Paramedics' experiences and educational needs when participating end-of-life care at home – A mixed method study

Leena K. Surakka[1,2], Minna Hökkä[3,4], Kari Törrönen[5], Pekka Mäntyselkä[1,6], Juho T. Lehto[7,8]

[1] University of Eastern Finland, Institute of Public Health and Clinical Nutrition, Kuopio, Finland

[2] Siun sote - North Karelia Social and Health Services Joint Authority, Palliative care center

Joensuu, Finland

[3] Kajaani University of Applied Sciences, Kajaani, Finland

[4] Medical Research Center Oulu, Oulu University Hospital and University of Oulu, Finland

[5] Siun Sote - North Karelia Social and Health Services Joint Authority, Fire and Rescue Department, Joensuu, Finland

[6] Kuopio University Hospital, Primary Health Care Unit, Kuopio, Finland

[7] Faculty of Medicine and Health Technology, Tampere University, Tampere, Finland

[8] Palliative Care Centre and Department of Oncology, Tampere University Hospital, Tampere, Finland

Corresponding author:

Leena K. Surakka, M.D.
Chief physician
Siun sote - North Karelia Social and Health Services Joint Authority, Palliative care center
Joensuu, Finland
Noljakantie 17 a C
80130 Joensuu
FINLAND
Email: leena.surakka@siunsote.fi
Tel: +358-50-310 8789

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Abstract

Background: Paramedics face end-of-life care patients during emergency calls and more recently through planned protocols. However, paramedics experiences and educational needs concerning preplanned end-of-life care at home remain largely unknown.

Aim: To describe experiences and educational needs of the paramedics included in the end-of-life care protocol.

Design: A mixed method study with a questionnaire including open ended questions and numeric evaluations on a Likert scale.

Setting/Participants: The questionnaire was delivered to and answered by all the 192 paramedics working in North Karelia fire and rescue department during the time of the data collection in 2017.

Results: Over 80% of the paramedics agreed that the protocol helped them to take care of the patients and to improve the quality of end-of-life care. Visits to the patients were considered useful and the end-of-life care as a meaningful work by 76.5% and 62.5% of the paramedics, respectively. The paramedics expressed challenges in psychosocial aspects, communication, symptom management and their role in end-of-life care. Encountering and communication with the families as well as managing the most common symptoms were emphasized as educational needs. Using a patient controlled analgesia device emerged as an example of practical educational aspect.

Conclusions: Paramedics considered end-of-life care at home meaningful but called for more competency in supporting and encountering the families and in symptom management. Our results can be utilized when developing end-of-life care protocols and education for the paramedics. Patients' and families' views on the paramedics' participation in end-of-life care should be evaluated in the future.

Keywords

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

What is already known about the topic?

- Paramedics face end-of-life care patients at home during acute health crises and more recently through preplanned protocols.
- Paramedics report minimal training in palliative care although further education may improve their competency.

What this paper adds?

- Most of the paramedics agreed that the end-of-life care protocol help them to take care of the patients and to improve the quality of end-of-life care.

- The paramedics expressed challenges in psychosocial aspects, communication, symptom management and their role in end-of-life care.
- Paramedics called for more competency in supporting and encountering the families and in symptom management.

Implications for practice, theory or policy?

- These results can be utilized when developing end-of-life care protocols and education for the paramedics.
- Patients' and families' views on the benefits of the paramedics' participation in end-of-life care as well as the effects on costs and on symptom control should be evaluated in the future.

Backround

Many patients wish to be cared at home in the end of their lives[1-5]. Paramedics face these incurably ill patients after emergency calls in different health crises at home[6-19]. About half of these visits to patients in palliative care are needed for symptom control or general deterioration of health[6,16]. Pain and respiratory problems seem to be the most common symptoms for which help from paramedics is needed[6,9,16,20-21]. However, the care of palliative care patients has not traditionally perceived as the main task of paramedics and only small proportion of all emergencies are related to palliative care[6,9,11,14,22]. The traditional role of paramedic has been in lifesaving. They have faced the patients in end-of-life care without a knowledge of their medical history or care plans[7,13,18,23,24]. Only recently paramedics have started to take part in the end-of-life care at home by preplanned protocols[6,25,26].

