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Were clinical routines for good end-of-life care maintained in hospitals and nursing homes during the first three months of the outbreak of COVID-19? A national register study

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Abstract

Context

Although the COVID-19 pandemic might affect important clinical routines, few studies have focused on the maintenance of good quality in end-of-life care.

Objectives

The objective was to examine whether adherence to clinical routines for good end-of-life care differed for deaths due to COVID-19 compared to a reference cohort from 2019, and whether they differed between nursing homes and hospitals.

Methods

Data about five items reflecting clinical routines for persons who died an expected death from COVID-19 during the first three months of the pandemic (March-May 2020) were collected from the Swedish Register of Palliative Care. The items were compared between the COVID-19 group and the reference cohort, and between the nursing home and hospital COVID-19 deaths.

Results

1316 expected deaths were identified in nursing homes and 685 in hospitals. Four of the five items differed for total COVID-19 group compared to the reference cohort: fewer were examined by a physician during the last days before death, pain and oral health were less likely to be assessed, and fewer had had a specialised palliative care team consultation ($p < .0001$, respectively). Assessment of symptoms other than pain did not differ significantly. The five items differed between the nursing homes and hospitals in the COVID-19 group, most notably regarding the proportion of persons examined by a physician during the last days (nursing homes – 18%, hospitals – 100%).

Conclusion

This national register study shows that several clinical routines for end-of-life care did not meet the usual standards during the first three months of the COVID-19 pandemic in Sweden. Higher preparedness for and monitoring of end-of-life care quality should be integrated into future pandemic plans.

Key message

This national register study shows that clinical routines for end-of-life care in nursing homes and hospitals did not meet the usual standards during the first three months of the COVID-19 pandemic in Sweden.

Key words

COVID-19, palliative care, end-of-life care, nursing homes, hospitals

Running title

Clinical routines for end-of-life care during COVID-19

Introduction

During the emerging COVID-19 pandemic, hospitals are struggling to provide healthcare to patients in intensive care units and in regular wards. It has also been apparent that a large proportion of all deaths due to COVID-19 has occurred in a population of frail elderly people in nursing homes, both in Sweden (1) and internationally (2, 3). While many countries, including Sweden, have focused on not overwhelming the hospitals with patients in order to avoid preventable deaths and morbidity, there has been little focus on how to achieve good quality in end-of-life care for patients dying from COVID-19.

Providing end-of-life care to persons with COVID-19 is challenging, with difficulties in the involvement of family members due to the risk of spreading the disease, lack of personal protective equipment, and a strained healthcare system. Little is known about the influence of these factors on quality of end-of-life care. On the whole, end-of-life care quality for persons dying from COVID-19 is sparsely described.

The availability of specialised palliative care services varies between different cities and regions in Sweden (4). Older persons with multiple diseases have less access to specialised palliative care than younger people (5). Under normal circumstances, the vast majority of elderly people in Sweden die in nursing homes and acute hospital wards (5). This was even accentuated during the first three months of the pandemic. According to the National Board of Health and Welfare in Sweden, up until 8th June, 2020, 4567 people had died of COVID-19. Of these, 2095 (46%) died in a hospital, 2194 (48%) in nursing homes, and 278 (6%) in another or unknown place (1). There are known differences in adherence to clinical routines in end-of-life care between different places of death in Sweden. Specialised palliative care has better adherence compared to nursing homes and nursing homes have better adherence compared to hospitals (6).

In Sweden, municipalities are responsible for nursing homes and caring for the elderly outside hospitals. The workforce in nursing homes consists mainly of assistant nurses, but registered nurses, occupational therapists and physiotherapists are also employed (7). Physicians are not employed by nursing homes; instead, the regions are responsible for allocating medical recourses, e.g. physicians (7). There are no national statistics on time allocated to physicians at nursing homes [e-mail communication with Henrik Lysell, National Board of Health and Welfare]. A nursing home typically has 20-60 residents divided into several wards. To the best of our knowledge, such a nursing home in Sweden typically receives regular visits from a physician 4 hours per week. The physicians are also available by telephone and for acute visits.

