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CAncer Patients with pre-existing **SE**vere **ME**ntal **D**isorders

QUALITY IN PALLIATIVE CARE

PhD Dissertation

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AI

M36 Colpilot and Grammarly was used to optimise grammar, language, and clarity in parts of the dissertation. No AI tools were used for scientific work, data analysis, interpretation, or development of the study's results.

Outline of the thesis

This thesis is based on the project 'Quality in Palliative Care for Patients with Severe Mental Disorders'. This was a multi-method study conducted from 2023-2026. The project originated in the Department of Oncology at Aarhus University Hospital, Denmark. Danish and English summaries are found on the first pages. **Chapter 1** defines the issues for the thesis. The aim of the thesis is given in **Chapter 2**. **Chapter 3** describes the methods and materials. **Chapter 4** goes through the results. **Chapters 5 and 6** discuss the methods and results. **Chapter 7** summarises the conclusions relevant to the aims of the project. **Chapter 8** gives perspectives and offers suggestions for future research. A full reference list of the thesis is provided, the three papers are shown, and finally, **Appendices** include participant information and consent materials, interview guides, unpublished sub-analysis and questionnaires.

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Motivation

During my early years as a young doctor working across different departments, I developed a particular interest in the care of patients with severe mental disorders, not least because of clear disparities in the treatment they often receive. Now, three years later, I remain strongly motivated to understand the unique challenges patients with severe mental disorders may face at the end of life, and to continue doing research that can improve the quality and equity of care for patients with severe mental disorders in palliative settings.

List of original papers

This PhD thesis is based on the following three original studies:

I. *Experiences With End-of-Life Care for Patients with Pre-Existing Severe Mental Disorders, Their Relatives, and Healthcare Professionals*
Bøndergaard KB, Møller JE, Nielsen MK, Videbech P, Neergaard MA.
Published in International Journal of Mental Health Nursing, 2025

II. *Quality in Specialist Palliative Care for Patients with Pre-Existing Severe Mental Disorders: A Retrospective Cohort Study*
Bøndergaard KB, Nielsen MK, Videbech P, Møller JE, Johnsen SP, Eriksen JG, Groenvold M, Hannigan B, Neergaard MA.
Published in Palliative Medicine, 2026

III. *Quality in Palliative Care for Patients With Pre-existing Severe Mental Disorders – A Questionnaire Study with Danish Health Care Professionals*
Bøndergaard KB, Nielsen MK, Videbech P, Møller JE, Videbech NM, Fløe LE, Neergaard MA.
Submitted to Journal of Mental Health, April 2026

Additional papers published during the PhD

I. *Barriers in cancer trajectories of patients with pre-existing severe mental disorders – A systematic review*

   Bentson TM, Fløe LE, Bruun JM, Eriksen JG, Johnsen SP, Videbech P, Brogaard T, Andreassen P, Mygind A, Bøndergaard KB, Neergaard MA.

   Published in Psychooncology, 2023

II. *End-of-life care for cancer patients with pre-existing severe mental disorders – a systematic review*

   Svansson H, Bøndergaard KB, Videbech P, Nielsen MK, Møller JE, Fløe LE, Bentson TM, Neergaard MA.

   Published in Annals of Palliative Medicine, 2024

III. *Burnout and psychosocial working environment in specialised palliative care: A cross-sectional study of a multiprofessional cohort*

   Gronlund JK, Møller CM, Bøndergaard KB, Neergaard MA.

   Published in Palliative Medicine, 2026

IV. *Symptom burden and quality of life in patients with severe mental disorders initiating cancer treatment*

   Fløe LE, Mygind A, Eriksen JG, Videbech P, Bøndergaard KB, Neergaard MA.

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Kirstine Bundsbæk Bøndergaard, Aarhus 2026

Abbreviations

SMD	Severe Mental Disorders
SPC	Specialist Palliative Care
EOL	End-Of-Life
ACP	Advance Care Planning
GP	General Practitioner
HCP	Health Care Professionals
ICU	Intensive Care Unit
ED	Emergency Department
EPJ	Electronic Patient Journal
DPD	Danish Palliative Database
EORTC QLQ-C15-PAL	The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire, Core-15 Palliative
PROMS	Patient Reported Outcome Measures
QoL	Quality of Life
95%CI	95% Confidence Interval
IQR	Inter quartile range
RR	Relative Risk
MR	Median Risk

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Dansk resumé

Baggrund: Den sidste del af livet kan være præget af betydelig lidelse for terminalt syge patienter med samtidig svær psykisk sygdom og deres pårørende. I Danmark tilbydes palliativ behandling både på basalt og specialiseret niveau. Viden om kvaliteten af palliativ behandling til patienter med i forvejen eksisterende svær psykisk sygdom har dog hidtil været begrænset.

Formål: Det overordnede formål med ph.d.-projektet var, gennem tre delstudier, at undersøge oplevelser med og kvaliteten af lindrende behandling til patienter med livstruende sygdomme, som samtidig har svære psykiske sygdomme.

Metoder: De tre individuelle studier der indgår i denne afhandling, brugte forskellige metodiske tilgange:

1. Et kvalitativt interviewstudie med patienter, pårørende og sundhedsprofessionelle.
2. Et retrospektivt kohortestudie baseret på data fra Dansk Palliativ Database.
3. Et spørgeskemastudie blandt sundhedsprofessionelle i palliative enheder samt praktiserende læger.

Resultater: Kvaliteten af palliativ behandling til patienter med svær psykisk sygdom blev generelt vurderet god, men præget af væsentlige forskelle i forløb og adgang. Patienter med svær psykisk sygdom udfyldte sjældnere symptomscreeningsskemaer ved opstart af specialiseret palliativ indsats og oplevede længere ventetid før opstart af specialiseret palliativ behandling, hvis de havde været i psykiatrisk behandling det sidste leveår. Deres samlede forløb i palliativt regi var kortere end hos patienter uden et aktivt psykiatrisk forløb.

Nogle forløb bar præg af, at sundhedsprofessionelle kunne opleve usikkerheder ved at tale med patienterne om deres psykiske lidelse og det at være terminalt syg, hvilket kunne føre til mindre åbenhed og kommunikation. Tværfagligt samarbejde og koordinering var udfordret i nogle forløb, hvor sundhedsprofessionelle vurderede kvaliteten dårligere, når patienten fx blev henvist for sent.

Forbedringsmuligheder omfatter fokus på at styrke patienten i relationer til pårørende og sundhedsprofessionelle, åben og nysgerrig kommunikation samt styrket samarbejde på tværs af sektorer. Fokus på symptomscreening og rettidig henvisning til specialiseret palliativ indsats kan potentielt styrke kvaliteten.

Perspektiver: Resultaterne peger på specifikke opmærksomhedspunkter i mødet med patienter, der både har palliative behov og svær psykisk sygdom. Disse kan anvendes af både klinikere og beslutningstagere med henblik på at styrke kvaliteten af palliativ behandling i Danmark.

English summary

Background: The final phase of life can involve substantial suffering for terminally ill patients with pre-existing severe mental disorders and their relatives. In Denmark, palliative care is provided at both basic and specialised levels. However, knowledge about the quality of palliative care for patients with pre-existing severe mental disorders has so far been limited.

Aim: The overall aim of this PhD project was, through three sub-studies, to explore experiences with, and the quality of, palliative care for patients with life-threatening illnesses who also have severe mental disorders.

Methods: The three individual studies included in this thesis used different methodological approaches:

1. A qualitative interview study involving patients, relatives, and healthcare professionals.
2. A retrospective cohort study based on data from the Danish Palliative Care Database.
3. A survey among healthcare professionals in palliative care units, as well as general practitioners.

Results: The quality of palliative care for patients with severe mental disorders was generally assessed as high but characterised by differences in care pathways and access. Patients with severe mental disorders completed symptom assessment forms less frequently at the start of specialised palliative care and experienced longer waiting times before initiating specialised palliative care, particularly if they had received psychiatric care in the last year of life, and their total time in palliative care was shorter than for patients without an active psychiatric trajectory.

Some care pathways were affected by healthcare professionals’ uncertainty when discussing mental illness and terminal disease, which could reduce openness and communication. Interdisciplinary collaboration and coordination were challenging in some cases, and healthcare professionals assessed the quality as poorer when, for example, the patient was referred too late.

Opportunities for improvement include strengthening the patient’s relationships with relatives and healthcare professionals, maintaining open and curious communication, and enhancing collaboration across sectors. A stronger focus on symptom screening and timely referral to specialised palliative care may potentially improve quality.

Perspectives: The findings highlight specific areas of attention when caring for patients who have both palliative needs and severe mental disorders. These insights may be useful for clinicians and decision-makers aiming to improve the quality of palliative care in Denmark.

1. Background

1.1 Severe Mental Disorders

According to the World Health Organisation (WHO), nearly one in seven people worldwide lives with a mental disorder, and the global incidence continues to rise (1, 2). WHO defines mental disorders as clinically significant disturbances in cognition, emotional regulation, or behaviour. This thesis focuses on severe mental disorders (SMDs), defined by WHO as ICD-10 diagnoses of moderate-to-severe depression (F32-33), bipolar disorder (F30-31), schizophrenia (F20), and other psychotic disorders (F21-29) (3).

People living with SMDs face major health inequalities, including premature mortality (4). In a Danish context, nationwide register data show that mortality remains more than twice as high among patients with SMDs compared with those without SMDs (5). This excess mortality is primarily driven by chronic somatic conditions and social disadvantage (5). Evidence further shows strong associations between SMD and physical multimorbidity (6), underscoring the urgency of addressing health inequalities in this group.

Stigma remains a major barrier, and several studies highlight how mental disorder-related stigma among health care professionals (HCPs) affects, for example, cancer trajectories (7, 8). Such stigma contributes to diagnostic overshadowing and poorer clinical outcomes (9).

At the same time, patients with mental disorders are markedly underrepresented in clinical research, as study protocols frequently exclude them (10). This limits generalizability and reinforces knowledge and care gaps. Overall, having an SMD remains associated with poorer treatment, hereby poorer cancer treatment compared with the general population (11, 12), unmet health needs, and elevated mortality (13, 14). Despite this well-documented vulnerability, knowledge about palliative care for patients with SMDs remains scarce.

1.2 Palliative Care and End-of-Life Care

Palliative care aims to improve the quality of life for patients and their families facing challenges associated with life-threatening illness (15). Key elements that characterise palliative care include relief of symptoms and the concept of ‘total pain’, encompassing physical, mental, existential, spiritual, and social pain (16). The term ‘total pain’ emphasises that pain is a multidimensional symptom that can significantly reduce the quality of life for patients with serious illnesses. Globally, the need for palliative care is rising as populations age (15).

End-of-life care focuses on support for people in their last hours, days, or months of life, when treatment to control or cure their disease has stopped (17).

Palliative care in Denmark is divided into basic and specialist settings. Basic palliative care is provided by general practitioners (GPs), municipality home care nursing services, and non-palliative care hospital departments, accessible at all hours and free of charge. Specialist palliative care (SPC) is provided by hospices and specialist palliative care teams often affiliated with hospitals, offering support and expertise. GPs or hospital physicians can refer to these teams or hospices if additional specialist palliative care assistance or advice is required (18).

1.2.1 Palliative Care elements

The main goal of palliative care is to improve quality of life (QoL) (19). Patients with the same symptoms or diseases can have very different QoL, which underscores its subjective nature.

To measure health-related QoL and ensure systematic symptom screening of patients with palliative needs, a shortened version of the widely used health-related quality of life questionnaire in oncology (European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire, EORTC QLQ-C30) was developed to help identify palliative needs (20). This questionnaire, EORTC QLQ-C15-PAL, has 15 items and covers core items for palliative care needs. The standard procedure for patients receiving SPC in Denmark is to complete the questionnaire at baseline of treatment and again after 1-4 weeks.

Also, focusing on the voice of the patient is a core value in palliative care. To ensure the patients' needs and wishes are heard, the Advance Care Planning (ACP) conversation is an important tool (21). The conversation is a process in which the patient, together with HCPs and family members or relatives, can define thoughts and wishes regarding his or her future health care should he or she become incapable of participating in medical treatment decisions. ACP has also been suggested to improve QoL (22).

1.3 Palliative Care and Severe Mental Disorders

Patients with both SMD and life-threatening somatic illness can be in a particularly vulnerable position (18). Their needs may be complex and difficult to assess and address (23). Barriers exist at system, professional, and patient levels, e.g., fragmented pathways, stigma, and taboo surrounding mental disorders (7, 8, 11). One essential factor to improve the quality of end-of-life for this patient group is earlier involvement of palliative care and highly skilled communication by HCPs, using communication as an intervention (24).

Studies reveal disparities in access to and quality of SPC (23, 25). Swedish patients with psychosis and cancer were less likely to receive SPC (26), and Danish data link SMD to a lower probability of receiving SPC (12). On the other hand, our 2023 review found that patients with SMD and cancer had longer palliative trajectories and more adequate care, but less high-intensive end-of-life care, such as hospitalisations, chemotherapy, and other active treatments (25). Whether this reflects an earlier referral to SPC due to less active treatment and, therefore, still reflects disparities, remains unclear.

Also, the quality of palliative care that patients with SMDs receive is important. A 2021 review identified four themes influencing palliative care quality: healthcare system structure, professional challenges, care contexts, and lived experiences of SMD (23). Regarding health care services in the last year of life, a 2025 study reported more unplanned care and a higher likelihood of dying in care homes rather than at home or in hospices for patients with pre-existing SMDs (27).

Despite these findings, knowledge about palliative care for patients with SMDs remains limited (28).

1.4 Quality in palliative care

The quality of palliative care is challenged by limited capacity and competencies (29).

Quality in specialist palliative care in Denmark is monitored through indicators published annually by Danish Palliative Database (DPD) as a part of the national clinical quality databases to support continuous improvement (30). These indicators are listed in Table 1:

Table 1: Quality indicators from the Danish Palliative Database 2023 annual report

Indicator	Standard*
1) Referred patients who are not dead or too ill before contact with palliative care	≥ 80%
2) Waiting time from referral to first SPC visit within 10 days	≥ 90%
3a) Cancer patients who have received specialist palliative care before their death	≥ 35%
3b) Patients with other diagnoses than cancer who have received specialist palliative care before their death	Not defined
4) EORTC completion at baseline	> 50%
5) Patients being discussed at a multidisciplinary conference	≥ 80%
6) EORTC completion 1-4 weeks after start of SPC	> 40%

*Standard is the goal for the quality indicator, meaning the goal is that ≥90% of the referred patients should be seen within 10 days

The 2024 report from the Danish Palliative Care Database (DPD) showed that approximately one in five patients died or became too ill before receiving specialist palliative care, and nearly one in five waited more than 10 days from referral to first SPC contact. Patients were generally referred late in their disease trajectory (29).

However, what constitutes high-quality palliative care varies between patients, due to different needs and preferences, so these DPD indicators capture only part of the overall quality of palliative care. For instance, dying at home is in the literature associated with high-quality palliative trajectories but not considered a quality indicator (31). A 2020 review identified 288 quality indicators to evaluate care for patients with cancer in advanced stages or at the end-of-life (32). Only a small proportion of those indicators had received adequate testing of predefined measurement properties (acceptability, evidence base, definition, feasibility, reliability, validity) and overall appropriateness for use: only 15 indicators were recommended for use. For instance, in their mapping, physical aspects of care (symptom assessment, pain relief, and care processes) accounted for the largest number of indicators, whereas psychosocial and spiritual or cultural domains were rarely represented. Also, another category involved access to and early palliative care interventions, use of emergency departments, and hospitalisations (32).

1.5 Quality in palliative care for patients with SMDs

In recent years, there has been a growing focus on palliative care for patients with SMDs, yet the evidence base remains limited and heterogeneous. Recent evidence synthesis, including the MENLOC study, highlights that the existing research is predominantly based on heterogeneous case studies with limited methodological robustness. The MENLOC evidence synthesis identified recurrent challenges, including diagnostic delay, diagnostic overshadowing, uncertainty around decision-making capacity, and the need for cross-disciplinary collaboration (23). Another review only focusing on patients with cancer found, compared to patients without SMDs, more palliative-oriented care and less high-intensive-end-of-life (HIEOL) care for patients with SMDs (25). This means, for instance, greater hospice involvement and fewer Intensive Care Unit (ICU) admissions, Emergency Department (ED) visits, late chemotherapy, and in-hospital deaths. These results were based on large cohort studies from the U.S. and France, particularly for patients with depression and bipolar disorders. However, findings are not unambiguous; a Taiwanese study reported more use of ICU and invasive interventions near death for patients with schizophrenia (33). Also, a study among patients with cancer and psychosis found lower receipt of SPC, fewer ED visits, and fewer hospital deaths (26). In a Danish nationwide cohort study, patients with lung cancer and SMD were less likely to receive SPC, including hospice, and less likely to receive HIEOL (12). These findings reveal a critical gap in our understanding of palliative care quality for patients with SMDs. Existing quality indicators, both national and international, focus primarily on physical and process-oriented aspects of care and do not adequately capture the experiences, vulnerabilities, and structural barriers relevant to patients with SMDs. This underscores the need to investigate how quality in palliative care is defined, delivered, and experienced by patients with SMDs.

2. Aims and hypotheses

The main aim of this PhD thesis was to gain knowledge about the quality of palliative care for patients with SMDs. The aim and hypothesis for the three sub-studies were as follows:

2.1 Study I

This interview study aimed to explore the experiences of patients, their relatives, general practitioners (GPs), SPC nurses, and physicians with palliative care for patients with SMDs.

Hypothesis: Barriers to high-quality palliative care exist for patients with SMDs.

2.2 Study II

This register-based cohort study aimed to investigate quality in specialist palliative care among Danish Patients with pre-existing severe mental disorders using data from the Danish Palliative Database.

Hypothesis: Disparities exist in quality of SPC for patients with SMDs.

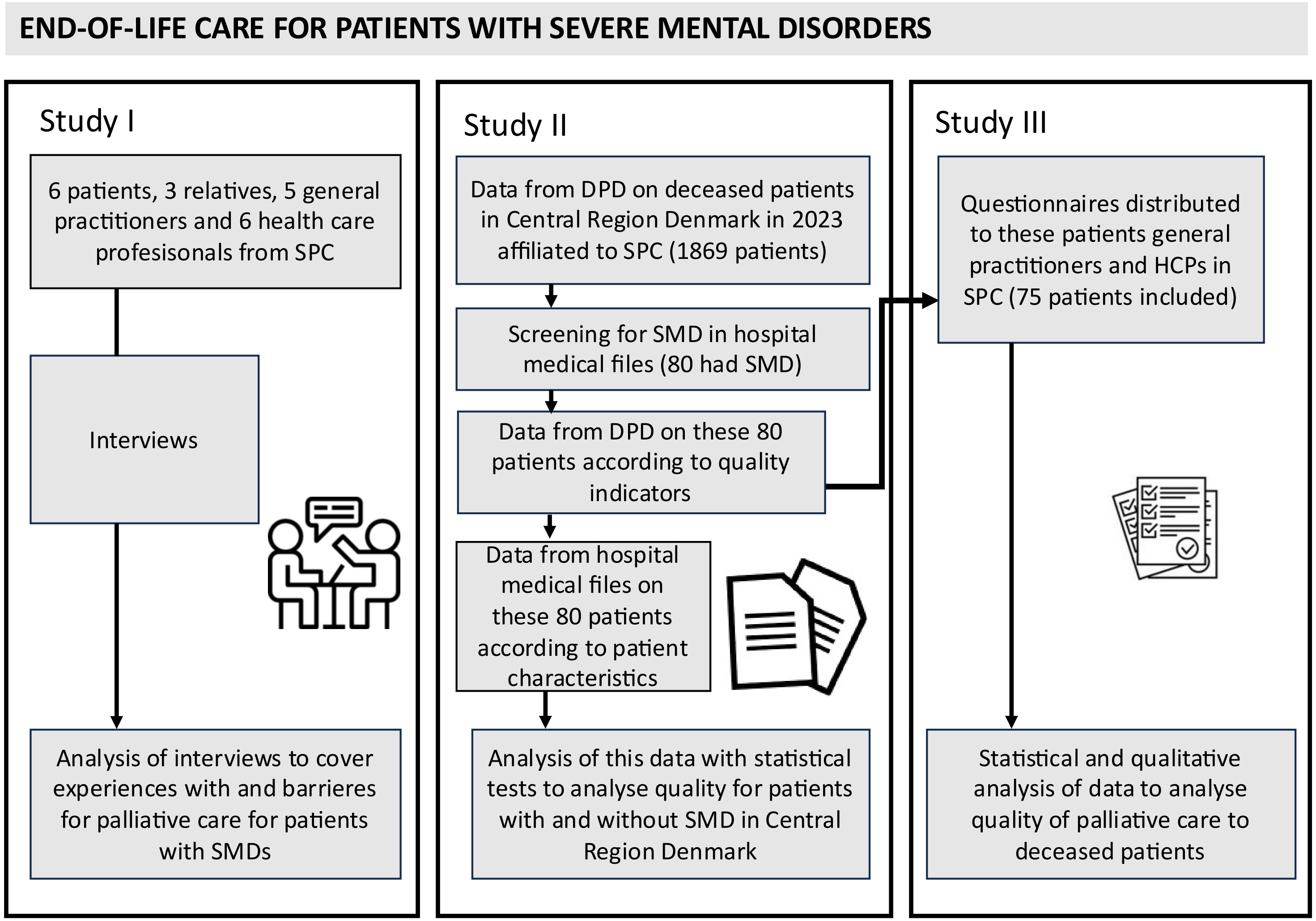
2.3 Study III

This questionnaire study aimed to investigate Health Care Professionals' (HCPs) perspectives on the quality of palliative care for patients with pre-existing SMDs at end-of-life.

Hypothesis: Quality in palliative care to patients with SMDs depends on several factors, e.g. social status, healthy relations to family members and HCPs, and place of death.

3. Methods

This thesis is based on three individual studies employing different methods. The following chapter presents the materials and methods, beginning with an overview in Figure 1.



Abbreviations:
SMD: Severe mental disorders
SPC: Specialist palliative care
DPD: Danish Palliative Database

Figure 1: Overview of the three studies, methods and participants

3.1 Setting

The Danish health care system is tax-funded, ensuring free and equal access to healthcare services for all citizens, regardless of income, social status, or diagnosis (34). The system is organised into two sectors: The primary and secondary health care sectors. Primary care is mainly provided by GPs, community nurses and other HCPs, while secondary care is delivered by hospitals and different specialised teams. More than 99% of the population is registered with a GP, who offers basic palliative care in collaboration with municipal home nursing services (34). Specialised palliative care (SPC) is provided by hospices and hospital-based palliative care teams. Patients can be referred to SPC by GPs or hospital physicians when specialised palliative treatment or advice is required.

Denmark is divided into regions. The Central Denmark Region has 1.3 million citizens and covers 13.000 square meters. It covers approximately 30% of Denmark's total area (35). In the Central Denmark Region, there is one university hospital and ten regional hospitals/health units, including the pre-hospital and psychiatry unit (36). Furthermore, there are five hospices and five SPC teams.

Hospices and SPC teams typically include physicians with formal specialisation in palliative care, experienced nurses, psychologists, and, in some cases, physiotherapists, occupational therapists, priests, and social workers.

3.2 Data sources

3.2.1 Electronic patient record system (Study II)

All Danish regions use electronic health record systems. The Central Denmark Region uses the Electronic Patient Journal (EPJ), which provides HCPs with an overview of patients' medical history and treatment, including notes from physicians and nurses, medical prescriptions, test results and diagnostic imaging (37). EPJ contains notes from hospitals and hospices but excludes records from GPs, private hospitals, and clinics.

3.2.2 Danish Palliative Database (Study II and III)

The Danish Palliative Database (DPD) is a national clinical quality database established in 2010 (30). It includes nearly all patients referred to SPC in Denmark since January 1, 2010, with close to 100% completeness (30). DPD contains clinically relevant variables such as referral details, type and dates of SPC contact, clinical and sociodemographic factors, multidisciplinary conference discussion, and patient-reported outcomes using the EORTC-QLQ-C15-PAL questionnaire (European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core-15-Palliative) (20). The database also monitors six quality indicators: 1) Proportion of referred and eligible patients admitted to SPC, 2) proportion of patients who waited less than 10 days from referral to first contact with SPC, 3) proportion of patients who died from cancer and had SPC contact, 4) proportion of patients who died from non-cancer diseases and had contact with SPC, 5) proportion of patients completing the patient-reported outcome measure (EORTC-QLQ-C15-PAL) at baseline and 6) proportion of patients discussed at a multidisciplinary conference (30).

3.3 Participants

3.3.1 Study I

Participants were identified through SPC units in the Central Denmark Region between August 2023 and December 2023. Inclusion criteria were age ≥18 years, ongoing SPC trajectory, and a pre-existing SMD. Patients who were able to provide informed consent were invited by SPC professionals, after which the first author contacted them for further information. SPC professionals assessed cognitive and physical abilities as inclusion criteria for participation in interviews, based on an overall judgement rather than formal testing. See Appendix I (Provided in Danish) for Participant Information and Consent Materials.

3.3.2 Study II

This study included data on adults (≥18 years) referred to SPC who died in 2023. The inclusion criteria were having a trajectory in SPC, being ≥18 years and having an SMD. Patients were identified using unique civil registration numbers from DPD. Hospital records were screened for ICD-10 diagnoses to determine whether patients had an SMD, defined as moderate- to severe depression (F32-33), bipolar disorder (F30-31), schizophrenia (F20), or other psychotic disorders (F21-29). Among 1,869 patients, 80 (4.3%) had pre-existing SMDs. Specific information from medical records was transferred to a RedCap database hosted at Aarhus University (38). To classify a mental disorder as pre-existing, diagnoses occurring after cancer or amyotrophic lateral sclerosis were excluded. For chronic progressive illnesses such as chronic lung disease or heart failure, diagnoses made within two years after the somatic condition were also excluded.

3.3.3 Study III

Study III included HCPs treating deceased patients from the cohort in Study II. Patients were identified by linking civil registration numbers from DPD to hospital medical records. Contact details for HCPs were also obtained from hospital records. GPs, physicians, and nurses from five SPC teams, five hospices, and one SPC inpatient department were invited to participate by completing a questionnaire, see Appendix IV (Provided in Danish) for Participant Information.

3.4 Data

Data comprised interviews, registry data, and questionnaires.

3.4.1 Study I

The study explored the informants' lifeworld's using four tailored interview guides, respectively for patients, relatives, GPs, and SPC professionals (39). Trustworthiness was ensured through author review and adjustment after two pilot interviews. Questions focused on concrete experiences. See Appendix II for Semi-Structured Interview Guides (Translated to English).

The dataset included 15 hours of audio-recorded interviews, mostly face-to-face encounters, for example, in patients' homes, in hospitals, at hospice or at the GPs' practice. Also, two telephone interviews with GPs were conducted. Interviews lasted between 24 and 73 min (median: 43 min). Interviews were transcribed and stored in NVivo (40). To ensure triangulation, two interviews were cross-coded by two research group members in addition to the first author (41).

3.4.2 Study II

Hospital records provided SMD diagnosis, SMD onset year, somatic diagnosis and onset year, active trajectory in psychiatric department 1 year before death, use of psychiatric medication, terminal grant, treatment level, ACP (Advance Care Planning) conversation, inj. of morphine or midazolam 14 days before death and place of death. A codebook (Supplementary 1 in Study II) lists search terms used for data extraction. DPD data included patient demographics (age, sex, children), living arrangements, place of death, SPC affiliation, health-related quality of life (EORTC QLQ-C15-PAL scores) (20) and referral source (GP/other physician). Data were collected manually and managed in RedCap (38, 42).

Four out of six quality indicators given by DPD were analysed (See Table 2): (1) waiting time from referral to first SPC visit (days), (2) discussion at a multidisciplinary SPC conference, (3) EORTC completion at baseline and (4) EORTC completion after 1-4 weeks, see table 2. Additional quality measures included time from SPC contact to death and death in the hospital.

Table 2: The quality indicators from DPD chosen for analysis

Indicator	**Standard***
3) Waiting time from referral to first SPC visit within 10 days	≥ 90%
4) Discussion at a multidisciplinary SPC conference	≥ 80%
5) EORTC completion at baseline	≥ 50%
6) EORTC completion after 1-4 weeks	>40%

*Standard is the goal for the quality indicator, meaning the goal is that ≥90% of the referred patients should be seen within 10 days

3.4.3 Study III

Three questionnaires were developed for different HCP groups, with overlapping questions when possible. The development was strongly inspired by the validated VOICES questionnaire for bereaved relatives (43) and a questionnaire developed for GPs on place of death, palliative care and GP involvement (31). Also, the development was inspired by interview data from Study I in this thesis. Questionnaires included fixed-response and free-text items, enabling quantitative and qualitative analysis. Questionnaires were distributed electronically, and data were collected and stored in RedCap (38, 42). Demographic questions covered age, gender, profession, and work setting. Other questions assessed perceived quality of palliative care during patients' final months and days, ACP conversations, and symptom relief (physical, psychiatric, social and existential). Free-text questions invited reflections on care quality, improvements, and memorable aspects of patient trajectories. See Questionnaires in Appendix V (Provided in Danish).

3.5 Analysis

3.5.1 Study I – Qualitative data

Analysis followed Braun and Clarke's six-step Reflexive Thematic Analysis, using inductive coding and themes were developed collaboratively (See Table 3) (44-46). To enhance trustworthiness, some of the material underwent cross-coding by three of the authors (KBB, MKN and JEM) and discussion during data sessions. External qualitative researchers also reviewed selected material to broaden interpretation. Selected quotes illustrate themes.

