det som står her?
Evt oppfølgingsspørsmål*; diskutere noen spesifikke tema i retningslinjen; trekke frem særlig det som har med fastlegens rolle og krav til kompetanse i retningslinjen.*
Er det noe dere savner – som ikke er nevnt/ omtalt i retningslinjen?

Er retningslinjen svaret på fastlegens utfordringer?
– og hvis ikke – hva trenger fastlegene for å utføre jobben?

9.5 Consent to participate in focus groups

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

PALLIASJON I PRIMÆRHELSETJENESTEN, FASTLEGENS ROLLE I ET SAMHANDLINGSPERSPEKTIV

Dette er et spørsmål til deg om å delta i et forskningsprosjekt for å utforske hvordan fastleger definerer og tenker om sin rolle og utfordringer i arbeid med «palliative pasienter» i primærhelsetjenesten og deres forhold til retningslinjen på området. Studien tar sikte på å utdype noen aspekter/ resultater fra en tidligere spørreskjemaundersøkelse, samt å få ny kunnskap fra 1.personperspektivet. Du har blitt spurt om å delta i studien fordi du er fastlege og kan gi nyttig innsikt i problemstillingen. Prosjektet er knyttet til NTNU, institutt for samfunnsmedisin og sykepleie.

HVA INNEBÆRER PROSJEKTET?

Du blir bedt om å delta i et fokusgruppeintervju. Et fokusgruppeintervju skal i hovedsak være en diskusjon mellom deltagerne. Jeg har valgt en form for dette fokusgruppeintervjuet der jeg selv som forsker ikke vil delta direkte i gruppediskusjonen, men ønsker at det er dere selv som styrer diskusjonen. Målet er at dere som gruppe diskuterer temaet slik dere bruker å diskutere andre temaer. Jeg vil underveis stille noen spørsmål som skal være med på å sette tema for gruppediskusjonen.

Det er fint om den som er leder i gruppa til vanlig kan styre diskusjonen slik dere pleier, og at han/hun kan være ekstra oppmerksom dersom mange snakker i munnen på hverandre. Denne samtalen tas opp på video og lydbånd så dersom dere har pasienthistorier bør disse anonymiseres (AA, MM, ikke presis alder, ikke presise steder etc.). Utskriften av denne samtalen vil ikke komme til å inneholde navn, alder, stedsangivelse. Videoen utleveres ikke til noen og er bare til støtte ved utskriften for å identifisere de enkelte deltakere som får bokstavkoder M1, M2, K1, K2 osv.” Intervjuet vil ta 1 - 1,5 timer.

MULIGE FORDELER OG ULEMPER

Å delta i prosjektet innebærer ingen risiko for deg som deltaker. Bruk av tid til intervjuet og reising kan være en ulempe for noen. Fordeler ved å delta er at man her kan bidra til kvalitetsbedring for eget fag, samt oppnå ny kunnskap om temaet gjennom samtale med kolleger.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte: Anne Fasting, tlf 41478027, email: anne.fasting@ntnu.no

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

FORSIKRING [BESKRIV DET SOM ER AKTUELT]

Forsikring av studiedeltakere er ikke aktuelt da det ikke er risiko knyttet til deltakelsen.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnr. 2017/903 hos REK (28.06.2017).

Samtykke til deltakelse i PROSJEKTET

Jeg er villig til å delta i prosjektet

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato	Signatur
	Rolle i prosjektet

9.6 Additional file 1, Paper III

Summary of the 2015 revision of the Norwegian guideline for palliative care

Who is covered by the action program

The action program takes upon treatment, nursing, and care for patients with uncurable cancer and limited life expectancy. In some recommendations the palliative patient population is limited to include patients with life expectancy of less than 9-12 months. In reality the palliative phase is a process starting when it is acknowledged that the disease is incurable, and that ends when the patient dies. Palliative care also includes mourning and follow-up of relatives.

Much of the available knowledge and documentation in palliative care is linked to cancer patients. De general conditions described in this action program, will however also be valid for palliative patients with other diagnoses. Palliative care is performed within most medical fields and at all levels of the health service.

Chapter 1. Introduction

This chapter describes the basic features of palliative care, such as the patient population, treatment culture and the basic elements of investigation and treatment. All patients with serious, advanced disease have a right to necessary medical aid, and therefore falls within the priority regulation.

Chapter 2. Characteristics and challenges of palliative care

The chapter describes the contents of palliative care work and conditions of the palliative population that requires special competence. The contents are based on established professional practices both nationally and internationally, and for the subjects where grading of evidence is found possible and relevant, this is undertaken.

Chapter 3. Trajectory times

In the course of 2015, 28 trajectories for cancer will be implemented, including trajectory deadlines for the different cancer diagnoses. These deadlines will replace the existing limits of 5, 10 and 20 working days.

Chapter 4. Symptoms and conditions

The chapter consists of clinical guidelines for investigation and treatment of central symptoms and conditions in palliative care. The guidelines mainly concern patients with cancer. The general level of evidence in palliative treatment is deficient and often based on experience.

Chapter 5. Implementation of the recommendations

The chapter presents propositions as to how the action program's recommendation for organization, education, competence, and professional quality can be implemented.

Chapter 6. Process and method for the preparation of the guideline.

In this chapter the National centre of healthcare knowledge (Kunnskapsssenteret) has described the methods involved in the preparation of the action program.

Appendix 1. Organization

In this appendix a standard for the palliative care service in the various organizational units in hospital and primary care is presented. The tasks of each unit are described together with the requirements for the clinical service provision and organization, including involved personnel, premises, and equipment. The recommendations rest on public evaluations and reports, and the document "Standard for palliative care".

Appendix 1. Competence requirements

Optimal palliative care warrants that all personnel have the necessary professional competence. This includes knowledge, skills, and attitudes.

In this appendix requirements for the competence of relevant groups of professionals (nurses, doctors, physiotherapists, social workers, clinical nutritionists, occupational therapists, auxiliary nurses, priests, psychologists, and other relevant professionals within palliative care) and how this competence currently can be achieved. The working group also promotes several proposals for measures to increase competence in palliative care.

The account is based on the following division of competence levels:

Level A: Basic competence. This should be mastered by all health workers within the relevant groups of professionals and must be taught in the in the basic education.

Level B: Necessary competence for health professionals who treat palliative patients as part of their clinical work, both in the community and in hospitals.

Level C: Necessary competence for health workers that work in palliative teams and palliative units. This level equals specialist competence.

Appendix 3. Relevant web-sources

Provides a list of relevant web-sources for various parts of palliative care.

10. Papers I - III

Paper I

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BMC Family Practice

RESEARCH ARTICLE

Open Access

Palliative care in general practice; a questionnaire study on the GPs role and guideline implementation in Norway

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Abstract

Background: Patients in need of palliative care often want to reside at home. Providing palliative care requires resources and a high level of competence in primary care. The Norwegian guideline for palliative care points to the central role of the regular general practitioner (RGP), specifying a high expected level of competence. Guideline implementation is known to be challenging in primary care. This study investigates adherence to the guideline, the RGPs experience with, and view of their role in palliative care.

Methods: A questionnaire was distributed, by post, to all 246 RGPs in a Norwegian county. Themes of the questionnaire focused on experience with palliative and terminal care, the use of recommended work methods from the guideline, communication with partners, self-reported role in palliative care and confidence in providing palliative care. Data were analyzed descriptively, using SPSS.

Results: Each RGP had few patients needing palliative care, and limited experience with terminal care at home. Limited experience challenged RGPs possibilities to maintain knowledge about palliative care. Their clinical approach was not in agreement with the guideline, but most of them saw themselves as central, and were confident in the provision of palliative care. Rural RGPs saw themselves as more central in this work than their urban colleagues.

Conclusions: This study demonstrated low adherence of the RGPs, to the Norwegian guideline for palliative care. Guideline requirements may not correspond with the methods of general practice, making them difficult to adopt. The RGPs seemed to have too few clinical cases over time to maintain skills at a complex and specialized level. Yet, there seems to be a great potential for the RGP, with the inherent specialist skills of the general practitioner, to be a key worker in the palliative care trajectory.

