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Brief Report

COVID-19: Symptoms in Dying Residents of Nursing Homes and in Those Admitted to Hospitals

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Abstract

Objective: To compare symptom prevalence and relief in residents who died in nursing homes with residents who were acutely referred to hospitals.
Design: Data on symptoms during the last week of life from the Swedish Register of Palliative Care (SRPC).
Setting and Subjects: Nursing homes ($n = 1903$ deaths) and hospitals in Sweden ($n = 202$ nursing home residents who were admitted to hospital before death). Data were retrieved on August 24, 2020.
Results: Residents who died in hospitals had more breakthrough symptoms of breathlessness (60% vs. 31%, $p < 0.0001$) and delirium (41% vs. 25%, $p < 0.0001$) than those who died in nursing homes. When symptoms were present, complete symptom relief was seen less often in hospitals compared with nursing homes (breathlessness, 28% vs. 47%, $p < 0.001$; delirium, 10% vs. 35%, $p < 0.0001$; respiratory secretions, 30% vs. 55%, $p < 0.0001$).
Conclusion: Despite access to oxygen and pharmacologic/nonpharmacologic therapies in hospitals, symptom relief in dying nursing home residents acutely admitted to hospitals was lower compared with those who died in nursing homes, possibly because of differences in patient characteristics.

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

Introduction

There have been many descriptions of the initial symptoms of the COVID-19 disease, which can be divided into systemic, respiratory, gastrointestinal, or cardiovascular categories.[1] However, there are limited data on symptoms that are present in acutely dying patients.[2] Moreover, the existing data are difficult to interpret as symptom presentation and burden depend on demographic and contextual factors; symptoms may vary greatly between a young patient with acute respiratory distress syndrome (ARDS)[3,4] or a patient in a hospital palliative care setting,[5] and an elderly nursing home resident who is already dying in the early phase of a COVID-19 infection.[6]

Early in the outbreak, most data originated from intensive care units, describing patients with severe ARDS,[3,4] and many scientists extrapolated these findings to all COVID-19 deaths, although symptom burden might differ in elderly dying persons, and may actually be milder. Aiming to examine this, we recently (2020) conducted a study where we compared 253 nursing home deaths and 137 hospital deaths at the beginning of the pandemic.[6] Surprisingly, significant breathlessness was found in 73% of patients dying in hospitals, while only in 35% of those dying in nursing homes; the proportion of patients who obtained complete relief of breathlessness was also higher in nursing homes. This seemed ambiguous, but when further examination was performed, we found that a substantial portion of nursing home residents died within the first seven to eight days of the disease—the first phase of the disease that is characterized by fever, cough, and pronounced fatigue, but not by pneumonia.

Since that publication, there have been many more deaths from COVID-19, especially in Swedish nursing homes. An ongoing debate in Sweden exists about the appropriate place of death for nursing home residents suffering from COVID-19, to best help patients avoid unnecessary suffering. With regard to breathlessness, well-documented studies and guidelines underline the benefits of nonpharmacological measures, including

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optimal positioning, opening windows, controlled breathing techniques, and maintaining calm.[7–9] When pharmacological measures are needed, opioid use is especially recommended, based on several well-performed studies.[9–11]

Still, some critics claim that dying nursing home residents should be transferred to hospital departments with access to oxygen, as they believe that oxygen treatment may cause symptoms to become milder or resolve better in acutely dying patients.

In our first publication,[6] complete data on 253 deaths in nursing homes were analyzed. In this report, access to about 2105 deaths was obtained, of which 202 were acutely admitted to hospitals where they later died. For these reasons, this study aimed to examine whether symptoms are similar in this extended data set, and whether symptoms and symptom relief were comparable in residents who died in hospitals.

Aims

Using data on nursing home residents who died in nursing homes and those transferred to hospitals, this study aimed to compare the main characteristics, central symptoms, symptom relief, and human presence in patients dying in the two health care settings.

Patients and Methods

Data source and variables

As in a recently published study from our group,[6] the validated[12,13] Swedish Register of Palliative Care (SRPC), a nationwide quality register with $\sim$60% coverage of all deaths, was used. SRPC encourages registered nurses and physicians to retrospectively register a questionnaire about end-of-life care focusing on the last week of life, save for one question about parenteral fluids during the last 24 hours of life. Significant symptoms during the last week of life, regardless of intensity, are registered in a Yes/No format. If a symptom is present, symptom relief is graded as complete relief, partial relief, or no relief. The method used is described in detail in the *Journal of Palliative Medicine*.[6] The questionnaires in the current study were completed by staff jointly in 29% of the cases and by a single employee in 71% of the cases. The responsible registrant was a registered nurse in 99.7% of the questionnaires.