Table 3: Reflexive thematic analysis is divided into six steps as outlined by Braun and Clarke. The process is iterative going back and forth between the steps (45-47).

Phase 1: Familiarisation	An iterative process of conducting interviews, verbatim transcription, and initial coding. The first author repeatedly read the data, engaging critically and reflexively.
Phase 2: Coding	Codes were developed during reading and analysis. Two research group members contributed in data sessions, and one interview was reviewed with external qualitative researchers.
Phase 3: Generating initial themes	Codes were grouped under shared meanings to form initial themes.
Phase 4: Developing and reviewing themes	Themes were discussed in the research group; the main themes were selected.
Phase 5: Defining and naming themes	Themes were clearly defined and named.
Phase 6: Creating the report	Findings were synthesized and presented coherently.

3.5.2 Study II – Quantitative data

Descriptive statistics were used to describe the cohort. For dichotomous outcomes, 2x2 tables were constructed to show the number of patients meeting the indicator criteria in each group. Relative risks (RRs) with 95% confidence intervals (CIs) were estimated by using contingency tables and risk ratio calculations (48-50). For continuous outcomes, mean ratios (MRs) were estimated via generalised linear models with Poisson distribution and log link, combined with robust variance estimation. Although traditionally applied to count data, this approach provides valid relative risk estimates for continuous outcomes (48, 49, 51). Robust standard errors were used to account for potential model misspecification. STATA was used to analyse the data (52).

3.5.3 Study III – Quantitative and qualitative data

Questionnaire data included both free-text items and fixed-response options, requiring both qualitative and quantitative analysis.

3.5.3.1 Quantitative data

Descriptive statistics were applied to fixed-response items: counts and percentages for categorical variables, and medians with interquartile range (IQR) for continuous variables. Pearson's chi-square test was used to assess group differences. STATA was used to analyse the data (52).

3.5.3.2 Qualitative data

Thematic analysis was used for free-text responses. Codes were generated inductively and organised into themes by the first author (KBB) and discussed with co-authors (JEM and MAN) to ensure trustworthiness.

3.6 Ethical considerations

The Central Denmark Region Committees on Health Research Ethics approved the studies (Reference ID: 1-45-70-94-23). The project was also registered in the Central Denmark Region's internal research database (Reference ID: 1-16-02-219-23). Additional approval from the Department of Oncology, Aarhus University Hospital, permitted access to medical files. Also, the project was mentioned for the Central Denmark Region Committees on Health Research Ethics and was accepted for conduction without approval from the committee.

3.6.1 Study I

Participants received written and oral information and provided informed consent. Participation was voluntary. Responses were anonymised in reporting. Having an SMD often results in lower research participation due to exclusion because of the SMD. Participation in interviews never changed the patient's treatment, as the interviewer was only interviewing and not involved in treatment. Furthermore, patients were only invited to participate if their HCPs found it ethically responsible due to their somatic status, sometimes being terminally ill, and their mental status.

3.6.2 Study II and III

Health care professionals (HCPs) participated voluntarily after a written invitation and information.

4. Results

The key results from the three sub-studies are presented in the following section. A detailed description can be found in the full versions of the studies (Study I-III).

4.1 Study I: Experiences with Palliative Care For Patients with Severe Mental Disorders

The study cohort included 20 informants. Of nine patients approached, six agreed to participate (66.7%). Patients also consented to contact informants closely related to them, such as relatives (three), GPs (five), and SPC professionals (six), to provide different perspectives on each case. Patients were mostly women (67%) and ranged in age from 63 to 73 years (median: 68 years). The SMDs comprised moderate to severe depression, schizophrenia, acute psychosis and bipolar disorder. The life-limiting diseases were cancers and non-cancers, such as lung and breast cancer, and terminal kidney disease. Four themes were developed through thematic analysis from the interview data, as follows:

1) Thoughts about the future

Thoughts about the future included both fears, for instance, dying without dignity, in pain or alone, but also wishes. Some patients had wishes about travelling, feeling physical freedom or spending time with their family. Also, all patients with SMD wanted to talk about and plan their place of death.

2) Relations in end-of-life

Relations were a recurring theme in our data. Both spending time with relatives and maintaining healthy, close relations were important in the end-of-life. Hence, relatives sometimes perceived the relations as complicated due to conflicts and discrepancies. Furthermore, both patients and relatives wanted a healthy and stable relationship with SPC professionals and GPs. Actually, GPs described patients with SMDs as 'VIP-patients', whom they wanted to spend extra time on, to ensure trust.

3) Changes in psychiatric symptoms at end-of-life

The data both contained cases of end-of-life trajectories where patients experienced changes in, and others where patients experienced stabilising in psychiatric symptoms in end-of-life. Some HCPs reported psychiatric symptoms stepped into the background when the patient got a terminal diagnosis. Other patients experienced an increase in depressive symptoms after the terminal diagnosis.

4) The role of openness

The overall impression in the data was willingness to talk openly about SMD and end-of-life, both from patients, GPs and SPC professionals' perspectives. Still, some SPC professionals articulated insecurities about SMDs and were afraid of patients' reactions if they asked openly. GPs often knew the patients through many years and generally had less fear of confrontation. Almost every patient wanted to talk openly with HCPs about their SMDs and wanted to be asked openly, with the freedom to decide which questions they would answer. Also, discussing and planning the EOL was a strong wish.

4.2 Study II: Quality in Specialist Palliative Care for Patients with Severe Mental Disorders: A Retrospective Cohort Study

A total of 2313 trajectories and 1869 individual patients were included (See Figure 2). Eighty patients (4.3%) who had 93 SPC pathways (4.0%) were registered as having an SMD. The sociodemographic characteristics of patients with and without SMDs are presented in the full paper (Table 1). Patients with SMDs were younger at death, more often referred with organ failure, more likely to live alone and fewer had children, compared to patients without SMDs. Hospice pathways and dying in hospice were less likely, and dying at home was more common among patients with SMDs.

Four out of six quality indicators from DPD were analysed and compared between patients with and without SMDs. One significant difference was found: patients with SMDs were less likely to complete EORTC at baseline compared to patients without SMDs (RR:1.49 (95% CI:1.15;1.95)).

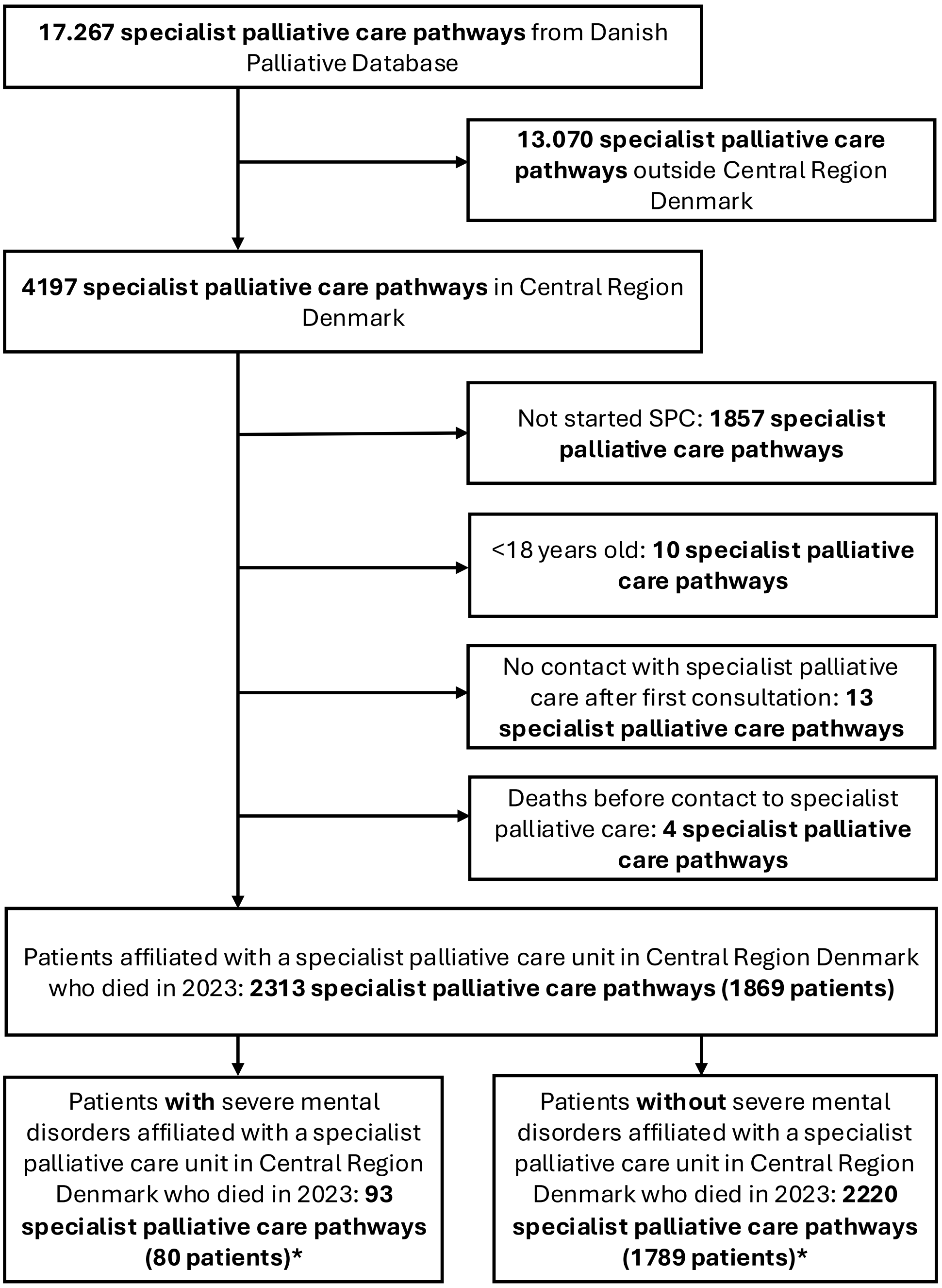
Additionally, possible quality markers such as the duration of the SPC pathway and hospital death were analysed, and no differences were found.

An analysis of patients with SMDs having and not having an active care pathway in psychiatry one year before death was conducted. The purpose of this sub-analysis was to use active pathways in the psychiatric department within last year before death as an indicator of the severity of the mental disorder.

Analysing quality indicators, a difference was found in waiting time from referral to first SPC contact, where patients with active pathways in psychiatry waited longer (MR:3.48(95%CI:1.06;11.39). Also, those with active pathways in psychiatry had shorter pathways in SPC, compared to patients with SMDs but no active pathway in psychiatry one year before death (MR:0.44(95% CI:0.20;0.96)).

Also, we conducted an additional, unpublished sub-analysis of 14 patients diagnosed with SMD after terminal diagnosis. The findings, summarised in Appendix III, showed minimal sociodemographic or clinical differences compared with patients without SMD or those with pre-existing SMD.

Figure 2: Flowchart of study population, Study II



Severe mental disorders included: ICD-10 diagnosis F20-F25, F28-F31, F32.1-9, F33.1-9
* Some patients had a pathway in both hospice and a hospital based palliative care team

4.3 Study III: Quality in Palliative Care for Patients with Severe Mental Disorders in Health Care Professionals' Perspectives

The same cohort of 1,869 patients was used as in Study II. 75 patients with SMDs met the inclusion criteria (See Figure 3). This amount differs from Study II (80 patients), as 5 patients were excluded due to only being assessed once by an SPC team. A total of 123 questionnaires were returned by HCPs, with an overall response rate of 76%. Respondents included 46 GPs, 20 hospice staff, and 57 SPC professionals from teams or in-bed departments, with response rates varied by setting (64% for GPs, 80% for hospices and 88% for SPC teams). Each patient trajectory had at least one completed questionnaire (See Figure 4).

The characteristics of patients included and HCPs participating in the questionnaires are shown in Table 1 in the paper. The median age of included patients was 66 years (IQR: 60-76), and most patients had depression as their psychiatric diagnosis (63%). Lung and airway cancers were the most prevalent terminal illnesses. Among responding HCPs, 80% were physicians, 19% were nurses. The median age of respondents was 52.5 years, and most were females (80%).

Across settings, HCPs generally perceived that patients and relatives received all the necessary support from the health care system and the municipality in the final three months of life. GPs answered '*Yes*' in 87% of cases, answering whether patients and relatives received the needed support, see Table 3 in the paper. Ratings of symptom control, particularly social and existential aspects, were more mixed, with many HCPs reporting that support in these areas was only provided 'Some of the time'. These findings indicate gaps in addressing non-physical dimensions of suffering for patients with SMDs. Despite this, the overall quality of palliative care was most often rated as '*Good*' or *'Very good'*, especially in the final two days of life, with hospice staff gave the highest ratings. Most HCPs reported that the psychiatric diagnosis did not negatively affect the care delivered.

Free-text responses highlighted three recurring themes:

1) Collaboration and timing:
Good cross-sector collaboration was seen as essential for high-quality care, while poor coordination and late referrals reduced quality.

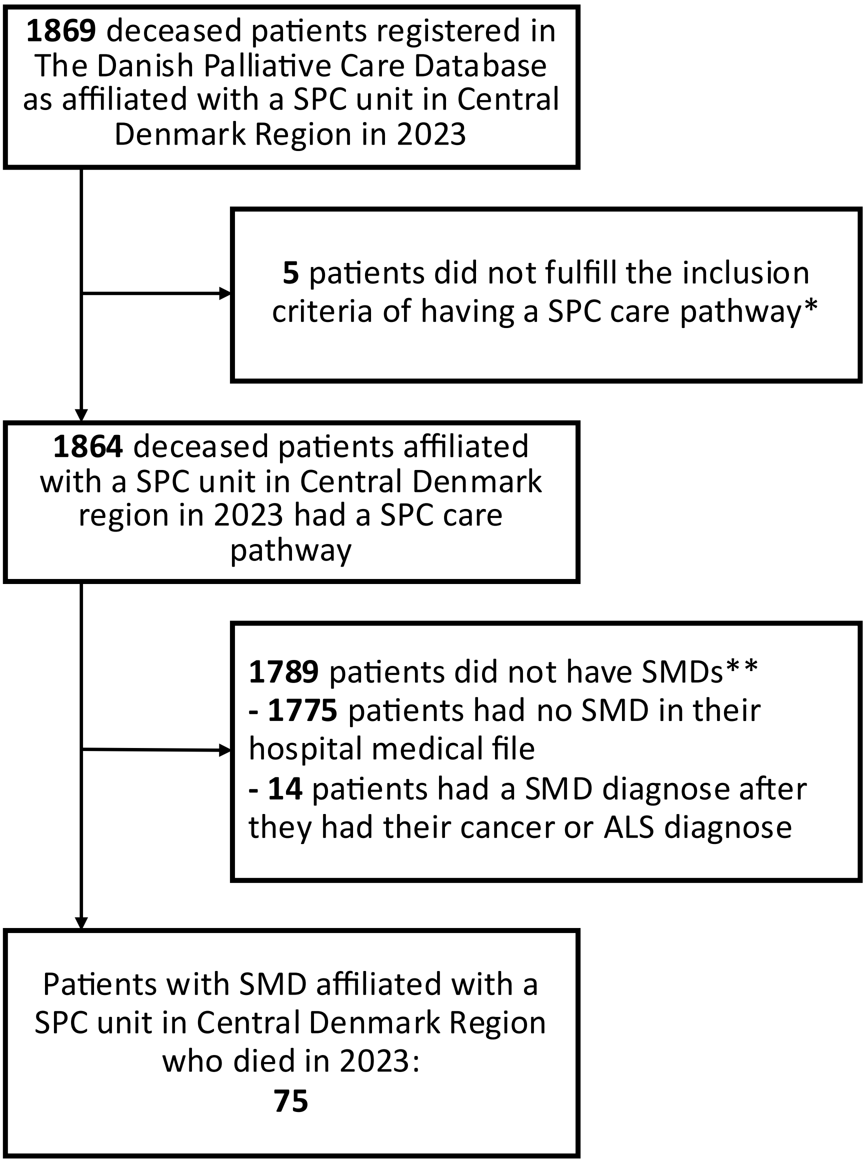
2) Communication and relations:
Meaningful end-of-life conversations were considered central; when psychiatric symptoms or communication difficulties limited participation, care quality declined. Relational continuity, especially with GPs, supported better advance care planning.

3) Complexity:

Anxiety, mistrust, refusal of visits, and difficult family dynamics were recurring barriers to high-quality trajectories.

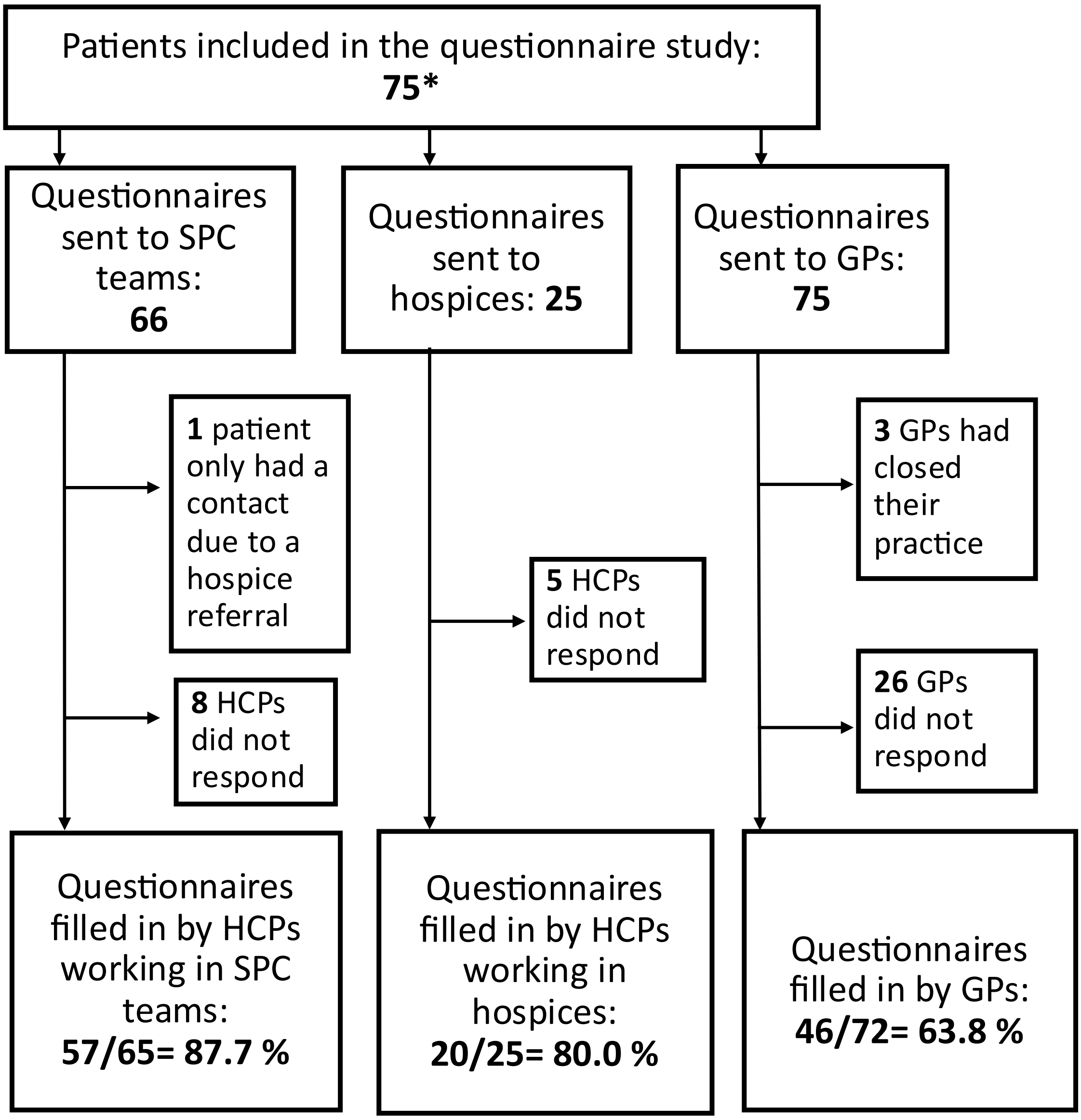
Comparisons showed no clear associations between care quality and diagnosis or gender. Younger patients <70 years tended to receive higher-quality care in the final days, but small numbers prevented firm conclusions.

Figure 3: Flowchart of study population, Study III



Abreviations:
SMD: Severe Mental Disorder
SPC: Specialised Palliative Care
*: The 5 patients were only assessed once by a SPC team
**: SMDs included: ICD-10 diagnosis: F20 – F25, F28-F31, F32.1-9, F33.1-9

Figure 4: Flowchart of questionnaires, Study III



Abreviations:
GP: General practitioner
HCP: Health Care Professionals
SMD: Severe Mental Disorder
SPC: Specialised Palliative Care
*: More than 75 questionnaires were distributed due to some patients having more than one trajectory, e.g. both a questionnaire to their GP, hospice and/or palliative care team. In all, 166 questionnaires was distributed, hereby 123 completed. For all patients at least one questionnaire was completed.

5. Methodological considerations

This section describes key methodological considerations across the three studies. Together, the studies constitute a multi-method PhD project grounded in different methodological traditions.

5.1 Multi-method approach

Although the project combines qualitative and quantitative components, the studies were conducted independently, with integration only occurring during interpretation. Consequently, the overall design reflects a multi-method rather than a mixed-methods approach (53). Each method illuminates complementary aspects of palliative care for people with SMDs.

5.2 Study I: Methodological strengths and limitations

The semi-structured interviews generated nuanced insights into experiences of sensitive topics rarely captured elsewhere (54). Including the perspectives of patients, relatives and HCPs strengthened credibility (55). Team-based analysis enhanced the interpretive rigour. Key methodological limitations relate to participant selection, the researcher's background, and the study context.

5.2.1 Participant-related bias

Social desirability may have influenced, especially HCPs, to present themselves in a favourable light, particularly when discussing professional responsibilities or stigma-related topics (56). *Recall bias* affected all participant groups reflecting on past events (57). *Courtesy bias* occurred where participants misperceived the interviewer's professional affiliation (58).

5.2.2 Interviewer-related bias

The interviewer's clinical experience with SMDs may have shaped follow-up questions and interpretations, although reflexive discussions within the research team aimed to minimise this influence (59).

5.2.3 Study design-related bias

Sampling bias may have influenced the study; patients were recruited by HCPs at specialist palliative care services, which likely excluded individuals with the most severe symptoms, including those less stable or too unwell to participate. This limits representativeness – reflected in a low number of patients with schizophrenia or other psychoses, and potentially introducing selection and non-response bias (60). Some eligible patients may have been missed due to reliance on contact persons and clinical coding. *Selection- and non-response bias* may also have occurred, as those who agreed to participate, both patients and HCPs, likely differed from those who declined or were never approached (61). For instance, two patients initially showed interest in participating, but became suspicious about the study's intentions and withdrew their consent.

5.2.4 Context-related bias

Interviews were conducted in varied settings (patients' homes, hospices, clinics, and by telephone), which may have influenced openness and comfort (62). Audio recordings may also have moderated responses to sensitive issues (63).

5.2.5 Analysis-related bias

Although team coding and peer discussions reduced *Interpretive bias,* analytic choices may still reflect the interviewer's professional background (54, 55).

5.3 Study II: Methodological strengths and limitations

This register-based cohort study efficiently captured a large population and avoided recall bias. However, reliance on existing clinical data introduces specific risks.

5.3.1 Selection and misclassification bias

Patient identification depended on ICD-10 codes, which vary in accuracy across clinicians and settings. As a result, some patients with relevant diagnoses may not have been included, and misclassification could affect both exposure and outcome measures (64). Extraction of additional variables from records also carries a risk of incomplete or inconsistent documentation (60).

5.3.2 Confounding bias

Patients with SMD are likely to differ systematically from comparison groups in factors such as comorbidities or social conditions. Without statistical adjustment, residual confounding is expected (65).

5.4 Study III: Methodological strengths and limitations

The questionnaire contained both fixed and free-text options. Broad HCP perspectives were conducted, but results remained affected by several sources of bias relevant to self-reported data.

5.4.1 Selection bias

Non-response bias may have occurred if those who answered differ systematically from those who didn't. Representativeness can be threatened, due to HCPs with special interests, for e.g. psychiatric illness or palliative care, who can be overrepresented. Offering compensation to GPs reduced but did not eliminate this risk.

5.4.2 Information bias

Information bias may have occurred as responses relied on HCPs' recall and interpretation of patient trajectories. Also, variation in how respondents understand questions can systematically skew the data (66).

5.4.3 Confounding bias

Confounding bias may have influenced the results, as different respondent groups (GPs, hospice- and SPC staff) differ in experience, clinical role, and level of patient contact. This could have influenced the evaluated quality of the patient trajectory. Such differences can act as confounders in self-reported data (58).

5.4.4 Social desirability bias

HCPs may have wished to present their own or colleagues' efforts positively, particularly regarding sensitive areas such as psychiatric disease and end-of-life decision making (65).

5.5 Cross-study validity considerations

The use of different methodological approaches (interview data, register data and questionnaire data) strengthens the overall validity of the thesis. The qualitative data adds depth, the register study provides population-level robustness, and the questionnaire study contributes systematic professional perspectives. Taken together, these methods improve the robustness and transferability of the overall conclusions, despite the limitations of each individual design.

6. Discussion and clinical implications

The main findings of the three studies are discussed in the following section. Each study has a more detailed discussion in the Studies I-III.

6.1 Main findings in each study

Across the three studies, palliative care for patients with SMDs was generally found to be of high quality, although important nuances emerged. Study I, the interview study, showed that patients with SMDs hold thoughts, wishes, and fears about EOL in the same way that could be expected for patients without SMDs. Supportive relations with relatives and HCPs were crucial to well-being, and psychiatric symptoms did not necessarily worsen when faced with a life-limiting diagnosis. Openness about both SMD and EOL facilitated meaningful conversations, although the willingness to engage depended on trust, time, and individual needs.

Study II, the register-based cohort study, highlighted that patients with SMDs died younger and more frequently from non-cancer conditions compared to patients without SMDs. Also, specific challenges within the Danish SPC system were found. Patients with SMDs completed fewer symptom assessments, and when receiving active psychiatric treatment in the last year of life, experienced longer waiting times before initiation of SPC and had shorter SPC trajectories.

Study III, the questionnaire study, found that HCPs generally perceived the quality of palliative care for patients with SMDs as high, and most HCPs did not believe the psychiatric diagnosis negatively affected care. However, free-text answers revealed nuances: quality was shaped by collaboration and timing, communication and relations, and the complexity of individual cases. Interestingly, a tendency was found towards HCPs reporting particularly high quality among patients <70 years and those with schizophrenia or other psychotic disorders. However, the analysis was conducted in small populations and not published due to the small number of observations and resulting uncertainty.

6.2 Comparison with existing literature and clinical implications

6.2.1 The voice of the patient and participation

Including patients' perspectives is a core indicator of quality in palliative care. In Study I, patients with SMDs highlighted the importance of openness regarding both SMD and EOL issues and expressed a wish for HCPs to approach these topics with curiosity. This aligns with evidence showing that patients value attention not only to medical issues but also to their personal experiences and narratives (67).

Study III revealed that some HCPs experienced insecurities when communicating with patients with SMDs, e.g. due to the patient having low trust in the HCP, or difficulties processing information. Despite these concerns, research indicates that patients with SMDs are capable of expressing treatment preferences for EOL scenarios (68) and participating meaningfully in ACP conversations (69). In our study, more than half of the patients had participated in ACP during care, suggesting that participation is both feasible and desired.

A recent review, although focused on palliative care to patients in general rather than patients with mental disorders, emphasises that patients both want and expect to participate in shared decision-making, and that enabling such participation is the responsibility of HCPs and the organisations providing palliative care (70). In contrast, another review on EOL care for patients with SMDs showed that HCPs often struggle to initiate EOL conversations with patients with SMDs due to stigma and lack of structured ACP, leading to suboptimal EOL Care (71).

Another way to incorporate the patient's voice is through patient-reported outcome measures (PROMs). Study II showed that patients with SMDs completed fewer 'symptom and quality of life assessments' than patients without SMDs. Completion is likely to depend on timing, symptom burden, cognitive capacity, and clinical prioritisation. Also, HCPs sometimes seek to protect patients with SMDs from the perceived burden of participating in research. This aligns with evidence showing that populations deemed vulnerable are often unnecessarily excluded from research due to well-intentioned protective motives among HCPs (72). This was also seen in Study I, where HCPs played an important role in the inclusion of patients. Patients with SMDs may furthermore face additional barriers to complete PROMs, underscoring the importance of supportive approaches to ensure that their symptoms and priorities are captured – that their voices are heard.

6.2.2 Quality of palliative care to patients with SMDs

In Study III, many HCPs assessed the overall quality of palliative care for patients with SMDs as good, and several noted that SMD did not, in itself, reduce the standard of care. This aligns with Study I, where patients with SMDs often remained psychologically stable and demonstrated strong coping capacities when facing terminal illness and expressed a high level of support and help from SPC units and GPs. Together, these results question the assumption that SMD most often complicates palliative care.

However, the studies also revealed important nuances. HCPs in Study III frequently reported that support for social and existential needs was only provided *some of the time*, indicating gaps in addressing non-physical aspects of suffering. This aligns with national evidence, which, although focused on the general Danish hospital-based palliative care population rather than patients with SMDs, prioritises physical symptoms, whereas spiritual, social and existential care is less systematically incorporated (73).

