


Palliative care need screening and specialised referrals fell during the COVID-19 pandemic: a nationwide register-based study

Maiken Bang Bang Hansen ^{1,2}, Mogens Groenvold,^{1,3} Mathilde Adersen,¹ Henry Jensen,⁴ Else Helene Ibfelt,² Morten Aagaard Petersen,¹ Mette Asbjørn Neergaard,^{5,6} Henrik Møller,² Tina Bech Olesen⁴

¹The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark
²Department of Cancer and Cancer Screening, The Danish Clinical Quality Program – National Clinical Registries (RKKP), Copenhagen, Denmark
³Department of Public Health, Copenhagen University, Copenhagen, Denmark
⁴Department of Resources and Innovation, The Danish Clinical Quality Program – National Clinical Registries (RKKP), Copenhagen, Denmark
⁵Palliative Care Unit, Department of Oncology, Aarhus University Hospital, Aarhus, Denmark
⁶Department of Clinical Medicine, Aarhus University, Aarhus, Midtjylland, Denmark

Correspondence to

Mrs Maiken Bang Bang Hansen, The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark; maiken.bang.hansen@regionh.dk

Received 11 April 2023
 Accepted 12 April 2023



© Author(s) (or their employer(s)) 2023. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Hansen MBB, Groenvold M, Adersen M, et al. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2023-004324

ABSTRACT

Objectives Few studies have examined whether access to, and quality of, specialised palliative care changed during the COVID-19 pandemic. This study investigated changes in access to and quality of specialised palliative care during the pandemic in Denmark compared to previously.

Methods An observational study using data from the Danish Palliative Care Database combined with other nationwide registries was conducted, including 69 696 patients referred to palliative care services in Denmark from 2018 to 2022. Study outcomes included number of referrals and admissions to palliative care, and the proportions of patients fulfilling four palliative care quality indicators. The indicators assessed admissions among referred, waiting time from referral to admission, symptom screening using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core-15-Palliative Care (EORTC QLQ-C15-PAL) questionnaire at admission, and discussion at multidisciplinary conference. Logistic regression analysed whether the probability of fulfilling each indicator differed between the pandemic period and pre-pandemic, while adjusting for possible confounders.

Result Number of referrals and admissions to specialised palliative care were lower during the pandemic. The odds for being admitted within 10 days of referral was higher during the pandemic (OR: 1.38; 95% CI: 1.32 to 1.45) whereas the odds for answering the EORTC questionnaire (0.88; 95% CI: 0.85 to 0.92) and for being discussed at multidisciplinary conference (0.93; 95% CI: 0.89 to 0.97) were lower compared with pre-pandemic.

Conclusions Fewer patients were referred to specialised palliative care during the pandemic,

WHAT WAS ALREADY KNOWN?

- ⇒ The COVID-19 pandemic affected societies and healthcare systems with restrictions implemented during the pandemic in most countries.
- ⇒ Patients, caregivers and healthcare providers have reported changes in palliative care provision during the pandemic.
- ⇒ Few studies have investigated changes in the provision of palliative care during the pandemic. The studies were, however, often conducted by a single palliative care service and often only included data from a limited period of the pandemic.

and fewer were screened for palliative care needs. In future pandemics or similar scenarios, it is important to pay special attention to referral rates and to maintain the same high level of specialised palliative care.

INTRODUCTION

The COVID-19 pandemic was a global health crisis, which caused close to 7 million deaths worldwide.¹ In Denmark, to date three major waves of the COVID-19 pandemic have occurred: in the spring of 2020, in the winter of 2020/2021 and again in the winter of 2021/2022.²

In efforts to mitigate the impact of the COVID-19 pandemic on the healthcare system and to minimise the spread of the infection, population-wide restrictions ('lockdowns') were imposed in Denmark on 11 March 2020 and subsequently. Large parts of the society were closed down and, within the healthcare system, elective procedures were cancelled or

WHAT ARE THE NEW FINDINGS?

- ⇒ A lower number of referrals and admittances to specialised palliative care services were observed during the pandemic. However, possibly due to the fewer referrals, the probability of being admitted within ten days after referral was higher during the pandemic.
- ⇒ Patients were less likely to report their symptoms at admission and to be discussed on multidisciplinary conference.
- ⇒ Nationwide data covering the entire pandemic showed changes in provision and quality of palliative care during the COVID-19 pandemic compared with the pre-pandemic period in Denmark.

WHAT IS THEIR CLINICAL SIGNIFICANCE?