Patients

All nursing home residents who died with a COVID-19 diagnosis and an expected death based on their disease trajectory (=an affirmative response to the question ''Based on the disease trajectory, was the death expected?'') ($n=1903$) were compared with those who were acutely admitted to and died in the hospitals ($n=202$). Data were retrieved on August 24, 2020. In congruence with the Public Health Agency (Folkhälsomyndigheten), any death with a COVID-19 diagnosis should be considered death from COVID-19.[14]

Statistics

T-test and chi-square tests were used.

Ethics

The study was approved by the National Ethics Authority (Etikprövningsmyndigheten, Dnr 2020-02,186).

Results

Of the 2105 deceased persons examined, 1903 nursing home residents died in their respective nursing homes, while 202 residents were admitted to hospitals where they later died. Patients admitted to hospitals were younger (83.3 years vs. 86.7 years, $p<0.00001$) and were more often men ($p<0.0001$) in comparison with nursing home resident deaths (Table 1).

The occurrence of central symptoms is compared in Table 1. Breakthroughs of breathlessness and delirium were more frequently seen in residents dying in hospitals (60% vs. 31%, $p<0.0001$ and 41% vs. 25%, $p<0.0001$, respectively). When any of the central symptoms— breathlessness, anxiety, delirium, or respiratory secretions—was present, complete relief of symptoms was achieved less frequently in residents dying in hospitals ($p<0.01$ to $p<0.0001$). Parenteral/enteral fluids during the last day of life were prescribed to a greater extent for patients in hospitals (38% vs. 6%, $p<0.0001$).

In nursing homes, at least one person was present at the time of death in 68% of the cases, compared with 57% of the cases in hospitals ($p<0.01$). Family or relatives were present in 17% of nursing home deaths, and 22% of hospital deaths, which was not statistically significant.

"Do not know"-responses

There were significant proportions of ''I do not know'' answers (Table 2) reported for central symptoms. This was more prominent in hospitals than in nursing homes in most comparisons.

Discussion

In this study, it was found that nursing home residents who were acutely admitted to and subsequently died in hospitals had more breakthrough symptoms in the form of breathlessness and delirium. When symptoms such as breathlessness, anxiety, delirium, and respiratory secretions were present, complete relief was more often achieved for patients in nursing homes. Surprisingly, there were some ''I do not know'' responses for central symptoms. In the case of agonizing symptoms such as breathlessness and anxiety, 10% and 18%, respectively, of hospital responses were ''I do not know,'' while there were less unknown responses in nursing homes (5% and 6%, respectively). The actual reason for the increased number of ''I do not know'' answers in hospitals remains unknown. A possible explanation is the larger proportion of patients with delirium, who may not have been able to describe their symptoms. Another explanation might be that in nursing homes, staff members are well acquainted with the residents, which makes it easier for them to observe the onset of new symptoms.

The most interesting finding is the higher proportion of breathlessness and lower proportion of complete symptom relief in hospital care, compared with nursing homes.

These findings can be explained in two ways. First, although oxygen, which is freely available in hospitals, plays a central role in managing hypoxia in potentially curable patients, its role in alleviating breathlessness in acutely dying patients is less defined. In contrast, nonpharmacological measures such

Table 1. A Comparison between All *Expected* Deaths in Nursing Home Residents Dying of COVID-19 ($N=1903$) and All Deaths in Those Nursing Home Residents Who Were Admitted to Hospitals and Died in Hospitals ($N=202$)

	Nursing home residents who died in nursing homes	*Nursing home residents who died in hospitals*	p[a]
Age (range)	86.7 (57–107)	83.3 (30–107)	<0.0001
Female sex (%)	819/1903 (43)	128/202 (58)	<0.0001
Symptoms and symptom relief			
Breathlessness[b] (%)	556/1811 (31)	109/182 (60)	<0.0001
Complete relief[c]	261/556 (47)	30/109 (28)	<0.001
Partial + complete relief[c]	541/556 (97)	102/109 (94)	<0.05
Anxiety[b] (%)	1015/1797 (56)	102/165 (62)	NS
Complete relief[c]	769/1015 (76%)	63/102 (62)	<0.01
Partial + complete relief[c]	1007/1015 (99)	102/102 (100)	NS
Delirium[b] (%)	423/1676 (25)	63/155 (41)	<0.0001
Complete relief[c]	148/423 (35)	6/63 (10)	<0.0001
Partial + complete relief[c]	346/423 (82)	38/63 (60)	<0.0001
Respiratory secretions[b] (%)	956/1867 (51)	97/194 (50)	NS
Complete relief[c]	530/956 (55)	29/97 (30)	<0.0001
Partial + complete relief[c]	938/956 (98)	90/97 (93)	<0.01
Fluids			
Parenteral/enteral fluids, nutrition during the last day of life (%)	116/1889 (6)	74/197 (38)	<0.00001
Human presence at death			
Someone present	1212/1793 (68)	112/196 (57)	<0.01
Family member(s) present	301/1793 (17)	43/196 (22)	NS