As stated above, Study II showed that patients with SMDs completed fewer EORTC questionnaires at SPC baseline. Reduced symptom screening limits systematic identification of pain and other concerns, diminishing opportunities to optimise treatment – a notable issue given that opioid use is often considered a marker of high-quality EOL care (32). This finding mirrors a 2025 review showing that patients with SMDs receive less analgesia at EOL compared to those without SMDs (74), driven by a combination of factors, including diagnostic overshadowing, stigma, clinicians' uncertainty, and insufficient integration between psychiatric and palliative care services.

Study II also documented longer waiting times for SPC and shorter SPC trajectories among patients receiving active psychiatric care in the last year of life. This aligns with the MENLOC synthesis, which identified diagnostic overshadowing and delays as recurrent challenges for people with SMDs (23), potentially contributing to and partially explaining later referral and shorter SPC involvement.

Overall, the three studies suggest that palliative care for patients with SMDs is generally of high quality once they access SPC, but that existential support and systematic symptom assessment are less consistently delivered. Given that access to SPC is itself inequitable (12), questions remain about the quality of care for the substantial proportion of patients with SMDs who never enter SPC pathways. This underscores that while palliative care for this group often functions well, it does not function equally well across all domains.

6.2.3 Inequity and structural barriers

The three studies in this dissertation include only patients with SMDs who had already gained access to SPC and a registered psychiatric diagnosis. This limits generalisability, as existing evidence shows clear inequities in access to SPC for individuals with SMDs (12, 26). A substantial proportion of these patients never reach SPC at EOL, and little is known about the care they receive, their symptom burden, or their unmet needs. Under-recording of psychiatric conditions in hospital data likely contributes to the 'dark number' of patients with mental health problems who are not identified in routine registries and therefore remain invisible.

Access to SPC appears to be shaped by relational and communicative factors (75). Research suggests that strong family caregivers often act as advocates, facilitate communication and support decision-making (76). Consequently, patients with SMDs, who more often lack stable relatives, may be at a heightened risk of inequity in accessing SPC (76). Study III further emphasised the importance of collaboration and timing across psychiatric services, general healthcare, and SPC. HCPs described difficulties providing sufficient care when referrals came too late, when palliative needs were not recognised early, and when responsibilities across sectors were unclear. Such factors may contribute to delayed or absent referral and thereby reinforcing structural inequities. This is concerning, as early palliative involvement has been shown to improve palliative care quality (77). Furthermore, the fact that patients with SMDs often have complex needs should, if anything, lead to a higher proportion of this population being referred to SPC, which is specifically equipped to address complex EOL needs.

Together, these findings indicate a need for more systematic structures to ensure earlier, more equitable identification of palliative needs among patients with SMDs.

6.2.4 Clinical implications

The clinical implications arising from the three studies can be considered at two levels: individual and system level.

Individual level

Results from the included studies show the importance of initiating ACP conversations early, as this supports patient autonomy and helps ensure that care reflects patients' values and preferences. The studies indicate that flexible and adaptable communication, for example, using clear language and stepwise information, can help overcome barriers related to trust, cognitive load and emotional strain. Moreover, several studies highlight that stigma and diagnostic overshadowing can undermine patient participation; therefore, the studies indicate that explicit openness (e.g., involving patients' perspectives, naming uncertainties, and checking understanding) can strengthen psychological safety. Finally, results from the included studies show that the value of relational continuity, for instance through a named responsible HCP, may further strengthen the care pathway for patients with SMDs.

System level

Results from the studies also show that system-level efforts are needed to strengthen the quality of palliative care for patients with SMDs. Studies indicate that supporting patients with SMDs in completing PROMs, such as EORTC questionnaires, may enhance symptom identification and facilitate a timelier clinical response. Furthermore, the findings support the view that structural efforts could include fast-track referral pathways for patients with complex mental-somatic trajectories, which could help minimise delays and ensure earlier access to SPC.

The studies emphasised the importance of shared care between psychiatry, primary, and specialist palliative care to bridge gaps in responsibility. Strengthened cross-sectoral communication, especially in transitions between psychiatric care, hospital departments, general practice and SPC, may reduce delays and prevent patients from being overlooked or not being identified as eligible for SPC.

In addition, further education in palliative care and mental disorders at both pre- and post-graduation levels is needed. The studies indicate that education initiatives on mental disorders for palliative care clinicians and, conversely, increased palliative care education to staff working in psychiatric services, could reduce diagnostic overshadowing and support more collaboration. Finally, findings suggest that HCPs could benefit from specific training in communication, especially when navigating the interplay between mental health symptoms and palliative care needs.

7. Conclusion

The three studies in this thesis all focused on the quality of palliative care provided to Danish patients with pre-existing SMDs and collectively highlight both structural and clinical challenges in ensuring high-quality EOL care. Through the studies, we identified barriers that hinder access to timely, high-quality palliative services, including fragmented care pathways, where patients receiving psychiatric care during their final year of life experienced longer waiting times from referral to the start of SPC. Also, their total time in palliative care was shorter compared to patients without active psychiatric care. Fewer symptom assessment forms were completed when patients also had SMDs. Also, interdisciplinary collaboration and coordination were challenging in some cases, which led to lower assessed quality if the patient was, e.g., referred to SPC too late.

We showed that patients with SMDs often receive specialist palliative care later in the trajectory than patients without mental disorders, and that their symptom burden and psychosocial needs may remain insufficiently addressed. We also demonstrated that HCPs across specialities express uncertainty about how to communicate with this population, despite a strong willingness to make an extra effort to deliver high-quality care.

At the same time, we identified important facilitators, such as proactive cross-sectoral collaboration, HCPs being curious and facilitating open communication with patients, and the acknowledgement of the complexity in living with both mental illness and a life-limiting somatic disease.

Together, the findings underscore the need for more integrated clinical pathways, competence development, and organisational structures that support shared responsibility between psychiatric and somatic services as well as between basic and specialised palliative care professionals. Strengthening these elements may help reduce disparities and ensure that patients with SMDs receive timely, person-centred care that is aligned with their values and needs at the end of life.

Ultimately, this thesis contributes to a growing body of evidence indicating that palliative care for patients with SMDs remains an underinvestigated field with significant potential for improvement. Although some of our studies demonstrated high-quality palliative care for these patients, important areas for improvement were also identified. Addressing these will be essential for ensuring more equal access to and quality of palliative care for an often underserved population who are at high risk of having complex needs.

8. Perspectives and future research

The findings from our three studies highlight several important directions for future research on palliative care for patients with SMDs.

Across all studies, our findings point to substantial gaps in cross-sectoral collaboration and professional competence. Future efforts should focus on integrated care pathways between psychiatry and SPC, fast-tract referral options for patients with complex mental-somatic trajectories and targeted education for health care professionals. As a natural progression of this work, developing a CASEMED-PAL model focused on palliative care trajectories for patients with SMDs would constitute a valuable next step. Such a model could be informed by the existing CASEMED model designed to support patients with SMDs through cancer trajectories (78).

Study II showed lower completion of symptom assessments among patients with SMDs, yet the actual content of their PROM responses has not been analysed. Examining symptom assessment data specifically for this group represents a natural next step in extending the findings of this dissertation. Such work could generate more accurate knowledge on symptom profiles of patients with SMDs, concerns and priorities, and strengthen the patient-centred approach in research.

Finally, conducting research on EOL care for patients with SMDs raises ethical dilemmas. Including patients who are both approaching EOL and living with SMD raises questions about autonomy, vulnerability, and the risk of causing distress. Still, patients in our Study I expressed willingness and felt the meaningfulness of contributing their knowledge to a research project. Using patients with SMDs' voices in research is important to improve the quality of palliative care, specifically for this group.

Furthermore, we only investigated care pathways of patients with SMDs who already reached SPC, which makes patients with SMDs who never reach SPC a largely overlooked group, where key evidence gaps remain. Their care pathways, symptom burden and unmet needs remain insufficiently understood. Future studies should therefore focus on mapping and characterising the pathways of this ‘hidden population’, including barriers, cross-sectoral transitions and facilitators for timely identification and referral to SPC.

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Declaration of co-authorship concerning article for PhD dissertations

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This declaration concerns the following article/manuscript:

Title:	Experiences With End-of-Life Care for Patients With Pre-Existing Severe Mental Disorders, Their Relatives, and Healthcare Professionals
Authors:	Kirstine Bøndergaard, Jane Ege Møller, Mette Kjærgaard Nielsen, Poul Videbech, Mette Asbjoern Neergaard

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E. No or little contribution (<10%)
F. N/A

Category of contribution	Extent (A-F)
The conception or design of the work:	B
Free text description of PhD student's contribution ***(mandatory)*** The PhD student conducted the main part of the work under continuous supervision from the main supervisor and last author, who provided academic guidance and critical revision of all stages of the project.	
The acquisition, analysis, or interpretation of data:	B
Free text description of PhD student's contribution ***(mandatory)*** With continuous co-author guidance, the PhD student contributed with acquisition, analysis and interpretation of data.	
Drafting the manuscript:	A
Free text description of PhD student's contribution ***(mandatory)*** The PhD student drafted the manuscript with review and editorial help from co-authors.	

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- F. N/A

Category of contribution	Extent (A-F)
The conception or design of the work:	B
Free text description of PhD student's contribution ***(mandatory)*** The PhD student conducted the main part of the work under continuous supervision from the main supervisor and last author, who provided academic guidance and critical revision of all stages of the project.	
The acquisition, analysis, or interpretation of data:	B
Free text description of PhD student's contribution ***(mandatory)*** With continuous co-author guidance, the PhD student contributed with acquisition, analysis and interpretation of data.	
Drafting the manuscript:	A
Free text description of PhD student's contribution ***(mandatory)*** The PhD student drafted the manuscript with review and editorial help from co-authors.	

Submission process including revisions:	A
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The article/manuscript is: Published ☐ Accepted ☐ Submitted ☒ In preparation ☐

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If accepted or submitted, state journal:

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Your contribution

Please rate (A-F) your contribution to the elements of this article/manuscript, **and** elaborate on your rating in the free text section below.

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The conception or design of the work:	B
Free text description of PhD student's contribution ***(mandatory)*** The PhD student conducted the main part of the work under continuous supervision from the main supervisor and last author, who provided academic guidance and critical revision of all stages of the project.	
The acquisition, analysis, or interpretation of data:	B
Free text description of PhD student's contribution ***(mandatory)*** With continuous co-author guidance, the PhD student contributed with acquisition, analysis and interpretation of data.	
Drafting the manuscript:	A
Free text description of PhD student's contribution ***(mandatory)*** The PhD student drafted the manuscript with review and editorial help from co-authors.	
Submission process including revisions:	A

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Study I

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ORIGINAL ARTICLE

Experiences With End-of-Life Care for Patients With Pre-Existing Severe Mental Disorders, Their Relatives, and Healthcare Professionals

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Keywords: health personnel | mental disorders | palliative care | patients | qualitative research

ABSTRACT

Knowledge is needed about end-of-life care among patients with pre-existing severe mental disorders: Schizophrenia, bipolar disorder, and depression. This study aimed to explore the experiences with end-of-life care for patients with severe mental disorders, their relatives, specialised palliative care nurses and physicians, and general practitioners. Twenty semi-structured interviews were conducted and analysed using reflexive thematic analysis, hereby six interviews with patients, three with relatives, five with general practitioners, and six with specialised palliative healthcare professionals. Patients were selected with help from healthcare professionals. Four main themes were produced: thoughts about the future, healthy relations in end-of-life, changes in psychiatric condition in end-of-life, and the role of openness. Patients with severe mental disorders had wishes and fears for the future, and all participants expressed that healthy relations were crucial for patients at the end-of-life. However, sometimes this was challenged by prior complex relationships. It differed whether patients experienced a change in their psychiatric condition after having a terminal disease. Openness about severe mental disorders and end-of-life were regarded as important. Having the opportunity to openly discuss both wishes, fears, and mental disorders with healthcare professionals and having healthy relations are important for patients with severe mental disorders at the end-of-life. Insecurity about severe mental disorders among specialised palliative care professionals may lead to less openness about severe mental disorders. To optimise end-of-life care, patients need professionals to be present and available to discuss problems related to social, physical, existential, and psychiatric conditions.

1 | Introduction and Background

The end-of-life (EOL) trajectory of patients with life-limiting diseases often results in suffering for patients and their relatives (O'Malley et al. 2021). This difficult situation may be further complicated if patients also have pre-existing severe mental disorders (SMD), for example, moderate-to-severe depression, bipolar disorder, schizophrenia, and psychotic disorders (Zedan et al. 2023). Studies show that patients with SMDs receive cancer therapy of lower quality than the background population and that they have a higher mortality than patients without SMDs (Bentson et al. 2023; Plana-Ripoll et al. 2020). However, little is known about EOL care for patients with SMD. A literature review from 2023 found that cancer patients with SMD have longer trajectories of specialised palliative care (SPC) but receive less high-intensive EOL care, for example, acute hospitalisations the last month before death, intensive care unit admission the last 14 days before death, and surgery (Svansson et al. 2024). However, according to a recent study by Bergqvist et al. (2024), Swedish patients with psychotic disorders and cancer were less likely to receive SPC compared to patients without psychotic disorders. This was also the case in a study from New Zealand, who identified, that people diagnosed with SMD were 3.5 times less likely to access SPC compared to the general population (Butler and O'Brien 2018). Hence, these studies present conflicting results on whether patients with SMDs receive quality EOL care compared to patients without SMDs. Furthermore, patients with SMDs are often excluded from research projects, and in-depth descriptions of experiences with EOL care to this patient group are lacking. This study aimed to explore the experiences of patients, their relatives, general practitioners (GPs), and SPC nurses and physicians with EOL care for patients with SMD.

2 | Methods

2.1 | Design

A qualitative, explorative design was chosen based on semi-structured individual interviews with patients in palliative trajectories suffering from pre-existing SMDs, their relatives, and healthcare professionals (HCPs), that is: GPs, SPC nurses and SPC physicians. The QOREC checklist was followed to ensure accuracy and completeness of reporting (Tong, Sainsbury, and Craig 2007).

2.2 | Procedure and Participants

The Danish Health Care system operates on a tax-funded basis, providing unrestricted access to healthcare services for all citizens (Schmidt et al. 2019; Pedersen, Andersen, and Søndergaard 2012). Over 99% of the population is registered with a GP, who offers basic palliative treatment alongside municipality home care nursing services, which are accessible at all hours and free of charge. SPC is provided by hospices and palliative care teams affiliated with hospitals, offering support and expertise. GPs or hospital physicians can make referrals to these teams if additional palliative assistance or specialised advice is required. From August 2023 to December 2023, the SPC units in the Central Region Denmark contributed by including patients from hospices and palliative care teams. The inclusion criteria for patients were an ongoing SPC trajectory and having a pre-existing SMD. Patients who were able to give informed consent were invited to participate by SPC professionals and afterwards contacted by the first author and given further information about the study. The SPC professionals also assessed whether the patients were cognitively and physically able to participate in interviews. This assessment was not conducted using specific tests but through individual evaluations of the patient's capacity and an overall ethical review of whether participation was appropriate for each patient. Nine patients were asked to participate, and six agreed (66.7%). We asked patients for permission to contact and interview informants directly related to them, for example, one relative, their GP, and SPC professionals to obtain different perspectives of every patient case.

2.3 | Data Collection

Adopting a phenomenological standpoint, we aimed to explore the lifeworld perspectives of the informants (Neubauer, Witkop, and Varpio 2019). Four different interview guides were made specifically for the different types of informants (patients, relatives, GPs, and SPC professionals). To ensure trustworthiness, the interview guides were reviewed by all authors and adapted following two pilot interviews (see Data S1). Participants were asked questions about their experiences by the first author (Neubauer, Witkop, and Varpio 2019). An example of a question was: “If you think back to the last time you talked to your GP about your mental disease, what did you talk about?” or “Do you remember the first time you heard about the SPC Unit? What was your thoughts?” The questions sought to explore specific descriptions of situations rather than obtain cognitive assessments, e.g. “Did you like the service provided from The Palliative Care Team? Yes/no?”.

The interviews lasted between 24 and 73 min (median: 43 min) (see Table 1). Two out of the five interviews with GPs were conducted by telephone; the other interviews were conducted in face-to-face encounters, for example, in patients' homes (5), in hospitals (8), at hospice (2), or in the GP's practice (3) according to the informant's preference.

2.4 | Data Analysis

Data consisted of a total of 15 h of audiotaped interviews. The interviews were continuously transcribed verbatim by the first author and transferred into NVivo, a qualitative data analysis software (NVivo 2020). Data were analysed using reflexive thematic analysis, following the steps suggested by Braun and Clarke, including creating codes in an inductive, reflexive manner (see Table 2) (Braun and Clarke 2023, 2006, 2021a).

Besides the first author, two members of the research group contributed to the coding process of two of the interviews, cross-referring to ensure triangulation of the data (Noble and Heale 2019). Furthermore, some data were discussed with a multidisciplinary research group, including experienced qualitative researchers, both physicians and non-medical experts.

2.5 | Ethics

2.5.1 | Participant Consent Statement

All participants were thoroughly informed about the project and provided written and oral consent before the interviews.

TABLE 1 | Characteristics of the informants in the 20 interviews.

Informants	All participants ($n=20$)	Patients ($n=6$)	Relatives ($n=3$)	General practitioners ($n=5$)	Specialised palliative care professionals ($n=6$)
Age in years median (min, max)	54 (40, 74)	68 (63, 74)	47 (47, 73)	54 (40, 63)	46 (42, 64)
Sex, *n* (%)					
Female	15 (75.0)	4 (66.7)	2 (66.7)	4 (80.0)	5 (83.3)
Length of the interview in minutes, median (min, max)	43 (24, 73)	58 (35, 73)	48 (44, 51)	41 (24, 50)	39 (33, 52)
Life-limiting diagnosis, *n* (%)					
Lung cancer	—	3	—	—	—
Other diagnosis than lung cancer	—	3	—	—	—
Profession, *n* (%)					
Doctor	—	—	—	5 (100.0)	3 (50.0)
Nurse	—	—	—	—	3 (50.0)

TABLE 2 | Reflexive thematic analysis is divided into six steps according to Braun and Clarke. The process is iterative and goes back and forth between the steps.

Phase 1: Familiarisation	This process was iterative with ongoing conduction of interviews, verbatim transcription, and coding of interviews. The first author was reading and re-reading the data and got a first impression of the data and started to engage critically and reflexively and asking questions
Phase 2: Coding	The codes were created along the way as the material was read and analysed. Besides the first author, two research group members contributed to the coding process in a data session comparing codes and discussing interesting, provoking, and relevant segments. Furthermore, one interview was shown, discussed, and analysed with a group of external qualitative researchers at a data session to open the data further
Phase 3: Generating initial themes	Some of the codes were collected under different headlines with shared meaning. Initial themes were generated actively where the authors played a central role in the process
Phase 4: Developing and reviewing themes	The initial themes were presented and discussed in different interdisciplinary research group meetings. We selected the main themes and opted out some themes as well
Phase 5: Defining and naming themes	The final themes were named and defined with clear and concise descriptions
Phase 6: Creating the report	The findings were synthesised and presented in a coherent and meaningful way

Patients were also asked to sign an informed consent confirming that their relatives, GP, and HCPs in SPC could participate and discuss their EOL trajectory. Participants had the opportunity to withdraw from the study at any time before and after the interview. Participants were also informed about how the data would be used in the study as anonymised quotes.

2.5.2 | Ethics Approval

The study was submitted to The Central Denmark Region Committees on Health Research Ethics and accepted without approval from the Committees (number 1-10-72-6-23). The study was registered in the internal registry of research projects within the Central Denmark Region (number 1-16-02-219-23).

3 | Results

3.1 | Participant Characteristics

Twenty interviews were conducted. Six patients and three relatives (a son, a daughter, and a spouse); five GPs; and six SPC nurses and physicians from SPC units were interviewed individually (see Table 1). The patients' life-l imiting diseases were breast cancer, lung cancer, neuroendocrine tumours, and termi-nal kidney disease. The SMDs comprised moderate and severe depression, schizophrenia, acute psychosis, and bipolar disor-der. Patients were mostly women (66.7%) and between 63 and 73 years old (median: 68 years). Four patients lived alone and two lived with spouses (see Table 1).

In general, all patients and relatives were satisfied with the palliative care they received. They expressed how they felt very welcome and prioritised in the palliative trajectory.

> But overall, and I could keep emphasizing this: Knowing that they're there… I can handle a lot, but there should be someone standing behind me who knows what they're doing. And in there [SPC-unit red.], they do.
>
> Patient (3.1)

The following four themes were produced through the analysis: (1) Thoughts about the future; (2) Relations in the EOL period; (3) Changes in psychiatric symptoms in EOL; (4) The role of openness (see Table 3). The perspectives from the different informants will be presented in themes and not separated by type of informant to enlighten the different themes from different perspectives.

3.2 | Thoughts About the Future

The patients had different thoughts about the future according to their EOL and EOL care. Some thoughts were fears, whereas others were wishes for EOL.

3.2.1 | Fears

Professionals indicated that patients were afraid to die in pain, without dignity, and alone.

> I also think that in this case there has been a need for multiple conversations to dampen his anxiety. Or to remedy it because his anxiety is very much tied to the future he faces. You could say that his anxiety is not unlike the kind that other people or other patients experience.
>
> SPC physician (Informant 4.3)

From this SPC professional's perspective, fear and anxiety concerning the future are present for this patient and recurrent thoughts for other patients in SPC as well.

TABLE 3 | The four main themes and related sub-themes from the interviews.

Themes	Sub-themes
Thoughts about the future	Fears
	Wishes
Relations in EOL	Relations with relatives
	Relations with healthcare professionals
Changes in psychiatric symptoms in EOL	
The role of openness	Conversations about SMD
	EOL/Advance Care Planning conversations

The experience of the SPC professional was echoed by a patient who expressed fear concerning pain and indignity. This patient had lost a family member years ago due to cancer and remembered the pain and indignity in his EOL. He was afraid of facing the same.

> I hope to spend my final days in a way that does not involve a world of pain. Because, well… I hope to avoid it so that I can leave this place with a little bit of dignity.
>
> Patient (Informant 5.1)

3.2.2 | Wishes

Some of the patients talked about wanting to travel.

> Yes, I would love to travel to Spain! But I'm not sure I dare to go when it comes down to it.
>
> Patient (Informant 1.1)

This quote illustrated a recurrent tension between dreams and hopes for the future that was restricted or held back by uncertainty.

Another dimension of wishes for the future was related to physical activity and feeling free.

> My main goal is to be free from that thing (red. walker) and, what's it called… cycling. I miss it… I have a nice electric bike and I hope to get to use it again. Oh, that freedom, you know. Charging down the bicycle lane at full speed. I want that again.
>
> Patient (Informant 5.1)

This quote expresses a feeling of longing to regain some skills that the patient had lost due to illness. The quote about travelling also expresses some of this, the wish to be able to do something again, that previously had been associated with life quality for the patient.

Spending time with family was one of the most pronounced wishes across the patient interviews.

> Well, I want to spend time with my children and grandchildren… My goal is that the next time they come visit, they stay over and spend the night like they used to… I've been dreaming about a weekend like that. Otherwise, they'll just come in the morning and leave at 5 in the afternoon. But I'd like to have them in the room next to me, sleeping… I'd be able to hear them and their voices, all the time…
>
> Patient (Informant 2.1)

In this example, the closeness of being together was important for the patient, not doing something specific together but simply staying close together and being present in the same house. For another patient, it was important to travel with her daughter to spend quality time together just the two of them.

In addition, wishes about the place of death were expressed. These were specific and included not to die alone, a wish to die in a specific place, for instance, hospice, at a relative's house, or at home. This indicated that although future thoughts about the place of death were in their nature individual, all patients with SMD wanted to talk about it and plan it.

Overall, patients had clear wishes regarding time with their family and being able to travel, regain, or keep physical skills that they had before the somatic illness.

3.3 | Relations in EOL

The importance of relations was a recurring theme in our data. Both spending time with relatives and having healthy and close relationships were important in EOL.

3.3.1 | Relations with Relatives

As stated above, patients said they wanted to spend most of their time with family and close friends. However, relatives mentioned complex relationships with the patients for various reasons. Many years of conflicts, misunderstandings, and lack of trust were mentioned. Relatives wanted the EOL period to be as painless and uncomplicated for the patient and themselves as possible, and this wish kept one relative from going into discussions with the patient.

> That's why I don't engage in unnecessary conflicts. I don't think it's worth it.
>
> Relative (Informant 3.2)

The relative acknowledged that the relation had changed a lot due to the terminal illness because she did not want to make her mother feel sad, but the relative missed the old dynamics where a quarrel could be used as a redeeming element in their relationship. This was an example of a general tendency of a patient with SMD would leave family relations with unresolved conflicts. This would also challenge the current possibility of having a healthy relationship.

Another relative stated:

> I've also made it clear that I need to take a step back in order to protect myself. Cause I'll break down a few days later, and that's not an option when I also have a life of my own to manage.
>
> Relative (Informant 4.2)

Hence, relatives perceived that conflicts and discrepancies made the relations complicated and conflicts in close family relations played a big role in EOL. Some relatives also wanted the system to cover relational needs by offering the patient someone to talk to or a visiting friend.

3.3.2 | Relations With HCPs

Both patients and relatives wished that SPC professionals and GPs would spend enough time and capacity to create a meaningful relation and avoid having biased or prejudiced opinions because of the SMD. GPs talked about patients with SMDs in terms of "VIP-patients." They wanted to spend extra time to get to know the patient and create trust. However, the GPs also expressed that this patient group could sometimes be difficult to help.

> That's the kind of thing where I'm thinking, "This is damn meaningful work." So, I use some extra time on her, trying to find out what she wants and what her state of mind is… It's about trust, trying to figure out… well, being curious about them and to them.
>
> GP (Informant 6.4)

The importance of a year-long relationship between the GP and patient was stated in this quote:

> I could be the one who still shows up and provides some moral support for him. I could show him that he's still in my thoughts and that he can discuss things with me—things he might not feel comfortable discussing with the people in the palliative care unit.
>
> GP (Informant 5.4)

The GPs found that the long-lasting relation with the patient was valuable and could hardly be replaced by new SPC professionals.

A relative mentioned that it could require some extra time and investment for the SPC professionals to understand her mom's needs as she sometimes did not express her needs very clearly.

> I hope the SPC professionals see her for the person she is and that they are able to see through some of the things that she says. Reading between the lines… Sometimes she says one thing and means something different, you know?
>
> Relative (Informant 3.2)

Some aspects of good quality EOL care were in the opinion of one relative also mentioned as the HCPs being present and showing interest in the patient.

> If there is one important word, it's probably presence, I think. And I feel like she [the patient red.] gets a lot of that there, right? [hospice red.]. There are people there who care about her.
>
> Relative (Informant 6.2)

Overall, the relatives wished for their mother/father/spouse to have meaningful and caring contact with HCPs.

3.4 | Changes in Psychiatric Symptoms in EOL

The data contained different descriptions that included EOL trajectories with changes and others with stabilised psychiatric symptoms. One patient with recurring depression had changed in mood after being diagnosed with terminal illness. Even though, she did not express it in the interview herself, the study enabled insight from people around her, who had noticed the mood change.

> She's become a bit sad. But it's also because, like I said, my mom has always… There have been times where she's been depressed. Especially in my childhood. I remember that. Especially now, with all this, you know. But I think she has become more introverted, like a different person, especially in the past six months.
>
> Relative (Informant 3.2)

When asked, the patient denied feeling depressed, but her daughter saw it from another perspective.

The GP to the same patient said:

> She is a bit sad, and it's actually quite visible on her. But she doesn't sit down and talk to me about it, no… In my opinion, she hasn't been willing to accept any help.
>
> GP (Informant 3.4)

This discrepancy in the results indicated that it is important for HCPs to be particularly aware of the psychiatric condition of patients with SMDsii who are in EOL trajectories since the patient has not necessarily addressed a change.

Some HCPs experienced, that psychiatric symptoms were stabilised or stepped into the background when the patient got a terminal diagnosis. One GP found it paradoxical but not rare and concluded that the EOL period would not necessarily affect the psychiatric condition.

> It's not really my impression that he has declined mentally. He has been surprisingly robust, considering the diagnosis. He's accepted it. I feel like we see other reactions than we expected sometimes, you know?
>
> GP (Informant 4.4)

A relative to the same patient had the opinion that the coping strategy was almost attention-seeking.

> When he got the cancer diagnosis, he concluded that he was, in fact, quite happy with his life. But the diagnosis was a turbulent rollercoaster for me. How should I adjust to the notion that suddenly now, life is just great? There was now a straight-ahead path to the end. His perspective changed… and his optimism almost made me nauseous, because for so many years he said that he didn't want to live… and then he goes into this cancer experience with what you could almost describe as excitement. Things were exciting now, and he seemed to crave the attention he got from the health care system.
>
> Relative (Informant 4.2)

The relative perceived that the cancer diagnosis was an opportunity for the patient to receive attention from the healthcare system, and that the patient used the situation as a distraction from the mental suffering he had for several years. Thus, what from the HCP's perspective was a betterment in the psychiatric condition was perceived to be negative, that is, nauseating from a relative perspective. This finding is an example of the complexity of patient-relative relations. This may also show that having an SMD is still connected with stigma.