- ⇒ In future pandemics or other crises to healthcare, it is important that referring doctors in the primary and secondary healthcare sector maintain the same level of contact with patients with life-threatening illnesses to assure identification of palliative care needs and referral to specialised palliative care when needed. If physical consultations are reduced telemedicine could be considered. Telemedicine may also be a solution when patients or relatives do not wish contact with healthcare professionals due to fear of getting infected.
- ⇒ Palliative care services should maintain focus on having patients report their symptoms at admittance in order to be able to provide the best possible palliative care.

postponed, and resources were reallocated to take care of patients in need of hospitalisation because of COVID-19. Moreover, throughout the pandemic, large efforts were made to protect individuals with life-threatening disease, for example, advanced cancer, from exposure to COVID-19 infection because of an increased risk of death.³

These population-wide restrictions have been shown to affect (directly or indirectly) the number of healthcare contacts. A study from the UK found that the number of primary care contacts declined markedly after the introduction of population-wide restrictions.⁴ Similarly, a study from Denmark showed that the number of hospital admissions for all major non-COVID-19 conditions decreased during national lockdowns.⁵ Furthermore, the number of patients diagnosed with cancer in Denmark was lower during the COVID-19 pandemic in 2020 compared with the year before.⁶ Nonetheless, to date no studies have examined the provision of palliative care in the Nordic countries during the pandemic.

Many palliative care providers in the UK reported being busier during the COVID-19 pandemic compared with previously⁷ but only a few quantitative studies have investigated changes in palliative care provision during the COVID-19 pandemic.^{8–10} These studies have shown conflicting results with a reduction in workload and an increase in the availability of palliative care beds in Toronto,¹⁰ an increase in the number of hospitalised patients at a single hospital in Italy,⁹ an

unchanged number of patients admitted to five hospitals in Scotland⁸ as well as no changes in waiting times for admission in Italy⁹ but shorter waiting times in Scotland.⁸

It is possible that the provision and quality of specialised palliative care were lower during the COVID-19 pandemic due to the changes in the healthcare system, for example, with restrictions and new tasks implemented or staff moved to other functions. Large studies with nationwide data from palliative care services, including data from the entire COVID-19 period, are warranted to understand whether and how the provision and quality of specialised palliative care changed during the COVID-19 pandemic. This is possible by using data from nationwide Danish registries.

We examined whether the provision and quality of specialised palliative care changed during the COVID-19 pandemic compared with the pre-pandemic period. This was examined by assessing whether the number of referrals and number of admissions to specialised palliative care differed during the pandemic and whether fulfilment of four quality indicators of specialised palliative care were altered during the pandemic, compared with the pre-pandemic period.

METHODS**Setting and data sources**

Denmark holds a population of about 5.8 million inhabitants¹¹ and has a tax-financed healthcare system based on the principle of free and equal access for all citizens to most healthcare services. In Denmark, specialised palliative care is provided by 19 hospices and 24 hospital-based palliative care teams.¹² The population-based administrative and health registries in Denmark can be linked through the unique personal identifier.^{13 14}

The Danish Palliative Care Database was the main data source in this study, and includes all individuals referred to specialised palliative care in Denmark since January 2010 with information on socio-demographic factors, diagnosis as well as information on referrals, admissions and clinical quality measures.¹² Data in the database are routinely collected with the aim of assessing quality of specialised palliative care in Denmark. This register-based study linked data from the database to data from other nationwide registries. Information on sex, age, diagnosis and variables on clinical measures were retrieved from the database. Information on region of residence, ethnicity and cohabitation status was obtained from the Danish Civil Registration System¹⁵ and educational level from the Population's Education Register.¹⁶

Study population

The study included all individuals aged 18 years or older referred to specialised palliative care from 1 January 2018 to 3 January 2022.

Variables

The date of referral to specialised palliative care was used to divide the study population into the pre-pandemic period versus pandemic period, which was the main explanatory variable in this study. The pre-pandemic period was from 1 January 2018 to 31 January 2020. The pandemic period was from 1 February 2020 to 3 January 2022. The pandemic period included three lockdown periods in Denmark, that is, 1st lockdown (11 March 2020–15 April 2020), 2nd lockdown (16 December 2020–27 February 2021) and 3rd lockdown (15 December 2021–3 January 2022).

Study outcomes were:

- ▶ Number of all referrals to specialised palliative care.
- ▶ Number of admittances to specialised palliative care.

Proportion of patients admitted to specialised palliative care, who:

- ▶ Waited ≤ 10 days from referral to admission.
- ▶ Were screened for symptoms and problems using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core-15-Palliative Care (EORTC QLQ-C15-PAL)¹⁷ questionnaire at admission.
- ▶ Were discussed at a multidisciplinary conference.