''I do not know'' was an option for most questions. Therefore, numbers may not sum to group totals.
[a]$p<0.05$ was considered statistically significant.
[b]The 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.''
[c]For each symptom, ''Complete relief'' is a subset of ''Partial and complete relief.''

as positioning, open windows, and pharmacological interventions in the form of low-dose opioids might be beneficial.[7,8] These measures are used in hospitals, but are also freely available in nursing homes.

Second, patients dying from COVID-19 in nursing homes are, in general, older and possibly frailer than residents admitted to hospitals. This is supported by local data in the Stockholm region, where the median duration from the first symptom to death is only a median of eight days (range 0–30 days) in nursing home residents, based on 481 deaths (consultants C. Molnar and S, Amér, pers. comm.). Those admitted to acute hospitals in this study were significantly younger and probably judged as having a chance to recover. It is also likely that they had more severe symptoms that were difficult to relieve with limited medical resources in nursing homes. Nonspecific dyspnea in dying COVID-19 patients with several comorbidities is probably much easier to relieve[7] than dyspnea in COVID-19 patients who live long enough to develop bilateral pneumonia, and, in some cases, ARDS due to a cytokine storm.[15]

Another interesting finding was that only 6% of nursing home residents had parenteral fluid treatment during their last day of life, compared with 38% of residents in hospitals. In the frail, elderly, acutely dying person, hyperhydration is a well-known risk factor for dyspnea.[16,17] Moreover, the literature suggests that artificial hydration has little to no role in

Table 2. Proportion of ''I Do Not Know''-Responses

Characteristics	*Nursing home residents who died in nursing homes*	*Nursing home residents who died in hospitals*	p[a]
Breathlessness (%)	92/1903 (4.8)	20/202 (9.9)	<0.01
Anxiety (%)	106/1903 (5.6)	37/202 (18.3)	<0.0001
Delirium (%)	227/1903 (11.9)	47/202 (23.2)	<0.0001
Respiratory secretions (%)	36/1903 (1.9)	8/202 (4.0)	NS
Parenteral/enteral fluids, nutrition during the last day of life (%)	14/1903 (0.7%)	5/202 (2.5%)	<0.05
Someone present	110/1903 (5.8)	6/202 (3.0)	NS

A comparison between nursing home residents deceased due to COVID-19 in nursing homes or in hospitals.
[a]p Values indicate differences between nursing homes and hospitals. $p<0.05$ was considered statistically significant.

alleviating symptoms during dying.[18] However, as artificial hydration might be life-saving in certain phases of a COVID-19 infection, the continued medical justification must be reviewed when a person approaches death. Hydration should be given in any case of uncertain prognosis, but carefully reviewed in the dying.[19]

A striking finding was that having someone present at the time of death was much less common than usual[20] in both settings, which was especially true for that person being a relative. This has consequences for the patient, who dies alone, and the family members who miss the last opportunity to say goodbye. Moreover, staff may experience an ethical stress when they cannot be with the dying patient to their desired extent.[21]

Strengths and limitations

To the best of our knowledge, this is the largest study on symptoms and symptom control in nursing home residents where a comparison is possible, as the same instrument and routines are used for the collection of data (SRPC) in nursing homes as well as in hospitals. Staffing differs greatly, however; in nursing homes, more than 90% of the staff are assistant nurses or may even lack formal education, whereas hospitals are to a high degree staffed by registered nurses and physicians. However, in both settings, more than 99% of the reports were completed by registered nurses, and by others in only a few cases; therefore, the figures are relatively comparable.

A limitation was that the residents were not randomly allocated to nursing homes or hospitals. As such, those acutely admitted to hospitals differed in terms of mean age and sex distribution. It is unknown whether the patient groups differed in their symptom presentation, symptom intensity, or whether there were other factors such as family requests when a decision was made to admit them to hospitals.

Conclusions

Symptom relief in dying residents was not superior in hospitals, despite access to oxygen. This is possibly explained by the fact that those residents admitted to hospitals were younger and might have suffered from more severe forms of breathlessness. Nonpharmacological and pharmacological measures, especially opioids, still constitute the mainstay in symptom relief and are available in both settings. More clinical studies are needed to elucidate the role of oxygen in breathlessness in dying patients, and also in potentially curable hypoxic patients, where oxygen might be life-saving.

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