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COVID-19 Content

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

Lisa Martinsson, MD, PhD, Peter Strang, MD, PhD, Jonas Bergström, MD, and Staffan Lundström, MD, PhD
Department of Radiation Sciences (L.M.), Umeå university, Umeå; Department of Oncology-Pathology (P.S., S.L.), Karolinska Institutet, Stockholm; Stockholm and R & D Department (P.S., S.L.), Stockholms Sjukhem Foundation, Stockholm; and Palliative Care Unit Stockholms, Sjukhem Foundation (J.B.), Stockholm, Sweden

Abstract

Context. Although the coronavirus disease 2019 (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 because of COVID-19 compared with 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. About 1316 expected deaths were identified in nursing homes and 685 in hospitals. Four of the five items differed for total COVID-19 group compared with 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 a specialized palliative care team consultation ($P < 0.0001$, 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. J Pain Symptom Manage 2021;61:e11−e19.

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

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 coronavirus disease 2019 pandemic in Sweden.

Address correspondence to: Lisa Martinsson, MD, PhD, Department of radiation sciences, Umeå university, SE-90187 Umeå, Sweden. E-mail: lisa.martinsson@umu.se

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Introduction

During the emerging coronavirus disease 2019 (COVID-19) pandemic, hospitals are struggling to provide health care to patients in intensive care units and regular wards. It has also been apparent that a large proportion of all deaths because of COVID-19 has occurred in a population of frail elderly people in nursing homes, both in Sweden[1] and internationally.[2,3] Although many countries, including Sweden, have focused on not overwhelming the hospitals with patients 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 because of the risk of spreading the disease, lack of personal protective equipment, and a strained health care 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 specialized palliative care services varies between different cities and regions in Sweden.[4] Older persons with multiple diseases have less access to specialized 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 June 8, 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. Specialized palliative care has better adherence compared with nursing homes, and nursing homes have better adherence compared with 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, for example, physicians.[7] There are no national statistics on time allocated to physicians at nursing homes (electronic 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 four hours per week. The physicians are also available by telephone and for acute visits.

Symptom control is central to end-of-life care and 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 because of 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 specialized palliative care teams can be an alternative to referral to specialized palliative care wards.[12,13] The extent of specialized 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 because of COVID-19 compared with 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 health care units (i.e., hospitals, nursing homes, palliative care units, and primary health). The ELQ is answered by health care 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 health care 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 were collected by the authors on June 4, 2020, at 10 AM local time. All cases reported

to have died expectedly in hospitals and nursing homes because of COVID-19 in Sweden, and reported by the health care to the SRPC up until this time, were included in the study. These cases include persons assessed by the health care staff reporting to the SRPC to have died of 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 was 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 were compared with the reference cohort. The distribution of men/women was analyzed with a Chi-squared test, and age distribution was analyzed with a t-test. The Chi-squared 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 specialized palliative care was consulted. These analyses only included yes and no answers. *P*-values below 0.05 were considered significant. When the Chi-squared 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 previously 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 who died in nursing homes as well as 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 do not know in the ELQ, and these answers were excluded from the main analysis. The Chi-squared test was used to compare cases with do not 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 of 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 ($P < 0.0001$). In the nursing home group, 733 (55.7%) were women, and the corresponding figure in the hospital group was 272 (39.7%) ($P < 0.0001$).

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 (0.06%) were younger than 18 years. There was a larger proportion of women ($P < 0.0001$) and a higher proportion of hospital deaths ($P < 0.0001$) in the cohort from 2019 compared with the COVID-19 group, whereas the age distribution did not differ significantly (Table 1).

During 2019, 189 nursing home residents were admitted to and died within specialized palliative care and reported to the SRPC. Total deaths within

Table 1
Age, Gender, and Place of Death for All Deaths From COVID-19 Compared With a Reference Cohort From 2019

	Deaths From COVID-19 ($n = 2001$)	Reference Cohort From Year 2019 ($n = 33,447$)	*P*
Age, mean (range)	84.6 (0−107)	84.5 (1−111)	NS
Female gender, *n* (%)	1005 (50.2)	18,850 (56.4)	<0.0001
Hospital deaths, *n* (%)	685 (34.2)	21,298 (52.2)	<0.0001

COVID-19 = coronavirus disease 2019; NS = not significant.
Only including expected deaths.