Symptom control is central to end-of-life care and is included in the definition of palliative care from the World Health Organization (8). Structured assessments of pain and other symptoms are routines considered essential for symptom control (9). Structural assessment of oral health is also considered good end-of-life care (10). There is little in the literature about oral health problems during end of life due to COVID-19, but it is well-known that oral health problems are common during end of life in other diseases. Oral health should be assessed to find treatable problems, such as dry mouth and oral candidiasis (11). This is especially important in oxygen treatment, which tends to dry out the oral cavity. Commonly used drugs during end-of-life care, such as opioids and glycopyrronium, can also cause xerostomia.

When a person being cared for has symptoms or other problems that are not fully alleviated or solved, consultation with specialised palliative care teams can be an alternative to referral to specialised palliative care wards (12, 13). The extent of specialised palliative care involvement for COVID-19 patients is not known.

The objective of this study was to examine whether adherence to clinical routines for good end-of-life care differed for deaths due to COVID-19 compared to a reference cohort from 2019, and whether they differed between nursing homes and hospitals.

Methods

Data about end-of-life care for persons with COVID-19 during the first three months of the pandemic were collected from the Swedish Register of Palliative Care (SRPC), a national quality register that collects data through an online end-of-life questionnaire (ELQ) from healthcare units (i.e. hospitals, nursing homes, palliative care units and primary health). The ELQ is answered by healthcare staff online, in most cases by a registered nurse or a doctor, after the death of a patient (14). For all reported deaths, demographic data and data on diagnoses are collected, whereas the whole ELQ is only completed when death was expected, based on the disease trajectory. The SRPC data collection process was developed during a validation process using medical record data (15, 16) and by feedback from healthcare staff and carers for the elderly. The SRPC data have previously been used for descriptive studies in end-of-life care for patients with cancer (17), cardiovascular diseases (18), lung diseases (19), stroke (20), dementia (21), end stage kidney disease (22), neurological diseases (23), and in a nursing home setting (24).

Data from the SRPC was collected by the authors on 4th June, 2020, at 10 AM local time. All cases reported to have died expectedly in hospitals and nursing homes due to COVID-19 in Sweden, and reported by the healthcare to the SRPC up until this time, were included in the study. These cases include persons assessed by the healthcare staff reporting to the SRPC to have died from both

laboratory and clinically verified COVID-19. Information was collected about age, gender, and five end-of-life care items reflecting care routines. The previous validity study of the ELQ showed a level of agreement between ELQ registrations from the SRPC and data collected from the medical records of above 0.7 for the items used in this study (15). ELQ reliability has not been examined.

All expected deaths in nursing homes and hospitals reported to the SRPC during 2019 (all causes of death) were used as a reference cohort. Data from all persons reported to the SRPC to have died expectedly from causes other than COVID-19 during 2020 up until data collection were also collected for comparison. The total coverage of deceased persons in the SRPC (all diagnoses) is estimated to be 52% in hospitals and 76% in nursing homes (5).

The combined group of persons deceased from COVID-19 in nursing homes and hospitals was compared with the reference cohort. The distribution of men/women was analysed with a Chi-square test and age distribution was analysed with a t-test. The Chi-square test was used to compare the following five items reflecting care routines: whether the patient was examined by a physician during the last days in life, whether pain was assessed and documented during the last week of life, whether symptoms other than pain were assessed during the last week of life, whether oral health was assessed during the last week of life, and whether specialised palliative care was consulted. These analyses only included “Yes” and “No” answers. P values below .05 were considered significant. When the Chi-square test was not applicable, Fisher’s exact test was used.

A subgroup analysis of the COVID-19 group was conducted. The same analysis process as that described above was used to compare the group of residents deceased from COVID-19 in nursing homes with the group of persons deceased from COVID-19 in hospitals. In addition, the five items were compared between the COVID-19 nursing home subgroup and the subgroup of the reference cohort from 2019 that died in nursing homes, and between the COVID-19 hospital group and the subgroup of the reference cohort who died in hospitals. Nursing home residents who died in hospitals were included in the hospital subgroup.

The five items examined can be answered with “Don’t know” in the ELQ, and these answers were excluded from the main analysis. The Chi-square was used to compare cases with “Don’t know” answers separately per item between the COVID-19 group and the reference cohort.

The working procedure and study design were examined by the Ethical Review Board in Sweden, and they had no ethical objections to the study (registration number 2020-02186). The study was conducted with consent from the SRPC management group.