Hence, our data showed that while some patients experienced an increase in depressive symptoms after the terminal illness, others experienced a decrease in psychiatric symptoms. These findings may seem paradoxical, as SMD does not automatically make EOL trajectories more difficult, although more depressive symptoms may appear after the terminal diagnosis.

3.5 | The Role of Openness

Another important theme in the data was the overall willingness to talk openly about SMD and EOL. Patients, GPs, and SPC professionals had different views of this issue. Some SPCs had insecurities about SMDs and were afraid of the patients' reactions if asked openly. The GPs often knew their patients very well through the years and generally had less fear of confrontation about SMDs. Almost every patient wanted to talk about their SMD with HCPs. They also wanted to discuss and plan their EOL.

> I will decide what questions I answer… but it is always fine to be asked.
>
> Patient (Informant 6.1)

3.5.1 | Conversations About SMD

The SPC professionals expressed ambivalence according to conversations concerning SMDs. One talked about the ability she had simply to sit down with the patient, be present, ask questions, and talk openly about mental suffering and SMD without feeling uncomfortable. Others mentioned feeling insecure and felt they lacked knowledge about SMDs and therefore did not feel comfortable to ask about it.

> I remember her reaction when I asked her about it [SMD red.]—it was such an easy conversation. She was in no way offended and it wasn't uncomfortable. Not at all. And when my colleagues learned that I had asked, they were like, 'What, wow, you are so brave', and I was like, it wasn't hard at all.
>
> SPC nurse (Informant 3.3)

The colleagues' experience was that asking openly about SMD was a brave action more than a standard part of their job. However, openness is not an unambiguously defined term but can mean different things to different people.

> No, we didn't talk about it [SMD, red.]. It would have been good to approach the topic, but we didn't… It's a good idea to talk to them [SPC professionals, red.] about it, we could do that. But there are things I keep to myself. It depends on who I'm talking to, with my situation and all.
>
> Patient (Informant 5.1)

From this perspective, the idea of having conversations about SMD was acknowledged; however, there was still some scepticism about the degree of sharing information with SPC professionals.

Total directness was another approach.

> I probably did need to talk about it [to SPC professionals, red.] because I am generally an open person. It's been many years since I stopped hiding things because doing that is also part of what an alcoholic does.
>
> Patient (Informant 4.1)

A third approach showed a more private style, where the patient did not need to address the SMD.

> I don't feel like we need to talk so much about it [SMD, red.] I feel it inside, what happened back then. But today I also know why, and what it really was. So no, I don't feel like we've had a need to talk about it. Or at least I haven't.
>
> Patient (Informant 3.1)

To sum up, some patients appreciated openness and found it obvious to talk with SPC professionals about their SMD; others had things they wanted to keep for themselves and addressed their ability to say yes and no to these open questions. None of the patients would be offended to be asked openly and politely about their SMD.

3.5.2 | EOL/Advance Care Planning Conversations

The general tendency in the study was that patients with SMDs wanted to be asked openly about their wishes and plans for EOL. Some patients wanted to discuss it in-depth, whereas others did not. One GP mentioned one of her patients, who did not want to talk about death with the SPC team or with anyone.

> He told me: 'I don't want to talk about death, I get in a bad mood about it. I want to talk about the amount of life that I have after all.' You've got to be careful, you know? That you don't force that topic on people.
>
> GP (Informant 2.4)

Other patients wanted to plan their EOL in advance and discuss the place of death and funeral. One patient said when talking about SPC professionals asking open questions about death:

> I feel resolved about it [death, red.]. When they lift me out of the church, I want 'Always look on the bright side of life' to be playing if we can get the priest in on it. And some 'Stairway to heaven'.
>
> Patient (Informant 4.1)

When asked about their wishes for an EOL, most patients mentioned several wishes, and it was clear that they already had reflected, on how they wanted their EOL time to be.

One patient talked about future wishes in a conversation he had with the SPC professional.

> She also told me that it would be great if I started writing down my final plans and wishes… And I'm working on it now. 'Yes, I want to take my small family on a summer house trip, I do.' And with wishes, well, there's the hospice. So, things like the Western Sea, right? And hospice. That's pretty concrete. It's important to me that we will be together, all of us.
>
> Patient (Informant 4.1)

This quote showed how the SPC professional guided the patient with specific tools to concretise what was important for him in EOL.

These findings indicated that patients with SMD want to make decisions about future treatment and need to be involved in the planning of it due to their wishes to achieve a better EOL trajectory.

4 | Discussion

4.1 | Main Findings

The study finds that patients with SMDs have thoughts, wishes, and fears concerning the EOL period that are not different from what could be expected for patients without SMDs. Likewise, healthy and close relationships in EOL are one of the most important factors for patients with SMDs' well-being in EOL, not only with relatives but also with HCPs.

The study shows that patients with SMDs do not necessarily experience a worsening in their psychiatric symptoms due to being diagnosed with a life-limiting disorder. In some cases, the SMD even seems to play a smaller role than before. Others, however, may experience a worsening in, for instance, depressive symptoms.

Furthermore, openness related to both talking about the SMD and EOL is stressed as important. We find that openness is not just about being asked directly but that the willingness to talk about it with SPC professionals depends on trust, time, and individual needs. Some patients do not want to discuss their psychiatric disorder with people they just met but only with someone they have known during years of treatment, for example, their GP or their psychiatrist. Finally, all patients agreed that it always was okay to be asked, and they would be able to reject talking about the topic if they do not want to. Invitation to discuss openly EOL and planning EOL with SPC professionals is warranted.

4.2 | Comparison with Other Literature

In our study, most of the patients both have clear wishes for and fears about the future. In a study by Sweers et al. (2013) about EOL care perspectives of patients with schizophrenia, the majority of patients do not fear death. The same study also finds that patients with schizophrenia overall have the same expectations about EOL as every other patient.

In our study, the need for healthy relationships in EOL is an important but not surprising finding. Some of the relatives in our study mentioned conflicts and years of misunderstandings within the family that complicate the relations. They wish that the system can fill in some of the needs in relationships, for example, by providing a visiting friend or having a close relationship with the GP. In consistency with other studies, our research shows that relatives of patients with SMD can be burdened when they become ill due to somatic conditions (Zedan et al. 2023). This can also lead to unmet needs if the relative is overburdened.

A study from 2021 finds that patients in palliative care can experience mental issues and have specific mental healthcare needs (O'Malley et al. 2021). They also find that palliative care teams, including psychology and psychiatry services, improved patient well-being. Our study finds that the patient's mental condition is not automatically worsened when getting a terminal diagnosis and having a pre-existing SMD. At the same time, another study finds, that patients with a strong death wish sometimes have an underlying mental disorder (Wilson et al. 2016). Therefore, it might require some extra attention when a patient with an SMD is in EOL care. One challenge can also be distinguishing depression from grief and sadness in patients receiving palliative care (Widera and Block 2012). To our knowledge, there is no evidence showing that patients with SMD will worsen their psychiatric condition when receiving a terminal diagnosis.

Health care professionals often think that people with SMDs lack decision-making capacity, but the literature demonstrates that these patients, in general, are capable of making decisions about EOL care (Shalev et al. 2017; Foti et al. 2005). At the same time, an interview study from 2023 finds that patients with SMDs are uncomfortable speaking about death (Knippenberg et al. 2023). Nevertheless, the respondents in this study are realistic concerning wishes and expectations regarding EOL, for example, where they prefer to stay, and most of them also have thoughts about planning their funeral. Conversely, it is also known that HCPs can be hesitant to take these conversations with patients with SMDs because they are afraid the patient will react inappropriately to the questions or not benefit from them (Shalev et al. 2017). Our study shows that patients with life-l imiting diseases and SMDs are thinking about EOL, have clear wishes, and want to discuss and plan their EOL together with HCPs. However, a Danish study from 2024 finds, that HCPs in the Oncology Department reported lacking knowledge about SMDs, which often leads to insecurities before the patient shows up in the department (Bruun et al. 2024). This tendency of lacking knowledge about SMDs among HCPs can be reduced by teaching HCPs in SMDs.

4.3 | Strengths and Limitations of the Study

A major strength of the study was the representation of patients' voices. Patients with SMDs are often excluded from research. Furthermore, we also represent the voices of relatives, GPs, and SPC professionals which gives different perspectives. In addition, the qualitative design made it possible to gain in-depth descriptions and knowledge of the experiences with EOL care for this patient group. Another strength of this study and the analysis of data was the cross-disciplinary team of researchers, which included both physicians and non-medical experts with extensive experience in qualitative research.

A limitation of the study is the probability of selection bias. Only one patient with the diagnosis of schizophrenia is represented. It may be demanding to participate in an interview, and the most psychiatric and somatic ill patients have not participated. This could have affected our results in a way that the experienced challenges were not as problematic as they could have been. Some of the interviews were particularly challenging to conduct because individual informants were hesitant in their answers or had difficulties understanding the essence of the question if it was too long or complex.

Another limitation of the study is that patients with one SMD do not necessarily face the same challenges as patients with another SMD (e.g., depression vs. schizophrenia). The expression of different SMD diagnoses varies significantly, as do the challenges in EOL care.

A third limitation is the relatively low number of participants in the study, which may have prevented us from achieving full data saturation. While repeated themes and variations were identified, additional interviews might have revealed new themes. However, we find that our in-depth analysis provides “thick” descriptions (Geertz 1973) of the participants' experiences, which outweighs the lack of saturation. Moreover, the value of data saturation in reflexive thematic analysis (the approach in this study) has been questioned (Braun and Clarke 2021b).

Patients were recruited to participate in the study by SPC professionals. This is a potential limitation, because the institutions may unconsciously have selected patients who were the most positive towards the institution and some patients could have missed inclusion due to less obvious SMDs, for example, if they had a depression several years ago. Also, the relatives and HCPs who participated were selected from the participating patients. Therefore, the selection bias is consistent across all informants.

4.4 | Relevance of Findings for Policy or Practice

The present study shows that HCPs in general should consider inviting patients with SMDs for conversations about SMD and EOL, as this group may benefit from discussing and planning their preferences in line with patients in general.

4.5 | Implications for Future Research

Future studies are needed to explore how patients with SMD are cared for at the EOL especially the last days before death to gain insights into the quality of palliative actions and whether barriers to optimal care exist for this patient group.

5 | Conclusion

In this study, exploring experiences according to EOL care for patients with pre-existing SMDs, their relatives, SPC professionals, and GPs, the most important finding was that having healthy relationships is a very strong wish for patients in EOL. The insecurity among SPC professionals about openness according talking about SMD and wishes for EOL with patients having SMD, could sometimes lead to less conversations and openness about these topics. Patients with SMD had thoughts about the future, primarily according to fears and wishes, like patients in EOL trajectories in general. Furthermore, it was found that pre-existing SMD in addition to terminal disease does not necessarily make the trajectory more complex.

6 | Relevance for Clinical Practice

Existing studies present conflicting results on whether patients with SMDs receive quality EOL care compared to patients without SMDs. The results of this study demonstrate that healthy and close relationships with relatives and HCPs are important in EOL, but prior conflicts sometimes complicate this. Patients with SMDs do not necessarily experience a change in their psychiatric condition when facing terminal illness. SPC professionals may feel insecure when approaching patients with SMDs in EOL trajectories. This study shows that patients with SMDs wish to be asked about their SMD and plan their future and that their EOL trajectories not necessarily is complicated because of the pre-existing SMDs.

Author Contributions

All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors and are in agreement with the manuscript. The authors' contributions were as follows: Designed study: K.B., P.V., M.K.N., J.E.M., M.A.N. Data collection: K.B. Data analysis: K.B., P.V., M.K.N., J.E.M., M.A.N. Drafting and commenting on the paper: K.B., P.V., M.K.N., J.E.M., M.A.N.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Study II

Bøndergaard K, Nielsen MK, Videbech P, Møller JE, Johnsen SP, Eriksen JG, Groenvold M, Hannigan B, Neergaard M

Quality in specialist palliative care for patients with pre-existing severe mental disorders: A retrospective cohort study

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A Part of Sage

Quality in specialist palliative care for patients with pre-existing severe mental disorders: A retrospective cohort study

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Abstract

Background: Previous studies show ambiguous results concerning quality of palliative care among patients with severe mental disorders, defined as schizophrenia, moderate to severe depression, and bipolar disorders.

Aim: To investigate quality in specialist palliative care among Danish patients with pre-existing severe mental disorders using data from the Danish Palliative Database.

Design: Danish cohort study linking data from the Danish Palliative Database and hospital medical files.

Setting/participants: All adult decedents in 2023 from Central Denmark Region affiliated with specialist palliative care. Hospital records were screened for severe mental disorders. Quality indicators included: Place-of-death, days from referral to death, specialist palliative care waiting time, discussion at multidisciplinary conferences and completion of symptom assessment.

Results: Of 1869 patients, 80 (4.3%) had pre-existing severe mental disorders. Compared to patients without mental disorders, these patients died younger and more often from non-cancer conditions. They were less likely to complete symptom assessment (Risk Ratio (RR): 1.49 (95% CI: 1.15;1.95)). Those who also received active psychiatric treatment experienced longer waiting times for specialist palliative care (Mean ratios (MR): 3.48 (95% CI: 1.06;11.39)) and shorter palliative care pathways (MR: 0.44 (95% CI: 0.20;0.96)) than patients without active psychiatric treatment.

Conclusion: Danish patients with active severe mental disorders were less likely to complete symptom assessment, had longer waiting times and shorter specialist palliative care pathways. Future efforts should focus on timely access to specialist palliative care and health professionals supporting completion of symptom assessments in this population.

Keywords

palliative care, mental disorders, health inequities, delivery of health care, terminal care

What is already known about the topic?

- Previous research about palliative care for patients with severe mental disorders shows ambiguous results.
- Some studies show less access to specialist palliative care for patients with pre-existing severe mental disorders posing a concern due to equality.

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What this paper adds?

- This study highlights disparities in end-of-life care between people with and without severe mental disorders in Denmark regarding different quality indicators.
- The study found that patients with severe mental disorders to a lesser extent filled out symptom assessments compared to patients without severe mental disorders.
- The study also found that patients with an active psychiatric treatment had longer waiting time to specialist palliative care and shorter specialist palliative care pathways compared to patients with severe mental disorders without active psychiatric treatment 1 year before death.

Implications for practice, theory or policy?

- The study showed disparities in the completion of symptom assessment, in waiting times to specialist palliative care and length of specialist palliative care pathways stressing a focus on access to health care for patients with severe mental disorders.
- More knowledge is needed on reasons for the found inequality and how to overcome barriers to optimal specialist palliative care to patients with severe mental disorders.

Introduction

Patients with pre-existing severe mental disorders, defined as schizophrenia, other psychotic disorders, moderate to severe depression, and bipolar disorders, may represent a vulnerable group at the end-of-life, often with complex needs that are difficult to assess and address.[1] Barriers to high-quality palliative care occur at system, professional, and patient levels, such as fragmented pathways, stigma, and taboos surrounding psychiatric illness.[2–4] Stigmatizing attitudes among healthcare professionals may further affect clinical decisions and care quality.[5] Qualitative and mixed-methods studies suggest care can be improved through early involvement of palliative care services and open communication addressing social, physical, existential, and psychiatric needs.[6,7] Patients with mental disorders also experience substantial health inequalities, premature mortality,[8] and poorer cancer treatment quality than the general population.[4,9] Despite high mortality risk among patients with severe mental disorders, knowledge about their palliative care is missing.[10]

Palliative care improves quality of life[11] and specialist services are delivered by specialist teams or hospices.[12] However, regarding the quality of palliative care for patients with severe mental disorders, findings show ambiguous results. For example, Swedish patients with psychosis and cancer were less likely to receive specialist palliative care,[13] and a Danish cohort study linked severe mental disorders with lower probability of receiving specialist palliative care.[9] Likewise, more unplanned care and more institutional deaths in the last year of life were found among Welsh patients with severe mental disorders.[14] A Taiwanese study even found increased use of intensive care and invasive interventions near death for patients with schizophrenia.[15] On the other hand, a review from 2024 revealed that patients with cancer and severe mental disorders were referred earlier to specialist palliative care, received longer palliative involvement and less high-intensive end-of-life care, such as fewer hospitalizations, emergency department visits, late chemotherapy, and in-hospital deaths.[13,16] These divergent findings might reflect methodological heterogeneity across studies, including different definitions of severe mental disorders, differences between cancer and non-cancer cohorts, and inconsistent measures of palliative care quality, making overall conclusions difficult.

Quality assessment in palliative care is further challenged by the absence of universally validated indicators. Hundreds of end-of-life quality indicators exist, but only a small proportion have undergone rigorous testing, most focusing on pain or process-related aspects.[17,18] In Denmark, national quality indicators from the Danish Palliative Database provide systematically monitored, population-based measures of referral timelines, access to specialist palliative care, multidisciplinary conferences, and patient-reported outcomes.[19,20]

Despite growing attention to palliative care for patients with severe mental disorders, it remains unknown whether they receive specialist palliative care that meets established national quality standards. This study examined quality in specialist palliative care among patients with severe mental disorders, especially if the care meets Danish national quality indicators compared with patients without severe mental disorders.

Methods

Study design

The retrospective cohort study used data from the Danish Palliative Database and hospital medical files of deceased patients from Central Denmark Region affiliated with specialist palliative care, who died in 2023.[19]

Setting

The Danish health care system is tax-funded with universal access.[21,22] Over 99% of residents are registered with a general practitioner who, together with municipal nursing services, delivers basic palliative care. In case of complexity, general practitioners or hospital physicians refer to specialist palliative care provided either in-bed hospices or by hospital-affiliated palliative care teams in hospitals or patients' homes. Central Denmark Region encompasses 10 specialist palliative care units for adults (five hospices and five teams). Since 2010, all units have reported data to the Danish Palliative Database, with 100% completeness.[19]

Study population

Eligible participants were adults (⩾18 years) referred to specialist palliative care who died in 2023. Identification was based on unique personal registration numbers, and medical records were transferred to RedCap.[14] The first author screened all medical records in 2024 and registered whether patients had a severe mental disorder defined as ICD-10 diagnoses of moderate-to-severe depression (F32–33), bipolar disorder (F30–31), schizophrenia (F20), or other psychotic disorders (F21–29).

To classify mental disorders as pre-existing, mental diagnoses recorded after cancer or amyotrophic lateral sclerosis were excluded. For chronic progressive illnesses (e.g. chronic lung disease or heart failure), mental diagnoses recorded within 2 years after the somatic condition were excluded to avoid capturing reactive, illness-related symptoms; mental diagnoses occurring before or more than 2 years after the somatic condition was retained.

Data collection and variables

Descriptive variables. The study consisted of data from the Danish Palliative Database[19] and hospital medical files. Danish Palliative Database includes all patients referred to specialized palliative care in Denmark, both those receiving specialist palliative care and those who are referred but not admitted for different reasons. Patients are registered at end of contact.[20] Extracted variables included: Patient age (years), sex (female/male/other), referral diagnosis (somatic diagnosis), having children (yes/no), place of living (home/institution), living arrangements (alone/with others), place of death (home/hospital/Specialist palliative care unit/another place), specialist palliative care affiliation (team/hospice), health-related quality of life, European Organization for Research and Treatment of Cancer-QLQ-C15 PAL (EORTC)-scores[23]) and the referral institution (general practitioner/other physician).

From medical records, we extracted: Severe mental disorder diagnosis (yes/no), debut of severe mental disorder diagnosis (year), type of severe mental disorder diagnosis (schizophrenia, other psychotic disorders, moderate to severe depression, and bipolar disorders), type of somatic diagnosis that led to death (diagnosis) and debut of somatic diagnosis (year). The following variables were extracted using a list of search words (Supplemental File 1): Active psychiatric treatment (contact with hospital based psychiatry in the last year of life; yes/no), Advance Care Planning conversation throughout the palliative care pathway (time from first contact with specialist palliative care until death or discharge from the service), (yes/no), date of Advance Care Planning conversation, prescription of morphine or midazolam as an injection solution within 14 days before death (yes/no), treatment with psychiatric drugs 1 year before death (yes/no), and date of death.

Data were collected manually by the first author, verified by the last author when needed, and managed using RedCap hosted at Aarhus University.[24,25]

Quality indicators. Four Danish Palliative Database indicators were included: (1) Waiting time from referral to first specialist palliative care visit (days), (2) Discussion at a multidisciplinary specialist palliative care conference at any time during the pathway (yes/no), (3) Completion of EORTC[23] from 3 days before to the date of first contact with specialist palliative care (baseline; yes/no) and (4) Completion of EORTC after 1–4 weeks (yes/no).

Additionally, 'Time from first specialist palliative care contact to death' (days), and 'Death at hospital' (yes/no) were included.

Statistical analysis

The cohort was characterized using descriptive statistics. Patients diagnosed with severe mental disorders were compared with patients without severe mental disorders concerning characteristics of patient and palliative care pathways along with quality indicators. Also, patients with severe mental disorders across the three diagnosis groups were compared with descriptive statistics (depression, bipolar disorders, and schizophrenia/other psychotic disorders). To analyze the severity of the severe mental disorder patients with severe mental disorders who had an active treatment in psychiatric department were compared with those without active treatment.

Relative risks (RRs) and corresponding 95% confidence intervals (CIs) were estimated for dichotomous outcomes using unadjusted log binomial regression.[26–28] For continuous outcomes, we estimated unadjusted mean ratios (MR) using a generalized linear model with a Poisson distribution and log link, combined with robust variance estimation.[26,27,29]

STATA were used for analyzing data (StataCorp, College Station, TX).[30]

Ethical considerations

The Central Denmark Region Committees on Health Research Ethics approved the study (Ref: 1-45-70-94-23). The project was notified for the internal research database (Ref: 1-16-02-219-23). Additional approval was obtained to access hospital medical files. To protect confidentiality, categories with fewer than three patients were combined in reported tables.

Results

In 2023, 4197 care pathways in specialist palliative care in Central Denmark Region were registered in Danish Palliative Database. 1857 specialist palliative care pathways never started, 10 care pathways involved patients under the age of 18, 13 care pathways ended after first visit from specialist palliative care, and 4 patients died before start, resulting in 2313 specialist palliative care pathways, comprising 1869 individual patients (Figure 1). The median age at death was 72 years (IQR: 64;79), 48% were females, and 15% were referred due to non-cancer conditions (Table 1). Most deaths occurred in hospices or specialist palliative care departments (52%).

Comparisons according to having severe mental disorders or not

Characteristics. Eighty patients (4.3%) with 93 specialist palliative care pathways (4.0%) were registered as having severe mental disorders (Table 1).

Patients with and without severe mental disorders differed in sociodemographic characteristics and healthcare utilization (Table 1). Patients with severe mental disorders were younger at death, more often referred to specialist palliative care due to non-cancer conditions, more likely to be living alone, and fewer had children compared to patients without severe mental disorders. At the care pathway level, patients with severe mental disorders were less likely to have a hospice stay, less likely to die in hospice, and more likely to be dying at home compared to patients without severe mental disorders.

Quality indicators. Quality indicators between patients having and not having severe mental disorders were compared (Table 2). Concerning hospital death and length of specialist palliative care pathways, there were no significant differences between the groups. Concerning the four Danish Palliative Database quality indicators, one significant difference was found in filling in baseline EORTC, where patients with severe mental disorders were less likely to complete EORTC compared to patients without severe mental disorders (RR: 1.49 (95% CI: 1.15;1.95)).

Comparison of patients with and without active treatment in psychiatry

Characteristics. As an indicator of the severity of the mental disorder, patients with SMDs were divided in groups of having or not having an active treatment in psychiatry 1 year before death. (Table 3). Those with active treatments were predominantly male.

Quality indicators. Patients with an active psychiatric treatment had longer waiting time from referral to first specialist palliative care contact (MR: 3.48 (95% CI: 1.06;11.39)) and shorter specialist palliative care pathways (MR: 0.44 (95% CI: 0.20;0.96)) compared with patients without an active psychiatric treatment (Table 3). Other quality indicators showed no significant differences.

Comparison of patients with different severe mental disorder diagnosis groups

Characteristics. Due to very small sample sizes in the subgroups of mental illness, only descriptive comparisons were made (Supplemental File 2). Patients with depression were more likely to receive subcutaneous morphine and/or midazolam in the last 14 days before death. At the care pathway level, patients with schizophrenia were less often referred by general practitioners compared with the other groups. Quality indicators were not analyzed in subgroups of mental illness because of low numbers.

Discussion

Main findings

This register-based cohort study is the first to assess quality indicators in specialist palliative care for patients with severe mental disorders. Patients with severe mental disorders were younger and more frequently referred for non-cancer conditions compared to those without severe mental disorders.

Significant differences were found concerning quality indicators. Patients with severe mental disorders were less likely to complete symptom assessment, emphasizing the need for targeted symptom screening. Additionally, those with an active psychiatric treatment within the last year before death experienced longer waiting times before starting specialist palliative care and had shorter length of palliative care compared to patients without active psychiatric treatment.

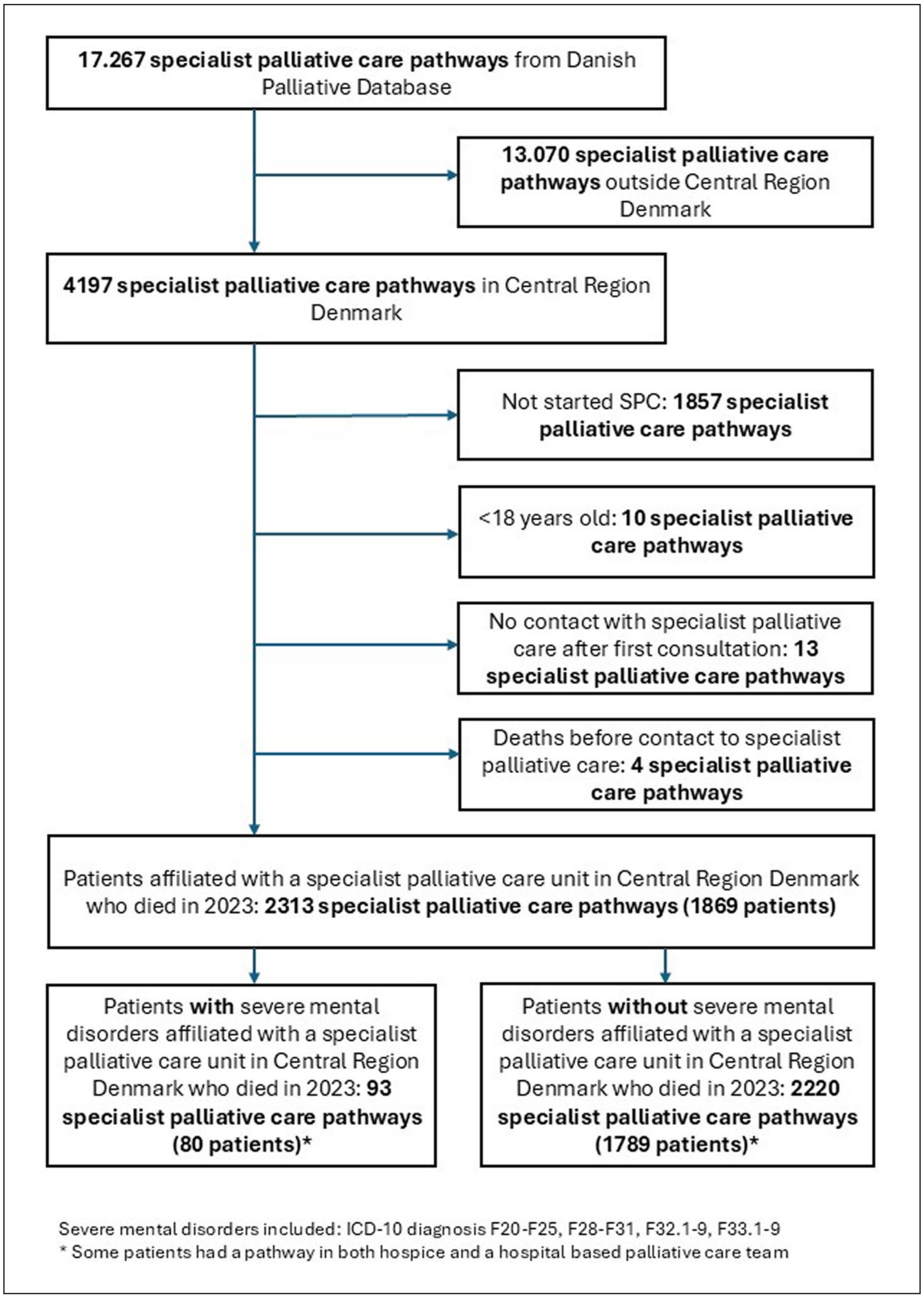

Figure 1. Flowchart of study population.

Comparison with existing findings

This study shows disparities in the quality of specialist palliative care for patients with severe mental disorders. Although this study did not evaluate overall access, recent registry data from Sweden and Denmark indicate lower access to specialist palliative care for patients with severe mental disorders.[9,13] These prior findings complement our focus on quality indicators during specialist palliative care rather than access itself.

Examining all patients with severe mental disorders collectively, no difference was found in the length of specialist palliative care pathways. This differs from earlier research revealing longer palliative care periods but less access to high-intensive end-of-life care for cancer patients with severe mental disorders.[16] Subdividing the group based on the presence of an active psychiatric treatment revealed that those with active psychiatric care had significantly shorter palliative care pathways, indicating later referral to specialist palliative care. Early referral

Table 1. Sociodemographic characteristics and health utilization of patients affiliated with specialist palliative care in Central Denmark Region who died in 2023.

