

# Preplanned participation of paramedics in end-of-life care at home: A retrospective cohort study

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## Abstract

**Background:** Paramedics commonly face acute crises of patients in palliative care, but their involvement in end-of-life care is not planned systematically.

**Aim:** To evaluate a protocol for end-of-life care at home including pre-planned integration of paramedics and end-of-life care wards.

**Design:** Paramedic visits to patients in end-of-life care protocol were retrospectively studied.

**Setting/Participants:** All of the patients who had registered for the protocol between 1 March 2015 and 28 February 2017 in North Karelia, Finland, were included in this study.

**Results:** A total of 256 patients were registered for the protocol and 306 visits by paramedic were needed. A need for symptom control (38%) and transportation (29%) were the most common reasons for a visit. Paramedics visited 43% and 70% of the patients in areas with and without 24/7 palliative home care services, respectively ( $p < 0.001$ ); while 58% of all the visits were done outside of office hours. Problems were resolved at home in 31% of the visits. The patient was transferred to a pre-planned end-of-life care ward and to an emergency department in 48% and 16% of the cases, respectively. More patients died in end-of-life care wards in areas without (54%) than with (33%) 24/7 home care services ( $p = 0.001$ ).

**Conclusions:** Integration of paramedics into end-of-life care at home is reasonable especially in rural areas without 24/7 palliative care services and outside of office hours. The majority of patients can be managed at home or with the help of an end-of-life care ward without an emergency visit.

## Keywords

Emergency medical services, home care services, end-of-life care, palliative care, paramedics

### What is already known about the topic?

- Paramedics are involved in palliative care at home during acute crises, but their visits usually lead to transfers to emergency departments.
- Patients in end-of-life care at home in rural areas do not receive 24/7 palliative home care services like patients in urban areas.

### What this paper adds?

- A planned protocol integrating paramedics into end-of-life care at home allows a majority of the problems to be taken care of at home or by transferring the patient to a pre-planned end-of-life care ward.
- Integrated support from paramedics in end-of-life care is especially needed in rural areas without 24/7 home care services and outside of office hours.

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### Implications for practice, theory or policy?

- Paramedics should be integrated in palliative care pathways - not only as transferrers, but as a part of a palliative home care team, especially in rural areas without 24/7 palliative home care services.
- The effects on costs and on symptom control as well as the views of the patients and families regarding the paramedics' involvement in end-of-life care at home should be further assessed.

## Background

The demand for palliative care services is increasing in Europe due to an ageing population and the increase in the prevalence of non-communicable diseases.<sup>1,2</sup> European Association for Palliative Care (EAPC)<sup>3</sup> and World Health Organization (WHO)<sup>2</sup> state that people should be able to receive end-of-life care in their preferred place. Most patients in palliative care wish to be cared for and prefer to die at home.<sup>4</sup> However, the majority of patients are transferred to hospital during their last days of life and die there.<sup>5–10</sup> In rural areas and outside of office hours, it is challenging to offer end-of-life care services at home.<sup>11–14</sup>

Paramedics are commonly involved in treating patients in palliative care at home after emergency calls in health crises and exacerbation of symptoms.<sup>5,15–19</sup> Some of these issues could be taken care of at home by the paramedics and many drugs available in the ambulance could be used in symptom management.<sup>16,17</sup> However, paramedics are more familiar with life-sustaining interventions than the management of patients in end-of-life care and report receiving minimal training in palliative care.<sup>16,17,19</sup> In addition, it is often difficult to arrange for out-of-hours care.<sup>16</sup> Therefore, the majority of the patients in end-of-life care at home are still transported to hospital by paramedics after an initial evaluation.<sup>17</sup>

Improved education in palliative care and specific protocols for end-of-life care may enable paramedics to provide palliative care rather than transport patients routinely to hospital.<sup>19–24</sup> Although guidelines for symptom management are available to paramedics, ambulance services should still be integrated more precisely into the planning and providing of end-of-life care at home.<sup>15,17,23,25</sup>

An end-of-life care protocol for paramedics has been developed in North Karelia, Finland. The protocol integrates the emergency ambulance services into municipal palliative care services delivered for patients preferring to receive end-of-life care at home. We evaluated the visits of paramedics and resource usage through this protocol.

## Methods

Our research question was: What is the frequency, reasons and timing of paramedic visits via the end-of-life protocol and do these visits differ between the areas with

and without around the clock (24/7) palliative care services? Our study design was a retrospective cohort study.