Healthcare personnel need a wide range of competencies to provide high quality palliative care[27-30]. Paramedics are trained in decision-making processes, communication, handover processes, analgesic care and acting as mediators between the pre- and in-hospital services[17]. These competencies may also help them to offer palliative care. Previous studies[9,17-18,23-24,31] have shown that conflicts in care goals, legal issues, organizational policy and clinical practice guidelines may challenge paramedics when treating palliative patients. Paramedics report minimal training in palliative care[8,14,17,32] although further education may improve their competency[14]. Only little is known of paramedics' own perceptions of challenging situations in end-of-life care at home and their educational needs[22].

In 2015, the end-of-life care protocol for paramedics was started in North Karelia. It aims to enhance the end-of-life care delivered at home with an extended role of paramedics. In our previous study, we evaluated 306 visits of the paramedics through this protocol and found that 58% of the patients registered to the protocol needed a paramedic's visit most commonly due to a need for symptom control[6]. Majority of the problems could be resolved by the paramedics at home or by transferring the patient to the pre-planned end-of-life care ward without a visit to the emergency room. Although our previous findings support the feasibility of the protocol, the views and needs of the paramedics when providing end-of-life care at home remained unknown. To find out relevant aspects needed for quality end-of-life care provided by the paramedics, we explored the experiences, challenges and educational needs of the paramedics being involved in end-of-life care at home through the protocol.

Methods

Research questions

This study aimed to describe experiences and educational needs of the paramedics included in the end-of-life care protocol. Research questions were:

1. What are the experiences and perspectives of the paramedics about their involvement in end-of-life care at home through the end-of-life care protocol?
2. What are the paramedics views of the most difficult aspects of end-of-life care at home?
3. What are the paramedics perceived needs for education of the different issues of the care of an incurable patient?

Setting

North Karelia's Fire and Rescue Department provides paramedic services to the population of 161,000 people living in North Karelia, Finland. About 21 000 paramedic visits are provided annually, of which 300-400 are related to the preplanned protocol of end-of-life care. Usually, a citizen calls to emergency call centre (phone number 112) to get help in cases of medical emergency. In contrast, the patient and the caregivers registered to the pre-planned end-of-life care protocol received the direct phone number of the local paramedics' unit, where they were advised to call in case of a problem which could not be solved by the palliative home care team or whether the team was not available. Patient details (name and address) were informed to North Karelia's Fire and Rescue Department.

Patients admitted to the end-of-life care protocol wished 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. Patients had a written end-of-life care plan at home including information of a preplanned end-of-life care ward where they could have been transferred.

The bachelor's degree paramedics who are also registered nurses (health care professionals with a bachelor degree education of 4 years) responded to the end-of-life care calls in the protocol. Paramedics work in pairs or together with a licensed practical nurse (health care professionals with an vocational education of 3 years) of whom some were also fire fighters. In Finland, paramedics may consult the physician on-call by phone, but emergency physicians are involved in the treatment of a patient on the spot only in rare advanced and special occasions. Over half of the paramedics attended a 6-h training program covering various aspects of end-of-life care when the end-of-life care protocol was started.

When participating in the end-of-life care by preplanned protocol paramedics were advised to check the patient's end-of-life care plan and to manage the patient care accordingly or to follow the specific protocols including guidelines for the management of symptoms (pain, respiratory distress, nausea, deterioration of consciousness, convulsions and bleeding) and 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. Details of the protocol are described in our previous study[6].

Participants

All 192 paramedics who worked in North Karelia´s Fire and Rescue Department were invited to participate in the voluntary survey, which was delivered, completed and returned on the same day during training lessons arranged between the 29th of September and the 24th of November 2017 by author (KT). All of them received and returned the questionnaire. Answering the questions was voluntary. Of responders, 80 (42%) answered to the open question of the most difficult aspects in taking care of a patient in end-of-life care, and 71 (37%) to the question of educational needs.

Data collection

The data was collected with a paper questionnaire, which was developed to answer the research questions of this study by the authors of which one had widespread experience in the work of paramedics (KT) and two were physicians with special competency in palliative medicine (LS and JTL). The questionnaire was pretested by five paramedics after which some minor changes were made to clarify the questions. Responders' background factors and their experience as a paramedic, in end-of-life care, and on "End-of-life protocol for paramedics" were first asked. Thereafter, paramedics opinions on the involvement in end-of-life care at home and on the usefulness of the "End-of-life protocol for paramedics" was found out with six statements. The agreement to the statements was asked to score on a five-point Likert scale from 1 = "I totally disagree" to 5 = "I totally agree". The questionnaire ended up with two open ended questions: "On what topic related to the care of a patient with incurable disease would you wish to have more education?" and "What do you think is most difficult in taking care of a patient in end-of-life care at home?". The questionnaire is presented in the Supplementary material.