Keywords: Palliative care, Primary care, Palliative medicine, General practice, Clinical practice guidelines, Symptom assessment, Advance care planning

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Background

Palliative care and general practice

In recent years, there has been an increasing need for palliative care, both due to demographic changes increasing the amount of elderly and multimorbid patients, and to the success of modern cancer treatment increasing longevity [1, 2]. Most patients with palliative needs want to be cared for, and possibly die, in their own homes [3–5]. In Norway, less than 15% die in their own home [2]. The term "palliative care", is defined by the European Association for Palliative Care (EAPC), as the total care of patients with incurable, life threatening disease:

> *"Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Palliative care takes a holistic approach, addressing physical, psychosocial and spiritual care, including the treatment of pain and other symptoms. Palliative care is interdisciplinary in its approach and encompasses the care of the patient and their family and should be available in any location including hospital, hospice and community.*
> *Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death and sets out to preserve the best possible quality of life until death." [6]*

This means that not only cancer patients, but all groups of patients with life limiting disease, can benefit from the interdisciplinary approach of palliative care, even early on in the trajectory of the disease [1, 7].

The characteristics and core values of palliative care have many parallels to the person centered and holistic approach of general practice as described in the European definition of family medicine [8]. The World Health Organization (WHO) explicitly lists palliative care as one of the general practitioner's (GP's) tasks [9].

Thus, the GP should be well situated to contribute in the palliative care trajectory. Through the regular general practitioner (RGP) scheme in Norway [10], all residents are entitled to a RGP that is responsible for the coordination of medical care. At the time of the study, more than 99% of the Norwegian population was listed with an RGP [11].

The Norwegian guideline for palliative care

Alongside the increase in patients in need of palliative care, there has also been a shift of focus; from care given in institutions, towards care given at home for these patients [4, 12, 13]. This is demanding for the primary care services. The Norwegian guideline for palliative care comprises recommendations for treatment of specific symptoms, standards for organization of the service and competence requirements. Although the guideline is said to be relevant for all patients with life limiting disease, its origin and organization is within the Norwegian national program for cancer care [1], and the patient population within the palliative care units is described as consisting of 95% cancer patients [14]. The guideline attachment addressing organization and competence requirements was authored by a majority of hospital specialists, but also a nurse, and one specialist of general practice, working in a palliative care unit [14]. The guideline assigns the RGP a key role [1]; The RGP is supposed to coordinate all patient care, make house calls, and make an individual plan for how the patient can access medical help outside office hours, and when the RGP is absent. The guideline specifies a level of competence for all physicians who are involved in palliative care, including the RGPs. This level includes advanced procedural skills such as the use of specific symptom assessment-tools, e.g. the Edmonton Symptom Assessment System (ESAS-r) and mastering the principles of using a syringe driver for subcutaneous administration of medications. The RGP is also expected to work proactively towards involving other professionals when needed, such as specialized community nurses or hospital specialists. Advance care plans (ACP) and updated medical information should be available to all personnel involved with the patient. The use of joint meetings between hospital specialists and the RGP, ahead of discharge from hospital, is also strongly recommended [1].

Previous reports support that the RGP should adopt a central role in this work; the need for a coordinator has been demonstrated, and there also seems to be an association between the RGP making house calls and the patient being able to die at home [15–20]. However, previous findings indicates that there seems to be a discrepancy between the RGPs' actual clinical practice, and what the health authorities recommend in the guideline [1, 21, 22].

The use of guidelines in clinical practice

Clinical guidelines are important means for directing health care resources towards evidence-based practices [23]. Previous studies suggest that GPs have difficulties in adhering to guidelines in different fields [24–29]. According to the European Science Foundation, the process is working well from the initial idea, through research, meta-analysis, and Cochrane Review. The problem arises, however, because: "*The process from meta-analysis through guidelines to clinical practice is a source of considerable variation throughout Europe and therefore suffers from non-transparency and fragmentation*"[30].

As far as we know there has not been conducted any Norwegian study that has examined the extent to which the RGPs' practice comply with the guideline. The aim of this study is therefor to investigate the RGPs' adherence to the Norwegian guideline for palliative care. The questionnaire (Supplementary file 1) encompasses questions related to knowledge about, and attitude towards the guideline as well as self-reported experience and clinical practice in palliative care, all elements useful in the study of guideline implementation [30]. By creating a questionnaire exploring the RGPs' experiences with palliative care, we can also get information about the clinical reality in which the guideline is meant to be implemented. The study will contribute to information that might be important regarding both the development and implementation of guidelines in primary care, and to inform future organization of the palliative care service.

Methods

As no suitable, validated questionnaire could address our research question, we created a questionnaire based on elements drawn from the national guideline for palliative care (Supplementary file 1). Relevant topics from the guideline regarding the RGPs competence and role were chosen by the authors and validated by peers and one hospital specialist in palliative medicine. The questionnaire was sent by post to all 246 RGPs in the Norwegian county of Møre og Romsdal in 2014. The population of the county was approximately 250 000. The chosen county includes both rural areas with scarce populations, and urban districts with larger towns. The county has four local hospitals of different sizes. A reminder was sent to all RGPs two months after the original deadline. All answers were anonymous.

Most of the questions were related to themes in the guideline, particularly concerning the organization of the palliative care service, specific competence requirements for RGPs, and procedures of cooperation. The RGPs also answered questions related to their personal experience with palliative care and their understanding of own role, as well as their participation in terminal care at home. The questions were partly "yes / no", and partly 5-point Likert-type questions, ranging from "agree" to "disagree", as well as questions with fewer options or numeric information. Themes of focus were: "experience with palliative and terminal care", "use of guideline recommended procedures", "communication with partners", "RGP role" e.g. sense of being central participant in palliative care, and "confidence" in palliative care. The questionnaire items included both positive and negative statements for balance (Supplementary file 1). Nine of the respondents had chosen to answer the questionnaire as a group, using one form. Although their responses are included in the descriptive part, they were excluded when describing differences between subgroups. The form also provided space for freely written comments. Frequency analysis was performed by using the software SPSS statistics 25. All written comments in free text were analyzed for content.

Table 1 RGP characteristics

Total number responders n (%)	142 (100)
Regular general practitioner	130 (92)
Locum	12 (8)
Local Hospital	
Ålesund	46 (32)
Molde	39 (28)
Kristiansund	23 (16)
Volda	28 (20)
Other	6 (4)
Distance from local hospital	
< 30 min	73 (51)
30 min – 1hour	38 (27)
> 1 h	31 (22)
Size of patient list	
< 600	9 (6)
600 – 1000	66 (47)
> 1000 – 1500	62 (44)
> 1500	5 (3)
Combined work as nursing home doctor	54 (41)
1 – 4 h/week	19 (35)
5 – 7,5 h/week	24 (44)
> 7,5 h/week	11 (20)

Results

The response rate was 57%, as 142 out of 246 RGPs responded (Table 1). All participants worked in positions as RGPs, 8% being temporarily employed (locums). RGPs affiliated with all hospitals in the county, participated in the study. For half of the respondents (51%), the distance to hospital was less than half an hour. RGPs reporting to be affiliated with a hospital outside the county, all had more than 30 min or more travel distance to hospital. Most RGPs (91%) had between 600 and 1500 patients listed. Among the 41% of the RGPs also working as nursing home physicians, there was no significant geographic variation. Participant information is listed in Table 1, main results in Tables 2, 3 and 4, and Fig. 1.

RGP experience with palliative and terminal care

Close to one third of the RGPs (32%) reported not to have any patients with need for palliative care at the time, 39% had 1–2 such patients, and only 6% estimated to

Table 2 Guideline recommended procedures

	N (%)		
Use of guideline recommendations	**Agree**[a]	**Neutral**	**Disagree**[b]
I use forms for symptom assessment regularly	28 (20)	22 (16)	90 (64)
The use of such forms is unknown to me	40 (29)	19 (14)	80 (57)
The district nurses use such forms	41 (30)	25 (18)	72 (52)
I rely on forms for clinical decisions to a high degree	20 (15)	27 (20)	89 (65)
Palliative patients always have an ACP	32 (23)	37 (28)	67 (49)
Updated information always in patient's home	38 (28)	30 (22)	67 (50)
Medical information rarely available in patient's home	77 (57)	23 (17)	36 (26)

Likert-type questions for the use of guideline recommended procedures, N of respondents (valid %),

[a] Agree fully or partially, [b] Disagree fully or partially

currently have more than 5 palliative patients. Answers also indicated that they did not see all these patients regularly.

Only a minority (18%) of the RGPs agreed with the statement: "I see enough patients with palliative needs to maintain my competence in palliative care", whereas the majority (57%) disagreed.

One third (35%) of the RGPs had no experience with terminal care at home within the last 3 years, about half (47%) had been involved in only 1–3 such patients, and some (12%) had experienced 4–5 cases. Very few (6%) reported involvement in more than five patients over the last three years. Frequency of RGP participation in terminal care increased with increasing size of patient list, with 60% of RGPs with patient lists > 1500 patients reporting participation in 3–5 cases, and none of them reporting never to have participated in the last three years (Fig. 1).