### Study population and setting

All patients who had registered for the end-of-life care at home protocol for paramedics between the 1st of March 2015 and the 28th of February 2017 in North Karelia Finland were included in this retrospective cohort study. All the patients were followed until their death or the end of February 2018.

North Karelia has a population of 161,000 people living in a region that covers 22,000 km<sup>2</sup>. About 42% of the population live in the city of Joensuu. In this study, the area of Joensuu is defined as an urban area and the rest of North Karelia as rural based on the population density and availability of palliative care services. The only palliative home care team (Joensuu's hospital at home) available every day around the clock (24/7) operates in the area of the city of Joensuu (urban area), while different home care teams are available for a maximum period of 7.00 a.m. to 22.00 p.m. elsewhere (rural area). North Karelia's only secondary hospital is in Joensuu. In addition, there are also 14 community hospital wards. During the study period, about 42,000 paramedic visits were provided by North Karelia's Fire and Rescue Department, which provides ambulance medical services and paramedic services to whole population of North Karelia. This department also includes firefighting services.

### End-of-life care protocol for paramedics

In North Karelia, the end-of-life care protocol for paramedics started in 2015, with the aim of enhancing the end-of-life care delivered at home or in a nursing home on a 24/7 basis. All patients admitted to the protocol requested to be cared of at home at the end of their lives. Daily palliative care was provided by a home care team or by a nursing home staff. They informed patient details (name and address) to North Karelia's Fire and Rescue Department. Patients had a written end-of-life care plan available at their homes including information of a pre-planned end-of-life care ward where they could have been transferred. This primary end-of-life care ward was in the community hospital except in selected cases, in

which case it was in the secondary hospital. In addition, patients and their caregivers were informed about the direct phone number for the local paramedics' unit. This number was advised to be called in emergencies when the palliative home care team was unavailable to reach the patient's home fast enough, or the problem could not be solved.

The paramedics were advised to check the patient's end-of-life care plan and to manage the patient care accordingly. If the plan did not solve the problem, specific protocols were followed. These included advice for the management of symptoms (pain, respiratory distress, nausea, deterioration of consciousness, convulsions and bleeding) and guidelines including videos via mobile phones for the management of the patient-controlled analgesia device. Using the protocol guidelines, paramedics were able to provide treatment for the patient's symptoms at home, but they could consult a physician on-call or transport the patient to the preplanned end-of-life care hospital ward if needed.

Paramedics responding to the end-of-life care calls were registered nurses, who were also specialized in paramedic care. Over half of them (60%) attended a 6-h training program covering various aspects of end-of-life care. The training program and symptom management protocols were developed and implemented by two physicians with a special competency in palliative medicine (authors SL and KM of this paper), of which one had a specialty in emergency medicine (KM) as well. The protocol was planned to extend the role and scope of practice for paramedics whilst managing patients at home.

### Data collection

Data were collected during the study period from 1 March 2015 until the end of February 2018. Patient's in the protocol were identified from registry of the North Karelia's Fire and Rescue Department. Their demographic data, diagnosis, medication, caregiver and hospitalizations were achieved from electronic patient records. Time and reason for visit, symptoms, management given, physician consultation and reason and destination of a transfer were recorded from paramedics' case-forms. Time and place of death were recorded from death certificates.

### Statistical analysis

Descriptive statistics (medians, means, distributions) were used to describe the characteristics of the sample. Comparisons of the categorical variables such as the reason for paramedic visits were performed with Pearson's chi-Squared test and the continuous variables such as age of the patients or the number of paramedic visits with the Mann-Whitney U test as they were non-normally distributed. Two-sided *p*-values of less than 0.05 were accepted

**Table 1.** Patient characteristics.

Patients, <i>n</i>	252	
Age (years), median (range)	76.5	(28–102)
Male, <i>n</i> (%)	109	(43.4)
Diagnoses, <i>n</i> (%)		
Cancer	173	(68.7)
Cardiovascular diseases	30	(11.9)
Dementia	24	(9.5)
Others <sup>a</sup>	25	(9.9)
Area of living, <i>n</i> (%)		
24/7 palliative home care (urban area)	115	(45.6)
No 24/7 palliative home care (rural area)	137	(54.4)
Caregiver, <i>n</i> (%)		
Wife	71	(28.2)
Husband	46	(18.3)
Daughter/son	36	(14.4)
Staff of a nursing home	69	(27.4)
Living alone, without a designated caregiver	21	(8.3)
Other or missing	9	(3.5)
Survival (days), median (IQR) <sup>b</sup>	23	(8–61)

IQR: inter-quartile range.