Table 2
Age, Gender, and Place of Death for All Deaths From COVID-19 Compared With Non-COVID-19 Deaths From 2020

	Deaths From COVID-19 ($n = 2001$)	Non-COVID-19 Deaths From 2020 ($n = 14,000$)	P
Age, mean (range)	84.6 (0–107)	84.8 (0–212)	NS
Female gender, n (%)	1005 (50.2)	7834 (56.0)	<0.0001
Hospital deaths, n (%)	685 (34.2)	4350 (31.1)	<0.01

COVID-19 = coronavirus disease 2019; NS = not significant.
Only including expected deaths.

the specialized palliative care were 10,089 in 2019. These deaths within the specialized 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 ($P < 0.0001$) and lower proportion of hospital deaths ($P < 0.01$) compared with the COVID-19 cases, whereas the age distribution did not differ significantly (Table 2).

Comparison Between COVID-19 Deaths and Non-COVID-19 Deaths

Compared with 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 a specialized palliative care team consultation; $P < 0.0001$ 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 with the non-COVID-19 deaths from 2020, $P < 0.0001$ 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 with 671 (99.8%) of the hospital deaths ($P < 0.0001$) (Table 4). About 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 ($P < 0.0001$). Symptoms other than pain assessed during the last week of life were also more common in the nursing home group compared with hospitals ($P < 0.0001$). Oral health assessment was more common in hospitals ($P < 0.0001$), as were consultation with specialized palliative care teams ($P < 0.01$) (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 a specialized palliative care team consultation ($P < 0.0001$) 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 specialized palliative care team consulted ($P < 0.0001$) (Table 6).

Do Not Know Answers

All items used from the ELQ in this study can be answered by do not know. Compared with 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 ($P < 0.0001$, $P < 0.01$, and $P < 0.0001$, 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–May 2020) of the COVID-19 pandemic in Sweden. We found that quality assurance routines were less often performed compared with 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 with the reference cohort. The Swedish health care 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 patients into intensive care in Sweden even if it might sometimes require patients to be relocated. The capacity to handle end-of-life care has been neither the

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

	All COVID-19 Deaths[a]	Reference Cohort From 2019[a]	*P* (COVID-19 Deaths Compared With Reference Cohort From 2019)	Non-COVID-19 Deaths From 2020[a]	*P* (COVID-19 Deaths Compared With Non-COVID Deaths From 2020)
	n (%)			*n* (%)	
Examined by a physician during the last days before death	887/1884 (47.1)	20,997/32,814 (64.0)	<0.0001	7641/13,623 (56.1)	<0.0001
Pain assessed and documented during the last week of life	729/1816 (40.1)	14,751/31,016 (47.6)	<0.0001	6504/13,049 (49.8)	<0.0001
Symptoms other than pain assessed during the last week of life	499/1756 (28.4)	8419/29,813 (28.2)	NS	3914/12,623 (31.0)	NS
Oral health assessed during the last week of life	873/1746 (50.0)	18,183/30,505 (59.6)	<0.0001	7767/12,785 (60.8)	<0.0001
Specialized palliative care team consulted	56/1903 (2.9)	2346/31,959 (7.3)	<0.0001	882/13,449 (6.6)	<0.0001

COVID-19 = coronavirus disease 2019; NS = not significant.
[a]Only including expected deaths.
[b]Do not know was an answering option for all items. Therefore, numbers do not sum to group totals.

focus of the debate nor monitored by the authorities. Because this exceptional burden on the health care 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 who 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, whereas all but one hospital patient did. Notable is also the marked but lower difference regarding physician visits during 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 licensed health care 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

Table 4
Comparison Between Deaths From COVID-19 in Nursing Homes and Hospitals for the Five Examined Items