Statistical analyses

Patient characteristics for the study population were computed overall, for the pre-pandemic and the pandemic period.

The outcomes (ie, number of all referrals and admittances as well as the proportion of patients fulfilling each quality indicator) were computed by month during the study period.

The average number of referrals and admittances per year in the pre-pandemic period (2018–2019) and per year during the COVID-19 period (2020–2021) was compared with examining whether access to specialised palliative care changed during the pandemic compared with the pre-pandemic period.

Logistic regression analyses were performed to study whether fulfilment of each of the four quality indicators differed in the COVID-19 period compared with the pre-pandemic period with and without adjustments for: sex, age, region of residence, ethnicity, cohabitation status, educational level, diagnosis group and type of specialised palliative care service the patient was referred to. Age was entered as a continuous variable, whereas the other variables were categorical (see categories in [table 1](#)).

All analyses were conducted using SAS Enterprise Guide version 7.1.

RESULTS

Patient characteristics

The study included 69 696 patients referred to specialised palliative care between 1 January 2018 and 3 January 2022; 76.1% met the criteria for admittance and of all referred 61.7% of the patients were admitted ([table 1](#)). Half of the patients were women,

and the average age was 71. Most patients were of Danish origin (94.8%), had a medium to high level of education (54.4%), were married/living with a partner (53.9%) and were cancer patients (89.2%). Patient characteristics were similar in the pre-pandemic and during the COVID-19 pandemic.

[Figure 1](#) shows the number of referrals and admissions per month to specialised palliative care services over time. Numbers of referrals were lowest in the beginning of the pandemic (February–May 2020) where the first lockdown occurred (11 March 2020–15 April 2020).

Compared with the previous 2 years (ie, pre-pandemic period), the number of referrals and admittances were lower in the pandemic period. [Figure 2](#) shows the average number of referred patients per year as well as the average number of admitted patients per year for the pre-pandemic period and for the period during COVID-19. On average the decrease in referred patients was 744 per year, and the decrease in admitted patients was 675 annually during the pandemic period compared with before the pandemic.

The proportions of patients admitted (of all the referred patients who met the admittance criteria) and discussed at multidisciplinary conference were similar before and during the pandemic ([table 2](#)). The proportion admitted within 10 days from referral was higher during the pandemic, whereas the proportion who reported their symptoms at the start of palliative care on the EORTC questionnaire was lower ([table 2](#)).

ORs from the unadjusted and adjusted regression analyses were very similar ([table 2](#)). The odds for fulfilling three of the four indicators were different in the pandemic period compared with pre-pandemic period ([table 2](#)). The odds of being admitted within 10 days after referral to specialised palliative care was higher in the pandemic period compared with pre-pandemic (OR=1.38; 95% CI 1.32 to 1.45). On the contrary, there was lower odds in the pandemic period for patients to complete the EORTC QLQ-C15-PAL questionnaire at the start of palliative care (OR=0.88; 95% CI 0.85 to 0.92) and for patients to be discussed at a multidisciplinary conference (OR=0.93; 95% CI 0.89 to 0.97) compared with pre-pandemic.

DISCUSSION

Main findings

The number of referrals and admittances to specialised palliative care services was lower during the COVID-19 pandemic compared with the pre-pandemic period. Because the reductions in the numbers of referred and admitted patients were similar, the indicator measuring the likelihood of admission among referred, who met criteria for admittance, did not change. In contrast, among patients admitted to specialised palliative care, the probability of being admitted within 10 days from referral was higher during the pandemic than before. We found decreases in the two remaining quality

Table 1 Characteristics of all patients referred to SPC during the COVID-19 pandemic (1 February 2020–3 January 2022) and pre-pandemic (1 January 2018–31 January 2020).