<sup>a</sup>Neurodegenerative diseases (*n* = 8), liver or other gastrointestinal track diseases (*n* = 8), congenital diseases (*n* = 5), haematological diseases (*n* = 2), respiratory diseases (*n* = 1) and polyarthrosis (*n* = 1).

<sup>b</sup>Five patients were still alive at the end of the follow-up and one patient was lost from the follow up after travelling abroad.

as statistically significant. Data analyses were performed with SPSS Statistics, Version 25.

### Ethics

The study protocol was approved by the Research Ethics Committee of Northern Savo Hospital District and Kuopio University Hospital (412/2016). The study was also approved by the North Karelia's Fire and Rescue Department and the hospital district of North Karelia allowing access to the patient data. Data were later anonymized for study purposes.

## Results

### Patients

A total of 256 patients were registered for the end-of-life care protocol during the study period. Two patients dropped out from the protocol as their medical condition unexpectedly improved. One patient was never discharged from the hospital and another one was excluded due to ethical reason. Thus, the final study population consisted of 252 patients. The characteristics of the patients are shown in Table 1.

More than half of the patients lived in a rural area, and 69 patients (27%) lived in nursing homes. Cancer was the most common diagnosis with a proportion of two thirds

**Table 2.** Reasons for paramedic visits, days in hospital and place of death among patients receiving end-of-life care in the areas with 24/7 palliative home care services (urban) and without 24/7 palliative home care services (rural).

	All patients		Patients in urban areas		Patients in rural areas		<i>p</i> -value <sup>a</sup>
Patients, <i>n</i>	252		115		137		
Age (years), Median (range)	76.5	(28–102)	80.0	(29–99)	75.0	(27–102)	0.118
Paramedic visits, <i>n</i>	306		97		209		
Patients needing paramedic visits, <i>n</i> (%)	145	(57.5)	49	(42.6)	96	(70.1)	<0.001
Visits/patient, Mean (SD)	1.21	(2.31)	0.88	(1.523)	1.50	(2.776)	
Median (IQR)	1	(0–1)	0	(0–1)	1	(0–2)	<0.001
Time spent with a patient, Mean (SD)	0:45	(0:29)	0:41	(0:32)	0:46	(0:28)	
Median (IQR)	0:39	(0:26–0:58)	0:34	(0:26–0:45)	0:42	(0:26–1:02)	0.051
Reason for visit, <i>n</i> (% of visits)							
Symptom control	116	(37.9)	30	(30.9)	87	(41.6)	0.073
Pain	42	(13.7)	10	(10.3)	32	(15.4)	0.237
Respiratory symptoms	37	(12.1)	7	(7.2)	30	(14.4)	0.075
Neuropsychiatric symptoms	10	(3.3)	4	(4.1)	6	(2.9)	0.566
Other symptoms	27	(8.8)	9	(9.3)	19	(9.1)	0.858
Need for an ambulance transfer	88	(28.8)	42	(43.3)	46	(22.0)	<0.001
Deterioration of health	34	(11.1)	10	(10.3)	24	(11.5)	0.761
Deceased	22	(7.2)	5	(5.2)	17	(8.1)	0.348
Social reason <sup>b</sup>	17	(5.5)	4	(4.1)	13	(6.2)	0.456
Technical reason <sup>c</sup>	7	(2.3)	2	(2.1)	5	(2.4)	0.857
Other	10	(3.3)	4	(4.1)	17	(8.1)	0.197
Days in hospital before death							
Mean (SD)	8	(20.43)	7.31	(20.24)	8.55	(20.64)	
Median (IQR)	0	(0–6)	0	(0–4)	2	(0–7)	<0.001
Place of death, <i>n</i> (%)							
Home	60	(24.3)	33	(30.0)	27	(19.7)	0.055
Nursing home	64	(25.9)	38	(34.9)	26	(19.0)	0.005
End-of-life care ward	110	(44.5)	36	(33.0)	74	(54.0)	0.001
Secondary hospital	11	(4.5)	1	(0.9)	10	(7.3)	0.016
Other or missing	2	(0.8)	1	(0.9)	0	(0)	

<sup>a</sup>*p*-value between patients living in urban and rural areas.

