

Symptom Relief Is Possible in Elderly Dying COVID-19 Patients: A National Register Study

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Abstract

Background: Increasing numbers of people dying from COVID-19 are reported, but data are lacking on the way they die.

Objective: To study symptoms and symptom relief during the last week of life, comparing nursing homes with hospitals.

Design: The Swedish Register of Palliative Care with national coverage was used. Breakthrough symptoms were registered as Yes/No. Symptom relief was recorded on a 3-grade scale as *complete—partial—no relief*. All deaths in COVID-19 were contrasted to deaths in a reference population (deaths 2019). Deaths at nursing homes were compared with deaths in hospitals.

Setting and Subjects: All deaths in hospitals or nursing homes ($n=490$) were analyzed. Deaths in other settings (specialized palliative care wards [$n=11$], in palliative home care [$n=2$], or in their own homes [$n=8$]) were excluded ($n=21$). Only patients with expected deaths ($n=390$) were entered in the final analysis.

Results: Breathlessness as a breakthrough symptom was more common in COVID-19 patients than in the 2019 reference population ($p<0.001$) and relief of breathlessness, as well as anxiety, delirium, and death rattles was less successful in COVID-19 patients ($p<0.05$ to $p<0.01$ in different comparisons). Patients were older in nursing homes than in hospitals (86.6 years vs. 80.9 years, $p<0.001$) and more often female (48% vs. 34%, $p<0.001$). Breakthrough of breathlessness was much more frequently reported in hospital settings than in nursing homes, 73% versus 35% ($p<0.0001$), and complete relief was more rarely possible in hospitals, 20% versus 42% ($p<0.01$). The proportion of partial relief+complete relief was comparable, 92% versus 95% (ns). Also, anxiety and pain were more often completely relieved in nursing homes ($p<0.01$ in both comparisons).

Conclusion: The lower symptom prevalence in nursing homes may be explained by elderly frail residents dying already in the first phase of the COVID-19 disease, before acute respiratory distress syndrome develops.

Keywords: breathlessness; COVID-19; elderly patient population; hospital patients; nursing home patients; symptom relief

Introduction

THE COVID-19 PANDEMIC is creating fear not only among the public but also in health care staff, due to the alarming reports on large groups of dying patients with acute respiratory distress syndrome (ARDS). Symptoms at admission to hospitals are frequently reported,^{1–3} but little is written about *symptom relief* in the dying patients.

In studies so far, including a recent study on 5700 patients hospitalized in the New York City area,² focus has mainly been on describing initial symptoms such as fever and cough, risk

factors, including comorbidities, laboratory findings, and prognostic factors. With few exceptions, reports on deaths have been from hospitals and/or ICUs, where multivariable analyses have highlighted independent risk factors such as age, comorbidities, organ failure, elevated markers, for example, d-dimer.³ These data are important, especially for the development of COVID-19 care. However, from the individual, dying patient's point of view, symptom prevalence and the possibility to relieve distressing symptoms are even more important.

In hospital and ICU studies, the mean age is relatively low. In two Chinese studies, the median age at admission to

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Accepted July 23, 2020.

hospital and ICU were 56³ and 47 years,¹ respectively. In the recent New York study, median age at admission was 63 years.² However, emerging statistics show that when all deaths in COVID-19 are considered, the mean age is substantially higher. Recent data indicate that about 40–50% of deaths occur among elderly people in nursing homes,⁴ but little is known about the way they die. In Sweden, people residing at nursing homes are frail and elderly, with several chronic comorbidities and with a high need of daily support and attendance, whereas palliative care patients with complex symptoms and substantial *medical* needs are cared for in specialized palliative care services. Thus, Swedish nursing homes constitute a form of long-term facilities for persons needing much help with activities of daily living functions. Moreover, 60–70% are estimated to suffer from cognitive failure or are diagnosed with dementia. For this reason, Swedish nursing homes are very different from other accommodations for retired persons, for example, “65+ accommodations” for healthy elderly people who like the possibility to have access to social activities, communal restaurant facilities, and common social areas in adjunction to their apartment.

In 2019, the median period of care from admission to death was <2 years in nursing homes and the median age at death was about 86 years. Generally, an admission to a Swedish nursing home is approved only if six to eight home help visits per day are not enough for a person to reside in his or her own home. For this reason, the population dying due to COVID-19 at hospitals and nursing homes are different at least regarding age and frailty. Moreover, Swedish hospitals are mainly staffed with physicians and registered nurses, whereas the great majority of the staff in nursing homes (>90%) constitute of assistant nurses and only to a minor part of registered nurses. Physicians are not directly employed by the nursing homes but constitute a (scarce) resource provided by the county councils.