Results

A total of 862 persons who died from COVID-19 in hospitals and 1518 in nursing homes were identified. Of these, 685 and 1316 deaths, respectively, were reported as expected and thus included in further analysis. The first death was reported to the register during the first week in March. Mean age in the combined group was 84.6 years (ranging from 0 to 107), with 86.5 (52-106) in the nursing home group and 81.1 (0-107) in the hospital group ($p < .0001$). In the nursing home group, 733 (55.7%) were women and the corresponding figure in the hospital group was 272 (39.7%) ($p < .0001$).

The reference cohort consisted of 33,447 persons who died expectedly during 2019, of whom 18,850 (56.4%) were women. Mean age was 84.5 (ranging from 1 to 111) and 20 individuals (.06%) were under 18 years of age. There was a larger proportion of women ($p <.0001$) and a higher proportion of hospital deaths ($p < .0001$) in the cohort from 2019 compared to the COVID-19 group, while the age distribution did not differ significantly (Table 1).

During 2019, 189 nursing home residents were admitted to and died within specialised palliative care and reported to the SRPC. Total deaths within the specialised palliative care were 10,089 in 2019. These deaths within the specialised palliative care are not included in the reference population.

A total of 14,000 persons who had died expectedly from causes other than COVID-19 were identified. There was a larger proportion of women ($p < .0001$) and lower proportion of hospital deaths ($p < .01$) compared to the COVID-19 cases, while the age distribution did not differ significantly (Table 2).

Comparison between COVID-19 deaths and non-COVID-19 deaths

Compared to the reference cohort from 2019, four of the five end-of-life care routines examined were conducted less often in the total COVID-19 group: significantly fewer were examined by a physician during the last days before death, pain and oral health were less likely to be assessed, and fewer had had a specialised palliative care team consultation, $p < .0001$ in all four comparisons (Table 3). The same four end-of-life care routines seldom less often conducted in the total COVID-19 group compared to the non-COVID-19 deaths from 2020, $p < .0001$ in all four comparisons (Table 3).

Comparison between COVID-19 deaths occurring in nursing homes and hospitals

The number of persons examined by a physician during the last days of life was the item that differed most between the subgroups. Of the expected deaths included occurring in nursing homes, 216 (17.8%) residents were examined by a physician during the last day or days, compared to 671 (99.8%) of the hospital deaths, $p < .0001$ (Table 4). 625 (51.6%) persons in nursing homes were last examined by a physician a month or more before death.

Assessment of pain was more frequently done in nursing homes than in hospitals, $p < .0001$. Symptoms other than pain assessed during the last week of life were also more common in the nursing home group compared to hospitals, $p < .0001$. Oral health assessment was more common in hospitals, $p < .0001$, as were consultation with specialised palliative care teams, $p < .01$ (Table 4).

When comparing the nursing home subgroup to the nursing home deaths from 2019 in the reference population, significantly fewer were examined by a physician during the last days before death, pain and oral health were less likely to be assessed, and fewer had had a specialised palliative care team consultation, $p < .0001$ in all four comparisons (Table 5). When comparing the hospital subgroup to the part of the reference population from 2019 who died in hospitals, the only difference seen was that fewer in the COVID-19 group had a specialised palliative care team consulted, < .0001 (Table 6).

"Don't know"-answers

All items used from the ELQ in this study can be answered by "Don't know". Compared to the 2019 reference cohort, it was more common in the total COVID-19 group not to know when the patient was last examined by a physician, whether pain was assessed and documented during the last week of life, and whether oral health was assessed during the last week of life, $p < .0001$, < .01 and < .0001, respectively (Table 7).