	All		Pre-pandemic		During COVID-19	
	N	%	N	%	N	%
Total	69 696	100.0	37 194	100.0	32 502	100
SPC service the patient was referred to						
Palliative care team	35 837	51.4	19 685	52.9	16 152	49.7
Hospice	33 859	48.6	17 509	47.1	16 350	50.3
Fulfilled criteria for admittance						
Yes	53 021	76.1	28 552	76.8	24 469	75.3
No	16 675	23.9	8642	23.2	8033	24.7
Admitted to SPC						
Yes	43 030	61.7	23 139	62.2	19 891	61.2
No	26 666	38.3	14 055	37.8	12 611	38.8
Gender						
Female	35 039	50.3	18 769	50.4	16 270	50.1
Male	34 657	49.6	18 425	49.5	16 232	49.9
Age groups						
18–49 years	3367	4.8	1842	4.6	1,525	4.7
50–59 years	7284	10.5	3930	10.6	3354	10.3
60–69 years	16 622	23.9	9130	24.6	7 492	23.1
70–79 years	25 438	36.5	13 409	36.1	12 029	37.0
80 years or older	16 985	24.3	8883	23.9	8102	24.9
Range (years)	18–109		18–109		18–102	
Mean (years)	71.1		70.9		71.4	
Median (years)	73.0		72.0		73.0	
Ethnicity						
Danish origin	65 899	94.8	35 275	95.1	30 624	94.5
Western immigrant	1739	2.5	889	2.4	850	2.6
Non-western immigrant	1886	2.7	939	2.5	947	2.9
Educational level*						
Low (ISCED level 1–2)	23 829	34.9	13 044	35.9	10 785	33.9
Medium (ISCED level 3–5)	30 928	54.4	16 271	44.7	14 657	46.0
High (ISCED level 6–8)	13 444	19.7	7053	19.4	6391	20.1
Cohabitation status						
Living alone	32 054	46.1	16 919	45.6	15 134	46.7
Married/living with partner	37 470	53.9	20 184	54.4	17 286	53.3
Region						
Northern Denmark Region	7524	10.8	4192	11.3	3332	10.3
Central Denmark Region	15 857	22.8	8212	22.2	7645	23.6
Southern Denmark Region	14 160	20.4	7364	19.9	6796	21.0
Capital region	20 285	29.2	10 943	29.6	9342	28.8
Region Zealand	11 613	16.7	6323	17.1	5290	16.3
Diagnosis						
Cancer	62 483	89.7	33 483	90.0	29 000	89.2
Non-cancer	7204	10.3	3707	10.0	3497	10.8

*Short (ISCED level 1–2: primary education to upper secondary education), medium (ISCED level 3–5: vocational education and training to vocational bachelors educations) and long (ISCED level 6–8: bachelors programmes to PhD programmes).³⁴

ISCED, International Standard Classification of Education; SPC, specialised palliative care.

indicators: a lower probability during the pandemic for patients to report their symptoms and quality of life on the EORTC QLQ-C15-PAL questionnaire at time of admission to specialised palliative care and for patients to be discussed on a multidisciplinary conference.

Comparison with existing literature

This study documented nationwide changes in the provision and quality of specialised palliative care during the pandemic. Patients with life-threatening illnesses may especially have been shielded from