	Nursing Homes, *n* (%)[a]	Hospitals, *n* (%)[a]	*P*
Examined by a physician during the last days before death	216/1212 (17.8)	671/672 (99.8)	<0.0001
Pain assessed and documented during the last week of life	540/1216 (44.4)	189/600 (31.5)	<0.0001
Symptoms other than pain assessed during the last week of life	378/1054 (35.9)	121/564 (21.5)	<0.0001
Oral health assessed during the last week of life	519/1141 (45.5)	354/605 (58.5)	<0.0001
Specialized palliative care team consulted	27/1287 (1.2)	29/616 (4.7)	<0.01

Only including expected deaths.
COVID-19 = coronavirus disease 2019.
[a]Do not 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

	Nursing Home Deaths From COVID-19[a]	Nursing Home Part of Reference Cohort From Year 2019[a]	
	n (%)		*P*
Examined by a physician during the last days before death	216/1212 (17.8)	9083/20,808 (43.7)	<0.0001
Pain assessed and documented during the last week of life	540/1216 (44.4)	11,138/20,338 (54.8)	<0.0001
Symptoms other than pain assessed during the last week of life	378/1054 (35.9)	6578/19,924 (33.0)	NS
Oral health assessed during the last week of life	519/1141 (45.5)	11,789/19,585 (60.2)	<0.0001
Specialized palliative care team consulted	27/1287 (1.2)	1291/20,982 (6.2)	<0.0001

COVID-19 = coronavirus disease 2019; NS = not significant.
Only including expected deaths.
[a]Do not 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

	Hospital Deaths From COVID-19[a]	Hospital Part of Reference Cohort From Year 2019[a]	
	n (%)		*P*
Examined by a physician during the last days before death	671/672 (99.8)	11,913/12,005 (99.2)	NS[b]
Pain assessed and documented during the last week of life	189/600 (31.5)	3612/10,678 (33.8)	NS
Symptoms other than pain assessed during the last week of life	121/564 (21.5)	1840/9889 (18.6)	NS
Oral health assessed during the last week of life	354/605 (58.5)	6394/10,921 (58.5)	NS
Specialized palliative care team consulted	29/616 (4.7)	1055/10,977 (9.6)	<0.0001

COVID-19 = coronavirus disease 2019; NS = not significant.
Only including expected deaths.
[a]Do not 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 Do Not Know for All Deaths From COVID-19 in Nursing Homes Compared With a Reference Cohort From 2019

	Deaths From COVID-19, *n* (%)	Reference Cohort From Year 2019, *n* (%)	*P*
Last time examined by a physician	117/2001 (5.8)	633/33,447 (1.9)	<0.0001
Pain assessed and documented during the last week of life	185/2001 (9.2)	2431/33,447 (7.3)	<0.01
Symptoms other than pain assessed during the last week of life	245/2001 (12.2)	3634/33,447 (10.9)	NS
Oral health assessed during the last week of life	255/2001 (12.7)	2942/33,447 (8.8)	<0.0001
Specialized palliative care team consulted	98/2001 (4.9)	1488/33,447 (4.4)	NS

COVID-19 = coronavirus disease 2019; NS = not significant.
Only including expected deaths.

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 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 hospitalized, 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 hospitalized.[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 with 2019. We also found that three of the items were more often answered with do not know. The ELQ is answered retrospectively. The answers are based on either the reporting nurse or the 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 do not know answers for the COVID-19 cases compared with 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 health care staff with less time for proper assessment and documentation, health care 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 health care monitoring of end-of-life care given, but which can divert time from other duties. We believe that this reflects the health care 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 specialized palliative care team involved, one might wonder whether more involvement from specialized palliative care teams would have increased the overall care quality. To compare, in a study by Evans et al.,[29] 37% of critically ill general surgery patients received a palliative care consultation, and this was considered underutilization. The availability to, and organization of, specialized palliative care varies in Sweden,[4] and the prepandemic referral of nursing home residents to specialized palliative care was uncommon. In Sweden, all health cares are expected to be able to carry out general end-of-life care and that involvement of specialized 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 specialized

palliative care teams. Still, our results suggest that these teams were underused. During the severe acute respiratory syndrome 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 health care 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, that is, all deaths in the country are not reported to the register. It is likely that the health care 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 toward longer response times for health care units with many COVID-19 cases, so there may be a selection bias toward less strained health care 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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