In Swedish health care, there have been efforts to safeguard the quality of care for dying people, which have been previously described.⁵ The Swedish Register of Palliative Care (SRPC), a nationwide quality register of end-of-life (EOL) care, encourages all county councils and municipalities in Sweden to retrospectively complete a questionnaire about EOL care with focus on last week of life. The register provides EOL data and allows comparisons across different care settings. So far, 30 peer-reviewed publications based on SRPC data have been published. Owing to a reasonable coverage (~60% of all deaths in the country), some of the questions retrieved from the SRPC have even become national quality indicators for a good death in Sweden, adopted by the National Board of Health and Welfare.⁶

Aims

The aim of the study was to examine symptom control data on all reported COVID-19-related deaths in hospitals and nursing homes (data set retrieved April 24, 2020), using the SRPC, a validated national quality register.^{5,7} A further aim was to compare occurrence of breakthrough symptoms and relief of symptoms in hospitals and nursing homes, assuming a null hypothesis (H_0), that is, no differences between the groups.

Patients and Methods

The Methods section and the Results are reported based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) criteria.⁸

Study design

We conducted a descriptive national registry data study using the SRPC to characterize all registered patients who died in COVID-19 either in nursing homes or in hospitals and we contrasted them to a year cohort before the pandemic (all deaths registered in the SRPC in 2019).

Population

Study population. All registered patients who have died from COVID-19 as a cause of death (diagnosis made by respective physician) since March 01, 2020 (data retrieved April 24, 2020), $n=511$. An absolute majority ($n=490$) died either in nursing homes ($n=290$) or in hospitals ($n=200$). For this reason, others ($n=21$) were excluded to achieve as homogeneous groups as possible. Those excluded ($n=21$) died in specialized palliative care wards ($n=11$), in palliative home care ($n=2$) or in their own homes ($n=8$).

Of the remaining 490 patients (253 residents in the nursing homes and 237 patients in the hospitals), death was expected in 390 (79.6%) cases. For these persons, there are detailed data on symptoms and symptom control during the last week of life.

Reference population. All registered deaths in SRPC in 2019, $n=53,345$.

Variables and data source

The SRPC encourages health care to report all deaths, regardless of care form, cause, or trajectory. For all deaths, demographic data, place of death, cause of death, and so on are collected. A specific question is phrased in the following way: “Based on the disease trajectory, was the death expected?” For those patients where death, according to the staff, was expected ($n=390$), an anonymized end-of-life questionnaire (ELQ) with more detailed questions is available, with a total of 24 EOL questions, as well as information about the unit/service and the person(s) who completed the questionnaire. The ELQ is answered retrospectively online, as soon as possible after the patient’s death, by the nurse and/or the physician responsible for EOL care. The ELQ reflects symptoms during the last week of life. Only data documented in the patient records are considered.

The questionnaire contains data, for example, about demographics and the occurrence of breakthrough symptoms (regardless of intensity), and, when symptoms are present, also the degree of symptom relief during the last week of life. In this study, we focused on breathlessness, anxiety, delirium, death rattles, and pain, as well as on medication used to relieve symptoms. Prescriptions of parenteral nutrition/fluids were also analyzed.

Rating scales

For most items, the answers are provided in a Yes—No—Do not know format, for example, for the occurrence of symptoms. As regards relief of symptoms (e.g., relief of breathlessness), there are three alternatives: completely relieved—partly relieved—not relieved at all.

Selection bias

The SRPC is not mandatory, although its use is strongly encouraged. In total, ~60% of all deaths are reported, from

all services where death occur. In a year cohort, the coverage is highest for specialized palliative care (>90%), followed by nursing homes (75%), and hospitals (50%). Therefore, the proportion of deaths in nursing homes versus hospitals does not reflect the absolute number of deaths (as somewhat fewer acute hospital departments report data).

Study size

The study covers all reported COVID-19-related deaths (total cohort) until April 24, 2020.

Statistical methods, missing data

Fisher's (two-tailed) exact test and (two-tailed) *t* test were used. For most questions, the option "Do not know" is an alternative. Statistics were calculated on definite answers (Yes–No; or in the case of symptom relief: Complete—Partial—No relief). "Do not know" answers were analyzed separately (Table 3).

Ethics

According to the Swedish law, ethical review is only required for data on living persons. Therefore, according to the Swedish law (2003:460), fourth paragraph (2003:615), studies encom-

passing data on deceased persons with encrypted id-numbers (as in this case) are not subject to the Swedish law. The same law also waives the requirement to obtain informal consent.