Characteristics at patient level			
	In all (*N* = 1869)	Patients with a severe mental disorder diagnosis[a] (*n* = 80)	Patients without a severe mental disorder diagnosis[a] (*n* = 1789)
Age of patients in years at death (median (IQR))	72 (64;79)	68 (60;76)	73 (65;79)
Age groups of patients in years at death (*n* (%))			
80+	425 (22.7)	8 (10.0)	417 (23.3)
70–79	697 (37.3)	29 (36.3)	668 (37.3)
60–69	468 (25.0)	25 (31.3)	443 (24.8)
50–59	181 (9.7)	11 (13.8)	170 (9.5)
Under 50	98 (5.2)	7 (8.8)	91 (5.1)
Patient sex (*n* (%))			
Female	896 (47.9)	41 (51.3)	855 (47.8)
Male	973 (52.1)	39 (48.8)	934 (52.2)
Severe mental disorder[a] (*n* (%))			
Depression	49 (2.6)	49 (61.3)	NA
Bipolar disorder	16 (0.9)	16 (20.0)	
Schizophrenia and psychotic disorders	15 (0.80)	15 (18.8)	
Referral diagnosis (*n* (%))			
Cancer	1586 (84.9)	56 (70.0)	1530 (85.5)
Non-cancer conditions[b]	283 (15.1)	24 (30.0)	259 (14.5)
Referral diagnosis, specified (*n* (%))			
Cancer			
Lung and airway cancer	405 (21.7)	18 (22.5)	387 (21.6)
Other cancers	335 (17.9)	5 (6.3)	330 (18.5)
Gastro-intestinal cancer	222 (11.9)	3 (3.8)	219 (12.2)
Pancreas cancer	133 (7.1)	6 (7.5)	127 (7.1)
Breast cancer	130 (7.0)	4 (5.0)	126 (7.0)
Head-and-neck cancer	98 (5.2)	5 (6.3)	93 (5.2)
Gynecological cancer	98 (5.2)	3 (3.8)	95 (5.3)
Hematological cancer	74 (4.0)	5 (6.3)	69 (3.9)
Liver and biliary cancer	57 (3.1)	4 (5.0)	53 (3.0)
Unknown cancer	34 (1.8)	3 (3.8)	31 (1.7)
Non-cancer conditions[b]			
Other organ diseases (e.g., kidney and heart failure)	119 (6.4)	10 (12.5)	109 (6.1)
Lung diseases (e.g., COPD and lung fibrosis)	101 (5.4)	10 (12.5)	91 (5.1)
Neurological diseases	63 (3.4)	4 (5.0)	59 (3.3)
Having children (*n* (%))			
Yes	1622 (88.3)	60 (80.0)	1562 (88.6)
No	216 (11.8)	15 (20.0)	201 (11.4)
Missing's	31		
Place of living (*n* (%))			
Private	1743 (93.8)	65 (83.3)	1678 (94.2)
Institution (elderly care home)	88 (4.7)	8 (10.3)	80 (4.45)
Other	28 (1.5)	5 (6.4)	23 (1.3)
Missing's	10		
Living arrangement (*n* (%))			
Living with others	1092 (63.2)	30 (46.2)	1062 (63.9)
Living alone	636 (36.8)	35 (53.9)	601 (36.1)
Missing's	141		

(continued)

Table 1. (Continued)

Place of death (*n* (%))			
Home	556 (35.6)	28 (48.3)	528 (35.1)
Hospice or specialist palliative care hospital department[c]	815 (52.2)	20 (34.5)	795 (52.9)
Non-specialist palliative care hospital department	114 (7.3)	5 (8.6)	109 (7.3)
Temporary care home	77 (4.9)	5 (8.6)	72 (4.8)
Missing's	307		

Characteristics at SPC pathway level

	In all (*N* = 2313)	Specialist palliative care pathways of patients with a severe mental disorder diagnosis[a] (*n* = 93)	Specialist palliative care pathways of patients without a severe mental disorder diagnosis[a] (*n* = 2220)
Specialist palliative care affiliation[c] (*n* (%))			
Hospice	857 (37.1)	24 (25.8)	833 (37.5)
Team	1456 (63.0)	69 (74.2)	1387 (62.5)
Referred to specialist palliative care[c] from (*n* (%))			
General practitioner	588 (25.4)	27 (29.0)	561 (25.3)
Other physicians	1725 (74.6)	66 (71.0)	1659 (74.7)

IQR: inter quartile range; NA: non applicable; COPD: chronic obstructive pulmonary disease.

The study comprised 1869 individual patients covering 2313 specialist palliative care pathways affiliated with either in-bed hospice or hospital-based palliative care team or both.

[a] Severe mental disorders, defined as: moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders.

[b] Non-cancer conditions defined as: all terminal illnesses other than cancer: Heart, kidney and other organ failures.

[c] Specialist palliative care, defined as: in-bed hospice or hospital-based palliative care team.

indicates high-quality,[31] though long specialist palliative care pathways can also indicate earlier discharge from active cancer treatment, or a larger complexity in palliative care for patients with severe mental disorders that may lead to referral to specialist palliative care earlier. However, a study from 2025 found that having severe mental disorders do not necessarily make palliative care pathways more complex though they remain challenging for clinicians.[6] Despite this complexity, shorter specialist palliative care pathways for patients with active psychiatric treatment suggest disparities in care.

Regarding waiting times, no overall difference was found between patients with and without severe mental disorders. However, patients with active psychiatric treatment faced longer waiting times for specialist palliative care. A paper from 2021 stated that the structure between mental health and end-of-life care systems means that people with severe mental disorders at the end-of-life often have difficulty getting the services they need.[1] These system structures (e.g. organizational arrangements across psychiatric and somatic services such as care silos, parallel documentation, and stabilization procedures during acute psychiatric symptoms) may contribute to the prolonged waiting time for patients with severe mental disorders with active psychiatric treatment.[32] Waiting times can be prolonged if patients are psychiatrically admitted at or around the time of referral. Although this was likely not the case for most of the patients in our cohort, active psychiatric treatment in the year before death was interpreted as a marker of greater psychiatric symptom burden, which may reduce readiness to engage with new services. Also, diagnostic overshadowing is known to affect this patient population, for example, abdominal pain being misattributed to mental illness, which could influence both referrals and prioritization.[33] This is suggested to be explored further in future research.

Patients with severe mental disorders completed symptom screening less frequently at baseline and after 1–4 weeks, potentially hindering symptom management and lowering quality of palliative care. EORTC is sensitive and specific about clinically important symptoms and functional health impairments for patients in specialist palliative care.[34] Lower completion among patients with severe mental disorders likely reflects both patient-level factors (e.g. difficulty maintaining an overview due to active psychiatric symptoms) and provider-level barriers (e.g. time pressure, diagnostic overshadowing, and doubt about tool applicability during acute psychiatric symptoms).[4] In Danish specialist palliative care, EORTC QLQ-C15-PAL is routinely offered at first contact and after 1–4 weeks, usually nurse- or physician-initiated. Clinical judgment regarding a patient's ability to complete the questionnaire may lead to less completion, resulting in reduced systematic knowledge about symptom burden. A

Table 2. Quality indicators in specialist palliative care[a] pathways for patients affiliated with specialist palliative care[a] in Central Denmark Region who died in 2023.

Quality indicators at patient level

	In all (*N* = 1869)	Patients with a severe mental disorder[b] (*n* = 80)	Patients without a severe mental disorder[b] (*n* = 1789)	RR (95% CI)
Death in hospital (*n* (%))				
Yes	114 (7.3)	5 (8.6)	109 (7.6)	0.99
No	1448 (92.7)	53 (91.4)	1395 (92.6)	(0.91;1.07)
Missing's	307			

Quality indicators at specialist palliative care[a] pathway level

	In all (*N* = 2313)	Specialist palliative care[a] pathways of patients with severe mental disorders[b] (*n* = 93)	Specialist palliative care[a] pathways of patients without severe mental disorders[b] (*n* = 2220)	RR (95% CI) Or MR (95% CI)
Days from referral to death (median (IQR))	29 (9;81)	48 (11;118)	29 (9;80)	1.4 (0.8;2.4)
Waiting time from referral to first specialist palliative care[a] contact (*n* (%))[c]				
0–10 days	2123 (92.0)	83 (89.3)	2040 (92.1)	1.37
> 10 days	184 (8.0)	10 (10.8)	174 (7.9)	(0.75;2.50)
Missing's	6			
Discussed at a multidisciplinary conference (*n* (%))[d]				
Yes	1653 (71.5)	70 (75.3)	1583 (71.3)	0.86
No	659 (28.5)	23 (24.7)	636 (28.7)	(0.60;1.24)
Missing's	1			
EORTC[g] questionnaire filled in at the start for specialist palliative care (*n* (%))[e]				
Yes	1702 (73.6)	57 (61.3)	1645 (74.1)	**1.49**
No	610 (26.4)	36 (38.7)	574 (25.9)	**(1.15;1.95)**
Missings	1			
EORTC[g] questionnaire 1–4 weeks after affiliation with specialist palliative care (*n* (%))[f]				
Yes	657 (36.7)	24 (32.4)	633 (36.9)	1.07
No	1133 (63.3)	50 (67.6)	1083 (63.1)	(0.91;1.26)
Missing's	523			

IQR: inter quartile range; RR (95% CI): relative risk and 95% confidence interval for dichotomous variables, statistically significant RR values are shown in bold; MR (95% CI): mean ratio and 95% confidence interval for continuous variables, statistically significant MR values are shown in bold. The study comprised 1869 individual patients covering 2313 specialist palliative care[a] pathways affiliated with either in-bed hospice or hospital-based palliative care team or both.

[a] Specialist palliative care, defined as: in-bed hospice or hospital-based palliative care team.

[b] Severe mental disorders, defined as: moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders.

[c] Danish palliative care database indicator 2: first specialist palliative care contact within 10 days from referral. The standard in Danish Palliative Database is > 90%. The 10 day cut-point was chosen due to Danish Palliative Database standards, where the aim is, that > 90% of patients is seen within 10 days from referral. Six specialist palliative care pathways had values <0 days. These values were deleted and reported as missing's.

[d] Danish palliative care database indicator 5: discussion at a multidisciplinary conference. The standard in Danish Palliative Database is > 80%.

[e] Danish palliative care database indicator 4: EORTC Questionnaire filled in at start for specialist palliative care. The standard in Danish Palliative Database is > 50%.

[f] Danish palliative care database indicator 6: EORTC Questionnaire filled in 1–4 weeks after specialist palliative care-start. The standard in Danish Palliative Database is > 40%. Only specialist palliative care pathways where patients were still alive after the first week are included.

[g] EORTC QLQ-C15-PAL: European Organization for Research and Treatment of Cancer - Quality of Life Questionnaire - Core 15: A questionnaire for patients receiving palliative care.

recent mixed-methods review found that patients with schizophrenia tended to receive less analgesia in end-of-life.[35] This represents a clear disparity in end-of-life care and may be directly related to less symptom assessment in this patient population.

Patients with severe mental disorders died less frequently at hospice and more often at home compared to patients without severe mental disorders. The population was selected by all receiving either home-based or in-hospice specialist palliative care, whereby hospice care pathways are not unambiguously a sign of high-quality palliative care. The underlying reason remains uncertain, as it is generally not possible to determine whether dying at home or in a hospice reflects better

Table 3. Quality indicators in pathways for patients in specialist palliative care[b] who died in 2023, having a severe mental disorder[c], divided into having an active trajectory in psychiatry the last year before death or not.

Quality indicators at patient level

	In all (*N* = 80)	Patients with active psychiatric treatment 1 year before death (*n* = 25)	Patients with no active psychiatric treatment 1 year before death (*n* = 55)	RR (95% CI)
Death in hospital (*n* (%))				
Yes	5 (8.6)	a	a	0.96 (0.79;1.16)
No	53 (91.4)			

Quality indicators at specialist palliative care[b] pathway level

	In all (*N* = 93)	Specialist palliative care[b] pathways of patients with an active psychiatric treatment 1 year before death (*n* = 28)	Specialist palliative care[b] pathways of patients with no active psychiatric treatment 1 year before death (*n* = 65)	RR (95% CI) or MR (95% CI)
Days from referral to death (median (IQR))	48 (11;118)	28.5 (10.5;102.5)	50 (11;134)	**0.44 (0.20;0.96)**
Waiting time from referral to first specialist palliative care[a] contact (*n* (%))[d]				
0–10 days	83 (89.3)	22 (78.6)	61 (93.9)	**3.48 (1.06;11.39)**
> 10 days	10 (10.8)	6 (21.4)	4 (6.2)	
Discussed at a multidisciplinary conference (*n* (%))[e]				
Yes	70 (75.3)	19 (67.9)	51 (78.5)	1.49 (0.73;3.04)
No	23 (24.7)	9 (32.1)	14 (21.5)	
EORTC[h] questionnaire filled in at the start for specialist palliative care[f] (*n* (%)[d]				
Yes	57 (61.3)	18 (64.3)	39 (60.0)	0.89 (0.50;1.59)
No	36 (38.7)	10 (35.7)	26 (40.0)	
EORTC[h] questionnaire 1–4 weeks after affiliation with specialist palliative care[b](*n* (%))[g]				
Yes	24 (32.4)	6 (27.3)	18 (34.6)	1.11 (0.80;1.54)
No	50 (67.6)	16 (72.7)	34 (65.4)	
Missing's	19			

IQR: inter quartile range; RR (95% CI): relative risk and 95% confidence interval for dichotomous variables, statistically significant RR values are shown in bold; MR (95% CI): mean ratio and 95% confidence interval for continuous variables, statistically significant MR values are shown in bold. The study comprised 80 individual patients covering 93 pathways affiliated with either in-bed hospice or hospital-based palliative care team or both.

[a] Numbers <3.

[b] Specialist palliative care, defined as: in-bed hospice or hospital-based palliative care team.

[c] Severe mental disorders, defined as: moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders.

[d] Danish palliative care database indicator 2: first specialist palliative care contact before 10 days from referral. The standard in Danish Palliative Database is >90%. The 10 day cut-point was chosen due to Danish Palliative Database standards, where the aim is, that > 90% of patients is seen within 10 days from referral.

[e] Danish palliative database indicator 5: discussion at a multidisciplinary conference. The standard in Danish Palliative Database is > 80%.

[f] Danish palliative database indicator 4: EORTC Questionnaire filled in at start for specialist palliative care. The standard in Danish Palliative Database is > 50%.

[g] Danish palliative database indicator 6: EORTC Questionnaire filled in 1–4 weeks after affiliation with specialist palliative care. The standard in Danish Palliative Database is > 40%. Only trajectories where patients were still alive after the first week are included.

[h] EORTC-QLQ-C15-PAL: European Organization for Research and Treatment of Cancer - Quality of Life Questionnaire - Core 15: A questionnaire for patients receiving palliative care.

quality of care. Death at home may reflect patient preference[36,37] but may also indicate disparities where fewer patients with severe mental disorders are admitted to hospices.

No differences were found in hospital death between groups in the study. A Dutch study from 2023 revealed that relatives perceived quality in palliative care highest for patients who died at home or in a hospice compared to hospital.[38]

Clinical and research implications

The Danish Palliative Database monitors, evaluates and improves specialist palliative care quality.[20] This study contributes to understanding whether patients with severe mental disorders receive care aligned with established quality indicators. Quality indicators alone do not confirm care quality, but they offer insight into care processes. Further studies should explore whether patients, relatives, and clinicians perceive quality of palliative care similarly. Future research exploring patients' experiences of symptom relief and quality of life is needed. Enhancing specialist palliative care for patients with severe mental disorders may involve supporting EORTC completion early in care. Studies are needed to identify barriers to its use.

Strengths and limitations

A major strength in this study is the use of complete national samples from Danish Palliative Database. Also, the first author manually screened severe mental disorders diagnoses in hospital medical files using structured searches with fixed searching terms that enhanced data trustworthiness.

The data from the Danish Palliative Database are almost complete national samples. However, the quality indicators only capture selected aspects of palliative care. Furthermore, some severe mental disorder diagnoses may have been overlooked in the manual screening.

Another limitation concerns the use of EORTC QLQ-C15-PAL. Although routinely collected in Danish specialist palliative care, the instrument is primarily validated in cancer populations[34] and not specifically for individuals with non-cancer conditions or severe mental disorders, which is a limitation. The substantial amount of missing data may introduce measurement bias.

Concerning the generalizability of the findings, the regions in Denmark are considered homogeneous with the overall same structure of specialist palliative care consisting of outgoing specialist palliative care teams and in-patient hospices in each region. The findings may be generalizable to other countries with a tax-funded health care system.

Conclusion

This study shows disparities in specialist palliative care for Danish patients with severe mental disorders compared to those without. Patients with severe mental disorders were younger, and more often referred for non-cancer conditions rather than cancer. They were less likely to complete symptom assessments, and those with active psychiatric treatment experienced longer waiting time before starting specialist palliative care and shorter care durations. However, quality in specialist palliative care is more diverse than the reported indicators represent, and a full overview of the end-of-life quality requires a multi-method approach to investigate.

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All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors and agree with the manuscript. The author's contributions were as follows: Designed study: KB, PV, MKN, JEM, MAN. Data collection: KB, Data analysis: KB, PV, MKN, JEM, MAN. Drafting and commenting on the paper: KB, PV, MKN, JEM, MG, JGE, SPJ, BH, MAN.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data is not publicly available due to privacy or ethical restrictions.*

Supplemental material

Supplemental material for this article is available online.

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Supplementary 1. Codebook
Codebook over variables found by screening in the Hospital Medical Files, listed with the specific search words

Variables	Searching words
Active trajectory in psychiatric department 1 year before death	Screening the trajectories for different departments and dates, visits from the psychiatric department at other departments also count
Date of terminal grant	Terminal declaration, terminal grant
Date of marking of treatment level	Treatment level, resuscitation, screening the red light in right corner in the medical file
Advance Care Planning conversation	Conversation about future wishes for treatment and care
Inj. of morphine and midazolam last 14 days before death	Screening the medical overview
Active treatment with psychiatric drugs 1 year before death	Screening the medical overview. ATC codes N06+N05+N03. Tablets, indication should be severe mental disorder, not if drugs are given because of delirium
Place of death	Place of death, dead

Supplementary 2. Sociodemographic characteristics and health utilization of patients affiliated with specialist palliative care in Central Region Denmark who died in 2023, having a severe mental disorder**, divided into subgroups of mental illnesses and divided into having active treatment in psychiatric department 1 year before death or not. The study comprised 80 individual patients covering 93 specialist palliative care pathways affiliated with either in-bed hospice or hospital-based palliative care.

CHARACTERISTICS AT PATIENT LEVEL						
	In all (N=80)	Patients with depression (n=49)	Patients with bipolar disorder (n=16)	Patients with schizophrenia or psychosis (n=15)	Patients with active psychiatric treatment 1 year before death (n=25)	Patients with no active psychiatric treatment 1 year before death (n=55)
Age of patients in years at death (median (IQR))	68 (60;76)	72 (60;76)	69 (66;75)	60 (48;65)	66 (60;75)	70 (60;76)
Patient sex (n (%))						
Female	41 (51.3)	24 (49.0)	9 (56.3)	8 (53.3)	6 (24.0)	35 (63.6)
Male	39 (48.8)	25 (51.0)	7 (43.8)	7 (46.7)	19 (76.0)	20 (36.4)
Referral diagnosis (n (%))						
Cancer	56 (70.0)	34 (69.4)	12 (75.0)	10 (66.7)	16 (64.0)	40 (72.7)
Non-cancer conditions***	24 (30.0)	15 (30.6)	4 (25.0)	5 (33.3)	9 (36.0)	15 (27.3)
Place of living (n (%))						
Private	65 (83.3)	43 (91.5)	*	*	19 (86.4)	46 (90.2)
Institution/elderly care home/other	13 (16.7)	4 (8.5)			3 (13.6)	5 (9.8)
Missings	2	2			3	4
Living arrangement (n (%))						
Living with others	30 (46.2)	21 (48.8)	6 (54.6)	3 (27.3)	8 (42.1)	22 (47.8)
Living alone	35 (53.9)	22 (51.2)	5 (45.5)	8 (72.7)	11 (57.9)	24 (52.2)
Missings	15	6	5	4	6	9
Having children (n (%))						
Yes	60 (80.0)	40 (87.0)	12 (75.0)	8 (61.5)	16 (72.7)	44 (83.0)
No	15 (20.0)	6 (13.0)	4 (25.0)	5 (38.5)	6 (27.3)	9 (17.0)
Missings	5	3	0	2	3	2
Active treatment in psychiatry last year before death (n (%))						
Yes	25 (31.3)	11 (22.5)	6 (37.5)	8 (53.3)	25 (100)	0 (0.00)
No	55 (68.8)	38 (77.6)	10 (62.5)	7 (46.7)	0 (0.00)	55 (100)

Injection of midazolam/morphine last 14 days of life (n (%))						
Yes	65 (83.3)	44 (91.7)	11 (68.8)	10 (71.4)	19 (79.2)	46 (85.2)
No	13 (16.7)	4 (8.3)	5 (31.3)	4 (28.6)	5 (20.8)	8 (14.8)
Missings	2	1	0	1	1	1
ACP-conversation (n (%))						
Yes	31 (38.8)	21 (42.9)	4 (25.0)	6 (40.0)	10 (40.0)	21 (38.2)
No	49 (61.3)	28 (57.1)	12 (75.0)	9 (60.0)	15 (60.0)	34 (61.8)
Place of death (n (%))						
Home	28 (48.3)	17 (44.7)	5 (54.6)	6 (54.6)	8 (44.4)	20 (50.0)
Other	30 (51.7)	21 (55.3)	4 (44.4)	5 (45.5)	10 (55.6)	20 (50.0)
Missings	22	11	7	4	7	15
CHARACTERISTICS AT SPECIALIST PALLIATIVE CARE**** PATHWAY LEVEL						
	In all (N=93)	Specialist palliative care**** pathways of patients with depression (n=58)	Specialist palliative care**** pathways of patients with bipolar disorder (n=18)	Specialist palliative care**** pathways of patients with schizophrenia or psychosis (n=17)	Specialist palliative care**** pathways of patients with active psychiatric treatment 1 year before death (n=28)	Specialist palliative care**** pathways of patients with no active psychiatric treatment 1 year before death (n=65)
Specialist palliative care**** affiliation (n (%))						
Hospice	24 (25.8)	16 (27.6)	*	*	8 (28.6)	16 (24.6)
Team	69 (74.2)	42 (72.4)			20 (71.4)	49 (75.4)

Referred to specialist palliative care**** from (n (%))						
General practitioner	27 (29.0)	16 (27.6)	8 (44.4)	3 (17.7)	6 (21.4)	21 (32.3)
Other physicians	66 (80.0)	42 (72.4)	10 (55.6)	14 (82.4)	22 (78.6)	44 (67.7)

IQR: Inter quartile range
NA: Non applicable
COPD: Chronic obstructive pulmonary disease
*: Numbers < 3
**: Severe Mental Disorders, defined as: Moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders.
***: Non-cancer conditions defined as: all other terminal illnesses than cancer: Heart, kidney and other organ failures.
****: Specialist Palliative Care, defined as: in-bed hospice or hospital-based palliative care team.

Study III

Bøndergaard K, Nielsen MK, Møller JE, Videbech P, Fløe LE, Videbech NM, Neergaard M.

Quality in Palliative Care for Patients with Pre-existing Severe Mental Disorders – A Questionnaire Study with Danish Health Care Professionals

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Quality in Palliative Care for Patients with Pre-existing Severe Mental Disorders – A Questionnaire Study with Danish Health Care Professionals

Abstract

Background

Patients with severe mental disorders (SMDs) face disparities in end-of-life care, yet knowledge about the quality of palliative care is limited.

Aims

This study aimed to examine healthcare professionals' perspectives on palliative care for patients with SMDs.

Methods

Questionnaires were distributed to general practitioners (GPs) and specialist palliative care (SPC) professionals in the Central Region of Denmark regarding 75 deceased patients with SMDs sampled from the Danish Palliative Care Database. Data, including fixed-response and free-text answers, were analysed using descriptive statistics, chi2-tests, and thematic qualitative analysis.

Results

Of 162 questionnaires, 123 were completed (76% response rate ranging from 64% among GPs to 80% among hospice staff, and 88% among SPC teams). Most trajectories were rated as good or very good quality. Age below 70 years was associated with higher-quality palliative care, while psychiatric diagnosis and SMD severity did not negatively affect quality.

Free-text analysis generated three themes: (1) Collaboration and timing ensured high-quality care, (2) Communication and relations were crucial, and (3) Patients were sometimes complex to support.

Conclusions

Patients with SMDs generally receive high-quality palliative care, but qualitative analysis show that some trajectories remain challenged in relation to coordination, timing and communication around end-of-life decisions.

Introduction

Patients with pre-existing severe mental disorders (SMDs, defined as schizophrenia or other psychotic disorder, bipolar disorders, and moderate to severe depression) can be in a particularly vulnerable position when entering end-of-life [1]. This patient group may have complex needs and is facing disparities in the public health care system [2]. Access to palliative care among patients with SMD shows ambiguous results; one review found that patients with cancer and SMD more often received specialist palliative care (SPC), including hospice, and less frequently received high-intensive-treatment in end-of-life, including chemotherapy, hospitalization, emergency and intensive unit care, and died less frequently at hospital, compared to controls [3]. Other studies showed inequality in palliative care access and services in relation to SMD [4-8]. Hence, it appears that focusing on the provision of palliative care for patients with SMDs is crucial; however, evidence regarding the quality of the palliative care they receive remains limited [9].

Quality in palliative care is perceived individually and is difficult to measure [10]. Healthy and close relationships with relatives and health care professionals (HCPs) are among the most important values for patients with SMDs when facing end-of-life, even though they are not always easy to meet [10].

In a Danish context, quality in SPC is assessed by the Danish Palliative Care Database using quality indicators [11]. Examining these quality indicators we have previously shown that patients with SMD tend to lack symptom screening compared to patients without SMDs [12]. In addition, the study revealed that receiving active psychiatric treatment within one year before death was associated with shorter SPC pathways. This is a concerning finding, as early palliative care is associated with longer survival [13]. Not all aspects of care at end-of-life can be captured through register-based quality indicators. To address this gap, particularly for patients with pre-existing SMDs, HCPs can provide essential insights into palliative care pathways in the final months and days. This study aims to investigate HCPs' perspectives on the quality of palliative care for patients with pre-existing SMDs at the end of life.

Methods

Study design

This questionnaire study combined quantitative and qualitative analysis. It was conducted in 2024 among HCPs in the Central Denmark Region, who had been involved in the treatment of deceased patients with SMDs. The STROBE checklist was used to improve transparency and completeness in reporting [14]. The study is part of the Nationwide research initiative Cancer Patients with pre-existing Severe Mental Disorders (CASEMED) [15].

Setting

The Danish Health Care system operates on a public, tax-funded basis, providing unrestricted access to healthcare services for all patients, available at all hours and free of charge [16, 17]. General practitioners (GPs) provide primary palliative care alongside community nurses, nursing homes, and general hospital departments [18]. SPC is provided by hospices, palliative care teams affiliated with hospitals and palliative care departments with palliative beds, offering specialist support and expertise. GPs or hospital physicians can refer to SPC when additional palliative care or advice is required. However, the GP remains the patient's primary treating physician when the patient is not admitted to hospital or hospice.

Participants

The patient population in the study was patients who died in 2023 and had been affiliated with SPC in the Central Denmark Region. They were identified by linking unique civil registration numbers from the Danish Palliative Database to hospital medical files (Figure 1) [11]. The Danish Palliative Database includes all patients referred to specialised palliative care in Denmark, including those who are referred but do not start a specialised palliative care pathway for different reasons [11]. Patients are registered when the care pathway ends [19].

Hospital medical files were screened by the first author for SMD diagnosis and contact information on HCPs [12].

GPs, doctors, and nurses from five SPC teams, five hospices, and one SPC inpatient department were invited to participate in the study by completing a questionnaire (Figure 2).

Data and Questionnaires

Data were retrieved from patients' hospital files on psychiatric and somatic diagnoses and whether the patients with SMDs had active psychiatric treatment (contact with hospital-based psychiatry in the last year of life or not). Place of death (home, hospice, nursing home, hospital) was retrieved from the Danish Palliative Database.

The development of the questionnaires and themes covered were inspired by the validated questionnaire to bereaved relatives of patients receiving palliative care, VOICES [20, 21], as well as insights from other studies conducted by the research team [10, 22]. The themes covered by the questionnaires were: Demographics about HCPs, evaluation of support and quality of palliative care provided to patients or relatives in the last three months and the last days of life, symptom relief of physical pain, physical symptoms beyond pain, mental symptoms, social problems, and existential problems. These themes were evaluated alongside Advance Care Planning (ACP), and whether the SMD was considered to have an impact on the quality of palliative care. While a common set of questions formed the basis of the questionnaire for all three groups of HCPs, supplementary items were added to address the specific context of each group.

Data collection

Questionnaire data were collected and managed using REDcap electronic data capture tools hosted at Aarhus University [23, 24]. All the questionnaires were electronically distributed. The invitations to the GPs were sent by mail, containing information about the research project, a QR code, and a link to fill in the questionnaire electronically, linked to the specific patient. The GP most familiar with the patient was asked to fill in the questionnaire or hand out the questionnaire to a GP staff member e.g. a nurse, if this person had been more closely involved. GPs were remunerated for their time.

At hospices, invitations were sent via secure email to the main hospice e-mail addresses, asking the leader to distribute questionnaires to the specific HCP who had the closest contact with the patient.