Twenty-one of the RGPs (6%) had experienced that patients had not been able to die at home despite wishing to do so. Consideration for relatives (48%), inadequate symptom control (41%), and acute complications that could not be handled at home (48%), were most frequently acknowledged as contributing reasons for not achieving the patients' goal of dying at home.

The RGPs made several written comments regarding the amount of experience they had in palliative care;

- *"I have few patients needing palliative care, and this makes it difficult to get enough practice/experience"*
- *"Due to having so few patients, for instance only one on a syringe driver, I can't be updated on this. The palliative teams are important! There are many areas to keep updated on"*
- *"Most of these patients end up in institutions and I don't see them"*
- *"Too many questions [in the questionnaire] about palliative care, considering that we have so few palliative patients! My experience with palliative care comes mainly from the nursing home"*

The use of guideline recommended procedures and cooperation with partners

Details of the five-point questions for the use of guideline recommended procedures, reflecting guideline adherence, are given in Table 2. We found no difference in answers related to size of patient list, distance from hospital or RGP also working in nursing home.

Only one fifth of the RGPs use other assessment tools than the Visual Analog Scale (VAS), like the ESAS-r regularly, and approximately half of the responders reported that the district nurses did not use symptom assessment forms to report symptoms either. The RGPs largely

Table 3 self-reported role of the RGPs

	N (%)		
RGP role as central in palliative care	**Agree**[a]	**Neutral**	**Disagree**[b]
Central worker in palliative care	72(52)	40(29)	27(19)
Palliative patients consult regularly for pain relief	77(55)	33(24)	30(21)
Patients are mostly handled by specialists	52(37)	30(21)	58(42)
Patients do not need me, due to specialist involvement	22(16)	31(22)	86(62)
Available outside office hours when patient is palliative	65(47)	27(20)	45(33)
Specialists dictates treatment, RGP writes prescriptions	53(38)	29(21)	57(41)

5-point Likert-type questions for the RGP role as central in palliative care, N of respondents (valid %)

[a] Agree fully or partially, [b] Disagree fully or partially

Table 4 RGP confidence in palliative care

	N (%)		
RGP confidence in palliative care provision	**Agree[a]**	**Neutral**	**Disagree[b]**
I have sufficient knowledge of palliative care	58(41)	47(33)	37(26)
I feel secure in providing palliative treatment	79(56)	31(22)	31(22)
It is difficult to provide palliative care in general practice	28(20)	36(26)	76(54)
I need to improve my knowledge of palliative care	113(80)	17(12)	11 (8)
I feel insecure in the provision of palliative care	30(21)	36(26)	75(53)

Likert-type questions for the RGP confidence in palliative care provision, N of respondents (valid %),

[a] Agree fully or partially, [b] Disagree fully or partially

agreed to the usefulness of both symptom assessment forms and the sharing of updated information and ACPs. Still, only a few based their treatment on such forms, and half reported that their patients did not always have an ACP available to all levels in the healthcare service. Most agreed that they based palliative treatment on dialogue with the patient and previous knowledge of the situation. Nearly 60% of the RGPs reported that they had too few clinical cases for the symptom assessment forms to be useful to them.

Close to 70% of the respondents had never participated in a joint discharge meeting regarding patients needing palliative care, and only one respondent reported participating in such meetings regularly.

Most of the respondents (60%) agreed that communication between the healthcare service levels worked well, and that specialists and palliative teams were easily accessible for advising decisions (66%). Around 65% of the RGPs agreed that hospital specialists had a good understanding of the working methods and available resources in primary care. Most of the respondents (85%) agreed that the community care services followed up these patients adequately, and 72% reported that their palliative patients mainly achieved good symptom relief.

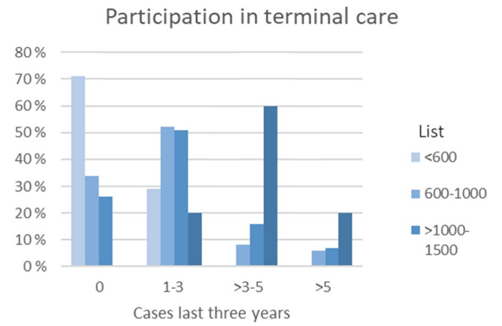

Fig. 1 participation in terminal care increased with increasing patient list of the RGP

There were some written comments on the item of symptom assessment tools, several conveying a reluctance towards assessment forms for palliative patients, both regarding ethical issues, due to time constraints, or arguing for a different approach all together:

- *"There is a demand for effectiveness, and no time for unnecessary procedures"*
- *"I think using [assessment] forms take a lot of time"*
- *"I'm sure these forms would be useful, had I known about them"*
- *"Palliative patients have limited resources, and it is unethical to bother them with such procedures"*
- *"In my experience, palliative care requires creativity, and medicine by "recipe" works particularly badly for this patient group"*
- *"I make the plans for the patient and assess the symptoms as we proceed in our conversation"*

The RGP role in palliative care.

Details of the items about the self-reported role of the RGPs are given in Table 3

About half of the responders reported that they were central workers in palliative care for their patients and about the same proportion reported to make themselves available outside their work hours when a patient is in the palliative setting. RGPs with more than half an hour distance from hospital more often agreed that they made themselves thus available (68%) than RGPs with less than 30 min distance (30%). They also to a larger extent reported to be central workers in palliative care, and to a lesser extent reported that patients were mostly handled by specialists, and that they did not need the RGP.

The participants wrote several comments on this topic, highlighting different, opposing views; on the one hand, several wrote that they do prioritize these patients and make house calls outside work hours, yet others argued strongly against making themselves available out of hours:

- *"I prioritize these patients and make house calls after my regular office hours"*
- *"It is ridiculous to expect the GP to be available 24 h a day"*

RGPs confidence in providing palliative care

Details for the items regarding the RGPs' confidence in the provision of palliative care is given in Table 4.

Most RGPs reported to be secure in the provision of palliative care and did not find it difficult to provide such care in general practice.

Discussion

Main findings

We found that each RGP had few patients needing palliative care and that they also had little experience with terminal care in the patient's home. Limited experience challenged the RGPs' possibilities to maintain advanced knowledge and skills in palliative care. Their clinical approach towards palliative care did not comply with the guideline; although the RGPs largely agreed to the usefulness of the recommendations, they did not use, and seemed unfamiliar with important work methods described in the guideline. Yet, most of the RPGs reported to see their role as central and seemed confident in the provision of palliative care. RGPs sense of centrality in the palliative trajectory was larger for those RGPs situated more than 30 min from hospital.

Strengths and limitations

The questionnaire (Supplementary file 1) opens for the possibility of biased self-reporting, leading participants to give exaggerated accounts of socially desired behavior [31]. This may also be a strength as there is no reason to suspect that the participants would report knowledge and skills they do not possess. The total anonymity of the survey could mitigate this bias, by allowing the respondents to express themselves more freely. Due to the importance of knowing distance from and affiliation to local hospital, information on age and gender of participants was not included in the survey, as these data could lead to identification of certain RGPs. The material gives no information of how these factors influences the answering, and challenges external validity. A response rate at 57% must be regarded as a strength as all RPGs in the county were invited, and GPs are known to typically have low response rates [32]. The non-responders (43%) may, however, present problems of participation bias, with the risk of failing to capture the full range of views. One could suspect non-responders possibly to find the topic of palliative care less relevant, and to be less active and interested in the subject of study than those who did answer the survey, thus causing over-estimation of experience and knowledge among the RGPs [33]. It has also been shown that GPs are less likely to respond to a survey the more time has passed since qualifying as doctors [33]. This may have caused more experienced RGPs not to answer, thus causing an under-estimation of the amount of experience and skills of the RGPs in our material. A previous study has shown such a positive relationship between age of the GP and both confidence about being a key worker, and likelihood of providing end of life care [34]. The total anonymity of respondents may have led to inappropriate mailing to RGPs that had already answered, causing some to answer the questionnaire twice. However, it is unlikely that many have taken the time to do this, especially as the reminder was sent shortly after the original deadline. Written comments were optional in the questionnaire and only a few respondents used this opportunity (Supplementary file 1). This may have resulted in only respondents with strong opinions commenting, and thus the results may not be representative for the total group. We still chose to include some comments in our results, thinking they convey attitudes and thoughts, apt to help in the interpretation of our findings. Although some missing data, this only caused minor alterations to our frequencies percentages results, and these are therefore given as valid percentages of those who answered. Due to sampling being restricted to one county, caution must be taken when generalizing from our findings. However, we do believe that the geographic spread of participants within the county is indicative of its representability. The area contains four hospitals of differing size, and is typical for many Norwegian counties, although lacking a larger university hospital. The data was collected in 2014. As there has not been structural changes to the palliative care services, competence requirements or general practice in Norway [1, 10, 35], we have no reason to think that our main findings are no longer valid.