<sup>b</sup>Exhaustion of the caregiver or patient's inability to manage at home.

<sup>c</sup>Problems related to medical equipment or administration of drugs or oxygen.

of the patients. The preplanned end-of-life care ward was located in a community hospital except in three patients for whom this was arranged in the secondary hospital.

By the end of the follow up, 246 (97.6%) of the patients had died. An end-of-life care ward was the most common place of death, while about a half of the patients died at home or in a nursing home (Table 2). All together 14 (5.7%) patients died in the secondary hospital (three in a preplanned end-of-care ward). 93% of the patients living in a nursing home also died there.

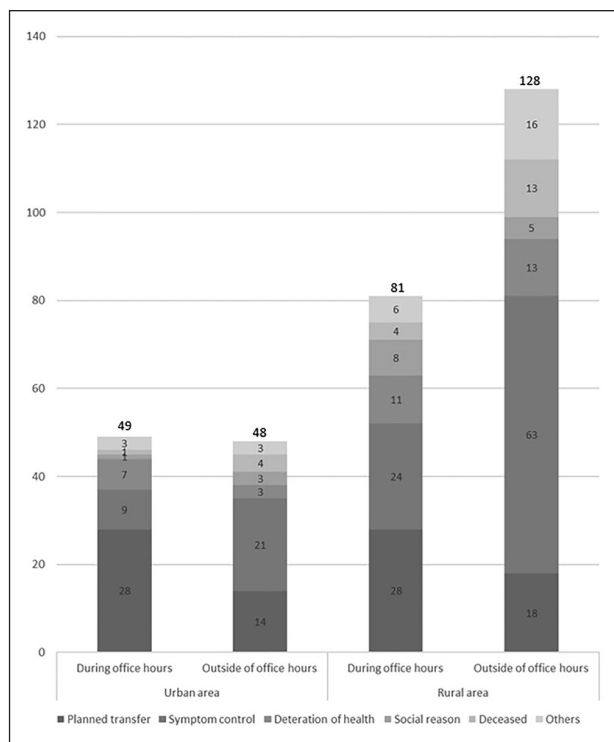
### Characteristics of the paramedic visits

The reasons for paramedic visits are shown in Table 2. The most common reason for contacting a paramedic was a need for symptom control (especially pain and respiratory symptoms). A transfer was needed after 210 (69%) of the visits (88 planned transfers), while 96 (31%) of the problems

were resolved without a transfer. A paramedic visit led to a transfer to a pre-planned ward, an emergency department or an out-patient palliative care clinic in 48%, 16% and 5% of the cases, respectively. An on-call physician was consulted during 116 visits (39%). Of the visits, 59.5% occurred at daytime (from 7 am to 3 pm), 21.6% in the evening (from 3 pm to 9 pm), and 19.0% during the night (9 pm to 7 am), while 42.4% of all visits were made during office hours (daytime from Monday to Friday excluding holidays).

### Patients in rural and urban areas

Paramedic visits were needed more often among patients living in rural area without 24/7 palliative home care services than in urban area (Table 2). The reasons and timing of the visits in rural and urban areas are shown in Figure 1. In urban and rural areas 49% and 61% of the visits occurred outside of office hours, respectively ( $p = 0.053$ ).



**Figure 1.** Reasons for paramedic visits during and outside office hours in urban and rural areas.

Almost half of the visits outside of office hours were done due to symptom control in both areas. Patients living in rural areas spent a longer time in hospitals and died more often in a pre-planned ward than those in urban areas.

### Patients with different diagnoses

Paramedic visits, the need for hospital care, and the place of death among patients with different diseases are shown in Table 3. Patients with advanced cancer or cardiovascular diseases needed most paramedic visits. Three of the 24 patients with dementia needed a total of five paramedic visits and two of these visits were made due to a planned ambulance transfer. Over half of the cancer patients died in the preplanned ward and 61% of the patients with other diagnoses died in a nursing home. Most of the patients who died at home had cancer, although the average time spent in a hospital before death was highest in cancer patients (11 days). About 11 (6%) of the cancer patients died in a secondary hospital, but none of the patients with other diagnoses did.

## Discussion

### Main findings

In this study on paramedics participating in end-of-life care at home, we showed that slightly over half of patients

needed a paramedic visit. The most common reason for a visit was a need for symptom control. Most cases were resolved at home or by transferring the patients to a pre-planned end-of-life care ward. Help from paramedics was needed more often in rural areas, where over half of the visits occurred outside of office hours.