Discussion

This national register study shows that clinical routines for end-of-life care did not meet the usual standards during the first three months (March to May 2020) of the COVID-19 pandemic in Sweden. We found that quality assurance routines were less often performed compared to the reference cohort from 2019 and to non-COVID-19 deaths from 2020. The lower quality was mainly seen in nursing homes, which also had a higher proportion of deaths compared to the reference cohort. The Swedish healthcare system is reported to have been struggling, but not overwhelmed in the way that has been reported from the hardest hit areas in the world. According to the daily reports on workdays from the National Board of Health and Welfare during the study period, nationally there was remaining capacity to admit more patient into intensive care in Sweden even if it might sometimes require patients to be relocated. The capacity to handle end-of-life care has neither been the focus of the debate, nor been monitored by the authorities. Since this exceptional burden on the healthcare is seen worldwide, it is likely that there has been a similar pattern of lower quality of end-of-life care in many countries during the COVID-19 pandemic. A better preparedness for good quality end-of-life care should be part of future pandemic plans. It has previously been proposed that preparedness for palliative care should be part of an influenza pandemic plan (2). It is not known how the quality of the end-of-life care has been affected in parts of the world with lower COVID-19 burden.

The most marked difference between the COVID-19 group and the reference cohort was the lower number of persons that had been examined by a physician during the last days of life. In the subgroup analysis, this finding was shown to be attributed to the nursing home group alone. Fewer than one fifth of the residents who died an expected death from COVID-19 in nursing homes had met with their physician during the last days, while all but one hospital patient did. Notable is also the marked but lower difference regarding physician visits the last days between hospital patients (99%) and nursing home residents before the pandemic (44%). This should be seen in the framework of Swedish nursing homes with a large responsibility for the registered nurses working in this context.

However, this study did not examine to what extent physicians were consulted via telephone or video, which could have been substantially higher. The National Board of Health and Welfare has written guidelines for care in nursing homes during the COVID-19 pandemic in an attempt to avoid spreading the disease. They state that the medical assessment does not always have to be bedside but can be done on the basis of personal knowledge. In those cases it should be done in consultation with the nurse in charge, together with distance monitoring of vital parameters, a symptom survey and possibly video visits (25). On the other hand, the National Board of Health and Welfare also states that the physician responsible should consult at least one other licenced healthcare

practitioner before deciding to withhold or discontinue potentially life-sustaining treatment (26). Another explanation for the lack of physicians' bedside assessment could be the Swedish system with different employers for the physicians and the nursing home staff, which hampers coordination. It seems as this construction did not enable a system flexible enough to adapt fully to the pandemic.

COVID-19 is a new disease with large variations in symptom severity, even among the most vulnerable group of elderly people with concomitant diseases. When it comes to deciding who would benefit from more intense medical interventions in the nursing home or a transfer to hospital, an examination by a physician would often be required to make the best possible decision. An exception can be made if the physician knows the resident well and there is a plan for such a situation in beforehand that has been discussed with the resident and the family. decisions about the most appropriate level of care. Based on knowledge of concomitant diseases, it is not necessarily always better for an elderly person at a nursing home with an acute disease to be hospitalised, if the situation can be managed at the nursing home. For example, there is evidence that people with dementia can experience a range of adverse outcomes when hospitalised (27). An increase in the physical presence of physicians at nursing homes would probably enhance the chances of making optimal decisions. Even before the pandemic, there was ongoing work in Europe to implement palliative care for the growing group of care home residents (28).

Pain and oral health were less likely to be assessed during the pandemic compared to 2019. We also found that three of the items were more often answered with "Don't know". The ELQ is answered retrospectively. The answers are either based on the reporting nurse or physician lacking personal knowledge of the deceased person's end-of-life care, and/or documentation in the medical records. When the reporting physician or nurse has not been part of the end-of-life care, lack of documentation prevents proper answers when reporting to the SRPC. Therefore, the increase in "Don't know answers for the COVID-19 cases compared to the reference cohort probably reflects less documentation in the medical records than normal. This shows that normal clinical routines for end-of-life care partly failed. Possible explanations include high workload on healthcare staff with less time for proper assessment and documentation, healthcare staff sick leave and more inexperienced temporary staff. Access to written guidelines on symptom assessment and nursing outcomes could possibly improve the situation.

A positive finding is that nursing homes were able to perform assessments of pain and other symptoms to a relatively high extent despite the very strenuous situation with lack of personal protective equipment and high levels of sick leave. Nursing homes and hospitals should also be acknowledged for continuing to report to the SRPC during the pandemic, a prerequisite for

healthcare monitoring of end-of-life care given, but which can divert time from other duties. We believe that this reflects the healthcare staff's willingness to provide good care and maintain high quality at a difficult time. Hospitals did not lower their quality to the same extent as nursing homes, but nursing homes had better adherence than hospitals to clinical routines regarding end-of-life care before the pandemic (6).