Findings in the light of current knowledge

Achieving death at home for those who wish is in many respects an ideal in palliative care [36] and GP participation in the trajectory is one of many factors identified as facilitators for achievement [15, 16]. The competence requirements and role assigned to the RGPs in the guideline is a means to govern RGP participation in the wanted direction [30, 35]. We found that one third of the RGPs had not participated in terminal care at home the last three years, and that most who had participated had only experienced a few cases. The proportion of patients dying at home yearly in Norway is about 15% or less [37], and a recent study showed that the potentially planned home deaths in Norway were 6.3% of all deaths [38]. This means that an individual RGP will potentially experience a home death in their population, on average, about every two to three years, perhaps even less, as we found that near 40% of RGPs perceive that these patients are mainly handled by hospital specialists. Furthermore, we found that seeing few patients with palliative care needs, challenges the RGPs ability to maintain their competence in the field at the level required by the guideline. The finding is consistent with previous studies of procedural skills practice and training [39–41] and in agreement with a previous Norwegian study by Austad et al. [29], who found that GPs find it difficult to keep updated on guidelines for specific diseases that they do not see regularly.

The low guideline adherence among RGPs is also in agreement with previous studies of guidelines. There is a debate as to whether this may be due to lack of willingness of the GP [27], or to the guideline content [25, 28]. Comprehensive guidelines, also makes it difficult for the GPs to adhere [29], and the GPs' situation of having multiple guidelines to follow simultaneously has been identified as one factor that may impede guideline adherence [29]. The guideline for palliative care, however, differs from previously studied guidelines as it can be viewed as not diagnose-specific, thus representing a common pathway for multiple diseases at the end of life [1]. Hence, there should be no mismatch between guideline and patients' needs due to multitude of guidelines for single diseases, as previously described [29]. Still, the RGPs seem unfamiliar with the contents of this guideline. Paradoxically, although recognizing the utility of forms like the ESAS-r for symptom assessment, the RGPs seemed to be reluctant to use them. They also seemed to recognize the utility of ACPs and available, updated medical information, but did not use them either. These paradoxes seem parallel to previous findings [27]; the GPs report to acknowledge the value of guidelines, yet seeming unable to use them, and the relevance of guideline content itself may be questioned [27]. Our data implies that the RGPs are not able to meet the competence requirement and maintain the skills they are expected to in the guideline, and it needs to be established how this affects the cooperation and division of labor within the health care services.

Our findings also indicate that the RGPs to a certain degree actively choose a different approach for various reasons. They seem to perceive that they have too few cases for the symptom assessment forms to be useful to them. At the same time they confirm that they commonly approach their patients through conversation and make use of their previous knowledge of the individual patient, consistent with the widely used patient-centered clinical method of general practice described by Levenstein et al. [42]. A Norwegian study has shown that RGPs, and especially experienced RGPs, also rely strongly on person-related knowledge about their patients and that too much standardization in patient care plans can hinder genuinely tailored, individual treatment [43]. This may indicate that the working methods described in the guideline, based on the specialist health services' way of doing it, do not harmonize with the more flexible person-centered approach and working methods in general practice, demonstrated in a previous study [44].

The GP as entry-point and coordinator of primary care is a trait shared by many European countries [45] and palliative care is one of the core values of general practice according to the WHO [9]. Our findings may therefore be relevant to European and other countries with a similar health care structure. Implementation of generated medical knowledge by means of clinical guidelines is a widespread strategy in the world today and understanding of the barriers for implementation is important [30]. Our findings challenge guideline content with respect to the complexity of the knowledge the RGP is expected to maintain when patient encounters are infrequent, and whether the recommendations in the guideline fits the working methods of general practice. The guideline [1] could represent a common pathway for several diagnoses, but as it describes the patient population as consisting mainly of cancer patients, together with its origin and formal organization within the cancer care program, it may not seem relevant for general practice [1]. Whereas cancer seem to be the most frequent patient group from the point of view of the specialist in palliative care units, frailty, organ failure and dementia dominate causes of death in primary care, confronting the GP with a large variety of trajectories [46], that perhaps are difficult to standardize, as pointed out in a recent editorial by Mitchell and Murray [47]. This also raises the issue of guideline applicability as a barrier for adherence [48].

We found that only one respondent reported to participate regularly in joint meetings with the hospital specialists upon discharge from hospital, and that nearly 40% of the RGPs perceived that hospital specialists mainly handled their palliative patients. Discharge planning is an important task for the hospital based palliative teams [49]. A customized approach is expected to be beneficial and should incorporate a clear "care transition" [50]. The finding may imply that the specialist level do not act according to the guideline recommendations either [1]. This is in agreement with a previous implementation study, who demonstrated low guideline adherence among hospital specialists when they were supposed to hand over tasks to GPs [51].

In 2017, an evaluation of the palliative care services in Norway was performed [52], the report describing the RGP as "on the sideline" of palliative care. Our finding that only one fifth of the RGPs do not see themselves as central in this work, and that most seem confident in the provision of palliative care, contrasts somewhat with this report. The finding that the RGPs to a high degree make themselves available out of normal work hours also challenges this report. To our knowledge, no other Norwegian health worker has been shown to make themselves available, in their spare time, and to such an extent, and this comes in addition to having high reported work hours in the first place [53]. These findings are consistent with previous findings of GPs' commitment towards cancer patients, and providing palliative care [44, 54].

The impact of distance from hospital on the RGPs perceived role in palliative care is an interesting finding. A previous Norwegian study found that that some rural and small-town GPs contributed considerably to cancer care in their patients' local communities [55]. In a recent Danish study, they found that rural GPs were more secure in the administration of subcutaneous medication than their urban colleagues [34], and in a Dutch study, rurally based GPs were more confident in administering emergency care than urban or metropolitan GPs [56]. In the latter study, this was perceived as linked to proximity to the hospital emergency services, leading to the urban GPs being surpassed. In the case of palliative care, the hospital based palliative teams in Norway are meant to be ambulatory, acting as consultants supporting primary care [1]. The teams should ensure equality of services regardless of geography, which is a widely recognized principal in health care organization [57]. Although cultural differences between rural and urban RGPs may contribute [56], our finding may also represent a distance decay effect [58], pointing towards the possibility of unwarranted variation in the specialist service provision.

Conclusions

RGP participation in the palliative care trajectory is important to achieve the goals set by the Norwegian health authorities. Still, the RGPs display low adherence to the national guideline and have not adopted the working methods recommended in palliative care. Reluctance towards symptom assessment forms and ACPs despite judging them useful, may indicate something more than unawareness of guideline content; The guideline recommendations, inherently based on the specialists' view of best practice, may not correspond with the existing working methods of general practice, making them difficult to adopt in the clinical reality of the RGP. Clinical experience is important, and the mismatch between guideline and practice in our study may thus be at least partially explained by the fact that the RGPs have too few clinical cases over time to maintain skills at a complex and specialized level. The competence requirement posed on the RGPs in this specific guideline, may thus be difficult to implement in general practice. It is also a paradox that as much as half of the RGPs see themselves as central, at the same time as public evaluations see them as missing in the trajectories. Our findings indicate a great potential for the RGP, contributing with the inherent skills and working methods of the specialty of general practice, to be a central, key worker in palliative care.

Abbreviations

ACP: Advance care plan; ESASr: Edmonton system assessment system, revised; EAPC: European Association for Palliative Care; GP: General practitioner; RGP: Regular general practitioner; VAS: Visual analog scale; WHO: World Health Organization.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12875-021-01426-8.

Additional file 1. Questionnaire translated to English. The questionnaire consists of the first part of the original questionnaire and contains all questions relevant for this article. The original questionnaire also comprised a separate section about education, not relevant for this article, and not included in the supplementary file.

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Authors' contributions

AF and IH took part in the planning of the study. AF created the questionnaire under the supervision of IH, distributed it and handled the data in SPSS. AF, IH and BPM all reviewed the results. The paper was written by AF, and IH and BPM read the paper and made improvements of the content and wording. AF, IH and BPM have read and approved the final manuscript.