Results

COVID-19 versus reference population

In Table 1, demographics and symptom data are compared between 390 expected deaths in COVID-19 and all registered deaths during 2019. Compared with 2019 population data, the deceased COVID-19 patients were older ($p < 0.05$), and a lower proportion were female ($p < 0.05$). Based on the disease trajectory, death was less often expected, according to the staff: 80% among the COVID-19 deaths, compared with 90% in the 2019 population ($p < 0.001$). Significantly more COVID-19 patients, 48% versus 25%, experienced a breakthrough of breathlessness during the last week of life ($p < 0.001$). Breathlessness was completely relieved in 31% and partly or completely alleviated in 94% (31% +63%) of the COVID-19 patients, which was lower than for the reference population (Table 1). This means that breathlessness remained unrelieved in 6% in the COVID-19 patients, compared with 3% in the 2019 reference population. The populations also differed in relief of anxiety, delirium, death rattles, and pain (Table 1).

TABLE 1. A COMPARISON BETWEEN PATIENTS DECEASED IN COVID-19 AND ALL REGISTERED EXPECTED DEATHS DURING 2019^a (N=390 OUT OF 490 COVID-19 DEATHS AND 46,698 OF 53,345 DEATHS IN 2019)

Characteristics	COVID-19 patients in hospitals and nursing homes, expected deaths	All registered expected deaths in 2019	p ^b
Patients (expected/all deaths), N	390/490	46,698/53,345	
Age, mean (range)	84.7 (47–104)	82.0 (0–111)	<0.001
Female sex (%)	189/390 (48)	25,437/46,698 (54)	<0.05
Breathlessness (%) ^{c,d}	173/362 (48)	11,271/44,419 (25)	<0.001
Complete relief	53/173 (31)	4715/11,271 (42)	<0.01
Partial+complete relief ^e	162/173 (94)	10,923/11,271 (97)	<0.02
Anxiety (%) ^{c,d}	197/348 (57)	24,356/42,539 (57)	NS
Complete relief	131/197 (66)	17,858/24,356 (73)	<0.05
Partial+complete relief ^e	194/197 (98)	24,215/24,356 (99)	NS
Delirium (%) ^{c,d}	77/329 (23)	10,817/41,120 (26)	NS
Complete relief	13/77 (17)	2952/10,817 (27)	<0.05
Partial+complete relief ^e	60/77 (78)	8565/10,817 (79)	NS
Death rattles (%) ^{c,d}	178/368 (48)	23,466/45,737 (51)	NS
Complete relief	72/178 (40)	11,335/23,466 (48)	<0.05
Partial+complete relief ^e	171/178 (96)	22,401/23,466 (95)	NS
Pain (%) ^{c,d}	210/368 (57)	33,500/45,157 (74)	<0.001
Complete relief	162/210 (77)	26,827/33,500 (80)	NS
Partial+complete relief ^e	209/210 (100)	33409/33500 (100)	NS
p.r.n. prescriptions strong opioid (%) ^c	376/390 (96)	44,474/46,557 (96)	NS
p.r.n. prescriptions tranquilizer (%) ^c	376/390 (96)	43,963/46,492 (95)	NS
p.r.n. prescriptions antiemetic (%) ^c	357/390 (92)	41,334/4,630,889	NS
p.r.n. prescriptions antimuscarinic (%) ^c	370/390 (95)	43,440/46,477 (93)	NS
Parenteral/enteral fluids, nutrition during the last day of life (%) ^c	57/379 (15)	5100/46,404 (11)	<0.05

^a"I do not know" was an option for most questions. Therefore, numbers may not sum to group totals.

^bp Values indicate differences between COVID-19 patients and all registered deaths in 2019. $p < 0.05$ was considered statistically significant.

^cData based on those whose death was expected, that is, 390 versus 46,698 patients.

^dThe question posed was "Did the person display breakthrough of any of the following symptoms at any time during the last week of life?" Alternatives for answers on symptom relief were "Completely," "Partially," and "Not at all."

^eFor each symptom, "Complete relief" is a subset of "Partial and complete relief."

p.r.n., as needed.

COVID-19 in nursing homes versus hospitals

Nursing homes and hospitals were contrasted in a separate analysis. Compared with patients dying at hospitals, deaths in nursing homes were more often expected, 90% versus 75% ($p < 0.001$). Those dying in nursing homes were significantly older and more often female, see Table 2. The greatest difference between the two groups was seen for breathlessness. Compared with hospitals, breathlessness occurred less often in nursing homes, 35% versus 73% ($p < 0.0001$), and complete relief was more often possible in nursing homes, 42% versus 20% ($p < 0.01$). However, partial+complete relief was possible in similar proportions, 95% and 92%, in nursing homes and hospitals, respectively (ns).