In SPC teams, the physician listed as being responsible for the patient was contacted by secure e-mail and invited to participate or pass the invitation on to the nurse, who had been most involved in the trajectory.

Two reminders were sent after four and six weeks. Finally, non-responding GPs were reminded by phone after two months.

Analysis

Since the questionnaires contained both free-text and fixed-response questions, the analysis combined quantitative and qualitative approaches.

Quantitative data

Descriptive statistics were used to examine the fixed-response answers. Statistics were reported as counts and percentages for categorical variables. Medians with interquartile range (IQR) were used for continuous variables.

Data were merged when counts were fewer than three to protect anonymity. Also, for that reason, 'Not at all', 'Don't know', and 'Not relevant', were merged with 'Some of the time' in most questions.

The answers from GPs concerning quality were dichotomized, and the categories very poor, poor, and middle were merged into *low quality*, and good or very good were merged into *high quality*. GPs answers were used as GPs were most likely to have been involved in the care trajectories. Chi^2 tests were used to find statistically significant differences between groups of high or low quality in the final three months and the final two days of life and analysed in relation to patient age, gender, and specific psychiatric or somatic diagnoses. STATA was used for analysing quantitative data [25].

Qualitative data

Free-text responses from the questionnaires were examined using thematic analysis, with codes generated for each category of respondents and across respondent types [26]. The free-text responses comprised 5300 words in all. The first author inductively generated and organized the initial codes into themes together with third author. Themes were developed across the different respondent groups. To ensure transparency and demonstrate that the data supported the interpretations, the open-ended responses were discussed with last author. This process served to confirm that the interpretations were grounded in the data.

Brief one- or two-word responses were excluded due to difficulties in interpreting them; the longest were analysed in depth. Selected quotes illustrate themes in the results.

Ethical considerations

Participation of HCPs was voluntary, and participants received written invitation and information. Answers were analysed anonymously. The Central Denmark Region committees on Health Research Ethics approved the study (Ref: 1-45-70-94-23). Also, the project was notified for the internal research database (Ref: 1-16-02-219-23). Additional approval was obtained to access medical files.

Results

In all, 1,864 deceased patients were assessed for inclusion, and 75 patients with SMD were included in the analysis (Figure 1).

A total of 123 questionnaires were completed: 46 by GPs, 20 by hospice HCPs, and 57 by HCPs from SPC teams/departments. In all, 162 questionnaires were distributed, and the overall response rate was 76%. For each patient, at least one questionnaire was completed; 37 patients had two and six patients had three questionnaires filled in.

In all, 75 questionnaires were sent to GPs, three had closed their practice, and 26 did not respond, resulting in a response rate of 63.9%. The specific response rates for different HCPs can be seen in Figure 2.

Characteristics of deceased patients and HCPs

Among the 75 included patients, the median age was 66 years (IQR: 60;76) (Table 1). Depression was the most common SMD diagnosis (63%), and lung and airway cancers were the most prevalent somatic terminal diseases (21%). 28% had a somatic diagnose other than cancer. Most patients died in their own homes, including nursing homes if they lived there permanently (57%), followed by hospices or palliative care departments at hospitals (35%) (Table 1).

Responding HCPs were primarily medical doctors (80%), 80% were females, and the median age was 52.5 years (IQR: 45; 59) (Table 2).

Quality in palliative care

Support

The overall assessment of support to the patient and family from the health care system and municipality during the final three months of life was positive, as rated by HCPs. GPs believed that patients and family/relatives received sufficient support in 87% of the cases. Professionals from SPC teams more often answered ‘Don’t know’ (n=25 (43.9)) (Table 3).

Relief of total pain

Five questions assessed total pain (Table 3). Physical pain was the category with the highest report of relief ‘All of the time’ (25-46%), followed by relief ‘All of the time’ of physical symptoms beyond pain

(21-29%). The lowest scores were reported in accordance to relief of mental symptoms, where between 65-67% reported 'Some of the time / Not at all / Don't know', together with the question regarding help to tackle social problems, where 55-79% reported 'Some of the time / Not at all / Don't know', in the final three months of life.

Overall quality of palliative care

Based on three questions, HCPs quantitatively evaluated the overall quality of palliative care for patients with SMDs, with most rating it as good or very good (Table 3). GPs rated the overall quality of care and treatment in the final three months of life as good or very good in 72% of cases. For hospice and palliative care teams, the corresponding proportions were 45% and 60%.

The overall quality of care and treatment in the final two days of life, with all services from the overall health care system in consideration, was quantitatively rated highest by hospice staff, where 80% rated the quality as good or very good, and a bit lower for GPs and SPC-teams (70% and 61%).

Collaboration and timing

In the free-text responses, all informants considered collaboration between departments, sectors, and HCPs to be crucial for the quality of the palliative trajectory. Effective collaboration was found to ensure high-quality palliative care, and, at the same time, when collaboration or timing did not work out well, HCPs saw this as a threat to high-quality palliative care.

A recurring focus on collaboration in the data was found to be essential to the patient's care, as emphasized by a GP: *'The really good collaboration between the home care nurses and me – and when the need occurred, also the hospital.'* Another HCP from an SPC team mentioned that collaboration with home care nurses made a difference: '*There was a strong collaboration with home care nurses who were very good in the relation to the patient and supported the home situation and the relatives and built a close contact with the patient who felt safe'.*

Concerning what could have been better in the trajectory, one GP expressed: *'Better cross-sectional coordination and transitions between sectors',* whereas an HCP from the SPC-team wrote: *'The patient was in the team (SPC-team, ed.) for a very short time. Palliative care initiated earlier in the trajectory would probably have ensured a better trajectory, also for the relatives.'*

Hence, HCPs viewed collaboration, timely referrals, and early intervention as crucial factors for ensuring high-quality palliative care.

Communication and Relations

Another key theme in the free-text answers was conversations about and wishes for end-of-life and the role of relations. In general, HCPs mentioned the importance of inclusion of the patients in decisions about end-of-life treatment and to decide for themselves how they wanted to spend their end-of-life. A recurring understanding was, that when patients could not participate in these conversations, the quality of palliative care declined. When these conversations took place despite challenges, they left a significant impression on HPCs.

Asked what made a special impact on them, one hospice HCP wrote: *'That it is possible to have such an important, existential conversation with a patient having expressive aphasia. The tears were running during the conversation, but the patient asked me to keep on, and maybe he felt relieved that I had the patience and creativity to have this difficult conversation with a person who could only say yes/no'.*

This illustrated that from the perspective of HCPs, engaging in existential conversations was considered highly valuable for the patients, and that they could be possible despite difficult circumstances.

Relational continuity was a precondition for meaningful end-of-life conversations: *'I knew the patient very well, we had good conversations about ending life.'* Also, the number of HCPs reporting that they had an ACP conversation with the patient was 59-70% (Table 3).

A GP addressed a psychiatric diagnosis as a challenge for conversations: *'Schizophrenia often made it challenging in difficult conversations and delivery of messages. Information had to be adapted to what she (the patient, ed.) could handle on the day, and often, we had to go with a plan and rely on the home care nurses to repeat it the next day for the patient.'*

Complexity

In the free-text answers, HCPs mentioned several barriers to high-quality palliative care, e.g., when the patient suffered from anxiety and had difficulty building trust with new HCPs. Also, complex family relations were mentioned as a barrier to ending life in a meaningful way. Interestingly, across the fixed-response answers, all HCPs did not think that psychiatric disease influenced the quality of palliative care provided in most cases, as 49-69% of HCPs answered ‘No’ when asked whether the psychiatric diagnosis influenced the palliative care provided (Table 3).

One HCP from the SPC team wrote: *‘The patient was difficult to help, did not want home visits’.* This example reflected a pattern that appeared across several cases in the analysis. HCPs who assessed the quality of care as low described situations in which patients declined home visits, resisted contact, or did not wish to engage with the support offered.

As stated above, most cases were not considered complex, but when they were, it was often reported as a consequence of difficult contact and relation to the patient because of psychiatric disease.

Comparing cases of good and poor quality

In the analysis of GPs’ evaluations, there were no significant differences in quality of palliative care in terms of gender, psychiatric or somatic diagnosis (Data not shown because of small numbers). Still, there was a tendency that patients with schizophrenia or psychotic disorders received higher quality (88% in the final three months of life and 100% in the final two days of life), compared to patients with depressive disorders (76% in the final three months of life and 87% in the final two days of life). However, numbers were low, with less than 10 patients having schizophrenia or psychotic disorders and causal conclusions cannot be made. A difference was also found between older and younger patients, where younger patients < 70 years seemed to receive a higher quality of palliative care in the final two days of life, compared to patients >69 years (Data not shown). This was also mentioned in the free-text answers where one HCP remembered every HCPs involved in a young patient’s trajectory gathering around in the attempt to deliver high-quality care for a vulnerable patient: *‘…. a young, mentally ill person marked by misery, where everyone (HCPs, ed.) seemed to support her.’*

Discussion

Main findings

In this study based on HCPs perspectives, patients with pre-existing SMDs overall received high-quality palliative care.

Most HCPs did not perceive that the psychiatric diagnosis had a negative impact on the quality of care. Free-text answers and the qualitative analysis showed that perceived high quality was shaped by three key factors: Collaboration and timing, Communication and Relations, and the overarching Complexity of these trajectories.

Relief of total pain varied considerably. Physical pain was the symptom with the highest proportion reporting full relief, whereas relief of mental symptoms and help with social problems were markedly lower, with a large amount indicating only partial or no relief in the last three months of life. These findings highlight substantial unmet needs particularly within the mental, social and existential dimensions of total pain.

Comparison with prior research

Quality in palliative care among patients with SMD

In line with this study, we previously examined quality indicators in the Danish Palliative Care Database in the same study population, and found largely comparable quality indicators for patients with and without SMD, though patients with SMD had lower completion of symptom screening, longer referral-to-contact times when psychiatric illness were active, and shorter SPC trajectories [12]. These patterns mirror international evidence showing poorer pain assessment and management for patients with SMDs in EOL [27], and align with the MENLOC synthesis, highlighting diagnostic overshadowing, fragmented care pathways, and insufficient cross-disciplinary collaboration [8]. Also, related studies highlight inequalities in EOL care for patients with SMD, including less likelihood of receiving SPC [6], more institutional deaths and increased unscheduled care in the final year of life [7].

Collaboration and timing

The qualitative analysis showed that timing and collaboration played important roles in the quality of palliative care. When collaboration, timing, and referrals worked well across sectors and HCPs, they were described as positive influences. Early palliative care is known to improve both quality of life and survival [13]. Also, the role of home care nurses and their collaboration with, e.g., GPs or SPC-teams were repeatedly highlighted as essential to patient care in this study. This aligns with studies showing that optimal palliative care at home depends on close collaboration among the patient, family, home care nurses, and GPs [28-30]. Thus, collaboration between HCPs seem to be equally important for trajectories of patients with SMD.

Communication and Relations

The importance of HCPs facilitating existential conversations with patients was highlighted in the present study. Good communication is widely considered central to high-quality end-of-life care [31]. In this study, some HCPs mentioned challenges related to patients' limited communication abilities, nevertheless, 59-70% across the HCP groups reported having an ACP conversation. Supporting this, Foti et al. found that patients with SMDs can express clear treatment preferences in EOL [32].

Complexity

Complex family relations are common in end-of-life care [33] and were identified as a challenge for patients with SMDs in this study, in line with previous findings[10]. Such complexity may leave patients with limited support increasing vulnerability. Consistent with this, the MENLOC synthesis from 2022 highlights that people with SMDs at end-of-life who lack social support risk becoming 'lost in the system' [4]. At the same time, a 2026 study reported patients with SMD were more likely than others to have a stable relationship with their GP, indicating that primary care may serve as a key support [34].

Differences in quality of palliative care

A tendency was found that patients <70 years and patients with schizophrenia and psychotic disorders received the highest perceived quality in the final three months and two days of life. One possible explanation is that their needs may be more visible to HCPs. Their symptoms, vulnerabilities, or need for support may appear more pronounced and therefore easier for staff to identify and respond to. This interpretation is supported by previous findings from our research group, indicating that HCPs often strive to make a difference for patients with great needs such as those with SMDs, and sometimes even classify them as 'VIP-patients' [10]. A Swedish study found that patients with cancer and co-occurring schizophrenia or other psychoses receive less SPC, compared to patients with cancer only [5]. In our study, however, once access to SPC was established, perceived quality was high. This underscores the importance of ensuring timely referral to SPC for patients with schizophrenia and other psychoses. Further research is needed to confirm these differences and clarify underlying mechanisms.

Strengths and limitations

A key strength was the inclusion of HCPs from three different parts of the health care setting, which nuances findings and strengthens generalisability and evaluation of palliative care quality in the final months and days of life. The combination between closed and open free-text options provided both quantitative assessments and more nuanced descriptions of care quality.

Limitations include small sample sizes (123 responses), potential positive bias as HCPs rated both their colleagues' and their own efforts and varying response rates across groups, which may have introduced non-response bias. The long interval between death and questionnaire completion (8-24 months) increases risk of recall bias, particularly for hospice staff with limited relational continuity. Many HCPs responded 'Don't know' to questions about total pain relief, indicating gaps in their insight into the final months, possibly due to short involvement; input from home nurses or relatives might have strengthened the study.

Patient selection based on ICD-10 codes may not fully reflect clinical relevance, leading to inclusion of patients with low SMD burden; one GP explicitly disagreed with the SMD classification.

Variation in the level of detail in free text answers further limits interpretive depth, and the absence of interviews reduces robustness and generalisability.

Clinical and research implications

The study supports prior research findings that patients with pre-existing SMDs face specific challenges in end-of-life care [3, 6]. Clinicians should focus on both supporting the patient's family relationships and maintaining healthy relationships with HCPs. Also, communication is crucial for this population, with a focus on offering ACP conversations.

The awareness of potential inequalities in palliative care for patients with SMDs has gained more focus in recent years. This study adds insight into quality and barriers from the perspective of HCPs and highlights the strength of collaboration between HCPs. Future research, especially interview studies with patients, relatives or HCPs, could reveal in-depth data and further perspectives on how to care for this patient population in end-of-life. Also, the observed differences by age and psychiatric diagnosis need to be explored in larger studies.

Conclusion

Patients in end-of-life with pre-existing SMDs generally receive high-quality palliative care, as assessed quantitatively by HCPs. However, qualitative free-text responses add nuance by illustrating that certain aspects of the palliative trajectory can be vulnerable in some cases. These vulnerabilities often relate to cross-sectional coordination, timing of palliative involvement, and the challenges of communication or relational continuity. These factors do not reduce care quality for the main part of the population, but they contribute to complexity in specific trajectories. Future research should focus on obtaining more detailed descriptions of quality and barriers to high-quality palliative care for this potentially vulnerable patient population.

Legends for Tables and Figures

Table 1. Characteristics of deceased patients in Central Denmark Region in 2023, affiliated with specialist palliative care, divided into patients with and without pre-existing severe mental disorder (SMD)

Table 2. Participating health care professionals’ characteristics

Table 3. Answers in 123 questionnaires for health care professionals in general practice, hospice and palliative care teams (N=123) *

Figure 1. Flowchart of study population

Figure 2. Flowchart of questionnaires included in the study

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Table 1: Characteristics of deceased patients in Central Denmark Region in 2023, affiliated with specialist palliative care, divided into patients with and without pre-existing severe mental disorder (SMD)

CHARACTERISTICS OF PATIENTS			
	In all (n=1864)	**Patients with SMDs** (n=75)	**Patients without SMDs** (n=1789)
Age of patients in years at death (median (IQR))	72 (64;79)	68 (60;76)	73 (65;79)
Gender n (%)			
Female	894 (48.0)	39 (52.0)	855 (47.8)
Male	970 (52.0)	36 (48.0)	934 (52.2)
Psychiatric diagnosis (n (%))	75		NA
Depression	47 (2.5)	47 (62.7)	
Bipolar disorder	14 (0.76)	14 (18.7	
Schizophrenia or other psychotic disorders	14 (0.76)	14 (18.7)	
Somatic terminal diagnosis (n (%))			
Cancer	***1584 (85.0)***	***54 (72.0)***	***1530 (85.5)***
Lung and airway cancer	403 (21.6)	16 (21.3)	387 (21.6)
Other cancers	335 (18.0)	5 (6.7)	330 (18.5)
Gastro-intestinal cancer	222 (11.9)	3 (4.0)	219 (12.2)
Pancreas cancer	133 (7.1)	6 (8.0)	127 (7.1)
Breast cancer	130 (7.0)	4 (5.3)	126 (7.0)
Head-and-neck cancer	98 (5.3)	5 (6.7)	93 (5.2)
Gynecological cancer	98 (5.3)	3 (4.0)	95 (5.3)
Hematological cancer	74 (4.0)	5 (6.7)	69 (3.9)
Liver and biliary cancer	57 (3.1)	4 (5.3)	53 (3.0)
Unknown cancer	34 (1.8)	3 (4.0)	31 (1.7)
Organ failure*	***280 (15.0)***	***21 (28.0)***	***259 (14.5)***
Other organ diseases (e.g., kidney and heart failure)	117 (6.3)	8 (10.7)	109 (6.1)
Lung diseases (e.g., COPD and lung fibrosis)	100 (5.4)	9 (12.0)	91 (5.1)
Neurological diseases	63 (3.4)	4 (5.3)	59 (3.3)
Place of death (n (%)**			
Home	556 (35.6)	28 (48.3)	528 (35.1)
Hospice / palliative care department at hospital	815 (52.2)	20 (34.5)	795 (52.9)
Nursing home	77 (4.9)	5 (8.6)	72 (4.8)
Hospital (non-palliative care department)	114 (7.3)	5 (8.6)	109 (7.3)

*: Organ failure defined as**:** all terminal illnesses other than cancer: Heart, kidney and other organ failures

**: 17 missings in patients with SMD and 285 missings in patients without SMD

Table 2: Participating health care professionals' characteristics

CHARACTERISTICS OF PARTICIPANTS	**N=123**		
Profession (n (%))			
Medical doctor	98 (80.0)		
Nurse and other professions	24 (19.7)		
Gender (n (%))			
Female	94 (79.7)		
Male	24 (20.3)		
Age of participants in years (median (IQR))*	52.5 (45;59)		
Place of work (n (%))			
General practice	46 (37.4)		
Hospice	20 (16.3)		
Palliative care team or palliative care department	57 (46.3)		
Years working in the profession (n(%)) **			
Less than 5 years	32 (26.0)		
5-10 years	35 (28.5)		
10-15 years	25 (20.3)		
More than 15 years	30 (24.4)		
Years of working in the profession divided in working places (n(%)) **	**General practitioner** (n=46)	**Hospice** (n=20)	**Palliative care team or department** (n=56)
Less than 5 years	4 (8.7)	4 (20.0)	24 (42.9)
5-10 years	14 (30.4)	10 (50.0)	11 (19.6)
10-15 years	11 (23.9)	0 (0.0)	14 (25.0)
More than 15 years	17 (36.9)	6 (30.0)	7 (12.5)

*: Only 74 HCPs answered this question, probably because each HCP answered more questionnaires

**: 1 missing

Table 3: Answers in 123 questionnaires for health care professionals in general practice, hospice and palliative care teams

QUALITY IN PALLIATIVE CARE*			
	General practitioners (n=46)	**Professionals from Hospice** (n=20)	**Professionals from Palliative Care Teams** (n=57)
SUPPORT			
Do you believe that the patient received all the support from the health care system and the municipality that they needed in the last 3 months of life? (n (%))			
Yes	40 (87.0)	NA	34 (60.7)
No	6 (13.0)		7 (12.5)
Don't know	0 (0.0)		15 (26.8)
Do you believe that the family/the relatives received all the help and support from the health care system and the municipality that they needed in the last 3 months of the patient's life? (n (%))			
Yes	40 (87.0)	NA	22 (38.6)
No	6 (13.0)		10 (17.5)
Don't know	0 (0.0)		25 (43.9)
Did you or your colleagues have an Advance Care Planning conversation with the patient? (n (%))			
Yes	27 (58.7)	12 (63.2)	39 (69.6)
No	19 (41.3)	7 (36.8)	17 (30.4)
RELIEF OF TOTAL PAIN			
To what extent did the patient experience relief from pain during the final 3 months of life? (n (%))			
All the time	21 (45.7)	6 (30.0)	14 (24.6)
Some of the time / Not at all / Don't know**	25 (54.3)	14 (70.0)	43 (75.4)
To what extend did the patient experience relief of physical symptoms (beyond pain) in the final 3 months of life? (n (%))			
All the time	13 (28.9)	5 (25.0)	12 (21.1)
Some of the time / Not at all / Don't know**	32 (71.1)	15 (75.0)	45 (78.9)
To what extent did the patient receive help to tackle their mental symptoms in the final 3 months of life? (n (%))			
All the time	4 (8.7)	4 (20.0)	8 (14.0)
Some of the time / Not at all / Not relevant**	32 (69.6)	13 (65.0)	37 (64,9)
Don't know	10 (21.7)	3 (15.0)	12 (21.1)
To what extent did the patient receive help to tackle their social problems (e.g., relations to relatives, job, accommodation) in the final 3 months of life? (n (%))			

All the time	11 (25.0)	9 (45.0)	12 (21.1)
Some of the time / Not at all / Not relevant / Don’t know	33 (75.0)	11 (55.0)	45 (78.9)
To what extent did the patient receive help to tackle their existential problems (e.g. guilt/shame, religious and spiritual problems) in the final 3 months of life? (n (%))			
All the time	2 (4.4)	5 (25.0)	9 (15.8)
Some of the time / Not at all / Not relevant	28 (60.9)	11 (55.0)	31 (54.4)
Don’t know	16 (34.8)	4 (20.0)	17 (29.8)
OVERALL QUALITY OF CARE			
How do you assess the overall quality of the care and treatment the patient received in the final 3 months of life, if you consider all the services from the overall health care system? (n (%))			
Very good	14 (30.4)	2 (10.0)	15 (26.3)
Good	19 (41.3)	7 (35.0)	19 (33.3)
Middle / Poor / Very poor	10 (21.7)	4 (15.0)	12 (21.0)
Don’t know	3 (6.5)	8 (40.0)	11 (19.3)
How do you overall assess the quality of the care and treatment during the final two days of life, if you take all the health care systems' services into consideration? (n (%))			
Very good	17 (37.0)	10 (50.0)	19 (33.3)
Good	15 (32.6)	6 (30.0)	16 (28.1)
Middle	3 (6.5)	0 (0.0)	6 (10.5)
Poor / Very poor / Don’t know ***	11 (23.9)	4 (20.0)	16 (28.1)
If you had to compare this palliative trajectory with other trajectories you have been involved in, how was the quality then? (n (%))			
The quality was better	9 (20.5)	3 (15.0)	7 (12.3)
The quality was average	30 (68.2)	17 (85.0)	35 (61.4)
The quality was poorer	5 (11.4)	0 (0.0)	10 (17.5)
Don’t know	0 (0.0)	0 (0.0)	5 (8.8)
Do you think that the psychiatric diagnosis had an influence on the quality in the palliative care provided? (n (%))			
Yes	14 (31.1)	7 (36.8)	18 (31.6)
No	31 (68.9)	12 (63.8)	28 (49.1)
Don’t know	0 (0.0)	0 (0.0)	11 (19.3)

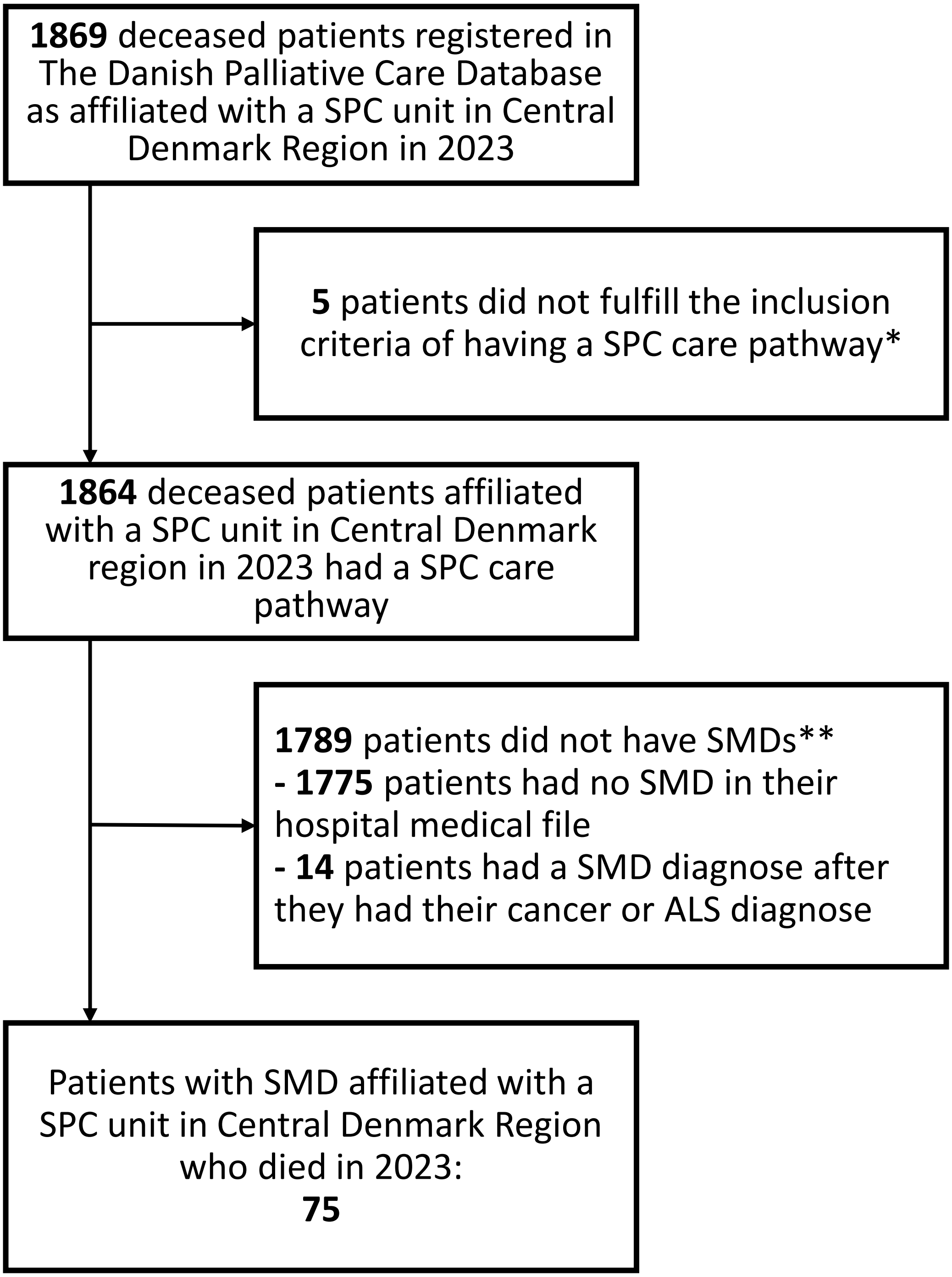
NA: Non-applicable

*Not all questions were presented for all health professionals, as the questionnaires were directed at the setting of each group of health professionals

**Due to a small number of answers in Not all, Don’t know and Not relevant, the categories were merged with ‘Some’ to protect anonymity

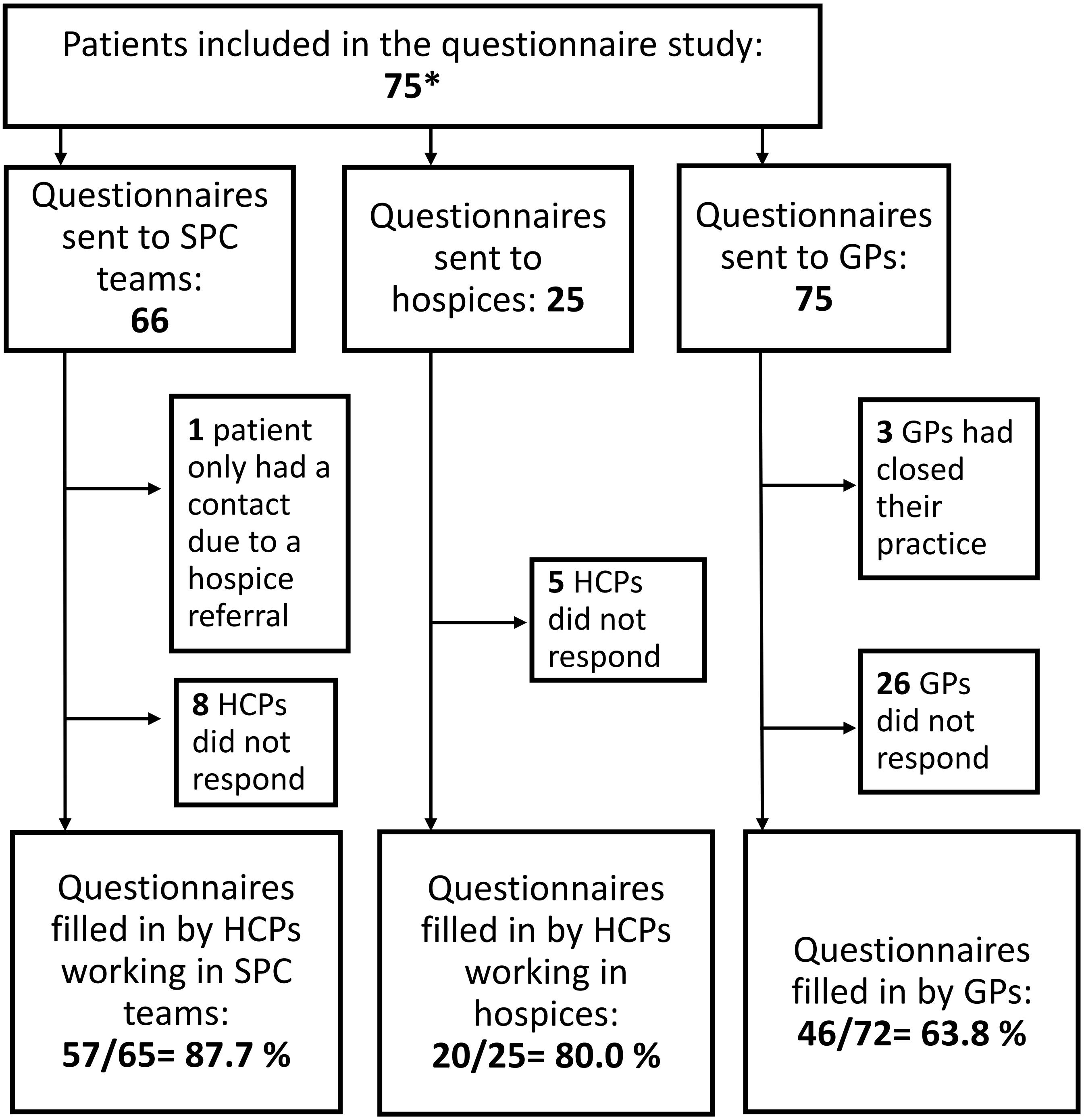
*** Due to a small number of answers in Poor and Very Poor, the categories were merged with ‘Don’t know’ to protect anonymity

Figure 1: Flowchart of study population



Abreviations:
SMD: Severe Mental Disorder
SPC: Specialised Palliative Care
*: The 5 patients were only assessed once by a SPC team
**: SMDs included: ICD-10 diagnosis: F20 – F25, F28-F31, F32.1-9, F33.1-9

Figure 2: Flowchart of questionnaires included in the study



Abreviations:
GP: General practitioner
HCP: Health Care Professionals
SMD: Severe Mental Disorder
SPC: Specialised Palliative Care
*: More than 75 questionnaires were distributed due to some patients having more than one trajectory, e.g. both a questionnaire to their GP, hospice and/or palliative care team. In all, 166 questionnaires was distributed, hereby 123 completed. For all patients at least one questionnaire was completed.