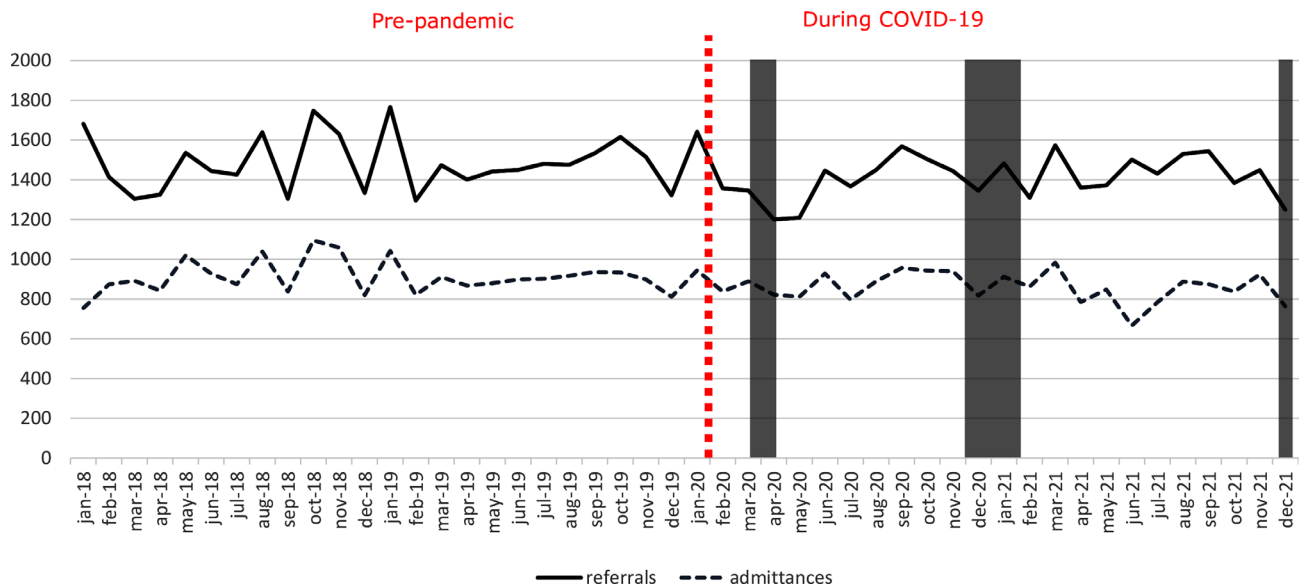


Figure 1 Referrals and admittances to specialised palliative care in the pre-pandemic period and during the COVID-19 pandemic. Dotted red line separates the pre-pandemic and pandemic period. The shaded areas are the three lockdown periods.

contact with relatives and the healthcare system to avoid exposure to COVID-19 infection. Several qualitative studies have shown how the life of patients admitted to specialised palliative care and their caregivers were affected by the pandemic, for example, a study from Sweden found many patients in specialised palliative home care (and their caregivers) experienced negative effects of reduced social contact due to restrictions and fear of being infected with COVID-19 and some even described the reduced social contact as torture. Most patients and carers did, however, not think their contact with the specialised palliative

care service was reduced and they valued the contact highly.¹⁸ Danish caregivers of patients in specialised palliative home care also expressed the fear of themselves or other would pass on COVID-19 to the patient and how it was difficult to get the most out of life due to COVID-19 restrictions. During some period of the pandemic they, also, expressed the frustration of not being able to visit the patient in the hospital and having less physical contact with the palliative home care service.¹⁹ In the pandemic, due to visitor restrictions and social distancing, physical consultations were to some extent replaced by telemedicine, and thus

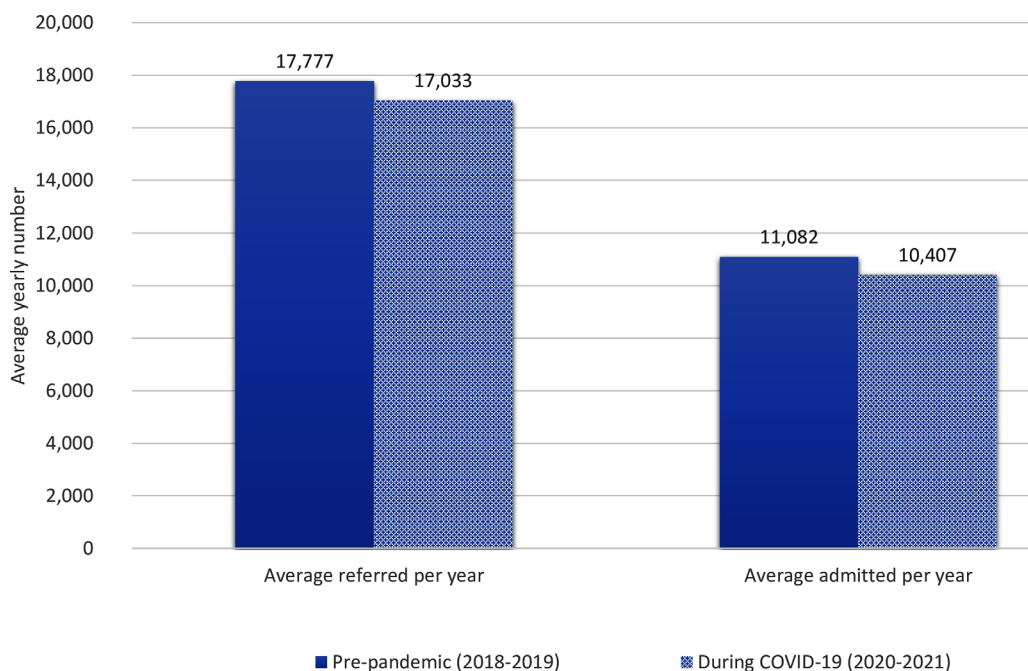


Figure 2 The average yearly number of patients referred to and admitted to palliative care in the pre-pandemic period and during the COVID-19 pandemic.