Data analysis

We used mixed method study to resolve research questions in data analysis[33]. Respondents' characteristics and Likert scores were analysed quantitatively by using descriptive statistics with proportions, medians and interquartile ranges. Open-ended questions were analysed qualitatively by an inductive content analysis meaning that the theoretical frameworks were not used as a starting point but instead the categories emerged from the data[34]. The data was transcribed verbatim from the questionnaires to a Word document and it was read several times to become familiar with its contents. Words, sentences or phrases which constructed a meaning were used as units of analysis with only the manifest content being analysed.

In the first phase meaningful expressions related to the study questions were reduced to codes independently by two researchers (L.S. and M.H.). Then they compared the identified codes and, when differences were found, discussed the issue together to find a consensus. In the second phase the reduced codes were grouped based on similarities in content. In the third phase subcategories, categories and main categories were created and named based on their contents (L.S and M.H). The categorization was critically checked by three other research team members (K.T., P.M. and J.L.). The abstraction was performed in a way that it applied to all data, namely in three levels in the table four and two levels in table five. The researchers made the final decisions regarding the analysis together as a team. The analysis was performed manually without a particular software. Researcher characteristics are shown in Table 1.

In reporting the findings, citations from the original data have been presented in italics. An example of the coding procedure how the subcategory 'Management of pain' was produced inductively is shown in Table 2. The COREQ checklist was used in reporting for this study[35].

Ethical issues

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. All participants were informed about the survey by a written announcement. Responding was voluntary and anonymous.

Results

The median age of participants was 34 years, range 20-63 (Table 3). Of the paramedics, 134 (70%) had a personal experience of cases taken care of according to the end-of-life care protocol, 53 (28%) had not yet taken care of patients specifically according to the protocol, and this information was missing from five paramedics. Proportions of the paramedics totally or partially agreeing the beneficial aspects of the "End-of-life care protocol for paramedics" were 82.3% for helping to take care of the patients, 84.3% for improving the quality of care and 86.0% for clarifying the limitations and goals of care (Figure 1). Most of the paramedic's (76,5%) totally or partially agreed that visit at the home of end-of-life care patient was useful, while 62.5% of them regarded the end-of-life care at home as a meaningful work. Anxiety was felt by 16.6% of the respondents when involved in end-of-life care.

The most difficult aspects of end-of-life care at home

Three main categories and 13 generic categories was produced based on the data (Table 4). From each main category an example of generic category with *subcategory* and *quote* is presented below.

The first main category 'Challenges in co-operation with patient and her/his family and carers' included five generic categories. Of those, 'Encountering the patient and her/his family and carers' was a generic category representing the highest amount of codes (32). *'Encountering the* family and carers' *of the patient in end-of-life care'* was the subcategory with most codes of the five subcategories found in that generic category.

> *"To encounter… the* family and carers' *with dignity…" K37*

'Challenges in the paramedic's role in end-of-life care pathway' was the second main category with six generic categories of which 'Challenges in the function of the end-of-life protocol' included most codes. Subcategory *'Paramedics are not able to utilize patient's medical history or overall advanced care plans'* included 9 codes.

> *"If there isn´t necessary care plans/information needed at home, it´s hard to get/search information" K91*

The third main category, 'Challenges in symptom control' included two generic categories. 'Challenges in the management of somatic symptoms' was generic category which included four codes and three subcategories, of which *'Management of pain'* includes two codes.

> *"To evaluate a need for pain medicine" K93*

Educational needs related to the care of a patient with incurable disease

Seven main categories, 22 subcategories and 92 reduced codes emerged from data (Table5). The main categories are described below with one *subcategory* and *quote*.

First main category 'Knowledge and skills in medical care' included most codes. It consisted of four subcategories. *'Management of Patient controlled analgesia device'* was the largest subcategory with 27 codes.

> *"I would like to have education of the equipment used in the end-of-life care, like Patient controlled analgesia devices…" K48*

Second main category 'Management of the most common symptoms of end-of-life care patient' included two subcategories. Of those, '*Management of pain'* included 12 codes.

