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

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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, 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.

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.

INTRODUCTION

The COVID-19 pandemic was a global health crisis, which caused close to 7 million deaths worldwide. 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
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.

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.

The number of hospital admissions for all major COVID-19 conditions decreased during national lockdowns. Similarly, a study from Denmark showed that the number of hospital admissions for all major non-COVID-19 conditions decreased during national lockdowns. Furthermore, the number of patients diagnosed with cancer in Denmark was lower during the COVID-19 pandemic in 2020 compared with the year before. 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 previously but only a few quantitative studies have investigated changes in palliative care provision during the COVID-19 pandemic. These studies have shown conflicting results with a reduction in workload and an increase in the availability of palliative care beds in Toronto, an increase in the number of hospitalised patients at a single hospital in Italy, an unchanged number of patients admitted to five hospitals in Scotland as well as no changes in waiting times for admission in Italy but shorter waiting times in Scotland.

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 inhabitants 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. The population-based administrative and health registries in Denmark can be linked through the unique personal identifier.

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. 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 System and educational level from the Population’s Education Register.

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) 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
Original research

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).

<table>
<thead>
<tr>
<th></th>
<th>All</th>
<th>Pre-pandemic</th>
<th>During COVID-19</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Total</td>
<td>69 696</td>
<td>100.0</td>
<td>37 194</td>
</tr>
<tr>
<td>SPC service the patient was referred to</td>
<td></td>
<td></td>
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<tr>
<td>Palliative care team</td>
<td>35 837</td>
<td>51.4</td>
<td>19 685</td>
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<td>Hospice</td>
<td>33 859</td>
<td>48.6</td>
<td>17 509</td>
</tr>
<tr>
<td>Fulfilled criteria for admittance</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>53 021</td>
<td>76.1</td>
<td>28 552</td>
</tr>
<tr>
<td>No</td>
<td>16 675</td>
<td>23.9</td>
<td>8642</td>
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<tr>
<td>Admitted to SPC</td>
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<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>43 030</td>
<td>61.7</td>
<td>23 139</td>
</tr>
<tr>
<td>No</td>
<td>26 666</td>
<td>38.3</td>
<td>14 055</td>
</tr>
<tr>
<td>Gender</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>35 039</td>
<td>50.3</td>
<td>18 769</td>
</tr>
<tr>
<td>Male</td>
<td>34 657</td>
<td>49.6</td>
<td>18 425</td>
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<td>Age groups</td>
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<tr>
<td>18–49 years</td>
<td>3367</td>
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<td>1842</td>
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<tr>
<td>50–59 years</td>
<td>7284</td>
<td>10.5</td>
<td>3930</td>
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<tr>
<td>60–69 years</td>
<td>16 622</td>
<td>23.9</td>
<td>9130</td>
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<tr>
<td>70–79 years</td>
<td>25 438</td>
<td>36.5</td>
<td>13 409</td>
</tr>
<tr>
<td>80 years or older</td>
<td>16 985</td>
<td>24.3</td>
<td>8883</td>
</tr>
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<td>Range (years)</td>
<td>18–109</td>
<td></td>
<td>18–109</td>
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<tr>
<td>Mean (years)</td>
<td>71.1</td>
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<td>70.9</td>
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<td>Median (years)</td>
<td>73.0</td>
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<td>Ethnicity</td>
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<tr>
<td>Danish origin</td>
<td>65 899</td>
<td>94.8</td>
<td>35 275</td>
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<tr>
<td>Western immigrant</td>
<td>1739</td>
<td>2.5</td>
<td>889</td>
</tr>
<tr>
<td>Non-western immigrant</td>
<td>1886</td>
<td>2.7</td>
<td>939</td>
</tr>
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<td>Educational level*</td>
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<td></td>
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<tr>
<td>Low (ISCED level 1–2)</td>
<td>23 829</td>
<td>34.9</td>
<td>13 044</td>
</tr>
<tr>
<td>Medium (ISCED level 3–5)</td>
<td>30 928</td>
<td>54.4</td>
<td>16 271</td>
</tr>
<tr>
<td>High (ISCED level 6–8)</td>
<td>13 444</td>
<td>19.7</td>
<td>7053</td>
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<tr>
<td>Cohabitation status</td>
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<td></td>
<td></td>
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<tr>
<td>Living alone</td>
<td>32 054</td>
<td>46.1</td>
<td>16 919</td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>37 470</td>
<td>53.9</td>
<td>20 184</td>
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<tr>
<td>Region</td>
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<td>Northern Denmark Region</td>
<td>7524</td>
<td>10.8</td>
<td>4192</td>
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<td>Central Denmark Region</td>
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<td>22.8</td>
<td>8212</td>
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<tr>
<td>Southern Denmark Region</td>
<td>14 160</td>
<td>20.4</td>
<td>7364</td>
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<td>Capital region</td>
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<td>29.2</td>
<td>10 943</td>
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<tr>
<td>Region Zealand</td>
<td>11 613</td>
<td>16.7</td>
<td>6323</td>
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<tr>
<td>Diagnosis</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>62 483</td>
<td>89.7</td>
<td>33 483</td>
</tr>
<tr>
<td>Non-cancer</td>
<td>7204</td>
<td>10.3</td>
<td>3707</td>
</tr>
</tbody>
</table>

*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...
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. 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. In the pandemic, due to visitor restrictions and social distancing, physical consultations were to some extent replaced by telemedicine, and thus
more contacts between palliative care providers and patients due to fewer referrals during the COVID-19 pandemic, which is in line with findings from a study in the Toronto area where most palliative care services experienced a reduced workload and more available palliative care beds during the pandemic, while contrasting other studies from Italy, UK, and Scotland that reported an increase in admissions and experienced business as usual or no change in palliative care provision.

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)

<table>
<thead>
<tr>
<th>Quality indicators</th>
<th>Pre-pandemic</th>
<th>During COVID-19</th>
<th>OR (95% CI) for fulfilling quality indicators during COVID-19 vs pre-pandemic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted when criteria for admittance were fulfilled</td>
<td>28 552</td>
<td>24 469</td>
<td>1.02 (0.97–1.06)</td>
</tr>
<tr>
<td>≤10 days of waiting from referral to admittance</td>
<td>23 139</td>
<td>19 891</td>
<td>1.39 (1.33–1.46)</td>
</tr>
<tr>
<td>Admitted who answered the QLQ-C15-PAL questionnaire at admittance</td>
<td>23 139</td>
<td>19 891</td>
<td>0.88 (0.84–0.91)</td>
</tr>
<tr>
<td>Admitted who were discussed on multidisciplinary conference</td>
<td>23 139</td>
<td>19 891</td>
<td>0.93 (0.89–0.97)</td>
</tr>
</tbody>
</table>

*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.
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 assure that patients’ symptoms are not overlooked19–30 and symptom severity is not underestimated.31–33

The lower probability of being discussed at a multidisciplinary 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 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 healthcare 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.

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REFERENCES

Original research