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AF is a specialist in general practice, works as a palliative care consultant, and has completed the Nordic Specialist course in Palliative care. IH is a Professor emerita in General practice at NTNU. BPM is a PhD, specialist in general practice and assistant professor at NTNU.

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Availability of data and materials

Data could be available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the regional committee for medical and health research ethics (REK) (2013/1732 / REK). All participants gave informed, written consent to the study by completing and returning the questionnaire.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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RESEARCH

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Finding their place – general practitioners' experiences with palliative care—a Norwegian qualitative study

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Abstract

Background: Modern palliative care focuses on enabling patients to spend their remaining time at home, and dying comfortably at home, for those patients who want it. Compared to many European countries, few die at home in Norway. General practitioners' (GPs') involvement in palliative care may increase patients' time at home and achievements of home death. Norwegian GPs are perceived as missing in this work. The aim of this study is to explore GPs' experiences in palliative care regarding their involvement in this work, how they define their role, and what they think they realistically can contribute towards palliative patients.

Methods: We performed focus group interviews with GPs, following a semi-structured interview guide. We included four focus groups with a total of 25 GPs. Interviews were recorded and transcribed verbatim. We performed qualitative analysis on these interviews, inspired by interpretative phenomenological analysis.

Results: Strengths of the GP in the provision of palliative care consisted of characteristics of general practice and skills they relied on, such as general medical knowledge, being coordinator of care, and having a personal and longitudinal knowledge of the patient and a family perspective. They generally had positive attitudes but differing views about their formal role, which was described along three positions towards palliative care: the highly involved, the weakly involved, and the uninvolved GP.

Conclusion: GPs have evident strengths that could be important in the provision of palliative care. They rely on general medical knowledge and need specialist support. They had no consensus about their role in palliative care. Multiple factors interact in complex ways to determine how the GPs perceive their role and how involved they are in palliative care. GPs may possess skills and knowledge complementary to the specialized skills of palliative care team physicians. Specialized teams with extensive outreach activities should be aware of the potential they have for both enabling and deskilling GPs.

Keywords: Palliative care, Primary care, Palliative medicine, General practice, Advance care planning, End-of-life care, Transitions of care, Norway

Background

Family medicine and palliative care

Palliative care in Europe is based on a comprehensive care philosophy comprising a holistic approach in a multi-disciplinary and multi-professional setting [1]. The patients can have symptoms that require simple or complex medical treatment and nursing care but may also suffer on a

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spiritual and existential level. Cicely Saunders, who first introduced this model of thinking, described this as “total pain”. The contemporary multi-disciplinary approach of palliative care focuses on the physical, mental, social, and spiritual aspects of suffering, including the family perspective [1, 2]. These principles are applicable to all patients with life-limiting illness and may also be relevant early in the disease [1, 3].

The palliative culture’s approach to the patient resembles the approach of the general practitioner (GP) in many respects [4]. Family medicine and general practice are, by their very nature, person-centred and based on a bio-psycho-social understanding of illness [5–7]. At the same time, GPs are generalists, and they relate to the entire life course from birth to death, including palliative care at end-of-life [8].

These two approaches differ somewhat from other medical fields and the specialities in the hospitals, where specialization may lead to fragmentation of treatment and care [9].

The GP’s role in palliative care

As most patients prefer to spend as much time as possible and die in their own home, the amount of home deaths is considered an important quality indicator for palliative care [3, 10–12]. In Norway, less than 15 percent of deaths take place in the home [13], and this is a low rate compared to other European countries [14]. Previous research suggests that GPs’ participation in this work could contribute to increase this rate [3, 15–20].

In Norway, the GP serves as the point of first contact and coordinator for healthcare, and access to specialist services requires a referral from a GP. By means of a listing system, all citizens are entitled to have a regular general practitioner (RGP) [21]. An RGP must be either a specialist in general practice, or in training for the speciality [21, 22]. There is a Continuing Medical Education program (CME), where groups of GPs meet regularly to maintain their competence. Beyond basic education, there is no mandatory curriculum in palliative care to practice as an RGP in Norway, or to become a specialist in general practice [22].

Palliative care in Norway is reinforced by specialized, multidisciplinary palliative care teams (PCTs). They are mainly hospital-based, work ambulatory towards primary care and has an advisor role [3]. Thus, the GPs are formally responsible for the medical care and the PCTs should not normally provide total care for the palliative patients residing at home [3].

GPs are described as missing in the palliative care trajectories, and difficult to integrate into the palliative care networks in primary care [23, 24]. We previously conducted a questionnaire study of GPs in Norway, finding that most GPs had few palliative patients at a time and that being involved in home death was a rare event, limiting their possibility of learning and maintaining complex skills and knowledge of palliative care [25]. Yet, about half of the RGPs saw themselves as central in providing palliative care in the primary care setting, challenging the prevailing views of the Norwegian GPs’ as “missing” or uninterested in palliative care [23]. These findings suggest variation in GPs’ involvement in palliative care that remains unexplained at this point.

The aim of this study is to explore GPs’ experiences in palliative care regarding:

- Their involvement in this work.
- How they define their role.
- What they think they realistically can contribute towards these patients.

Methods

Design

We aimed to explore experiences and perceptions, and thus a qualitative approach was chosen. Focus group interviews are deemed a quick and convenient way to gather data from several people and have the advantage that group interaction often stimulates good discussions [26]. We expected the group dynamics to further illuminate the variable attitudes and experiences we aimed to investigate. A semi-structured interview guide was designed to ensure that the same topics were explored in all interviews. The data for this paper are drawn from the first part of the interview guide exploring experiences with and role in palliative care (Additional file 1), whereas the second part of the interview provides the basis for another paper not yet published, focusing on barriers towards guideline implementation. We wanted to explore the GPs’ experiences of working with palliative care, followed by a discussion about their role in palliative care. The questions were open-ended and the order flexible. Related topics raised spontaneously were explored, and the participants could revisit previous topics if needed.

Participants, setting, and data collection

We approached established CME groups of RGPs and one tutorial group of RGP trainees. The groups were purposively recruited, aiming to include RGPs from both urban and rural settings, with different lengths of experience, and with variation in gender and age. The RGPs were affiliated with four different hospitals, and thus different PCTs. Groups were located by identifying the group administrators and were subsequently approached by AF personally and included if all the members agreed to participate. In this process, one group declined due to lack of time. Each individual participant gave written consent. For reasons of convenience, we invited groups from two counties in Mid-Norway to participate.

From February to June 2018 four groups with a total of 25 participants were interviewed once, at a location of their choice. The median age was 42. The mean patient list length was 1,032, and the mean amount of experience in general practice was 10.5 years. Groups 1 – 3 were CME groups. The fourth group was the tutorial group where the tutor was a specialist in general practice. The participants in this group were younger, with a median age of 32, excluding the tutor.

Details of the demographic and professional data are given in Table 1.

The interviews were moderated, recorded on audio tapes, and transcribed verbatim by AF. An experienced qualitative researcher participated as support and observer of the interviews, while also providing extensive field notes of the sparce non-verbal expressions of interest for the discourse. For each interview, the content was compared with the previous interviews and field notes in search of new topics. In the fourth interview new relevant topics did not evolve and the data was deemed as saturated, holding sufficient information power to illuminate our research questions [26, 27]. The interviews progressed in a calm manner, differences of opinions were welcomed with interest, and the participants politely gave room for each other in the discussion, with no overt negative emotions. The groups raised questions resulting in the discussion of topics not covered by the interview guide, such as doctors' delay and ethical considerations.