Table 2 Number and proportion of patients fulfilling quality indicators as well as ORs with 95% CIs for fulfilling the indicators during the COVID-19 pandemic (1 February 2020–3 January 2022) versus in the pre-pandemic period (1 January 2018–31 January 2020)

Quality indicators	Number and proportion fulfilling quality indicators						OR (95% CI) for fulfilling quality indicators during COVID-19 vs pre-pandemic		
	Pre-pandemic			During COVID-19			Unadjusted OR	Adjusted OR*	Adjusted OR*
	All (N)	Fulfil indicator (N)	Fulfil indicator (%)	All (N)	Fulfil indicator (N)	Fulfil indicator (%)			
Admitted when criteria for admittance were fulfilled	28 552	23 139	81%	24 469	19 891	81%	1.02 (0.97–1.06)	1.05 (1.00–1.10)	
≤10 days of waiting from referral to admittance	23 139	16 708	72%	19 891	15 586	78%	1.39 (1.33–1.46)	1.38 (1.32–1.45)	
Admitted who answered the QLQ-C15-PAL questionnaire at admittance	23 139	14 277	62%	19 891	11 646	58%	0.88 (0.84–0.91)	0.88 (0.85–0.92)	
Admitted who were discussed on multidisciplinary conference	23 139	16 678	72%	19 891	14 025	71%	0.93 (0.89–0.97)	0.93 (0.89–0.97)	

*Adjusted for the effect of sex, age, region of residence, ethnicity, marital status, educational level, diagnosis and type of SPC service the patient was referred to.

QLQ-C15-PAL, Quality of Life Questionnaire-Core-15-Palliative Care.

more contacts between palliative care providers and patients were done by video consultations^{20 21} or by telephone.¹⁹

The finding of lower number of referrals during the pandemic, observed in this study, is in accordance with results from a study from the Toronto area where most palliative care services experienced a reduced workload and more available palliative care beds during the pandemic,¹⁰ while contrasting other studies from Italy, UK and Scotland reported an increase in admissions⁹ and experienced business,⁷ or no change in palliative care provision.⁸

The reduction in referrals to palliative care services during the pandemic found in this study might be explained by COVID-19 restrictions, social distancing and fear among patients, relatives and healthcare personnel of COVID-19 and of exposing critically ill patients to COVID-19. This may have resulted in patients with palliative care needs have been seen less often by doctors resulting in fewer referrals to specialised palliative care services. Also, some patients and relatives may have refused to be referred to specialised palliative care—even though the treating physician found it relevant—because patients and relatives did not want more professionals in their homes or because of the fact that many hospices had restrictions on how many relatives were allowed to visit during the pandemic. A report from the National Audit Office of Denmark concluded that already before the pandemic palliative care needs were not assessed systematically among patients with life-threatening disease in the primary and secondary healthcare sector in Denmark,²² although it has been recommended by the Danish Health Authorities since 2011.^{23 24} The lack of systematic identification of patients in need of specialised palliative care may have worsened during the pandemic, due to restrictions, and because healthcare professionals may have needed to handle other urgent tasks.^{20 22} In Denmark, the capacity of specialised palliative care as measured by the first two quality indicators reported in this study is insufficient, that is, it is not possible to receive all referred patients and not sufficiently fast.²⁵ Moreover, unequal access to specialised palliative care has earlier been found, for example, among patients with lower income and educational levels as compared with patients with higher socioeconomic position.^{26–28}

The probability of being admitted within 10 days from referral was higher in the pandemic period compared with the pre-pandemic period, which was opposite to the findings from a palliative care team in an Italian hospital where no significant changes in waiting time were found.⁹ The different findings might partly be explained by fewer referrals to specialised palliative care during the pandemic in this study, whereas there were more referrals in the Italian study as well as the relatively much higher pressure on the healthcare system in Italy during the pandemic compared with

Denmark. Another explanation of our findings may be that Danish palliative care services were encouraged to set up initiatives in order to reduce waiting time following the National Audit report concluding there was a problem with waiting time.²²

This study found that patients were less often screened for palliative care needs at admittance to specialised palliative care services during the pandemic. The reason may be less time and focus on getting patients to fill in the EORTC QLQ-C15-PAL questionnaire because of COVID-19-related tasks. It is important to maintain systematic identification of palliative care needs to assure the best palliative care, in order to insure that patients' symptoms are not overlooked^{29 30} and symptom severity is not underestimated.³¹⁻³³

The lower probability of being discussed at a multi-disciplinary team conference during the pandemic found in this study may be explained by the number of persons in meetings was kept at a minimum in order to reduce the spread of COVID-19.

Strengths and limitations of the study

The study included nationwide data on all patients referred to specialised palliative care at all palliative care services in Denmark during the study period, minimising the risk of selection bias. The study also included data from the entire pandemic period in Denmark as opposed to most previous studies which included only data from a limited period of the pandemic. The nationwide registries provided high data validity and completeness.