> *"About management of pain specifically in end-of-life care" K37*

'Encountering and communication in end-of-life care' was the third main category with 14 codes of which six were included in the subcategory *'Encountering the* family and carers'.

> *"Encountering the patient (the dying and the* family and carers'*, encountering the underaged* family and carers' *in the end-of-life care)" K131*

The fourth main category 'Regular training in end-of-life care' consisted of three subcategories of which the subcategory with most codes was 'General training about end-of-life care'.

> *"End-of-life care at home comprehensively" K143*

'Supporting and counselling in end-of-life care' was the fifth main category which included four subcategories. '*Supporting the* family and carers' was the largest subcategory with three codes.

> *"Supporting the loved ones'" K62*

The sixth main category 'Knowledge and skills near to death' consisted of three subcategories. The subcategory *'Guidelines for procedures after the death'* included two codes.

> *"… and about the magnet which is used to stop pacemakers after death" K48*

The seventh main category 'Training in the end-of-life care protocol for paramedics" included three codes, of which two included in the subcategory *'Local differences in the end-of-life care protocol for paramedics*.

> *"…How are practices in different municipalities?" K100*

Discussion

Main findings

Most of the paramedics agreed that their involvement in end-of-life care at home through the protocol improves the quality and clarifies the goals of care. We found that paramedics perceptions in the difficulties in end-of-life care at home and their educational needs on the subject are widespread and share many similarities (Figure 2). The paramedics emphasized challenges in psychosocial aspects and communication in everyday practice, but the educational needs in symptom control such as management of pain emerged as well.

Co-operation with the patient and her/his family and carers

In this study, paramedics expressed many challenges in co-operation with the patient and her/his family and carers in end-of-life care at home including encountering, non-verbal and verbal communication. This is not surprising, as the communication with patients and their families has been reported as ethical challenge in the clinical practice even by specialist palliative care practitioners[36].

Paramedics also requested for more education in encountering, communication, supporting and counselling in end-of-life care. Our results are in line with previous studies, which identified supporting the patient and her/his family and carers as a nursing competence required by the professionals working in the basic level of palliative care[27-30,37] as well as in palliative paramedicine[22]. The importance of encountering is also highlighted by family members of end-of-life patient as they are shown to emphasize professionalism and compassion of the paramedics'[25].

Paramedics face challenges in different environments when patients' condition changes acutely, and a rapid decision making and actions are required. In those urgent situations, even more demanding communication skills may be needed than in palliative care wards or hospices, where the professionals usually have time to build up a trustful relationship with the family. Communication competences acquired during undergraduate education might be regressed during occupational activity[38]. Therefore, encountering and communication skills should be trained continually after graduation.

Essential non-technical paramedic skills include decision-making and communication[39], which have been identified important in palliative care practice as well[8,19,22-23,27,29,32]. However, paramedics perceived that overall evaluation and decision making at home, as well as conflicts on aim of care, were difficult aspects while taking care of end-of-life patients in our study. This is in line with previous studies showing that decision making and conflicts with care goals challenges paramedics in prehospital end-of-life care[8,13-14,17,19,23,31,40]and that they feel pressure to make rapid decisions[19,23]. As the paramedics are used to follow various protocols, we suggest that an end-of-life care protocol including advance care planning with goals of care, documented patients´ wishes and palliative care plan for each patient help paramedics to use their skills in the context of palliative care. This is supported by our finding that 86.0 % of the paramedics agreed that the instructions of our protocol clarified the limitations and goals of care.

Management of symptoms at home

Help of paramedics is most commonly needed for symptom relief of a patient in end-of-life care at home[6,9,16,19,21,25]. The ability of paramedics to manage symptoms in end-of-life care has also been highlighted by family members[25]. In this study, some paramedics brought up challenges in the management of somatic symptoms like pain and dyspnoea and many of them also expressed need for more education related to medical care and management of the symptoms. Symptom management and use of opioids have been identified as ethical challenges also in previous studies[36] and competence in managing the most common symptoms as one of the main nursing competences in basic palliative care[28-30].

Although encountering and psychosocial support are the cornerstones of palliative care, education on main aspects of somatic symptom control should not be overlooked. This was further highlighted by the finding that knowledge and skills for the use of patient controlled analgesia device was still regarded as an important issue. These technical skills are essential to handle, because paramedics' might be the only healthcare professionals working out-of-office hours in rural areas.