There were also differences as regards delirium (less common in nursing homes), and complete relief of anxiety and pain (more common in nursing homes), Table 2. Parenteral fluids to the dying were more often prescribed in hospitals ($p < 0.001$). For the alleviation of symptoms, there were adequate p.r.n. prescriptions in >87% of the cases, with no differences between nursing homes and hospitals, except for antiemetics that were more frequently prescribed in nursing homes ($p < 0.05$) (Table 2).

“I do not know”—answers

“I do not know”—answers were analyzed separately. In every comparison except for parenteral fluids, the proportion was significantly higher in hospitals, Table 3.

Discussion

Many of the reports, so far, are on COVID-19 patients with ARDS, struggling for their lives in respirators at ICUs. To our knowledge, this is the first systematic report on symptom prevalence and symptom relief focusing on dying patients outside ICUs.

Compared with the reference data, patients dying from COVID-19 were elderly, suffered more often from breathlessness that was difficult to completely relieve, whereas breakthrough pain was less common. Also, in general, there were more breakthrough symptoms in the COVID-19 population and the chance to symptom relief was lower.

However, the data from nursing homes with surprisingly low prevalence of symptoms—symptoms that in most cases were possible to alleviate completely or at least partially—are in contrast with anecdotal reports on agonized patients dying in ICUs. The core symptom, breathlessness, was reported in 35% in nursing homes, in great contrast to 73% at hospitals and almost in line with figures (25%) for the total cohort of all patients dying in 2019. Meanwhile, the possibility to complete relief of breathlessness was higher in nursing homes. Thus, our null hypothesis (comparable symptoms and symptom relief in dying persons regardless of services) was rejected.

A possible explanation is that these frail elderly people die early in the course, in most cases before ARDS develops. This is strongly supported by local data from nursing homes in the Stockholm region, where the median duration from first

TABLE 2. A COMPARISON BETWEEN PATIENTS DECEASED IN COVID-19 IN NURSING HOMES OR IN HOSPITALS FOR ALL REGISTERED EXPECTED DEATHS ($N = 390$)^a

Characteristics	Nursing homes	Hospitals	p ^b
Patients, <i>N</i>	253	137	
Age, mean (range)	86.6 (63–104)	80.9 (47–102)	<0.001
Female sex (%)	139/253 (55)	50/137 (36)	<0.001
Breathlessness (%) ^c	84/240 (35)	89/122 (73)	<0.001
Complete relief	35/84 (42)	18/89 (20)	<0.01
Partial+complete relief ^d	80/84 (95)	82/89 (92)	NS
Anxiety (%) ^c	131/241 (54)	66/107 (67)	NS
Complete relief	96/131 (73)	35/66 (53)	<0.01
Partial+complete relief ^d	129/131 (98)	65/66 (98)	NS
Delirium (%) ^c	38/228 (17)	39/101 (39)	<0.001
Complete relief	7/38 (18)	6/39 (15)	NS
Partial+complete relief ^d	28/38 (74)	32/39 (82)	NS
Death rattles (%) ^c	118/248 (48)	60/120 (50)	NS
Complete relief	54/118 (46)	18/60 (30)	NS (0.053)
Partial+complete relief ^d	115/118 (97)	56/60 (93)	NS
Pain (%) ^c	147/248 (59)	63/120 (53)	NS
Complete relief	122/147 (83)	40/63 (63)	<0.01
Partial+complete relief ^d	147/147 (100)	62/63 (98)	NS
p.r.n. prescriptions strong opioid (%)	243/253 (96)	133/137 (97)	NS
p.r.n. prescriptions tranquilizer (%)	242/253 (96)	134/137 (98)	NS
p.r.n. prescriptions antiemetic (%)	238/253 (94)	119/137 (87)	<0.05
p.r.n. prescriptions antimuscarinic (%)	243/253 (96)	127/137 (93)	NS
Parenteral/enteral fluids, nutrition during the last day of life (%)	16/249 (6)	41/130 (32)	<0.001

^a“I do not know” was an option for most questions. Therefore, numbers may not sum to group totals. The “I do not know” answers are analyzed in Table 3.

^b*p* Values indicate differences between nursing homes and hospitals. $p < 0.05$ was considered statistically significant.

^cThe question posed was “Did the person display breakthrough of any of the following symptoms at any time during the last week of life?” Alternatives for answers on symptom relief were “Completely,” “Partially,” and “Not at all.”