Given that less than 3% of all patients in this study had a specialised palliative care team involved, one might wonder whether more involvement from specialised palliative care teams would have increased the overall care quality. To compare, in a study by Evans et al, 37% of critically ill general surgery patients received a palliative care consultation and this was considered underutilisation (29). The availability to, and organisation of, specialised palliative care varies in Sweden (4), and the pre-pandemic referral of nursing home residents to specialised palliative care was uncommon. In Sweden, all healthcare is expected to be able to carry out general end-of-life care and that involvement of specialised palliative care is recommended when this level of care is insufficient. No national summary of the workload of the palliative care services during the pandemic is available. In the Stockholm Region, the region in Sweden with the highest number of deaths in absolute numbers, the nursing homes were actively encouraged to consult specialised palliative care teams. Still, our results suggest that these teams were underutilised. During the SARS epidemic, hospice wards in Taiwan showed a reduction in the number of occupied beds (30). It is possible that a similar tendency exists during this pandemic.

Based on the findings of this study, one factor to enhance the quality of end-of-life care during the pandemic could be a higher involvement of physicians for residents with COVID-19 in nursing homes, as well as an increased awareness on end-of-life issues in healthcare in general.

Strengths and limitations

Data were collected from a large national database which had been developed and validated before the pandemic. This enabled monitoring of previously defined clinical end-of-life care routines and comparison with a large reference cohort.

The coverage of the SRPC is not complete, i.e. all deaths in the country are not reported to the register. It is likely that the healthcare units reporting to the SRPC are more motivated to monitor and maintain their end-of-life care quality, resulting in a selection bias. This bias is also present in the reference cohort. The SRPC reports that they see a tendency towards longer response times for healthcare units with many COVD-19 cases, so there may be a selection bias towards less strained healthcare units in the sample.

COVID-19 as cause of death reported to the SRPC has not yet been verified via the Causes of Death Register at the National Board of Health and Welfare, which is a limitation. As the register is not collecting detailed data on unexpected deaths, we cannot comment on that subgroup.

Conclusion

This national register study shows that several clinical routines for end-of-life care in nursing homes and hospitals did not meet the usual standards during the first three months of the COVID-19 pandemic in Sweden. Physicians were only present bedside for a small proportion of the persons dying an expected death in the nursing homes. More involvement of physicians for residents with COVID-19 in nursing homes could be one factor for improvement. Higher preparedness for and monitoring of end-of-life care quality should be integrated in future pandemic plans.

Disclosures and acknowledgments

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Table 1. Age, gender, and place of death for all deaths from COVID-19 compared to a reference cohort from 2019. Only including expected deaths

	Deaths from COVID-19 (n=2 001)	Reference cohort from year 2019 (n=33 447)	p value
Age, mean (range)	84.6 (0 – 107)	84.5 (1 – 111)	N.S.
Female sex (%)	1 005 (50.2%)	18 850 (56.4%)	<.0001
Hospital deaths (%)	685 (34.2%)	21 298 (52.2%)	<.0001

Table 2. Age, gender, and place of death for all deaths from COVID-19 compared to non-COVID-19 deaths from 2020. Only including expected deaths

	Deaths from COVID-19 (n=2 001)	Non-COVID-19 deaths from 2020 (n=14 000)	p value
Age, mean (range)	84.6 (0 – 107)	84.8 (0 – 212)	N.S.
Female sex (%)	1 005 (50.2%)	7 834 (56.0%)	<.0001
Hospital deaths (%)	685 (34.2%)	4 350 (31.1%)	<.01

Table 3. Comparison between deaths from COVID-19 and reference cohort from 2019, and between deaths from COVID-19 and non-COVID deaths from 2020, for the five examined items. Only including expected deaths