A limitation of this study is that it did not include information from doctors referring patients to specialised palliative care on the reasons for referral or not, and whether and how their referral practice changed during the pandemic which may explain the lower number of referrals. Also, we do not know how often patients declined to be referred due to of fear of getting a COVID-19.

The study results may depend on factors such as organisation of the healthcare systems, COVID-19 infection rates and COVID-19 restrictions implemented. This should be kept in mind if generalising to other countries.

Future research

Changes in referral practice among doctors referring patients to specialized palliative care during the pandemic compared with previously would be relevant for future studies to investigate since that may help explain the lower number of referrals to specialised palliative care during the pandemic. Changes may have occurred if COVID-19 restrictions and social distancing resulted in less patient consultations and thereby a lower probability of identifying patients with palliative care needs who should have been referred to specialized palliative care, but also if some patients and relatives rejected referral to specialized palliative care

because they feared COVID-19 infection if, e.g., more professionals entered their home.

CONCLUSION

During the COVID-19 pandemic fewer patients were referred and admitted to specialised palliative care. Quality of care was maintained in some but not all areas. In future pandemics or other crises to the health-care system, it is important for healthcare professionals to implement workflows assuring patients with life-threatening illnesses in need of specialised palliative care are identified and referred. Also, specialised palliative care services should maintain the same level of systematic identification of palliative care needs in order to provide the best possible care.

Acknowledgements We would like to thank the Danish Palliative Care Database for access to the data used in the article and all the specialised palliative care units in Denmark that delivered data to the Danish Palliative Care Database.

Contributors All authors made substantial contributions to the design, analysis of data, critical revision and approved the publication, participating sufficiently to take responsibility for the content of this article. MBH is the guarantor of this article and responsible for the overall content of the article.

Funding The study was funded by the Danish Cancer Society Scientific Committee (grant number R321-A17417), and the Danish regions.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the Central Denmark Region's register of research projects (journal number 1-16-02-381-20). Patient consent is not required by Danish law for studies based on routinely collected register data.

Provenance and peer review Not commissioned; internally peer reviewed.

Data availability statement Data may be obtained from a third party and are not publicly available.

This article is made freely available for personal use in accordance with BMJ's website terms and conditions for the duration of the covid-19 pandemic or until otherwise determined by BMJ. You may download and print the article for any lawful, non-commercial purpose (including text and data mining) provided that all copyright notices and trade marks are retained.

ORCID iD

Maiken Bang Bang Hansen <http://orcid.org/0000-0001-9611-8131>

REFERENCES

- 1 WHO. Who coronavirus (COVID-19). Dashboard: WHO; 2023. Available: <https://covid19.who.int/>
- 2 Coste J, Quinquis L, Audureau E, *et al.* Non response, incomplete and inconsistent responses to self-administered health-related quality of life measures in the general population: patterns, determinants and impact on the validity of estimates—a population-based study in France using the mos SF-36. *Health Qual Life Outcomes* 2013;11:44.
- 3 Johannesen TB, Smeland S, Aaserud S, *et al.* COVID-19 in cancer patients, risk factors for disease and adverse outcome, a population-based study from Norway. *Front Oncol* 2021;11:652535:652535..