### Role of paramedics in end-of-life care at home

Although studies on paramedics' participation in palliative care exist, the uniqueness of our study is in the description of resource usage in a planned protocol of end-of-life care at home including the systematic involvement of paramedics. Support by paramedics was notable as over half of the patients needed a paramedic visit even though 29% of the visits were due to a planned transfer. On the other hand, the total resource demand on the North Karelia's Fire and Rescue Department was minor as the proportion of the visits to the patients in end-of-life care was under 1% of all ambulance calls during the study period. The median time needed for a visit was under 1 h, about one third of the cases were resolved at home, and only one patient out of seven was transported to the emergency department. Although our study was not planned to show the cost effectiveness of the protocol, we suggest that the total usage of the health care resources was not increased but probably even reduced.

In this study, about half of the paramedic visits were needed for symptom control or general deterioration of health. Pain and dyspnoea were the most common symptoms for which help from paramedics was needed. Our results are in line with a recent study by Lord et al.<sup>17</sup> and a study by Barbera et al.,<sup>26</sup> in which respiratory problems and pain were the most common reasons for paramedic visits and for cancer patients' visits to the emergency department during their final weeks. These results from the previous and present study highlight the importance of skills in pain and dyspnoea management among paramedics participating in palliative care.

An unscheduled transfer was needed in 56% of the paramedic visits made for reasons other than a planned transfer in our study, which is lower than the proportion of 74% found in a study by Lord et al.<sup>17</sup> This difference probably reflects the efficacy of our protocol in improving the paramedics' ability to take care of the patients' acute problems at home. Furthermore, the destination of transfer was a secondary hospital in only 16% of the transferred patients in our study, while the proportion of patients transferred to hospital was over 99% in the study by Lord et al.<sup>17</sup> An unplanned or urgent transfer from home to hospital is often precipitated by a sudden deterioration in the patient, life-threatening symptoms, and anxiety or problems relating to the coping of the caregivers.<sup>15-17</sup> In a study by Hoare et al.,<sup>16</sup> the ability of paramedics to keep



**Table 3.** Reasons for paramedic visits, days in hospital and place of death among the patients in different diagnosis groups.

	Diagnosis							
	Cancer		CVD		Dementia		Others	
Patients, <i>n</i>	173		30		24		25	
Age (years), median (range)	72	(28–93)	91**	(66–99)	86**	(76–102)	74	(27–97)
Paramedic visits, <i>n</i>	233		47		5		21	
Patients needing paramedic visits, <i>n</i> (%)	112	(64.7)	20	(66.7)	3	(12.5)**	10	(40.0)*
Reason for visits, <i>n</i> (% of visits)								
Symptom control	87	(37.3)	22	(46.8)	0		8	(38.1)
Need for an ambulance transfer	75	(32.2)	9	(19.1)	2	(40.0)	2	(9.5)*
Social	16	(6.9)	1	(2.1)	0		0	
Deterioration of health	26	(11.2)	5	(10.6)	0		3	(14.3)
Deceased	8	(3.4)	7	(14.9)**	1	(20.0)	6	(28.6)**
Technical	5	(2.1)	0		0		2	(9.5)*
Other	16	(6.9)	3	(6.4)	2	(40.0)**	0	
Days in hospital before death								
Mean (SD)	10.8	(23.7)	2.9	(6.6)	0	(0)	1.2	(3.5)
Median (IQR)	2	(0–10)	0	(0–2)**	0	(0)**	0	(0)**
Place of death, <i>n</i> (%)								
Home	46	(26.7)	4	(14.3)	1	(4.8)*	9	(36.0)
Nursing home	16	(9.3)	16	(57.1)**	20	(95.2)**	12	(48.0)**
End-of-life care ward	98	(57.0)	8	(28.6)**	0		4	(16.0)**
Secondary hospital	11	(6.4)	0		0		0	
Other	1	(0.6)	0		0		0	

\* $p < 0.05$  and \*\* $p < 0.01$  compared to patients with cancer.

patients who are close to the end of life at home was hindered by the limited availability and accessibility of additional care support in the community and a perceived ambulance service emphasis on hospital care. We suggest that integration of paramedics into the community health care system by end-of-life care protocol and especially the availability of a pre-planned end-of-life care ward are essential to reduce emergency visits and unnecessary hospitalizations. Our suggestion is supported by the fact that only about 5 % of the patients died in the secondary hospital outside a planned end-of-life ward in our study. In addition, paramedics need training in palliative care and a possibility to consult a doctor on call to be able to manage patient's acute problems at home.