Analysis

We performed a qualitative analysis inspired by interpretative phenomenological analysis (IPA) described by Smith [28–30]. The transcribed interviews were re-read several times by AF and BPM separately for an overall impression. We then worked through the transcripts, noting interesting topics and thoughts. The use

Table 1 Characteristics of the participating GPs (1-25) in groups (1-4)

Group	GP number	Gender	Age[b]	Practice	List length[b]	Setting	Specialist	Years as GP
1	1	M	40–45	Group	1400	urban	Yes	10
	2	M	40–45	Group	1450	urban	Yes	15
	3	M	40–45	Group	1200	urban	Yes	13
	4	F	45–50	Group	1100	urban	Yes	9
2	5	M	60–65	Group	1000	urban	Yes	29
	6	F	45–50	Group	1000	urban	Yes	15
	7	M	45–50	Group	1000	urban	No	10
	8	F	45–50	Group	600	urban	No	7
	9	M	65–70	Solo	700	urban	Yes	39
3	10	M	55–60	Group	1050	rural	Yes	8
	11	F	35–40	Group	1000	rural	Yes	6
	12	M	35–40	Group	1000	rural	No	6
	13	F	40–45	Group	1200	rural	Yes	11
	14	F	30–35	Group	550	rural	No	4.5
	15	M	60–65	Group	1000	rural	Yes	30
	16	M	40–45	Group	1000	rural	Yes	12
4	17	M	30–35	Group	900	rural	No	4.5
	18	F	30–35	Solo	1000	rural	No	2
	19	M	30–35	Group	1000	urban	No	1
	20	M	35–40	Group	1100	rural	No	3
	21	M[a]	45–50	Group	1100	rural	Yes	15
	22	F	30–35	Group	1350	urban	No	2
	23	F	25–30	Group	1050	rural	No	3
	24	M	30–35	Group	1300	rural	No	3.5
	25	F	30–35	Group	750	rural	No	3.5

M Male, *F* Female

[a] Group tutor

[b] Age given in intervals and list lengths rounded to ensure anonymity of participants

of language was reflected on. Based on this, codes and emergent themes were identified for each interview and connections across themes explored. When all the interviews were thus analysed, AF and BPM discussed patterns across the interviews, looking for superordinate, shared themes. We then applied the same approach, following each GP's voice through the interviews, with the intention to capture the particular (idiographic) accounts of individuals [28, 29, 31]. Author IH read and analysed the interviews independently, cross-checking whether identified themes corresponded with the overall impression from the interviews.

To enhance credibility and confirmability of the study, preliminary results were presented and discussed in different forums of peer researchers, GPs, and palliative care physicians.

The data was initially handled in the NVivo software and then transferred to Microsoft Word documents for the completion of the analysis.

Results

The material yielded rich descriptions of what the GPs perceived as their strengths in providing palliative care. Positive attitudes prevailed in all the groups, but when it came to their formal role in palliative care, no consensus emerged, as the GPs took differing positions. Below we present the findings with some illustrative examples.

Strengths of the GP in providing palliative care

The GPs highlighted characteristics of general practice that they believed were significant for their provision of palliative care, as well as relevant skills they relied on in this work.

In all the interviews, the GPs expressed confidence that they had *general medical knowledge*, sufficient to provide basic palliative care, as described by this GP:

> *GP 1: "But pain, nausea, constipation, ordinary palliative symptom relief, are problems I think many of us can deal with."*

The GPs thought that providing *continuity of care* could be important for their palliative patients. They described following their patients over several years, through various medical diagnoses and events. Having *personal knowledge* of both the patients and their families was regarded as unique for the GP and included knowledge about the patient as a person (personal traits, behavioral responses, hobbies of interest) as well as important life events. This relationship was also seen as important for the feeling of *safety for the patient*. Doctor 9 put it like this:

> *GP 9: "It can be quite reassuring to have a doctor who knows the patient. In many cases, that doctor has treated the patient for many years, and may be more than just some random doctor to them. They see you as a real person. At least I can say that many of my patients have been my patients since I started practising. That means we know each other well."*

Also, being *able to console* the patient and family when entering the palliative trajectory was highlighted as an important, yet challenging, task. One GP put it like this:

> *GP 21: "Usually when we console people in private like that, we tell them that everything is going to be okay. Don't worry, it will be fine. But under these circumstances, you can't say that, so you have to think of something else to say to them, that is, you have to come up with a different story. Then you have to be able to say something like 'We're going to do everything we can going forward.' That's what we'll do. You have to give them something in this situation, right?"*

Several of the GPs stated that they were *able to deal with the existential needs* of the patients and relatives. The GPs discussed how they saw it as an important, yet challenging, task to help the patients to come to terms with a serious diagnosis and a poor prognosis. As one GP described:

> *GP 13: "It can be a bit challenging to get the patient to concentrate on the right things early on, rather than putting things off. I don't want to be negative about the prognosis, but I know it's bad, and that things can take a turn for the worse quickly, so it's important to think through these things and to decide what is important. I find that challenging."*

Being the GP of family members also positioned them to *provide psychosocial care* for the whole family, not necessarily thinking of it as providing palliative care, but as part of their everyday work. Many reported to be RGP for several family members like spouses, parents, and children:

> *GP 22: "Yes, I think it was a little easier, maybe because I was, and still am, the whole family's RGP. Because of that, I saw them more frequently, like when the children were sick, that is, her grandchildren. And it was only natural that I discussed the mother then."*

The GP's position as *coordinator of care* was seen as valuable for palliative patients and particularly important in longer trajectories, elderly patients, and non-cancer diagnoses. The GPs stressed the importance of receiving realistic prognostic information to be able to recognize patients as palliative. RGPs receive discharge summaries from all the different specialists in hospitals and need this information, as highlighted by this GP:

> *GP 24: "But when they're just sitting there at the hospital, in front of the hospital doctor, sort of nodding their heads and trying to look like they understand, well, then maybe they can't even manage to react because they're in shock. I've experienced several times that they have come to me afterwards and said that they want to come to me every time to review the medical records in question, because I tell them what the records mean, to give them a better understanding."*

How GPs perceive their role in palliative care

Having generally positive attitudes

When it came to attitudes towards palliative care as a field, the GPs were generally positive. Although most expressed some ambivalence related to the demands, it was seen as *rewarding work* and something from which the GP would benefit both personally and professionally:

> *GP 10: "Of course, it's demanding, but it's also challenging in both medical and human terms, and it's interesting. You get really close to the patient, and sometimes even to the relatives. Sometimes I almost feel like I'm part of the family, especially towards the end, when there is fairly close follow up. Yes, it is a special situation, but I often find it a rewarding part of the RGP-patient relationship."*

They particularly highlighted the importance of being able to end a long-term doctor-patient relationship in a good way, fulfilling a need for closure. Although participation in planned home death varied greatly, this was highlighted as an ideal by GPs in all the interviews, as in this exchange from interview 2:

> *GP 6: "I was on an emergency, out of hours house call yesterday, to see a patient who was allowed to die at home. There was a tremendous sense of calmness and serenity under the circumstances." GP 8: "Yes, there is great dignity when they can be allowed to stay at home, as long as the relatives can handle it. Being in safe, familiar surroundings is really wonderful, in my opinion."*

As the work was seen as valuable, some of the GPs expressed a sense of loss when they perceived that care of the patient "disappeared" into the hands of others. Also, there seemed to be a transition over the years where some GPs had lost some of their tasks to others:

> *GP 9: "But I also feel, like GP 5 said, that we have lost a little ground. Considering some of the other things we're required to do, I think maybe this would be rather more worthwhile than a great deal of the other [things we do]. It would be prudent for us to maintain our expertise in this, and I think it would also be worthwhile for many patients as well."*

Describing their role – three positions towards palliative care

Whereas attitudes were generally positive, views about their formal role in this work varied. Across the interviews, no consensus emerged concerning the GP's role and how much they thought the GP should participate in palliative care. The different accounts followed three main patterns. We interpreted this as the GPs displaying different levels of involvement with palliative care. Although this involvement must be understood as ranging over a continuum, and not all the individual GPs' accounts contained enough information to be thus classified, three illustrative positions towards palliative care emerged: the highly involved, the weakly involved, and the uninvolved GP. The three positions, with their key characteristics, are presented and illustrated below:

The highly involved GP

GPs of this category were found in groups 3 and 4. They were represented by both older and younger GPs, specialists, and non-specialists, and both genders. Additionally, they all worked in rural environments.

The highly involved GPs described themselves as *the key worker* in palliative care in their community; they participated regularly in this work and would prioritize these patients. They thought of palliative care as a natural part of their job. They also described how they regularly participated in terminal care at home almost as a normal, everyday event:

> *GP 18: "Well, I've had a few patients over the years. There were two home deaths last week, I think."*

These GPs described themselves as being in charge and saw other trajectory participants as resources they could draw on. Cooperation was described according to predictable patterns, and the GPs were confident where to get help, both from hospital specialists and the community nursing service.