^dFor each symptom, “Complete relief” is a subset of “Partial and complete relief.”

TABLE 3. PROPORTION OF “I DO NOT KNOW”—RESPONSES

Characteristics	Nursing homes	Hospitals	p ^a
Death was expected (%)	10/290 (3.4)	17/200 (8.5)	<0.05
Breathlessness (%)	13/253 (5.1)	15/137 (10.9)	<0.05
Anxiety (%)	12/253 (4.7)	30/137 (10.9)	<0.001
Delirium (%)	25/253 (9.9)	36/137 (28.5)	<0.001
Death rattles (%)	5/253 (2.0)	17/137 (12.4)	<0.001
Pain (%)	5/253 (2.0)	17/137 (12.4)	<0.001
Parenteral/enteral fluids, nutrition during the last day of life (%)	4/253 (1.6%)	7/137 (5.1%)	NS

A comparison between patients deceased in COVID-19 in nursing homes or in hospitals.

^ap Values indicate differences between nursing homes and hospitals. $p < 0.05$ was considered statistically significant.

symptom to death is only six days (mean 6.2) (personal communication), which is much shorter than for patients dying in ICUs. In comparison, Guan et al. report that the median hospital stay (which was preceded by days with initial symptoms) for the severely ill patients in Wuhan, China, was 13 days.¹ If our tentative explanation holds true, admission of *dying* frail elderly to hospitals/ICUs for high-flow oxygen and/or for mechanic ventilator treatment will possibly prolong the dying process, eventually with more severe symptoms at the very EOL and increased suffering.

From a clinical point of view, the possibility to relieve symptoms is as central as the very occurrence of symptoms. In Swedish health care, the specialized palliative care units have propagated for evidence-based use of “four essential palliative drugs,” needed for quality care of the dying.⁹ Such palliative guidelines have been disseminated both to nursing home services and to acute hospitals. As seen from the data, these drugs are prescribed to a high extent, both in nursing homes and in acute hospitals.

The proportion of “I do not know” responses is of certain interest (Table 3). In this study, for all comparisons, the proportions were higher in hospitals. This may be due to several reasons. The ELQ is supposed to be retrospectively completed, based on data from the medical records. Insufficient documentation may result in several “I do not know.” Another reason might be that the person completing the questionnaire was not highly involved in the actual patient care. However, it cannot be out ruled that the differences also may reflect the actual interest in symptoms and symptom relief. If symptom control and support is the main focus of care in people dying from COVID-19, the proportions of “I do not know” should be low for central symptoms such as breathlessness and anxiety.

Strengths and limitations

One strength of this study is that it is, to best of our knowledge, the first study that actually report data on how people are dying, on symptom prevalence and on symptom relief. In a PubMed search (April 24, 2020) where COVID-19 were combined with “palliative,” “symptom” and “dying” only one article was identified.¹⁰ This article is about sug-

gestions on how palliative care principles can be applied in the emergency departments, but not on symptoms or on palliation of symptoms. The only article we identified as regards skilled nursing facilities focused on detection of COVID-19 and initial symptoms in nursing home residents.¹¹

Another strength is that we have access to national data from a validated quality register that has been used as a source for 30 previous peer-reviewed articles.

Although the proportions of deaths reported to the SRPC is acceptable (60%), we have no data on the others, which is a limitation. Another limitation is that we have relatively more registrations from nursing homes than from acute hospitals. A third limitation is that the ELQ is constructed in a way that full data are only reported on patients with expected deaths. This means, that we do not have data on the last day(s) of life for those persons where death was unexpected. A final limitation is that staffing in nursing homes and hospitals are different on a group level, with more registered nurses in hospitals. However, all ELQ were completed by registered nurses or (to a less degree) by physicians, regardless of place of care.

Conclusions

When studying all deaths related to COVID-19 and reported to the SRPC, a picture emerges of persons in a relatively high age, certainly different from the reports on patients dying at ICUs. The central and feared symptom, breathlessness, is much less frequent in nursing homes and when present, it is easier to relieve. Our data indicate that these differences are due to differences between the groups. Persons residing in Swedish nursing homes are elderly and frail and die much earlier in the course, before severe respiratory distress develops.

Acknowledgments

We thank the Swedish Register of Palliative Care (SRPC) for generously providing us with data for the study. Stockholm Sjukhem Foundation is acknowledged for providing good facilities in their Research & Development unit.

Funding information

This study was supported by the Stockholm Sjukhem Foundation’s Jubilee Fund.

Author Disclosure Statement

No competing financial interests exist.

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