### Patients in urban and rural areas

In our study, patients living in rural areas without 24/7 palliative home care services needed paramedic services more often than those in an urban area with 24/7 palliative home care services, especially outside of office hours. To our knowledge, previous studies have not specifically addressed the difference between urban and rural areas. However, the tendency to call paramedics due to patients' symptom crises in palliative care out-of-hours have been shown.<sup>17</sup> These findings are understandable as few community health care providers work outside of office hours

in rural areas, while in urban areas patients typically have somewhat better accessibility to 24/7 palliative care services. This was also the case in North Karelia, as the only round-the-clock palliative home care service available was in the city of Joensuu. The higher amount of resources needed for patients living in rural areas as well as the need for support outside of office hours should be taken into account when planning paramedics' involvement in end-of-life care at home.

Our study is in line with the study by Dumont et al.<sup>12</sup> as both studies showed a higher need for inpatient care among patients living in rural than in urban areas. Patients from the areas without 24/7 palliative home care services also died in a planned end-of-life care ward significantly more often than those living in the areas with 24/7 palliative home care services in our study. Providing round-the-clock end-of-life care at home in rural areas is challenged by longer driving times and difficulties in accessing the equipment and supplies needed in home care.<sup>13</sup> Inpatient costs, which comprise a significant part of the total costs during the last weeks of life, may be diminished by providing palliative care at home, perhaps with the support of paramedics.<sup>12,27</sup> However, the palliative care pathway should also include planned access to end-of-life wards or hospices as dying at home is not a realistic option for every patient especially in rural areas.

### Visits in patients with different diseases

About two thirds of the patients with cancer and cardiovascular diseases needed paramedic visits in this study, while only three patients (13 %) with dementia required a visit. Although many symptoms share similar prevalence during the last months of life regardless of the disease, the severity of the most important ones (dyspnoea and pain) are high in patients with cancer and heart diseases, probably increasing the need for acute care.<sup>17,28</sup>

In previous studies<sup>6,18</sup> many people living in residential care are shown to be hospitalized before death. In this study, the majority (93%) of the patients who lived in a nursing home also died there. Paramedics might support the staff of the nursing home in palliative care, helping in symptom control. However, other factors besides our end-of-life protocol, such as the palliative care skills of the nursing home staff, might have had a significant influence on our findings.

### Strengths and limitations

We present a real-life study with a relatively large number of patients on the systematic integration of paramedics into end-of-life care at home by a planned protocol. The alleviation of symptoms by the paramedics' visits and the opinions of the patients, families or paramedics were not evaluated. However, Carter et al.<sup>20</sup> showed in a recent study that patients and families appreciated the benefits of a protocol including paramedics in palliative care at home. These aspects should be further assessed in forthcoming prospective studies.

### Conclusion

Integrating paramedics into end-of-life care at home by a planned protocol and palliative training is reasonable, as over half of the patients need help from paramedics. With a protocol, most of the symptoms and other problems may be resolved at home or by transferring the patient to a planned end-of-life care ward without the need for an emergency visit or admission to a secondary hospital. Support from the paramedics is especially valuable in rural areas without 24/7 palliative home care services and outside of office hours. The effects on costs and symptom control as well as views of the patients and families regarding the paramedics' involvement in end-of-life care at home should be further assessed.

### Acknowledgements

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### Authors' contributions

LKS, JTL and PM were responsible for the study design, but all the authors participated in this. LKS, MP and MK participated in acquisition of the data. LKS, JTL and P.M. made the analyses of the data. All the authors contributed to the interpretation of the data and writing and drafting of the manuscript. All the authors participated sufficiently in the work to take public responsibility for appropriate portions of the content and approved the final version of the manuscript.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Ethical approval and patient consent

The study protocol was approved by the Research Ethics Committee of Northern Savo Hospital District and Kuopio University Hospital (412/2016). The study was also approved by the North Karelia's Fire and Rescue Department and the hospital district of North Karelia allowing access to the patient data.

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### Data availability

The data of this article including details of the end-of-life protocol are archived by the corresponding author according to Finnish regulations for research and authors share the data in a suitable way upon a reasonable request.

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