Appendix I: Study I, Participant Information and Consent Materials

End-of-Life of CAncer Patients with SEvere MEntal Disorders (CASEMED) - Challenges and Model of Care

Hjælp til inklusion af patienter til forskningsprojekt, studie 1

Kære CASEMED-kontaktperson

Nu får jeg brug for din/jeres hjælp til at inkludere patienter til mit første studie, der er et interview-studie. Jeg ønsker at inkludere i alt 6-10 patienter fra RM til interviews, hvor jeg vil spørge dem ind til deres sygdomsforløb. Jeg vil desuden udføre ”casenær sampling”, dvs. med patientens accept bede 1-2 pårørende til patienten, patientens praktiserende læge og 1-2 af jer sundhedsprofessionelle, som er særligt involverede i den pågældende patients palliative forløb, om ligeledes at medvirke i interviews.

Jeg får brug for din hjælp til:
Jeg vil gerne, at du/I igennem den næste tid løbende vil screene alle patienter (tilknyttede og ny-henviste patienter) i jeres enhed. De patienter, som har én af diagnosekoderne nævnt i boksen på næste side vil jeg rigtig gerne i kontakt med, hvis I vurderer, at de er i stand til at medvirke i et interview.

Det er en særligt sårbar patientgruppe, jeg ønsker at komme i kontakt med og mange af dem vil i denne fase af livet være for dårlige til at medvirke i interview. Nogle af dem vil desuden have et begrænset netværk. Jeg håber, I vil hjælpe mig med vurdere om patienterne vil kunne deltage i et 30-60 minutters interview.

Jeg vil bede dig eller en kollega om følgende, til de patienter, som har én af diagnoserne nævnt i boksen på næste side:

1) Informere mundtligt om projektet
2) Udlevere dokumentet ”Skriftlig information til patienter og pårørende”
3) Bede dem udfylde den vedhæftede samtykkeerklæring hvis de ønsker at medvirke i et interview
4) Kontakte mig telefonisk med CPR-nr. og tlf. nr. på patienten
5) Scanne og sende mig en kopi af den underskrevne samtykkeerklæring
6) Opbevare den originale samtykkeerklæring til jeg kan afhente den, alternativt sende originalen til mig til adressen opgivet nederst i dokumentet

Vedhæftet denne mail er en beskrivelse af projektet til jer sundhedsprofessionelle, ”Skriftlig information til patienter og pårørende” samt samtykkeerklæringen.

Samtykkeerklæringen som patienten skal underskrive, giver patienten flere valg I forhold til om han/hun selv vil medvirke i interview, og om pårørende, egen læge og professionelle i den palliative enhed må kontaktes.

Det er vigtigt at nævne, at det ikke er et nederlag, hvis en patient takker nej til at deltage. Jeg skal i Studie 1 kun i kontakt med 6-10 patienter fordelt ud over hele Region Midt.

De diagnosekoder (Under ”Diagnose” i EPJ) jeg ønsker at inkludere, er:

Skizofreni og psykoser	**Affektive lidelser**
F20 Skizofreni	F30 Manisk enkeltepisode
F21 Skizotypisk sindslidelse	F31 Bipolar affektiv sindslidelse
F22 Paranoide psykoser (kroniske, vedvarende)	F32 Depressiv enkeltepisode
F23 Akutte og forbigående psykoser	F33 Tilbagevendende (periodisk) depression
F24 Induceret psykose	
F25 Skizo-affektive psykoser	
F28 Anden non-organisk psykose	
F29 Non-organisk psykose, uspecificeret	

Først og fremmest ønsker jeg at sige tak for indsatsen på forhånd. Jeg ved, at det kræver en indsats i det daglige at tænke forskningsprojekter med ind i det vigtige arbejde, som I udfører. Jeg ser frem til at møde mange af jer, når jeg kommer og interviewer patienter, pårørende samt nogle af jer sundhedsprofessionelle, som projektet skrider frem. Jeg regner med at lave de fleste interviews allerede i efteråret 2023.

Tusind tak hvis I vil sende mig en mail eller ringe direkte til mig, når I har en patient, der potentielt kan inkluderes og medvirke.

Med venlig hilsen
Kirstine Bøndergaard
E-mail: kirbod@rm.dk
Tlf. 20182733

Adresse til fremsendelse af samtykkeerklæring
Aff. Kirstine Bøndergaard
Kræftafdelingen, Aarhus
Palle Juul-Jensens Boulevard 99
Kræftafdelingen, Forskergang 2, C108
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End-of-Life of CAncer Patients with SEvere MEntal Disorders - Challenges and Model of Care (CASEMED)

Information til patienter og pårørende om forskningsprojektet

BAGGRUND
Når man både har (eller har haft) en psykisk lidelse og en livstruende sygdom, kan det være svært at opnå den livskvalitet, man ønsker i den sidste del af livet. Der er ikke lavet meget forskning om kvaliteten af den lindrende behandling.

FORMÅL
Dette studie skal undersøge og forhåbentlig forbedre kvaliteten af den lindrende behandling til patienter med samtidig psykisk lidelse.

METODER
I dette studie vil vi bede flere patienter om at medvirke i interviews, der varer 30-60 minutter.
Hvis patienten giver samtykke, vil vi også interviewe 1-2 pårørende, praktiserende læge og sundhedsprofessionelle fra Enhed fra lindrende behandling eller Hospice, som kender forløbet.

PERSPEKTIV
Forskningsinitiativet vil have potentiale til at give mennesker med aktiv eller tidligere psykisk lidelse en bedre lindrende behandling i den sidste del af livet i fremtiden.

DELTAGELSE
Deltagelse betyder et interview af 30-60 minutters varighed enten i eget hjem eller hvor man opholder sig.
Deltagelsen i studiet er helt anonym og man kan til enhver tid trække deltagelse tilbage ved at kontakte projektlederen eller en af de sundhedsprofessionelle i forløbet.

Med venlig hilsen

Projektleder, læge, ph.d.-studerende
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Professor, overlæge
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Samtykke til deltagelse i et kvalitativt forskningsprojekt samt behandling af personoplysninger

End-of-Life of CAncer Patients with SEvere MEntal Disorders (CASEMED) - Challenges and Model of Care

Undertegnede ____ (navn og CPR-nr.)

giver hermed min underskrift og dermed samtykke til at deltage i et interview omhandlende mit palliative behandlingsforløb.

Jeg er, forud for afgivelse af mit samtykke, blevet informeret både skriftligt og mundtligt om projektet.

Jeg er indforstået med:

- Mine udsagn behandles fortroligt i projektet
- Mine udsagn må videregives til en eller flere medarbejdere, som arbejder på projektet. Medarbejderne har fælles dataansvar og tavshedspligt
- Mine udsagn må offentliggøres i <u>anonymiseret</u> form i forbindelse med offentliggørelse af projektet
- Min deltagelse i forskningsprojektet påvirker ikke min videre behandling i sundhedsvæsnet
- Den forskningsansvarlige går ind i min sygehusjournal og trækker data relevante for forskningsprojektet bl.a. diagnoser, tidspunkter for diagnoser og medicin
- Jeg er informeret om, at jeg til enhver tid kan trække mit samtykke til at deltage i forskningsprojektet tilbage. Jeg kan trække mit samtykke tilbage ved at kontakte Kirstine Bøndergaard (kirbod@rm.dk). Ved en sådan tilbagetrækning vil jeg fortsat have ret til de normale behandlingstilbud

---

Jeg giver hermed forskeren lov til at kontakte mhp. interview:	Ja	Nej
Mig	☐	☐
De pårørende, jeg har opgivet i forbindelse med projektet	☐	☐
Min egen læge	☐	☐
Læger og sygeplejersker i lindrende team/hospice	☐	☐

Jeg giver hermed samtykke til at den dataansvarlige må bruge mine udsagn fra interviewet og specifikke data fra journalen i forbindelse med forskningsprojektet CASEMED.

Dato:

Underskrift:

Ønsker du at modtage offentliggørelsen af resultaterne på mail?	Ja	Nej
	☐	☐

E-mail: ____

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8000 Aarhus C

Tlf.: +45 8715 0000
E-mail: au@au.dk
Web: www.au.dk

Projektansvarlig	**Hovedvejleder**
Kirstine Bøndergaard	Mette Asbjørn Neergaard
Læge, Ph.d.-studerende	Overlæge, Klinisk professor,
Kræftafdelingen, Aarhus	Enhed for Lindrende Behandling, Aarhus
kirbod@rm.dk	enhedforlindrendebehandling@rm.dk

Information til den interviewede
Data fra interview kræver ikke skriftligt samtykke i henhold til sundhedsloven. Vi vil alligevel gerne sikre os, at den interviewede person har givet tilladelse til at udsagnene fra interviewene bruges i projektet.

Behandling og opbevaring
Den dataansvarlige og projektansvarlige behandler personoplysningerne fortroligt. Oplysningerne vil blive opbevaret i 5 år.

Videregivelse af oplysninger
Oplysningerne vil ikke blive videregivet til andre medmindre der er givet samtykke hertil.

Dataindsigt
Interviewede personer kan når som helst rette henvendelse til de ansvarlige med henblik på at få kopi af oplysningerne.

Berigtigelse af oplysninger
Hvis den interviewede person mener, at der er registreret forkerte oplysninger, kan man bede den dataansvarlige om at berigtige oplysningerne. Det vil sige, at den dataansvarlige retter oplysningerne eller noterer, at oplysningerne er forkerte og registrerer de rigtige oplysninger. Den interviewede person har krav på, at den dataansvarlige ser bort fra oplysningerne indtil, det er afgjort, hvilke oplysninger, der er rigtige.

Tilbagekaldelse af samtykke og sletning af oplysninger
Hvis den dataansvarlige har indhentet et samtykke fra den interviewede person til at behandle oplysningerne, vil den interviewede til enhver tid kunne tilbagekalde samtykket. Den dataansvarlige kan derfor ikke fortsætte med at behandle oplysningerne efter samtykket er trukket tilbage.
Den interviewede har ret til at få slettet oplysninger, som den dataansvarlige har registreret om den pågældende, hvis oplysningerne ikke længere er nødvendige til det formål de blev indsamlet til. Oplysningerne skal også slettes, hvis den interviewede person tilbagekalder samtykket eller hvis oplysningerne ved en fejl er blevet behandlet ulovligt. Den interviewede har ikke krav på sletning af oplysninger, som er arkiverede efter arkivlovens regler i universitetets arkivsystem.

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End-of-Life of CAncer Patients with SEvere MEntal Disorders (CASEMED) -Challenges and Model of Care

Information til sundhedsprofessionelle om forskningsprojektet

BAGGRUND

Patienter, der modtager specialiseret lindrende behandling i den afsluttende del af livet, og som i forvejen har en svær psykisk lidelse, udgør en patientgruppe med særlige udfordringer.
Svære psykiske lidelser – Severe Mental Disorders (SMD) udgøres af skizofreni, manio-depressivitet og moderat til svær depression. Livets afsluttende fase kan være særligt udfordrende for denne sårbare patientgruppe. Der er ikke lavet meget forskning indenfor området, men enkelte studier indikerer, at kvaliteten af den palliative behandling er dårligere end for patienter, som ikke har SMD.

FORMÅL

Studiet skal undersøge og forhåbentlig forbedre det palliative tilbud til denne patientgruppe, så de kan afslutte livet bedre lindret, med en høj grad af værdighed og i overensstemmelse med deres ønsker.

METODER

I dette studie, som er det første af i alt tre del-studier i ph.d.-studiet, vil jeg bede flere patienter om at medvirke i interviews. Hvis patienten giver samtykke, vil jeg også interviewe 1-2 af patientens pårørende, patientens praktiserende læge og 1-2 sundhedsprofessionelle fra Enhed fra Lindrende Behandling eller Hospice, som er tilknyttet patienten. I form af interviews vil jeg forsøge at indsamle dybdegående informationer om, hvad der går godt, og hvad der kan gå bedre i de enkelte forløb. Styrken i studiet bliver at få bragt forskellige parters stemme i spil, som vil hjælpe med at belyse dette emne.

PERSPEKTIV

Forskningsinitiativet vil have potentiale til at give denne sårbare gruppe af døende patienter med SMD en bedre lindrende behandling i den sidste del af livet.

FORSKNINGSGRUPPEN

Leder af projektet, læge, ph.d.-studerende, **Kirstine Bundsbæk Bøndergaard**, Kræftafdelingen, AUH.
- Klinisk professor **Mette Asbjørn Neergaard,** Enhed for Lindrende Behandling, Kræftafdelingen, AUH
- Post.doc., speciallæge i almen medicin **Mette Kjærgaard Nielsen**, Aarhus Universitet
- Professor, overlæge i psykiatri **Poul Videbech**, Center for Neuropsykiatrisk Depressionsforskning, Psykiatrisk Center Glostrup, Københavns Universitet
- Lektor, Cand.mag., **Jane Ege Møller**, Institut for klinisk medicin, AUH

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Appendix II: Study I, Semi Structured Interview Guides

All interview guides were originally developed in Danish. The versions presented here are English translations. All interviews were conducted in Danish.

Patients

Focus	**Question**
Background information	Would you start by telling a little about yourself? - Age - Education/job - Marital status (Married, cohabitating, divorced, widowed, single) - Children (age, living at home) - Living arrangement - Mental health condition/diagnosis - Physical health condition/diagnosis
Personal experience	I would like to start by hearing about your current situation: - When did you become ill with your physical illness? - What happened? - How have you experienced being associated with palliative care unit/hospice?
Trajectory and mental health condition	- If you think back to the first time you heard about the palliative care unit/hospice, what did you think then? How was the first meeting? - What symptoms did you have when you started receiving palliative care? Pain, nausea, anxiety, uncertainty? Worsening of your mental health condition? - What can you manage on your own during the day? - Do you have relatives who help you daily? Has that person attended meetings with the palliative care unit/hospice? - Do you have any special wishes for the near future, something you would like to do or experience? Have you talked to anyone about it? - Have you told the staff at the palliative care unit/hospice about your mental health condition? If yes: Tell a little about how you felt about sharing it: What did you tell them? How did they react? Did they ask further questions about it? If no: Why haven't you talked to them about it? What is difficult? - How do you and your general practitioner talk about your mental health condition? Can you remember the last time you talked about it and what you discussed then?

Collaboration and communication	- Who has been involved in your treatment for your physical illness? Your general practitioner, home nurse, oncologist, psychiatrist, palliative care unit? - Have there been meetings with the palliative care team, you, possibly your relatives, and your general practitioner where everyone was present? - Has there been any discussion about where you would like to be physically in your final days and how that should happen? - How does the staff best support you? - What is the best experience you have had with the palliative care team/hospice? - Some patients need extra support and various services when dealing with an incurable illness. Have you needed this? Have you been offered: A social worker? A conversation with a priest/religious advisor? A psychologist? If yes: How was the support?
Potential	- What do you wish had been different to make this process better for you? - Put in another way: is there anything you wish for from for general practitioner, the palliative team, or at the hospice?
Final questions	- Is there anything else you would like to add? - If you were to give a piece of advice to the healthcare professionals who could potentially help other patients in palliative care with mental health disorders, what would it be?

Relatives

Focus	**Question**
Background information	Would you start by telling a bit about yourself? - Age - Education/Job - Living situation - Marital status (Married, cohabitating, divorced, widowed, single)
Personal experience	- How are you related to xx?
Trajectory	- How would you define your relation? Has your relation changed? - How close are you to xx? - Outline xx's medical history concerning both psychiatric illness and physical illness. - How long has xx been associated with the palliative care unit/hospice?

	- How did you, as a relative, experience your first meeting with the palliative care unit/hospice? What happened? - How would you describe the information you have received about xx's physical illness and treatment throughout the process and now? - How are you involved in the treatment of the physical illness as a relative, and is it at a level that xx/you desire? Can you provide examples?
Collaboration and communication	- How do you feel about xx's treatment here at the hospice/palliative care unit? - Have you experienced anything particularly positive at the hospice/palliative care unit? - Is there anything about the hospice/palliative care unit that concerns you or that you find problematic? - What is being done to ensure that xx makes the most out of the final time? - Does xx still have communication with caregivers from the psychiatric department or their general practitioner? What do they contribute? - Does xx need to talk to the staff at the palliative care unit/hospice about their mental illness? - Do you feel these conversations are being addressed? - How is xx's mental illness handled by the staff in the palliative care unit/hospice? Can you give some examples? - How is xx involved in decisions about their treatment?
Potential	- Have there been any situations or actions that have been particularly beneficial or good for xx? - What could contribute to xx having a good final time?
Final questions	- Is there anything else you would like to add? - If you were to give a piece of advice to the healthcare professionals who could potentially help other patients in palliative care with mental health disorders, what would it be?

General Practitioners

Focus	Question
Background information	Would you start by telling a bit about yourself? - Age - Education: Year of education, specialized training, years in general practice
Professional experience	- What is your experience with palliative care? - How many palliative care cases are you involved in annually? - Are you a nursing home physician? - How often do you encounter patients who have both a mental illness and are in a palliative care trajectory? - What are your initial thoughts about this patient group?

Trajectory	Regarding the specific case of patient xx: - Could you briefly outline this patient's medical history, concerning both psychiatric and physical illness? - How many years have you been GP for this patient? - What have been the biggest challenges overall? - What have been the major successes/what has gone well? - What is the current situation like? - Do you find that the palliative care trajectory differs for this patient compared to patients without mental illness? In what ways? - Have you played a role in the palliative care process for this patient? - What challenges have you experienced in the terminal phase with this patient? Can these challenges be attributed to the patient having a mental illness? - How can you contribute to ensuring that this patient has a good experience? - How do you discuss the patient's mental illness with them? Can you recall the last time you discussed it, and what was covered? - What role does this patient's network play in the trajectory? - Overall, what are your thoughts on the quality of this patient's treatment?
Collaboration and communication	- How would you describe the collaboration between the patient's relatives and yourself? - How would you describe the collaboration between the palliative care unit/hospice and yourself regarding this patient? - How would you describe the collaboration between relevant hospital departments (such as psychiatric/oncologic, others) and yourself regarding this patient? - How would you describe the collaboration between the home care nurses and yourself regarding this patient? - How would you describe the collaboration between social services and yourself regarding this patient?
Potential	- Have you thought along the way that it would be beneficial to change certain aspects of this patient's treatment? - Can anything be changed in the healthcare system, with the patient, or with you as the caregiver to improve this patient's experience? - Is there anything in the trajectory that has stood out positively, something that has gone remarkably well?
Personal experiences	- What are your initial thoughts when you are to meet a patient in a palliative care trajectory who also has a mental illness? - Are there any topics that are difficult to discuss?
Final questions	- Is there anything else you think we should discuss? - Is there anything that could help patients, healthcare professionals, or relatives to this patient group?

	- If you were to give a piece of advice to colleagues, what would it be?

Specialised Palliative Care Professionals

Focus	Question
Background information	Would you start by telling a bit about yourself? - Age - Education/job - Department - Seniority: Year of education specialized training
Professional experience	- How many years have you worked with palliative care? - What are your initial thoughts about this patient group? - How often do you encounter patients with mental disorders in palliative care?
Trajectory	Regarding the specific case of patient xx: - Could you briefly outline this patent's medical history: Reason for referral When did you first meet the patient? What are the prospects? - Do you find that the trajectory differs for this patient compared to patients without mental illness? In what ways? - What challenges have you experienced during the trajectory with this patient? Can these challenges be attributed to the patient having a mental illness? - Has anything in the treatment of this patient gone remarkably well? - What factors contribute to ensuring that this patient has a good experience? - What is important to you when speaking with this patient? - If you compare your conversations with this patient to others, are there any differences? What role does this patient's network play in the treatment process? - Overall, do you think this patient is having a good palliative care trajectory?
Collaboration and communication	- How would you describe the communication within the colleague group regarding this patient? - Has there been interdisciplinary collaboration/communication regarding this patient, for example with: The patient's general practitioner? The patient's relatives? If the patient has a psychiatrist? Who has done what?

Potential	- Do you think some things could be optimized to ensure that this patient has a good palliative care trajectory? - Can anything be changed within the healthcare system, with the patient, or with you as the caregiver to improve this patient's treatment course?
Personal experience	- Why did you choose to work with palliative care? - What is your initial thought when you are about to meet a patient in a palliative care trajectory who also has a mental illness? - How do you discuss the patient's mental illness with them? - Is there anything about palliative care for this patient group that stands out as being easier or differently accepted?
Final questions	- Is there anything else you think we should discuss? - What do you hope this project can contribute to? - Is there anything that could help patients, healthcare professionals, or relatives of this patient group? - Do you have any advice for other healthcare providers when meeting patients with mental disorders?

Appendix III: Study II, Sub-analysis of 14 patients diagnosed with SMD after a terminal diagnosis

The following two tables present data from a sub-analysis conducted in relation to Study II. These analyses have not been published elsewhere. The aim was to examine whether there were sociodemographic or health utilization differences among patients diagnosed with SMD after a terminal cancer or ALS diagnosis, as these patients were excluded from the main study cohort.
Among patients without SMDs, 14 individuals were identified with a newly registered SMD diagnosis after cancer or ALS, or with an SMD diagnosis recorded within two years after the chronic, somatic diagnosis. Compared with the 1,775 patients without SMDs, the group of 14 patients only differed statistically regard-ing referral diagnosis: those diagnosed with SMD after cancer or ALS were more often referred to SPC due to organ failure (36% vs 14%) (Table 1). We also compared the group of 14 patients with the 80 patients with pre-existing SMDs. No significant differences were observed between the groups (Table 2).

Table 1: Sociodemographic characteristics and health utilization of 14 patients affiliated with SPC in Central Region Denmark who died in 2023, having a SMD diagnosis after terminal illness compared to the 1775 pa-tients who were not registered with a SMD at all.

Table 1: CHARACTERISTICS AT PATIENT LEVEL				
	In all (N=1789)	**Patients with an SMD diagnosis after terminal illness** (n=14)	**Patients without an SMD diagnosis** (n=1775)	**p-value#**
Age of patients in years at death (median (IQR))	73 (65;79)	69.5 (59;77)	73 (65;79)	0.534
Age groups of patients in years at death (n (%))				0.165
80 +	417 (23.31)	3 (21.43)	414 (23.32)	
70-79	668 (37.34)	4 (28.57)	664 (37.41)	
60-69	443 (24.76)	3 (21.43)	440 (24.79)	
50-59	170 (9.50)	4 (28.57)	166 (9.35)	
Under 50	91 (5.09)	0 (0.00)	91 (5.13)	
Patient gender (n (%))				0.868
Female	855 (47.79)	7 (50.00)	848 (47.77)	
Male	934 (52.21)	7 (50.00)	927 (52.23)	
Referral diagnosis (n (%))				**0.023**
Cancer	1530 (85.52)	9 (64.29)	1521 (85.69)	
Organ failure¤	259 (14.48)	5 (35.71)	254 (14.31)	

Place of living (n (%))				
(missing data = 8)		*	*	
Private	1678 (93.85)			0.247
Institution (elderly care home)	80 (4.47)			
Other	23 (1.29)			
Living arrangement (n (%))				
(missing data = 126)				
Living with others	1062 (63.78)	8 (66.67)	1054 (63.76)	0.972
Living alone	601 (36.10)	4 (33.33)	597 (36.12)	
Having children (n (%))				
(missing data = 26)				0.447
Yes	1561 (87.26)	11 (78.57)	1550 (87.32)	
No	202 (11.29)	3 (21.43)	199 (11.21)	

IQR: Inter quartile range
#: Pearson Chi^{2} t-test or Two-sample Wilcoxon rank-sum (Mann–Whitney) test whenever appropriate
COPD: Chronic obstructive pulmonary disease
NA: Non applicable
SMD: Severe Mental Disorders, defined as: Moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders. Patients included in this study had their SMD before the terminal diagnose or more than 2 years after the diagnose that lead to death (but always before cancer and neurological diseases such as ALS)
SPC: Specialised Palliative Care, defined as: in-bed hospice or hospital-based palliative care team.
¤: Organ failure defined as all other terminal illnesses than cancer: Heart, kidney and other organ failures.
*: Numbers < 3

Table 2. Sociodemographic characteristics and health utilization of 14 patients affiliated with SPC in Central Region Denmark who died in 2023, having a SMD diagnosed after terminal illness compared to the 80 patients having pre-existing SMD.

Table 2: CHARACTERISTICS AT PATIENT LEVEL				
	In all (N=94)	**Patients with an SMD diagnosis after terminal illness** (n=14)	**Patients with a pre-existing SMD diagnosis** (n=80)	**p-value#**
Age of patients in years at death (median (IQR))	68 (60;76)	69.5 (59;77)	68 (60;76)	0.554
Age groups of patients in years at death (n (%))				
80 +	11 (11.70)	3 (21.43)	8 (10.00)	
70-79	33 (35.11)	4 (28.57)	29 (36.25)	0.311
60-69	28 (29.79)	3 (21.43)	25 (31.25)	
50-59	15 (15.96)	4 (28.57)	11 (13.75)	
Under 50	7 (7.45)	0 (0.00)	7 (8.75)	
Patient gender (n (%))				
Female	48 (51.06)	7 (50.00)	41 (51.25)	0.931
Male	46 (48.94)	7 (50.00)	39 (48.75)	

Referral diagnosis (n (%))				
Cancer	65 (69.15)	9 (64.29)	56 (70.00)	0.669
Organ failure¤	29 (30.85)	5 (35.71)	24 (30.00)	
Place of living (n (%)) (missing data = 2)				0.920
Private	77 (81.91)	*	*	
Institution (elderly care home)	9 (9.57)			
Other	6 (6.38)			
Living arrangement (n (%)) (missing data = 17)				
Living with others	38 (49.35)	8 (66.67)	30 (46.15)	0.192
Living alone	39 (50.65)	4 (33.33)	35 (53.85)	
Having children (n (%)) (missing data = 5)				0.625
Yes	71 (75.53)	11 (78.57)	60 (75.00)	
No	18 (19.15)	3 (21.43)	15 (18.75)	

IQR: Inter quartile range

#: Pearson Chi^2 t-test or Two-sample Wilcoxon rank-sum (Mann–Whitney) test whenever appropriate

COPD: Chronic obstructive pulmonary disease

NA: Non applicable

SMD: Severe Mental Disorders, defined as: Moderate to severe depression, bipolar disease, schizophrenia and other psychotic disorders. Patients included in this study had their SMD before the terminal diagnose or more than 2 years after the diagnose that lead to death (but always before cancer and neurological diseases such as ALS)

SPC: Specialised Palliative Care, defined as: in-bed hospice or hospital-based palliative care team.

¤: Organ failure defined as all other terminal illnesses than cancer: Heart, kidney and other organ failures.

*: Numbers < 3

Appendix IV: Study III, Participant Information

AARHUS UNIVERSITET

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UNIVERSITETS
HOSPITAL

Den sidste del af livet for patienter med svær psykisk sygdom

Kære *navn på kontaktperson (lægen) i specialiseret enhed (eller funktionspostkasse hvis ikke lægen arbejder der mere)*

Jeg skriver til dig for at invitere dig til at deltage i en spørgeskemaundersøgelse omhandlende patient *navn på afdøde patient og CPR-nr.,* som var tilknyttet din arbejdsplads.