Paramedic's role in end-of-life care

Paramedics have an important role in caring for patients in end-of-life care, although this potential task has only recently been recognized and still unfrequently organized[6-7,9,13,16-17,19,22-23]. Previous studies[11,19,23-24,27,32,40] have shown the urgent need for integration of palliative care into the healthcare system, development of palliative care pathways and finally, guidelines for paramedics to treat end-of-life patients. The end-of-life care by paramedics' needs a shift from a life-saving approach to a relief of suffering[17] and expanding their role from an ambulance transferer to a nurse of end-of-life-patient[6,25].

In this study, three quarters of the paramedics perceived that their visit to the end-of-life care patient was useful and over half of them regarded the end-of-life care at home as a meaningful work. However, in open questions many paramedics were doubtful about their skills and knowledge in end-of-life care and felt uncertainty with the idea, that end-of-life care belongs to them. This may be due to the fact, that training of the paramedics has traditionally been focused on lifesaving issues[8,14,23].

In our study, paramedics brought up challenges in co-operation with other health care professionals in end-of-life pathways, which is in line with previous studies[13,18,23,31]. Competency to collaborate with health care team is regarded as one of the nursing competencies in palliative care in general[28,29]. Demands for collaboration skills emphasizes when working out-of-office hours with changing co-workers, like paramedics do. Our and previous studies highlights the importance of teamwork in the training of paramedics as well as in the function of palliative care pathways.

Paramedics perceived challenges in the function of the "End-of-life protocol" and they expressed a need for training in it. This is understandable regarding that only few of all paramedic calls deal with end-of-life care[6,14,16]. Nevertheless, most of the paramedics agreed that the instructions of the "End-of-life care protocol for paramedics" help taking care of the patients and improve the quality of care. Integrating paramedics with the palliative care pathways emphasize the instructions included in the preplanned protocol.

Of the paramedics, 17% felt anxiety when involved in end-of-life care. Facing the expected death was considered as one of the most difficult aspects of end-of-life care in this study. This may be one of the sources of anxiety which paramedics need to handle with as the patient's family and caregivers need their support even when the death is anticipated[41].

In this, and some previous studies[8,17,19,22,23,32,40] paramedics expressed a need for regular training in end-of-life care. Improving their skills in end-of-life care might reduce feelings of stress[37]. Specific training program might improve paramedics' comfort and confidence in providing palliative care[25]. Thus, a regular training of end-of-life care skills should be included in the training curriculum of paramedics.

Strengths and limitations

The end-of-life protocol for paramedics started in 2015 and the data of this study was collected in 2017. Therefore, 28% responders didn't yet have a personal experience of the protocol. This might weaken the validity of the study on the part that applies to the protocol. On the other hand, also these paramedics could have taken part in the education according to the protocol, might been involved on the discussion about using protocol with their colleagues and had experience of end-of-life care at home without using the protocol. Therefore, we suggest that all the paramedics of the North Karelia's Fire and Rescue Department were in a way exposed to the end-of-life care protocol. In our study, the actual knowledge and skills of the paramedics in palliative care remains unknown as the results are based on self-assessment

instead of objective evaluation. As we did not ask the exact time when the paramedics had faced the patients or studied the protocol, recall bias could not been totally controlled.

The trustworthiness of this study was ensured by choosing a mixed method study. Confirmability was increased by using general and open question. This allowed us to examine paramedics' perceptions of the protocol quantitatively, but also to find the new aspects of their educational needs and challenges by open questions and qualitative approach. Credibility was facilitated though regular debriefings by team members as data were collected and coded, and as themes emerged. The response rate was high for quantitative part of the study as almost all paramedics working in the area during the study responded, but a lower proportion of paramedics responding to the open-ended questions can be seen as a limitation to our qualitative results. However, the open-ended responses represented repetitive themes indicating the saturation of data. We can assume that these results can be generalized among Finnish paramedics and others with similar working environment and education, but not necessarily in contexts very different from ours.

Conclusion

We described paramedics' perceptions in treating end-of-life patients with the preplanned protocol integrating them to end-of-life care pathway. End-of-life care at home was considered beneficial for a patient and a meaningful task for a paramedic. However, the paramedics described many challenges and educational needs starting from encountering and communication with the patient and the family and ending up with special issues in symptom control. Our results give utmost background for the development of protocols in end-of-life care and ongoing education in palliative care for the paramedics.

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