> *GP 16: "I think it would have been difficult to have a good death at home without an RGP involved, assuming the role of primary actor. You can use the palliative team as a resource, and the community nursing team can also be a valuable resource for implementation and observation, but in any case, the RGP is right in the thick of things, exactly where he or she has to be to make this work, in my opinion."*

These GPs described the presence of *clear clinical handover* processes from the hospital specialists, especially for cancer patients. The handover was typically signalled by cessation of curative treatment, as described by this GP:

> *GP 16: "It's fairly common to have an attending oncologist who's been in charge of the patient throughout the course of the curative treatment. Then at some point, the oncology department decides that it's time to discontinue the curative treatment and move on to palliative treatment. I experience this transition as being very clear."*

The highly involved GPs described how they proactively claimed a role or reclaimed the patient when entering the palliative phase. They also highlighted the importance of advance care plans (ACPs), and would make themselves available out of hours (OOH):

> *GP 15: "I've been involved in many palliative situations. I feel like the most beautiful deaths, the best for the patient and relatives alike, have been when people die at home. However, they have also been the best planned, most thoroughly organised deaths. Me being available on my mobile phone gives a sense of security to the patient, the home care team, and the relatives. However, I very rarely get such calls. I've never been rung up at night, and only a few times on evenings and weekends. When I have been contacted, it's been nice because things can be resolved quickly by phone."*

The weakly involved GP

GPs of this category were found in interviews 1 and 4. They were of varying gender and age (although none were over 50 years of age), both specialists and non-specialists, and worked in urban or rural environments.

The weakly involved GPs expressed ambivalence about what their role in palliative care was and debated whether other participants might do a better job, thus questioning their own ability to provide total care. They spoke about the PCTs as in charge of the palliative cancer patients and expressed unsureness about who was in charge in the case of non-cancer diagnosis. They rarely participated in planned home death and described how other professionals took over care and how they lost track of the patients:

> *GP 2: "The cancer patients are quickly taken over by a palliative team at the hospitals that often do the emergency house-calls too." GP 4: "Absolutely!"*

They displayed variable involvement in palliative care, often associated with specific circumstances. Having *a prior close doctor-patient relationship* was given as a factor in increasing involvement. They could be *actively involved by other participants* in the trajectory as described by this GP:

> *GP 22: "I actually played quite an important role at those times. But the municipal oncology nurse was in charge, and she called me in when they had meetings. And I always visited the family as well." Interviewer: "So, in other words, you were encouraged to play an active part in the process?" GP 22: "Yes. And it was actually very rewarding."*

These GPs described being more involved if *no clear hospital specialist was in charge*, e.g., when the patient had several illnesses and did not suffer from cancer. This would typically be older patients with longer, more unpredictive palliative trajectories. This GP described such a case where the patient was multimorbid:

> *GP 3: "I have a totally different story as well, about a time when I was left sitting with everything all on my own. But that wasn't cancer. There was no hospital specialist, or whoever. Maybe I could have consulted the people in the stroke unit when she was there, but it was what it was."*

The weakly involved GPs described a *less clear clinical handover process* for palliative care patients than the highly involved GPs. This topic included the *division of labour* and *quality of the information* transferred from the specialists. An ad hoc negotiation in the service from case to case, with no clear system, was also described – typically, the GP would perform the tasks if no one else would, as expressed by this GP:

> *GP 3: "When time is at a premium, I find myself dodging or skipping things, if there are others who can handle them. I step up when I have to, though."*

The weakly involved GPs were less inclined to be proactive than the highly involved GPs. They were ambivalent and presented reasons to not to contact the patient, take charge or make themselves available:

> *GP 21: "I think it is very important, because it is about protecting ourselves a little and having some time off. We can of course work constantly. Like, work every day, seven days a week, and never take a day off. I think it's important that we can tune out occasionally and take some time off."*

The uninvolved GP

GPs of this category were mainly found in interview 2. They were both older GPs and younger and could be specialists or non-specialists. They all worked in an urban environment.

The uninvolved GPs typically thought of palliative care as something GPs were little involved in and thought that these tasks belong with the palliative teams or other specialists. They described inconsistent involvement in palliative trajectories, and this mainly happened if the specialist in charge was not available – an exception from the "normal." Contact with the patient was described as lost when the patient disappeared into the hands of the hospital specialists. They did, however, describe more involvement in patients with non-cancer diagnoses or longer palliative trajectories. They reported sporadic involvement in planned home death, if at all:

> *GP 9: "It was a pure coincidence because the palliative care team was away, and I was contacted to make a house call. So, I went to see him, and it was a nice experience for both of us. He died the following week. But if the team not been gone [on summer holiday], we wouldn't have had that encounter."*

Cooperation seemed unpredictable to these GPs, and they didn't seem to know the structure of the palliative care services well, as evident from this statement:

> *GP 5: "I can just say, from my perspective, that our role in this has diminished significantly over the years. This has happened as the municipal teams have evolved, and the hospital also has a group, doesn't it?".*

They presented strong and compelling reasons not to be proactive. They pointed to the very nature of general practice, having no tradition for outreach activities, and pointed to the boundaries of their working hours. They discussed whether it was ethically appropriate to prioritise patients with palliative needs over other groups of vulnerable patients. They also found it problematic to invite themselves into the patient's home for a house call and then to charge them afterwards, as illustrated in the following quote:

> *GP 6: "We are, in point of fact, self-employed. It might sound silly, but it strikes me that I have a financial incentive for making house calls and I would like them to call. Or I could ring them up and ask if they would like me to come. But I'm not going to just show up, ring the bell and say: 'Here I am.' To be clear, this discussion is not just about palliative patients. There are no doubt many patients who might appreciate us reaching out to them."*

Discussion

Main findings

This study investigates GPs' experiences in palliative care concerning their role and involvement, from their own point of view. Whereas GPs generally had positive attitudes, they also saw working with palliative care as demanding. The participating GPs pointed to various aspects of being a GP as their strengths in palliative work. They highlighted elements of the structure of general practice as important, including characteristics such as a longitudinal relationship with the patient, unique knowledge of both patient and family, and the GP as coordinator of care, representing continuity of care. They reported to have skills to provide basic symptom relief due to possessing general medical knowledge and the ability to provide psychosocial as well as existential care for their seriously ill patients, but they also relied on support from the specialized PCTs. The PCTs were seen as mainly serving cancer patients, whereas getting specialist support for multimorbid patients was more difficult. At the individual level, the GPs displayed different positions towards their role in palliative care, from the highly involved GP who feels central to the palliative care process, through the weakly involved GP, to the GP who is uninvolved in palliative care. There was a rural – urban difference, with rural GPs being more involved in palliative care than their urban colleagues.

Strengths and limitations

Steps were taken to ensure trustworthiness of our results [32]. Consistency of results was ensured by author IH reading the interviews independently. Discussion of preliminary results with peers adds to the credibility of our results. Interpretative phenomenological analysis rests on a firm theoretical framework, a well described method, and a focus on extensive reflexivity, adding to the dependability and confirmability of findings [30]. To increase transferability of results, we have provided rich descriptions of the research setting, and our results are accompanied by direct quotes [32].

AF previously worked as an RGP and is currently working as palliative care consultant and BPM and IH are both experienced RGPs. Our experience gave us valuable insights and access to the field of interest. AF did not have previous knowledge of the groups beyond being acquainted with some of the participants from other professional settings. The moderator's role and how this could affect the group discussion became the subject of reflection in the analysis process supported by field notes, as described above.

Recruitment of GPs for research purposes is known to be difficult, and willingness to participate may be influenced by the GPs' interest in the subject studied [33]. Approaching established groups of GPs not only eased the inclusion, but recruitment at the group level also allowed for the inclusion of GPs without special interest in the topic. Restricting recruitment to one geographic region raises issues of representability; on the other hand, it allowed for purposeful and strategic sampling within this region. In Norway, the structure of the health regions is similar, and our sample of GPs does not differ significantly from other Norwegian GPs in terms of age, gender, and experience level, and we believe our results could be representative for many Norwegian counties.

The participants were peers and represented a fairly homogenous group of professionals. As these were preexisting groups, the familiarity between the participants allowed them to reflect openly and express themselves freely. In our view, this reduces concerns about group dynamics challenging the validity of analysing individual accounts within the material. Although the individual voices in a focus group must be interpreted in the light of the group context, the application of an IPA-approach to focus groups has been successfully conducted by several authors, and we believe it supported the exploration of individual (ideographic) aspects in our material [28, 29, 31].

Whereas focus groups stimulate discussion, it also opens for biases of self-presentation and social desirability [34]. For instance, expressions of strong positive attitudes towards palliative care could be exaggerated within the group, thus hindering views that conflicted with this. We did not, however, uncover any overt signs of this during the analysis [34]. The existing social ties of the group could also aggravate evaluation apprehension or normative influences [35]. This was particularly relevant for the fourth group, as the senior tutor took part in the group discussion, potentially taking a lead. This potential was considered before the interview and steps were taken to encourage all participants to take part in the discussion.