Spørgeskemaet tager ca. 10-15 minutter at udfylde. Hvis der er en kollega, der kendte patienten bedre, må du gerne videresende linket til vedkommende.

FORMÅL
Vi ønsker at undersøge kvaliteten af palliative forløb for afdøde patienter med forudgående svær psykisk sygdom. Som sundhedsprofessionel i den specialiserede indsats kan du bidrage med vigtig viden om forløbet i slutningen af patientens liv. Studiet skal undersøge og forhåbentligt forbedre det palliative tilbud til denne patientgruppe.

PRAKTIK
Ved at følge linket, kommer du til spørgeskemaet, som kobles til din patient, når du angiver patientens CPR-nummer.

Link til spørgeskema: ____________________________

For at udfylde spørgeskemaet kan du have brug for at tilgå den afdøde patients journal for at huske detaljerne. Når du går ind i journalen, kommer der en dialogboks op, hvor du skal vinge af i 'Forskning' og skrive 'Vedr. Kirstine Bøndergaards PhD' i kommentaren. Projektet er VID-godkendt og både læger og sygeplejersker har derfor rettighederne til at tilgå journalmaterialet fra egen afdeling/enhed for den specifikke, afdøde patient og videregive oplysninger til projektet.
Din leder er informeret om studiet og har modtaget VID-godkendelsen.

Du kan genoptage spørgeskemaet, hvis du ikke færdiggør det med det samme.
Hvis ikke du ønsker at deltage ved at følge et link eller du ikke kan få linket til at fungere, er du velkommen til at kontakte Kirstine Bøndergaard, kirbod@rm.dk, så sender finder vi en løsning.

Vi håber, at du vil deltage og på forhånd tusind tak for din tid.
Med venlig hilsen
FORSKERGRUPPEN

Kirstine Bundsbæk Bøndergaard	Leder af projektet, læge, ph.d.-studerende, AUH
Mette Asbjørn Neergaard	Klinisk professor, overlæge, AUH
Poul Videbech	Professor, overlæge i psykiatri, KU
Mette Kjærgaard Nielsen	Post.doc, speciallæge i almen medicin, FEAP, Aarhus
Jane Ege Møller	Lektor, cand.mag., AU

Palliative Care Research Aarhus

Kontakt:
Kirstine Bøndergaard
E-mail: kirbod@rm.dk
Tlf. 20182733

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Den sidste del af livet for patienter med svær psykisk sygdom

Kære ansatte på hospice

Jeg skriver til dig for at invitere dig til at deltage i en spørgeskemaundersøgelse omhandlende patient *navn på afdøde patient og CPR-nr.,* som har været indlagt på dit hospice.

Spørgeskemaet tager ca. 10-15 minutter at udfylde. Hvis der er en kollega (læge eller sygeplejerske), der kendte patienten bedre, må du gerne videresende linket til vedkommende, som kan besvare i stedet for dig.

FORMÅL
Vi ønsker at undersøge kvaliteten af palliative forløb for afdøde patienter med forudgående svær psykisk sygdom. Som sundhedsprofessionel i den specialiserede indsats kan du bidrage med vigtig viden om forløbet i slutningen af patientens liv. Studiet skal undersøge og forhåbentligt forbedre det palliative tilbud til denne patientgruppe.

PRAKTIK
Ved at følge linket, kommer du til spørgeskemaet, som kobles til din patient, når du angiver patientens CPR-nummer.

Link til spørgeskema: ___________________________

For at udfylde spørgeskemaet kan du have brug for at tilgå den afdøde patients journal for at huske detaljerne. Når du går ind i journalen, kommer der en dialogboks op, hvor du skal vinge af i 'Forskning' og skrive 'Vedr. Kirstine Bøndergaards PhD' i kommentaren. Projektet er VID-godkendt og både læger og sygeplejersker har derfor rettighederne til at tilgå journalmaterialet fra egen afdeling/enhed for den specifikke, afdøde patient og videregive oplysninger til projektet.
Din leder er informeret om projektet og har fået VID-godkendelsen tilsendt.

Du kan genoptage spørgeskemaet, hvis du ikke færdiggør det med det samme.
Hvis ikke du ønsker at deltage ved at følge et link eller du ikke kan få linket til at fungere, er du velkommen til at kontakte Kirstine Bøndergaard, kirbod@rm.dk, så sender finder vi en løsning.

Vi håber, at du vil deltage og på forhånd tusind tak for din tid.
Med venlig hilsen
FORSKERGRUPPEN

Kirstine Bundsbæk Bøndergaard	Leder af projektet, læge, ph.d.-studerende, AUH
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Mette Kjærgaard Nielsen	Post.doc, speciallæge i almen medicin, FEAP, Aarhus
Jane Ege Møller	Lektor, cand.mag., AU

Palliative Care
Research Aarhus

Kontakt:
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Tlf. 20182733

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Den sidste del af livet for patienter med svær psykisk sygdom

Kære navn på praktiserende læge

Jeg skriver til dig for at invitere dig til at deltage i en spørgeskemaundersøgelse omhandlende din afdøde patient xx, CPR-nr. xxxxxx-xxxx. Hvis en anden læge i lægehuset kendte patienten bedre, er du velkommen til at videregive invitationen til denne.
Spørgeskemaet tager ca. 10-15 minutter at udfylde.

FORMÅL
Vi ønsker at undersøge kvaliteten af palliative forløb for afdøde patienter med forudgående svær psykisk sygdom. Som praktiserende læge kan du bidrage med vigtig viden om forløbet i slutningen af patientens liv. Studiet skal undersøge og forhåbentligt forbedre det palliative tilbud til denne patientgruppe.

HONORAR OG PRAKTIK
Du honoreres efter PLO's takster for konsulentarbejde. For hvert spørgeskema udbetales et honorar svarende til 30 minutters arbejde, i alt 508,32 kr. Honoraret overføres til den konto eller det CVR nr., som du anfører i slutningen af spørgeskemaet. Projektet er godkendt af MPU.

Ved at taste linket nedenfor eller scanne QR-koden, bliver du ført direkte til spørgeskemaet, som kobles til din patient, når du angiver patiens CPR-nummer. Hvis du hellere vil modtage linket pr. mail, er du velkommen til at kontakte Kirstine Bøndergaard, kirbod@rm.dk for fremsendelse af link. Du kan også scanne QR-koden med din telefon og udfylde skemaet på telefonen.

Link til spørgeskema:

QR-kode:

Du kan genoptage spørgeskemaet, hvis du ikke færdiggør det med det samme.
Vi håber, at du vil deltage, og på forhånd tusind tak for din tid.

Med venlig hilsen
FORSKERGRUPPEN

Kirstine Bundsbæk Bøndergaard	Leder af projektet, læge, ph.d.-studerende, AUH
Mette Asbjørn Neergaard	Klinisk professor, overlæge, AUH
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Palliative Care
Research Aarhus

Kontakt:
Kirstine Bøndergaard
E-mail: kirbod@rm.dk
Tlf. 20182733

Appendix V: Study III, Questionnaires

Spørgeskema til praktiserende læger

Kvalitet i det palliative forløb for en afdød patient med en allerede eksisterende svær psykisk lidelse, som har haft dig som praktiserende læge

Dette spørgeskema er en del af et videnskabeligt forskningsprojekt. Vi ønsker at undersøge den pleje og behandling, den afdøde patient, der var tilknyttet din praksis, modtog i de sidste måneder af hans/hendes liv. Dine svar vil hjælpe med at danne et overblik over kvaliteten af plejen og behandlingen af den døende. Det er derfor vigtigt for os at høre dit perspektiv.

Dine svar på disse spørgsmål er fuldt fortrolige og anonymiserede. Du er velkommen til at skrive videre i fritekst i slutningen af spørgeskemaet.

Information om din rolle i forløbet
De følgende spørgsmål omhandler din rolle som praktiserende læge i forløbet, og hvor tit patienten gjorde brug af din hjælp i den sidste tid

Indtast venligst patientens CPR-nr på følgende måde: 0101558989 ________________________________

Din rolle i forløbet

Var du som praktiserende læge involveret i behandling af patienten de sidste 3 måneder af patientens liv?	○ Ja ○ Nej
Hvor ofte var patienten i kontakt med dig (telefonisk, online eller fysisk) i løbet af de sidste tre måneder?	○ En eller to gange ○ Tre eller fire gange ○ Fem gange eller mere ○ Ved ikke
Var patientens pårørende i kontakt med dig (telefonisk, online eller fysisk) i løbet af de sidste tre måneder?	○ Ja, de deltog i ét eller flere møder sammen med patienten ○ Ja, de var i kontakt med mig uden patientens tilstedeværelse ○ Nej
Var du som praktiserende læge på hjemmebesøg hos patienten i løbet af de sidste tre måneder?	○ Ja ○ Nej - jeg vurderede, at der ikke var behov for hjemmebesøg ○ Nej - jeg vurderede, at der var behov for hjemmebesøg, men patienten ønskede det ikke ○ Nej - jeg vurderede, at der var behov for hjemmebesøg, men det lod sig ikke gøre af andre årsager
Hvordan vurderer du samlet set kvaliteten af den behandling patienten fik af dig i de sidste 3 måneder af sit liv?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Pleje og behandling i hjemmet i de sidste 3 måneder af livet

Mener du, at patienten fik al den hjælp og støtte fra sundhedsvæsenet og kommunen, som vedkommende havde brug for i de sidste 3 måneder?	○ Ja ○ Nej
Mener du, at familien/pårørende fik al den hjælp og støtte fra sundhedsvæsenet og kommunen, som de havde brug for i de sidste 3 måneder?	○ Ja ○ Nej

Lindring i de sidste 3 måneder af livet

De følgende spørgsmål handler om de 4 hovedområder indenfor palliation: fysiske, psykiske, sociale og eksistentielle problemstillinger.

	Hele tiden	Noget af tiden	Slet ikke	Ved ikke	Ikke relevant
I hvilket omfang fik patienten lindret sine smerter i løbet af de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine fysiske symptomer (ud over smerter) i løbet af de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine psykiske symptomer i løbet af de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine sociale problemstillinger (fx relation til pårørende, arbejde, bolig) i løbet af de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine eksistentielle problemstillinger (fx skyld/skam, religiøse og spirituelle problemstillinger) i løbet af de sidste 3 måneder af sit liv?	○	○	○	○	○

Oplevede du, at patienten blev inddraget i beslutninger om pleje og behandling de sidste 3 måneder af livet?	○ Ja, fuldstændig ○ Ja, i nogen grad ○ Ja, i mindre grad ○ Nej ○ Ved ikke
Hvordan vurderer du samlet set kvaliteten af patientens pleje og behandling i de sidste 3 måneder af livet, hvis du tager alle sundhedsvæsenets ydelser i betragtning? Sæt kun kryds ved ét svar	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Akutte indlæggelser

Blev patienten på noget tidspunkt indlagt akut i løbet af de sidste 3 måneder?	○ Ja ○ Nej ○ Ved ikke
Tænker du efterfølgende, at den/de akutte indlæggelser var nødvendig eller bidrog med noget væsentligt for patientens tilstand?	○ Ja ○ Nej

Hjemmesygeplejersker

Var du involveret/i kontakt med hjemmesygeplejersker i forhold til patientens pleje og behandling i de sidste 3 måneder af patientens liv?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af hjemmesygeplejerskernes tilbud i de sidste 3 måneder af patientens liv?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Palliativt team/hospice

	Meget god	God	Middel	Dårlig	Meget dårlig	Ikke relevant	Ved ikke
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, patienten fik af det palliative team, hvis tilknyttet, i løbet af de sidste tre måneder af sit liv?	○	○	○	○	○	○	○
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, patienten fik på hospice, hvis patienten opholdt sig der, i løbet af de sidste tre måneder af sit liv?	○	○	○	○	○	○	○

Plejehjem

Var patienten på plejehjem i de sidste 3 måneder af sit liv?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, patienten fik på plejehjemmet, i løbet af de sidste tre måneder af sit liv?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

De sidste to dage af patientens liv og patientens død

	Ved ikke	I hjemmet	Hos pårørende	På plejehjem som var patientens hjem	På plejehjem under aflastningsophold	På en hospitalsafdeling (medregn ikke palliativt afsnit Gødstrup)	På et palliativt afsnit i Gødstrup	På hospice	På akutmodtagelsen eller skadestuen på et hospital	På intensivafdelingen på et hospital	Andet sted
Hvor tilbragte patienten primært de sidste to dage af sit liv?	○	○	○	○	○	○	○	○	○	○	○
Hvor døde patienten?	○	○	○	○	○	○	○	○	○	○	○

Hvis patienten tilbragte de sidste to dage et andet sted, skriv hvilket sted her:	________________________________
Hvis patienten døde et andet sted, skriv hvilket sted her:	________________________________
Var patienten klar over at han/hun skulle dø?	○ Ja ○ Nej ○ Ved ikke
Havde du som praktiserende læge nogle samtaler med patienten om, at han/hun skulle dø?	○ Ja ○ Nej
Havde du en Advance Care Planning samtale med patienten? (samtale vedrørende fremtidig pleje og behandling mellem sundhedsperson, patient og eventuel pårørende)	○ Ja ○ Nej
Var der nogle pårørende til stede sammen med patienten da han/hun døde?	○ Ja ○ Nej ○ Ved ikke
Mener du overordnet set, at det var det rigtige sted for patienten at dø?	○ Ja ○ Nej ○ Ved ikke
Var dødsfaldet ventet på det givne tidspunkt?	○ Ja ○ Nej ○ Ved ikke
Hvordan vurderer du samlet set kvaliteten af patientens pleje og behandling i de sidste to dage af livet, hvis du tager alle sundhedsvæsenets ydelser i betragtning?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Afrunding

Hvis du skulle sammenligne dette palliative forløb med andre palliative forløb, du har været involveret i, hvordan var kvaliteten så?	○ Kvaliteten var bedre ○ Kvaliteten var gennemsnitlig ○ Kvaliteten var dårligere
Mener du, at patientens psykiske lidelse fik indflydelse på kvaliteten af den palliative indsats?	○ Nej ○ Ja
Hvis ja, uddyb gerne på hvilken måde:	______________________________
Hvad var godt ved patientens forløb i de sidste 3 måneder af patientens liv?	______________________________
Hvad kunne have været bedre ved patientens forløb i de sidste 3 måneder af patientens liv?	______________________________
Hvad har gjort særligt indtryk på dig ved dette palliative forløb?	______________________________

Hvilket år blev du født?	○ 1944 ○ 1945 ○ 1946 ○ 1947 ○ 1948 ○ 1949 ○ 1950 ○ 1951 ○ 1952 ○ 1953 ○ 1954 ○ 1955 ○ 1956 ○ 1957 ○ 1958 ○ 1959 ○ 1960 ○ 1961 ○ 1962 ○ 1963 ○ 1964 ○ 1965 ○ 1966 ○ 1967 ○ 1968 ○ 1969 ○ 1970 ○ 1971 ○ 1972 ○ 1973 ○ 1974 ○ 1975 ○ 1976 ○ 1977 ○ 1978 ○ 1979 ○ 1980 ○ 1981 ○ 1982 ○ 1983 ○ 1984 ○ 1985 ○ 1986 ○ 1987 ○ 1988 ○ 1989 ○ 1990 ○ 1991 ○ 1992 ○ 1993 ○ 1994 ○ 1995 ○ 1996 ○ 1997 ○ 1998 ○ 1999 ○ 2000
Hvad er dit køn?	○ Kvinde ○ Mand ○ Andet ○ Ønsker ikke at svare

Hvor mange år har du arbejdet i praksis?	○ Under 5 år ○ 5-10 år ○ 10-15 år ○ 15-20 år ○ 20-25 år ○ Over 25 år
Anfør venligst nedenfor, hvordan du ønsker honoraret overført	○ Nem konto (Anfør dit CPR nr) ○ Firma (Anfør dit CVR nr) (Sæt kun kryds ved ét svar)
Anfør Firma / CVR nr. her	__________________________________
Anfør Nem-Konto / CPR nr. her	__________________________________
Hvis du ønsker at modtage resultaterne af denne undersøgelse når de er publicerede, angiv da din e-mail:	__________________________________

Spørgeskemaer er nu færdigt.
TUSIND TAK FOR DIN DELTAGELSE

Spørgeskema til sundhedsprofessionelle i palliative teams

Spørgeskema til sundhedsprofessionelle i Palliative teams

Kvalitet i det palliative forløb for en afdød patient med en allerede eksisterende svær psykisk lidelse, som har haft en særlig tilknytning til dig som sundhedsprofessionel

Dette spørgeskema er en del af et videnskabeligt forskningsprojekt. Vi ønsker at undersøge den pleje og behandling, den afdøde patient modtog i de sidste måneder af hans/hendes liv. Dine svar vil hjælpe med at danne et overblik over kvaliteten af plejen og behandlingen af den døende. Det er derfor vigtigt for os at høre dit perspektiv.

Dine svar på disse spørgsmål er fuldt fortrolige og anonymiserede. Du er velkommen til at skrive videre i fritekst i slutningen af spørgeskemaet.

Indtast venligst patientens CPR-nr på følgende måde: 0101558989	______________________________
Mener du, at patienten fik al den hjælp og støtte fra sundhedsvæsenet og kommunen, som vedkommende havde brug for i de sidste 3 måneder?	○ Ja ○ Nej ○ Ved ikke
Mener du, at familien/pårørende fik al den hjælp og støtte fra sundhedsvæsenet og kommunen, som de havde brug for i de sidste 3 måneder?	○ Ja ○ Nej ○ Ved ikke

Lindring i de sidste 3 måneder af livet

	Hele tiden	Noget af tiden	Slet ikke	Ikke relevant	Ved ikke
I hvilket omfang fik patienten lindret sine smerter i de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine fysiske symptomer (ud over smerte) i de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine psykiske symptomer i de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine sociale problemstillinger (fx relation til pårørende, arbejde, bolig) i de sidste 3 måneder af sit liv?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine eksistentielle problemstillinger (fx skyld/skam, religiøse og spirituelle problemstillinger) i de sidste 3 måneder af sit liv?	○	○	○	○	○

Oplevede du, at patienten blev inddraget i beslutninger om pleje og behandling de sidste 3 måneder af livet?	○ Ja, fuldstændig ○ Ja, i nogen grad ○ Ja, i mindre grad ○ Nej ○ Ved ikke
Hvis nej, uddyb gerne her:	________________________________
Var patienten klar over at han/hun skulle dø?	○ Ja ○ Nej ○ Ved ikke
Havde du eller dine kollegaer i teamet nogle samtaler med patienten om, at han/hun skulle dø?	○ Ja ○ Nej
Havde du eller dine kollegaer i teamet en Advance Care Planning samtale med patienten?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af patientens pleje og behandling i de sidste 3 måneder af livet, hvis du tager alle sundhedsvæsnets ydelser i betragtning?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Akut pleje og behandling modtaget udenfor almindelig arbejdstid

Var patienten på noget tidspunkt indlagt akut i løbet af de sidste 3 måneder af sit liv?	○ Ja ○ Nej ○ Ved ikke
Tænker du efterfølgende, at den/de akutte indlæggelser var nødvendige eller bidrog med noget væsentligt for patientens tilstand?	○ Ja ○ Nej

Hjemmesygeplejersker

Var du eller dine kollegaer i teamet i kontakt med hjemmesygeplejersker i forhold til patientens pleje og behandling i forbindelse med de sidste tre måneder af patientens liv?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af hjemmesygeplejerskernes palliative tilbud i de sidste 3 måneder af livet?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant ○ Ved ikke

Den praktiserende læge

Var du eller dine kolleger i teamet i kontakt med patientens egen praktiserende læge?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af den behandling patienten fik af sin praktiserende læge i de sidste 3 måneder af livet?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant ○ Ved ikke

Palliativt team

Hvordan oplevede du din relation med patienten i forløbet?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, patienten fik af det palliative team, i løbet af de sidste 3 måneder af livet?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant

Plejehjem

Var patienten på plejehjem de sidste 3 måneder af sit liv?	○ Ja ○ Nej ○ Ved ikke
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, som patienten fik på plejehjemmet i løbet af de sidste tre måneder af sit liv?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant

De sidste to dage af patientens liv og patientens død

Hvor tilbragte patienten primært de sidste to dage af sit liv?	○ Ved ikke ○ Hjemme ○ Hos pårørende ○ Plejehjem som var patientens hjem ○ Plejehjem under aflastningsophold ○ Hospitalsafdeling (fraset palliativt afsnit Gødstrup) ○ Palliativt afsnit i Gødstrup ○ Akutmodtagelse eller skadestue ○ Intensivafdeling ○ Hospice ○ Andet
Hvor døde patienten?	○ Ved ikke ○ Hjemme ○ Hos pårørende ○ Plejehjem som var patientens hjem ○ Plejehjem under aflastningsophold ○ Hospitalsafdeling (fraset palliativt afsnit Gødstrup) ○ Palliativt afsnit i Gødstrup ○ Akutmodtagelse eller skadestue ○ Intensivafdeling ○ Hospice ○ Andet
Hvis patienten tilbragte de sidste to dage af sit liv et andet sted, skriv stedet her:	______________________________
Hvis patienten døde et andet sted, skriv stedet her:	______________________________
Mener du overordnet set, at det var det rigtige sted for patienten at dø?	○ Ja ○ Nej ○ Ved ikke
Var der nogle pårørende til stede sammen med patienten da han/hun døde?	○ Ja ○ Nej ○ Ved ikke
Var dødsfaldet ventet på det givne tidspunkt?	○ Ja ○ Nej ○ Ved ikke
Hvordan vurderer du samlet set kvaliteten af patientens pleje og behandling i de sidste to dage af livet, hvis du tager alle sundhedsvæsnets ydelser i betragtning?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Afrunding

Hvis du skulle sammenligne dette palliative forløb med andre palliative forløb du har været involveret i, hvordan var kvaliteten så?	○ Kvaliteten var bedre ○ Kvaliteten var gennemsnitlig ○ Kvaliteten var dårligere ○ Ved ikke
Mener du at patientens psykiske lidelse fik indflydelse på kvaliteten af den palliative indsats?	○ Nej ○ Ja ○ Ved ikke
Hvis ja, uddyb gerne på hvilken måde:	____________________________
Hvad var godt ved patientens pleje og behandling i den tid patienten var tilknyttet palliativt team?	____________________________
Hvad var mindre godt ved patientens pleje og behandling i den tid patienten var tilknyttet palliativt team?	____________________________
Hvad har gjort særligt indtryk ved dette palliative forløb?	____________________________

Hvilket år blev du født?	○ 1944 ○ 1945 ○ 1946 ○ 1947 ○ 1948 ○ 1949 ○ 1950 ○ 1951 ○ 1952 ○ 1953 ○ 1954 ○ 1955 ○ 1956 ○ 1957 ○ 1958 ○ 1959 ○ 1960 ○ 1961 ○ 1962 ○ 1963 ○ 1964 ○ 1965 ○ 1966 ○ 1967 ○ 1968 ○ 1969 ○ 1970 ○ 1971 ○ 1972 ○ 1973 ○ 1974 ○ 1975 ○ 1976 ○ 1977 ○ 1978 ○ 1979 ○ 1980 ○ 1981 ○ 1982 ○ 1983 ○ 1984 ○ 1985 ○ 1986 ○ 1987 ○ 1988 ○ 1989 ○ 1990 ○ 1991 ○ 1992 ○ 1993 ○ 1994 ○ 1995 ○ 1996 ○ 1997 ○ 1998 ○ 1999 ○ 2000
Hvad er dit køn?	○ Kvinde ○ Mand ○ Andet ○ Ønsker ikke at svare

Hvad er din faggruppe?	☐ Læge ☐ Sygeplejerske ☐ Andet
Hvis anden faggruppe, angiv da hvilken her:	__________________________________
Hvor mange år har du arbejdet med specialiseret palliation?	○ Under 5 år ○ 5-10 år ○ 10-15 år ○ 15-20 år ○ 20-25 år ○ Over 25 år
Hvis du ønsker at modtage resultaterne af studiet, når der udgives en artikel, kan du anføre din mailadresse her:	__________________________________

Spørgeskemaer er nu færdigt.
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Spørgeskema sundhedsprofessionelle på hospice

Spørgeskema til sundhedsprofessionelle på hospice

Kvalitet i det palliative forløb for en afdød patient med en allerede eksisterende svær psykisk lidelse, som har haft en særlig tilknytning til dig som sundhedsprofessionel

Dette spørgeskema er en del af et videnskabeligt forskningsprojekt. Vi ønsker at undersøge den pleje og behandling, den afdøde patient modtog i de sidste måneder af hans/hendes liv. Dine svar vil hjælpe med at danne et overblik over kvaliteten af plejen og behandlingen af den døende. Det er derfor vigtigt for os at høre dit perspektiv.

Dine svar på disse spørgsmål er fuldt fortrolige og anonymiserede. Du er velkommen til at skrive videre i fritekst i slutningen af spørgeskemaet.

De første spørgsmål handler om lindring i den tid patienten var på hospice.

Indtast venligst patientens CPR-nr på følgende måde: 0101554466 ________________________________

Lindring i den tid patienten var på hospice

	Hele tiden	Noget af tiden	Slet ikke	Ikke relevant	Ved ikke
I hvilket omfang fik patienten lindret sine smerter i den tid patienten var på hospice?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine fysiske symptomer (ud over smerte) i den tid patienten var på hospice?	○	○	○	○	○
I hvilket omfang fik patienten lindret sine psykiske symptomer i den tid patienten var på hospice?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine sociale problemstillinger (fx relation til pårørende, arbejde, bolig) i den tid patienten var på hospice?	○	○	○	○	○
I hvilket omfang fik patienten hjælp til at tackle sine eksistentielle problemstillinger (fx skyld/skam, religiøse og spirituelle problemstillinger) i den tid patienten var på hospice?	○	○	○	○	○

Oplevede du, at patienten blev inddraget i beslutninger om pleje og behandling den tid patienten var på hospice?	○ Ja, fuldstændig ○ Ja, i nogen grad ○ Ja, men i mindre grad ○ Nej
Hvis nej, kommenter gerne her:	
Var patienten klar over at han/hun skulle dø?	○ Ja ○ Nej ○ Ved ikke
Havde du eller dine kollegaer på hospice nogle samtaler med patienten om, at han/hun skulle dø?	○ Ja ○ Nej
Havde du eller dine kollegaer på hospice en Advance Care Planning samtale med patienten?	○ Ja ○ Nej
Hvordan vurderer du samlet set kvaliteten af patientens pleje og behandling i de sidste 3 måneder af livet, hvis du tager alle sundhedsvæsnets ydelser i betragtning?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

Hvordan oplevede du din relation med patienten i forløbet?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ikke relevant
Hvordan vurderer du samlet set kvaliteten af den pleje og behandling, patienten fik i den tid patienten var på hospice?	○ Meget god ○ God ○ Middel ○ Dårlig ○ Meget dårlig ○ Ved ikke

De sidste to dage af patientens liv og patientens død

Døde patienten på hospice?	○ Ja ○ Nej
Var der nogle pårørende til stede sammen med patienten da han/hun døde?	○ Ja ○ Nej ○ Ved ikke
Mener du overordnet set, at det var det rigtige sted for patienten at dø?	○ Ja ○ Nej ○ Ved ikke
Var dødsfaldet ventet på det givne tidspunkt?	○ Ja ○ Nej ○ Ved ikke
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Afrunding

Hvis du skulle sammenligne dette palliative forløb med andre palliative forløb du har været involveret i, hvordan var kvaliteten så?	○ Kvaliteten var bedre ○ Kvaliteten var gennemsnitlig ○ Kvaliteten var dårligere
Mener du at patientens psykiske lidelse fik indflydelse på kvaliteten af den palliative indsats?	○ Nej ○ Ja
Hvis ja, uddyb gerne her på hvilken måde:	______________________
Hvad var godt ved patientens pleje og behandling i den tid patienten var på hospice?	______________________
Hvad var mindre godt ved patientens pleje og behandling i den tid patienten var på hospice?	______________________
Hvad har gjort særligt indtryk ved dette palliative forløb?	______________________

Hvilket år blev du født?	○ 1944 ○ 1945 ○ 1946 ○ 1947 ○ 1948 ○ 1949 ○ 1950 ○ 1951 ○ 1952 ○ 1953 ○ 1954 ○ 1955 ○ 1956 ○ 1957 ○ 1958 ○ 1959 ○ 1960 ○ 1961 ○ 1962 ○ 1963 ○ 1964 ○ 1965 ○ 1966 ○ 1967 ○ 1968 ○ 1969 ○ 1970 ○ 1971 ○ 1972 ○ 1973 ○ 1974 ○ 1975 ○ 1976 ○ 1977 ○ 1978 ○ 1979 ○ 1980 ○ 1981 ○ 1982 ○ 1983 ○ 1984 ○ 1985 ○ 1986 ○ 1987 ○ 1988 ○ 1989 ○ 1990 ○ 1991 ○ 1992 ○ 1993 ○ 1994 ○ 1995 ○ 1996 ○ 1997 ○ 1998 ○ 1999 ○ 2000
Hvad er dit køn?	○ Kvinde ○ Mand ○ Andet ○ Ønsker ikke at svare

Hvad er din faggruppe?	○ Læge ○ Sygeplejerske ○ Andet
Hvis anden faggruppe, angiv venligst hvilken:	__________________________________
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