	All COVID-19 deaths[a]	Reference cohort from 2019[a]	p value (COVID-19 deaths compared to reference cohort from 2019)	Non-COVID-19 deaths from 2020[a]	p value (COVID-19 deaths compared to non-COVID deaths from 2020)
Examined by a physician during the last days before death	887/1884 (47.1%)	20997/32814 (64.0%)	<.0001	7641/13623 (56.1%)	<.0001
Pain assessed and documented during the last week of life	729/1816 (40.1%)	14751/31016 (47.6%)	<.0001	6504/13049 (49.8%)	<.0001
Symptoms other than pain assessed during the last week of life	499/1756 (28.4%)	8419/29813 (28.2%)	N.S.	3914/12623 (31.0%)	N.S.
Oral health assessed during the last week of life	873/1746 (50.0%)	18183/30505 (59.6%)	<.0001	7767/12785 (60.8%)	<.0001
Specialised palliative care team consulted	56/1903 (2.9%)	2346/31959 (7.3%)	<.0001	882/13449 (6.6%)	<.0001

[a] "Don't know" was an answering option for all items. Therefore, numbers do not sum to group totals.

Table 4. Comparison between deaths from COVID-19 in nursing homes and hospitals for the five examined items. Only including expected deaths

	Nursing homes[a]	Hospitals[a]	p value
Examined by a physician during the last days before death	216/1212 (17.8%)	671/672 (99.8%)	<.0001
Pain assessed and documented during the last week of life	540/1216 (44.4%)	189/600 (31.5%)	<.0001
Symptoms other than pain assessed during the last week of life	378/1054 (35.9%)	121/564 (21.5%)	<.0001
Oral health assessed during the last week of life	519/1141 (45.5%)	354/605 (58.5%)	<.0001
Specialised palliative care team consulted	27/1287 (1.2%)	29/616 (4.7%)	<.01

[a] "Don't know" was an answering option for all items. Therefore, numbers do not sum to group totals.

Table 5. Comparison between nursing home deaths from COVID-19 and nursing home part of the reference cohort from 2019, for the five examined items. Only including expected deaths

	Nursing home deaths from COVID-19 (n)[a]	Nursing home part of reference cohort from year 2019 (n)[a]	p value
Examined by a physician during the last days before death	216/1212 (17.8%)	9083/20 808 (43.7%)	<.0001
Pain assessed and documented during the last week of life	540/1216 (44.4%)	11 138/20 338 (54.8%)	<.0001
Symptoms other than pain assessed during the last week of life	378/1054 (35.9%)	6578/19 924 (33.0%)	N.S.
Oral health assessed during the last week of life	519/1141 (45.5%)	11 789/19 585 (60.2%)	<.0001
Specialised palliative care team consulted	27/1287 (1.2%)	1291/20 982 (6.2%)	<.0001

[a] "Don't know" was an answering option for all items. Therefore, numbers do not sum to group totals.

Table 6. Comparison between hospital deaths from COVID-19 and hospital home part of the reference cohort from 2019, for the five examined items. Only including expected deaths

	Hospital deaths from COVID-19 (n)[a]	Hospital part of reference cohort from year 2019 (n) [a]	p value
Examined by a physician during the last days before death	671/672 (99.8%)	11 913/12 005 (99.2%)	N.S.[b]
Pain assessed and documented during the last week of life	189/600 (31.5%)	3612/10 678 (33.8%)	N.S.
Symptoms other than pain assessed during the last week of life	121/564 (21.5%)	1840/9889 (18.6%)	N.S.
Oral health assessed during the last week of life	354/605 (58.5%)	6394/10 921 (58.5%)	N.S.
Specialised palliative care team consulted	29/616 (4.7%)	1055/10 977 (9.6%)	<.0001

[a] "Don't know" was an answering option for all items. Therefore, numbers do not sum to group totals.

[b] Calculated with Fisher's exact test

Table 7. Number of cases per item that was answered with "Don't know" for all deaths from COVID-19 in nursing homes compared to a reference cohort from 2019. Only including expected deaths

	Deaths from COVID-19 (n)	Reference cohort from year 2019 (n)	p value
Last time examined by a physician	117/2001 (5.8%)	633/33447 (1.9%)	<.0001
Pain assessed and documented during the last week of life	185/2001 (9.2%)	2431/33447 (7.3%)	<.01
Symptoms other than pain assessed during the last week of life	245/2001 (12.2)	3634/33447 (10.9%)	N.S.
Oral health assessed during the last week of life	255/2001 (12.7)	2942/33447 (8.8%)	<.0001
Specialised palliative care team consulted	98/2001 (4.9%)	1488/33447 (4.4%)	N.S.