Findings in the light of current knowledge

The Norwegian healthcare structure has similarities with many countries in Europe, and our finding may be of particular relevance to countries with a similar listing system for GPs [21, 36–38]. The planning of palliative care in rural areas is recognized as a challenge in several countries, to which our findings about rural GPs may be relevant [39, 40].

Issues of GPs' participation in palliative care have been addressed in previous studies, and barriers such as resource concerns, access to palliative care expertise, or lack of formal training and knowledge have been identified [41]. The importance of GPs' participation in the palliative care trajectory, particularly when it comes to increasing time and planned home deaths, has been demonstrated by various authors both prior to [15–17, 19, 20] and contemporary with our study [42, 43]. Our findings add to this evidence by demonstrating that GPs have abilities and are aware of important strengths they could contribute to palliative care processes.

A key feature highlighted by the GPs in our material was the continuity of care provided by the GP, which is in line with previous findings [44, 45]. In a Norwegian study in 2020, likeliness of a home death increased with the number of home visits from the GP, whereas having to leave the home for GP consultations, OOH-services, or hospital admission was associated with a reduced likeliness of a home death [43]. A recent Danish study showed increased home death rates independently of the number of contacts with the GP in a clinic that adopted an active and structured approach to palliative patients [42], indicating that there is a link between the mere involvement of GPs in the palliative trajectories and the likeliness of achieving home death. A long-standing GP-patient relationship is known to reduce the use of OOH-service and hospital admissions in the general population [46]. Furthermore, it is known that continuity of care in primary care is important when organizing palliative care [45, 47], and according to a systematic review from 2021, the lack of continuity of care is associated with end-of-life hospital admissions OOH [48]. A recent Norwegian study found that GPs find it hard to avoid OOH hospital admissions if they have not been involved in the care of the patients [49]. In correspondence with this, our GPs could be right in thinking that the continuity they provide may be a particularly important contribution towards the palliative patients.

Our material suggests that the general medical knowledge that GPs possess could enable them to provide symptom control for many patients at the end-of-life. Most dying patients do not need specialized palliative care to achieve symptom control [50, 51]. Previous findings indicate that GPs are familiar with the treatment of symptoms that are frequent in palliative care and have skills to provide basic palliative care, whereas they do not seem to have the same awareness of the treatment of more uncommon symptoms, and bereaved relatives perceive patient outcome as poorer compared with other care settings [52, 53]. Also, GPs' skills and knowledge in palliative care has been shown to vary [54]. This brings into play the GPs' need for specialist support. In our study, all the groups seemed to cooperate with PCTs at some level, and even the highly involved GPs relied on advice from PCTs. Accumulated evidence indicates that primary care needs such support from specialist PCTs to provide good quality palliative care [55, 56].

We found that the GPs displayed different levels of involvement in palliative care, and there was no consensus about their formal role. As early as in the 1990s, it was pointed out that the evolvement of PCTs allowed for the "blurring of roles" and that GPs felt that the patients were "taken over" by the PCTs [40, 57]. More recently, Wyatt et al. demonstrated unclarity of the GP's role in end-of-life care and lack of a consensus of the GP's role among the GPs themselves [56]. Our findings suggest that the GPs' views about their own role is linked to how they perceive the role of the PCTs. Whereas the highly involved GPs described a close collaboration with the PCTs as an advisory resource, the less involved GPs described the PCTs as in charge of care, with the GP being on the side-line. This may suggest that it is not irrelevant how the collaboration between the GPs and the PCTs is undertaken. Evidence suggests expanding specialized palliative services is done at the expense of GPs' ability to participate and maintain essential competencies in palliative care [56]. These findings pinpoint a central premise that is also evident in our study: GPs' behaviour cannot be seen in isolation from the partners they collaborate with, as views about the GPs' role rest in part on what they perceive to be expected of them. Thus, GPs' general positive attitudes about palliative care do not by themselves determine the GPs' degree of involvement, as these subjective normative beliefs must be taken into account [58].

Our findings indicate that GPs have skills and knowledge that are unique to them. However, previous findings indicate that GPs could be bypassed when the community nurses get direct access to the PCT physicians, perceiving them as more skilled and more available [54]. Such deficient practices do not only put the GP on the side-line [54], but also indicate that the value of the GPs' contributions is not acknowledged. We argue that GPs' skills and competencies seems to be complementary to those of PCT physicians, in much the same way as between GPs and municipal oncology nurses [54]. This merits a focus on including the GPs in the multidisciplinary approach to the palliative patients.

We found that the less involved GPs also experienced unclarities in the clinical handover of palliative patients from the hospital specialists. For palliative patients, care transitions represent a particular challenge, and the timely exchange of necessary information is vital [49].

The tendency for rural GPs to be more involved than urban GPs in palliative care must be interpreted with caution due to our sample size. This is, however, in line with our previous questionnaire study, showing that rural GPs to a larger degree reported to be central in palliative care [25]. In an Australian study, rural and remote GPs were found to have more responsibility for their palliative patients and less support from the PCTs than their urban colleagues [40]. Growing evidence thus suggests that geography plays a part in the division of tasks between PCTs and GPs, in turn possibly reinforcing these differences, resembling the "cycle of causation" described by Wyatt et al. [56]. Such a mechanism could possibly lead to the enabling of rural GPs, accessing the PCTs as a remote resource, and the deskilling of urban GPs, being put on the side-line of PCTs that provide more of the care in urban environments. In Norway, although conforming to national legislation, the practical organization of primary care in different municipalities varies, and steps to accommodate for a longer travel distance from the hospital may be appropriate. For the hospital specialists, however, our findings seem like a departure from the ideal of equality of services, strengthening our suggestion of unwarranted variation in the specialist service provision from the findings in our previous study [25]. These connections may need further investigation. Furthermore, it seems unnecessarily costly to let specialist services perform tasks that primary care demonstrably could manage, and this also challenges the principle of lowest effective level of care set by the Norwegian government [59]. To be able to meet the requirements, GPs do however need sufficient time and resources, which is not the case for many GPs in Norway today [60].

Salient in all the interviews was a relatively weaker, or total lack of, specialist support for palliative patients with non-cancer diagnoses, in particular for multimorbid patients. Our material thus demonstrates the perseverance of the view of palliative care in general, and PCTs in particular, as relevant mostly for cancer patients. This is in breach with the definitions of palliative care [61] and represents a problem for the timely provision of palliative care to all patients in need, irrespective of diagnosis [62].

Conclusions

This study has shown that GPs encounter patients needing palliative care. They have evident strengths that could be important in the provision of palliative care for their patients. They rely on general medical knowledge and may need specialist support. The GPs we interviewed did not have a clear consensus about their role in palliative care. Multiple factors, including attitudes, collaboration, and clinical handover, seem to interact in complex ways to determine how GPs perceive their role and to what degree they are involved in palliative care.

Strengths, such as having a longitudinal, personal relationship with the patients and the continuity of care, may be unique to the GP, thus providing skills and knowledge complementary to the specialized skills of the PCT physician. Specialized teams with extensive outreach activities should be aware of the potential they have for both enabling and deskilling the GPs they collaborate with.

Abbreviations

ACP: Advance Care plan; CME: Continuing Medical Education program; EAPC: European Association for Palliative Care; GP: General Practitioner; IPA: Interpretative Phenomenological Analysis; OOH: Out-Of-Hours; PCT: Palliative Care Team; RGP: Regular General Practitioner; WHO: World Health Organization.

Supplementary Information

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Additional file 1. Interview guide focus group interviews; Palliative care in primary health care.

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Authors' contributions

AF, IH, and BPM took part in the planning of the study. AF created the interview guide under the supervision of BPM and IH, and the interviews were conducted by AF with the help of BPM. AF transcribed the interviews. AF, IH, and BPM all took part in the analysis of the data sets and reviewed the results. The paper was written by AF, and IH and BPM read the paper and made improvements of the content and wording. AF, IH, and BPM have read and approved the final manuscript.

Authors' information

AF is a specialist in general practice, works as a palliative care consultant, and has completed the Nordic Specialist course in Palliative care. IH is a professor emerita in General practice at NTNU. BPM is a PhD specialist in general practice and assistant professor at NTNU.

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Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available. Norwegian legislation requires data to be stored on a password-protected file on a university server for reasons of confidentiality and privacy. Access to the data is restricted to a period after completion of the project. Data could be available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was performed in accordance with the declaration of Helsinki and was approved by the regional committee for medical and health research ethics (Regionale komiteer for medisinsk og helsefaglig forskningsetikk) (2017/903/REK midt). All participants gave informed, written consent to the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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