- 4 Mansfield KE, Mathur R, Tazare J, *et al*. Indirect acute effects of the COVID-19 pandemic on physical and mental health in the UK: a population-based study. *Lancet Digit Health* 2021;3:S2589-7500(21)00017-0:e217-30..
- 5 Bodilsen J, Nielsen PB, Søgaard M, *et al*. Hospital admission and mortality rates for non-covid diseases in Denmark during covid-19 pandemic: nationwide population based cohort study. *BMJ* 2021;373:n1135:1135..
- 6 Skovlund CW, Friis S, Christensen J, *et al*. Drop in cancer diagnosis during the COVID-19 pandemic in Denmark: assessment of impact during 2020. *Acta Oncologica* 2022;61:658-61.
- 7 Sleeman KE, Cripps RL, Murtagh FEM, *et al*. Change in activity of palliative care services during the covid-19 pandemic: a multinational survey (covpall). *J Palliat Med* 2022;25:465-71.
- 8 Hetherington L, Johnston B, Kotronoulas G, *et al*. COVID-19 and hospital palliative care-a service evaluation exploring the symptoms and outcomes of 186 patients and the impact of the pandemic on specialist Hospital palliative care. *Palliat Med* 2020;34:1256-62.
- 9 Tummolo AM, Ricciotti MA, Meloni E, *et al*. Impact of the covid-19 pandemic on palliative care provision by a hospital-based unit: results from an observational study. *Ig Sanita Pubbl* 2022;80:124-35.
- 10 Wentlandt K, Cook R, Morgan M, *et al*. Palliative care in Toronto during the COVID-19 pandemic. *Journal of Pain and Symptom Management* 2021;62:615-8.
- 11 Choung RS, Locke GR III, Schleck CD, *et al*. A low response rate does not necessarily indicate non-response bias in gastroenterology survey research: a population-based study. *J Public Health* 2013;21:87-95.
- 12 Groenvold M, Adersen M, Hansen MB. Danish palliative care database. *Clin Epidemiol* 2016;8:637-43.
- 13 Schmidt M, Pedersen L, Sørensen HT. The Danish civil registration system as a tool in epidemiology. *Eur J Epidemiol* 2014;29:541-9.
- 14 Schmidt M, Schmidt SAJ, Adelborg K, *et al*. The Danish health care system and epidemiological research: from health care contacts to database records. *Clin Epidemiol* 2019;11:563-91.
- 15 Pedersen CB. The Danish civil registration system. *Scand J Public Health* 2011;39(7 Suppl):22-5.
- 16 Jensen VM, Rasmussen AW. Danish education registers. *Scand J Public Health* 2011;39(7 Suppl):91-4.
- 17 Groenvold M, Petersen MAa, Aaronson NK, *et al*. The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *European Journal of Cancer* 2006;42:55-64.
- 18 Nyblom S, Benkel I, Carling L, *et al*. Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialised palliative home care: a qualitative study. *BMJ Open* 2022;12:e059577.
- 19 Wind G, Vedsegaard HW, Marsaa K, *et al*. The significance of the COVID-19 pandemic for family caregivers of non-COVID-19 patients in need of specialized palliative care at home: a qualitative study. *Int J Qual Stud Health Well-Being* 2022;17:2113021.
- 20 Mathews J, Hannon B, Zimmermann C. Models of integration of specialized palliative care with oncology. *Curr Treat Options Oncol* 2021;22:44.
- 21 Levoy K, Foxwell A, Rosa WE. Palliative care delivery changes during COVID-19 and enduring implications in oncology nursing: a rapid review. *Curr Opin Support Palliat Care* 2022;16:94-101.
- 22 Rigsrevisionen F. Beretning Om adgangen TIL specialiseret palliation. København, Denmark, 2020.
- 23 Sundhedsstyrelsen. Anbefalinger for den palliative indsats. 2011:1-90.
- 24 Sundhedsstyrelsen. Anbefalinger for den palliative indsats. 2017:1-54.
- 25 Hansen MB, Adersen M, Groenvold M. Dansk palliativ database: årsrapport 2020. 2021: 1-71.
- 26 Adersen M, Thygesen LC, Jensen AB, *et al*. Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish palliative care database (DPD). *BMC Palliat Care* 2017;16:21.
- 27 Adersen M, Thygesen LC, Neergaard MA, *et al*. Cohabitation status influenced admittance to specialized palliative care for cancer patients: a nationwide study from the Danish palliative care database. *J Palliat Med* 2019;22:164-72.
- 28 Adersen M, Thygesen LC, Neergaard MA, *et al*. Higher admittance to specialized palliative care for patients with high education and income: a nationwide register-based study. *J Palliat Med* 2023;26:57-66.
- 29 Strömrgren AS, Groenvold M, Pedersen L, *et al*. Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. *Journal of Pain and Symptom Management* 2001;21:189-96.
- 30 Strömrgren AS, Groenvold M, Sorensen A, *et al*. Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating. *Acta Anaesthesiol Scand* 2001;45:1080-5.
- 31 Laugsand EA, Sprangers MAG, Bjordal K, *et al*. Health care providers underestimate symptom intensities of cancer patients: a multicenter European study. *Health Qual Life Outcomes* 2010;8:104.
- 32 Stephens RJ, Hopwood P, Girling DJ, *et al*. Randomized trials with quality of life endpoints: are doctors' ratings of patients' physical symptoms interchangeable with patients' self-ratings? *Qual Life Res* 1997;6:225-36.
- 33 Petersen MA, Larsen H, Pedersen L, *et al*. Assessing health-related quality of life in palliative care: comparing patient and physician assessments. *European Journal of Cancer* 2006;42:1159-66.
- 34 Eurostat. International standard classification of education (ISCED). 2021. Available: [https://ec.europa.eu/eurostat/statistics-explained/index.php?title=International_Standard_Classification_of_Education_\(ISCED\)#Background](https://ec.europa.eu/eurostat/statistics-explained/index.php?title=International_Standard_Classification_of_Education_(ISCED)#Background)